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USING A VIRTUAL WORLD TO TEACH JOINT PROTECTION TO PEOPLE LIVING WITH RHEUMATOID ARTHRITIS: A PILOT RANDOMISED CONTROLLED TRIAL

By

RASHID M KASHANI

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Author's Declaration

The author declares that at no time during the registration for the research degree, the author has been registered for any other University award. No work submitted for a research degree at Plymouth University forms part of any other degree either at the University or at another establishment. A listing of related work and conferences attended where research in progress was presented or published related to this study, even peripherally, is included in Appendices 14-16 of this dissertation.

This dissertation is 85 152 words, not including references and appendices.

Signed Date: November 30th, 2015

Rashid Kashani, BA, BSc, BScOT, MScOT (C)

Abstract

Background: Rheumatoid arthritis (RA) is a systemic autoimmune disease affecting an estimated 1% of the global population. Joint protection is one intervention with some quality evidence of efficacy for RA self-management. However, joint protection education is often provided only in urban centres during Arthritis Self-Management Programs (ASMPs) in classroom sessions at designated times. These programs, therefore, may not be available to all who need them. Providing and testing more accessible methods of delivering joint protection education to people living with RA may improve accessibility.

Aims: (i) To develop a virtual world (VW) intervention available via the Internet in Second Life®, that aims to improve the knowledge of joint protection among people with RA and (ii) to undertake a pilot randomised controlled trial (RCT) to assess the feasibility of conducting a subsequent large scale RCT.

Methods: First, qualitative interviews with occupational therapists and clients living with RA who had previous experiences teaching or taking arthritis self-management programmes were undertaken and thematically analysed. This analysis informed the design of the VW joint protection education intervention. Second, the intervention was constructed and tested with these same participants. Their feedback helped refine the VW intervention and select assessment tools for the pilot RCT. Third, in a pilot RCT, three primary methods of advertising and invitation were used to recruit subjects: (i) poster invitations with take-home paper copies from clinical settings; (ii) direct messages to Twitter® users living with RA; and (iii) online discussion forums. Participants were recruited after contacting the principal investigator, reading an invitation letter and giving written informed consent. Participants were randomised to intervention or (30-day) waiting list control group, and completed a series of measures. These were completed after 30 days of program access for the treatment

group and on enrolment in the study for the control group. Survey completion was online and included piloted knowledge-based questions about joint protection, validated during the second phase of the study with occupational therapists who were experts in joint protection education. A higher score was indicative of better joint protection knowledge. Standardized measures used on the survey included the Arthritis Impact Measurement Scale, Short Form, version II (AIMS2SF) and Pain Self-Efficacy Questionnaire (PSEQ).

Results: It was possible to develop a VW education program focused on RA and joint protection based on the content identified by participants in the first part of the study and test with the tools selected. The program developed included input from client users, following the theorectical basis of occupational therapy as a client-centred practice. Additionally, the program developed applied principles of adult-learning and the recommendations of existing programs regarding chronic disease management.

Recruitment of 50 participants for the pilot RCT was challenging, taking 6 months with low response rates for all three methods. The poorest response rates were to poster and paper invitations in clinical settings. The most effective means of recruitment was via electronic bulletin boards, such as blogs. All subjects, once randomised to the control or intervention group completed the online questionnaire. However, adherence to the intervention was poor; only 15 out of 25 randomised reported using the program. On the other hand, all 15 who used the program indicated that this medium was acceptable to learn about joint protection, despite 5/15 of these subjects reporting some difficulty accessing the program.

All participants completed the three questionnaires (knowledge, impact, pain self-efficacy) and these may be useful in a definitive RCT. Although the main purpose of using Intention to Treat Analysis in pilot studies is to practice and check that analysis is feasible, there was a positive statistically significant difference between the treatment ($\bar{x}$=52.8%) and control

($\bar{x}$=24%) group scores on a test of joint protection knowledge using an independent samples t-test (F value, 20.8 $p < 0.05$) comparing joint protection knowledge scores after the treatment group had access to the program for 30 days. A higher score was indicative of better joint protection knowledge. The difference between the two groups was considerable, with the intervention group score mean being more than double that of the control group. Given the magnitude of this difference between groups, a smaller difference between groups would also be worth finding. The difference between groups for the AIMS2SF and PSEQ were not statistically significant using an independent samples t-test (F values, 0.5 and 0.2) but there was some suggestion that the intervention group scored more favourably on some of the subscales more relevant to joint protection on both the AIMS2SF and PSEQ, particularly noteworthy was a higher score pertaining to ability to carry out work on both measures. In a definitive trial a sample size of 1250 participants would give 80% power to find a difference of 28.8% on joint protection knowledge, weighted score of 1.8 on the AIMS2SF and overall score of 1.8 on the PSEQ at 5% level of significance. Smaller samples would be required if the PSEQ was dropped as a measure in a future study. Sample sizes of 14 and 558 would be required for the joint protection knowledge and AIMS2SF respectively at the same level of power and significance.

Conclusion: A VW intervention to improve joint protection knowledge has been developed and is worth testing further. The intellectual contribution of the creation of this program using this methodology is that an occupational therapy based study using client input and priniciples of adult learning to create the intervention has been conducted, applying client-centred practice in research, which is, in reality, present in a minority of studies at this time.

A full RCT would be feasible, though very challenging, given the numbers of subjects required for recruitment, most likely recruiting via the Internet on relevant RA focus sites, such as RA bloggers, and using the same outcome measures as in this study. A sample size

of 1250 could feasibly be recruited in 36 months if a full time study were undertaken with suggestions discussed to assist with future study recruitment. However, given the number of study dropouts at enrolment seen in this study, close to double this number would be needed, entailing a recruitment period of up to 72 months, or 6 years, making a full RCT less practical. A future study may need to consider either a longer enrolment period, different outcome measures as well as address the limitations of this study, including the limited time of enrolment in this pilot RCT. However, longer enrolment duration would increase the amount of time required for a future full RCT, reducing the feasibility of a future study.

Findings from this study indicate that the program developed would likely to be useful to people who are not able to access the urban centred classroom based program. On the other hand, those participants who used the program incurred no costs, appeared to have no risks or detrimental impact with possible improvement in knowledge and self-efficacy. Now the intervention has been developed, refinement, maintenance, and use is low cost for service providers, so it could be used routinely now for those who prefer it to ASMPs with an ongoing preference trial.

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Chapter 1 – Literature Review

This chapter has been organised into nine sections. The first section describes the methodology used in the literature review. The second section is an overview of rheumatoid arthritis (RA), including the mechanisms of the disease as well as disease impact on the individual. The third section briefly discusses pharmacological options for RA management. The fourth section discusses barriers to pharmacological management of RA. The fifth section discusses non-pharmacological options for RA management, with further discussion of joint protection education. In section six, there is review of the current theories of adult learning and application of these theories to current practices in teaching chronic disease management to adult learners. As the media used in this study is considered an eHealth form of media, specific discussion regarding the current state of chronic disease management and eHealth is included and methodological concerns are discussed. The current state of adult learning and chronic disease management using eHealth is synthesized and a plan to address some of these issues is formulated, relevant to this study The seventh section is an overview of virtual worlds (VWs) and the current use of VWs, including their use in a variety of educational settings, clinical practice with specific patient populations and existing methodologies for conducting research in VWs. The eighth section outlines the problem pertaining to this study. In the ninth and final section of this chapter, a review of evaluation methods relevant to this study is presented.

1.1 Literature Review Methods

During the earliest phase of the literature review, a Research Librarian was consulted in the John Scott Medical Sciences Library in Edmonton, Alberta, Canada, to review available databases and grey literature that would best suit the aims and objectives of the proposed study. Formal quantitative study of VWs and RA does not appear to have taken place given

previous attempts at reviewing the literature. A search of multiple databases in January 2009 revealed that there were no studies involving this particular population, methodology and clinical intervention. This process was repeated again in October 2010, 2011, 2012 and 2013. Thus far, two articles about the same study were found that came close to the methods, type of intervention and population studied. The cited study was at the proposal stage in 2009 and initial testing stage in 2013 and was using an animated storyline about decisions to take a specific medication for RA, Methotrexate (Li et al., 2009), (Li et al., 2014). The intention of the literature review was to use the McMaster Critical Review Form (Law, et al., 1998) or FAME scale (Pearson et al., 2005) to do a more thorough critical review of individual studies. However, as even the study by Li et al. (2014), is not a completed study, but a developing one, it was not appropriate to use the McMaster or FAME reviews given that the article describes an intended process for its own pilot RCT.

Limits set for the literature searches included human studies, articles in English and articles published since 2000. The search terms used to date have included: virtual and arthritis, web and arthritis, serious social games and arthritis, joint protection and virtual, joint protection and web, joint protection and serious social games. These terms were selected, in part, to ensure searches included a descriptor of the population and the intervention. Terms like rheumatoid were left out in an attempt to increase the number of hits on databases. Terms like virtual were also used instead of virtual worlds in an attempt to include virtual reality as a title, potentially increasing the number of hits on databases. Sixteen databases were searched: CIRRIE, REHABdata, Cochrane Library, EMBR, OTSeeker, OTDBase, PEDro, Web of Science, TRIP, Scopus, AMED, CINAHL Plus, MEDLINE, EMBASE, ComDisDome and PsychInfo.

Searches in Grey Literature and hand searching the Journal of Virtual Worlds Research also revealed no similar studies. Grey literature searches included: Conference Papers Index, OCLC Papers First, Conference Proceedings Citation Index, OCLC Proceedings First, ProQuest Dissertations and Theses Full Text, Networked Digital Library of Theses and Dissertations, Dissertations and Theses at the University of Alberta, Theses Canada Portal and Google Scholar. The same search terms were used and an RSS alert was created to indicate if new editions of the Journal of Virtual Worlds Research were published.

The primary topics covered in the few articles found during the review of the literature included virtual surgeries, virtual means of assessing patients via the Internet and some articles discussing patient forums online in the form of chat rooms for social support. VWs offer a novel level of interaction and flexibility not seen in other forms of online interactions. Clinicians, researchers and educators need to be made aware of the potential benefits and risks in using these VWs. However, the literature search suggests that VWs are relatively new, and from a disease specific perspective, have undergone limited study to date, in rheumatology, this has mainly focused on fibromyalgia. Many diagnostic populations remain completely unstudied, especially within the domain of rheumatology, such as those living with myositis, and until now, include people living with RA. Given this is a novel medium, studies that are soundly developed and focus on specific populations such as this one, are required to determine what clinical effect, if any, this media may have (Kashani, et al., 2009).

Prior to reviewing the present state of RA management based on literature reviewed, an explanation is included in the following section regarding what RA is and the demographics of this disease.

1.2. Rheumatoid Arthritis (RA)

This section describes the art and science involved in diagnosing RA and who typically gets diagnosed with RA to inform approaches to interventions, including learning approaches, as discussed later in this chapter.

1.2.1 Diagnosis of RA

In order to appreciate the challenges facing people living with RA, a general understanding of how RA is diagnosed and whom it frequently affects is useful. What follows is a description of the disease and challenges faced by this client population, with emphasis on relevance to this study.

The aetiology and pathology of RA is clinically defined as a chronic syndrome of non – specific, and often symmetric, inflammation of the peripheral joints, potentially resulting in progressive joint damage to both the peri-articular and articular structures. The root cause of RA remains unknown, though multiple competing theories exist suggesting a genetic link, viral exposure, secondary response to trauma or exposure to environmental toxins. However, there are no studies with sufficient scientific rigour to definitively suggest what the root cause of RA may be linked to, though there exists specific demographic information to suggest who may be more at risk of developing the disease, as discussed in the next section.

Diagnosis of RA is dependent upon specific criteria. These criteria have been primarily intended as a communication tool for those involved in research versus clinical practice. However, for the purposes of clinical diagnosis, these criteria may also prove useful and have been developed as a consensus statement via the American College of Rheumatology and include the following:

- Morning stiffness lasting greater than one hour.
- Arthritis in three of more joints for greater than six weeks duration.
- Presence of rheumatoid nodules.
- A serum rheumatoid factor of greater than 24 on blood testing.
- Radiographic changes that include erosion or bony calcifications (most typically in the hands).

To be considered diagnosed with RA, the patient must meet at least four of these criteria. Additionally noted is that these criteria have been in existence since 1987 and have been recently updated (2010) to also include the presence of synovitis, or joint inflammation, in peripheral joints.

1.2.2 Laboratory findings in diagnosing RA

Laboratory findings in the diagnosing of RA often also include an elevated sedimentation rate. Synovial fluid may also be drawn from an inflamed joint and will be sterile, but cloudy in appearance, having an elevated white blood cell count of 3000–50 000 cells per microlitre. Additional tests include a red blood cell count, as many with the diagnosis may also be anaemic. Specific antibodies to cyclic citrulinated peptides, or anti–CCPs are also found on serological testing in 60–70% of people living with RA. In earlier disease, x rays may not show any of the aforementioned changes, but may show soft tissue swelling. Follow up x rays may show perarticular osteoporosis, a form of disuse atrophy, joint space narrowing or even bony erosions. The presence of bony erosions may be highly variable in both progression speed and clinical significance with respect to a patient's complaints and function. In other words, there is not a high correlation between the severity of the erosions and the severity of the disease impact.

1.2.3 Challenges in diagnosing RA

To add to the challenge of diagnosing RA, the aforementioned guidelines also caution that the individual may test negative on the serum rheumatoid factor test, having possible seronegative rheumatoid arthritis, or that an individual without RA, may have a false positive serum rheumatoid factor test up to 5% of the time. Furthermore, in early RA, only 30 % of those tested may have elevated rheumatoid factor, though over the lifetime, this rate increases to 80 %.

In order to support what may be occasionally inconclusive, or contrary laboratory results, additional studies support the use of self-administered questionnaires and the use of instruments to measure subjective complaints of pain in making a determination of the presence or absence of the disease. Taking a count of actively inflamed and damaged joints is also a supported practice, as well as using some of the preceding criteria as parameters of long term disease prognosis. Tenderness in inflamed joints is often the most sensitive physical finding while synovial thickening is the most specific physical finding and this eventually occurs in most involved joints. This is ascertained by history and hands on physical exam, not via blood work or imaging.

Given the unknown cause of RA, sometimes ambiguous laboratory results, and different forms that RA may take, such as seropositive and seronegative, there is a combination of science and art that may go into diagnosing this disease. However, there have been a number of studies, which indicate what occurs at the cellular level with this disease. Older studies have identified immunological changes are initiated that cause the immune system

to destroy the synovial structures covering peripheral joints. There is general consensus that RA is an autoimmune disease as a result of this earlier work.

More recent study has also concluded that the lining covering peripheral joints, the synovium, develops villous folds and thickens because of the increased colonization of lymphocytes and plasma cells. This research has implications for both pharmacological and non-pharmacological management of RA, which will be discussed in sections 1.3 and 1.5 of this chapter.

Given the challenges in diagnosis outlined here, frequently requiring attending a family physician practice, referral to rheumatologist, lab work and wait times, there can be delays of several months, sometime longer, between the time of symptom onset and diagnosis. Given the potential delays in diagnosis, this often leads to a delay in accessing treatment. Delays, as well as limiting access to treatment, may have lifelong negative implications for people living with RA, as the management of the key features of RA, discussed in the following section, is critical to preventing deformities, managing pain and maximizing functional abilities across the lifespan.

1.2.4 Key features of RA

1.2.4.1 Common early signs and symptoms

Signs and symptoms of RA are numerous and not only restricted to pain. However, pain is the area in which almost 70% of people living with RA would like to see improvement. Early onset of the disease is usually insidious with progressive joint involvement. However, presentation may also be abrupt with simultaneous inflammation in multiple joints, resulting in a more systemic presentation, sometimes even involving internal and sensory organ involvement, such as the lungs and eyes.

While initial manifestations may occur in any joint, symmetric involvement of the small hand joints, especially the proximal interphalangeal and metacarpal phalangeal joints, and the wrists, is typical. Early afternoon fatigue is also common. Stiffness in the morning or upon rising lasting for 30 minutes or prolonged inactivity, a phenomenon referred to as gelling, is also a common presenting complaint. Other complaints may include a history of general malaise, low fevers, loss of appetite, and depending on the rheumatoid variant, such as the presence of Sjogren's syndrome, dry eyes and mouth. If the disease has been more aggressive and not yet diagnosed or treated, patients may also describe the sudden appearance of bumps on the hands and elbows, which are typically rheumatoid nodules.

1.2.4.2 Common later stage signs and symptoms

With more advanced or aggressive disease, other common symptoms and signs are typically indicative of outward joint damage. These indicators may include the development of deformities, such as flexion contractures, ulnar deviation of the fingers, slipping of extensor tendons of the hand and wrist, development of secondary carpal tunnel syndrome and rupture of popliteal, or Baker's cysts, at the back of the knee, which may mimic the symptoms of a deep venous thrombosis.

Given the wide variety of symptoms, and varying means of diagnosis, the presentation of RA can obviously vary considerably in presentation on first visit to a physician's office and delays in diagnosis are not uncommon, entailing a delay in primary care treatment, as well as access to other allied health professionals specializing in rheumatic diseases, such as occupational therapists. This challenge in diagnosing and access to rapid treatment options has further implications given the demographics of who typically is affected by this disease, which will be outlined in the following section.

1.2.5 Demographics of clients with RA

1.2.5.1 Incidence of RA

While the true incidence of the disease is not known, current estimates indicate that between one and three percent of the global population has RA. Some of the issues with determining the incidence and prevalence rates stem from varying criteria used to diagnose the disease, as well as delay of time of symptom onset to time of diagnosis, which can vary from months to years in some cases.

1.2.5.2 Individual characteristics of people living with RA

The median age of onset is quite variable, though it appears to be most common within a range of 20-60 years of age, depending on the source of demographic reporting. Typically age of onset is about 40 years of age, during a person's working years. It is not a disease of old age and is frequently misunderstood by lay people and even health professionals with limited knowledge in rheumatic diseases, frequently confusing this with the more prevalent osteoarthritis, the degenerative arthritis typically diagnosed in older adults and in 10-15% of the population. Given this misconception, some RA advocates want the scientific community to remove the arthritis label and are lobbying to have RA renamed rheumatoid disease. To date, the term remains as RA and the literature reflects this.

RA is more prevalent in women than men; 75% of those living with RA are female or a 1:4 male to female ratio (Porter and Kaplan, 2013). There have been some studies to suggest that there may be some genetic predispositions to having RA, though these are not definitive. At least one study indicates that in Caucasian populations, a specific

pentapeptide is implicated in being genetically predisposed to having RA (Steinman et al., 2011). However, given the multifactorial nature of both the disease and its presentation across the world, this is of limited use in determining specifically who may be most at risk for developing the disease.

1.2.5.3 Life expectancy

Depending on the severity of the disease, life expectancy for those living with RA can be shortened in comparison to the general population. For those with poorly controlled or treated disease, life expectancy can be shorter, on average, by five years. About 15% of all diagnosed individuals are deemed to have serious disease, which is prognostically, equivalent to three-vessel coronary artery disease in terms of relative risk ratio. For those with poorly controlled disease, some of the largest long-term risks are heart attack and stroke.

Given the age and sex of those most frequently affected by RA, the aforementioned health threats posed by this disease and the potential real and hidden costs to society from this disease by affecting mainly people in their working years who would be most likely to also be raising children, one would anticipate that early, aggressive and multi-faceted interventions would be widely available. The Canadian Consensus Statement on Early Optimal Therapy in Early RA acknowledges that joint damage and disability occur early in RA and early diagnosis and treatment is desirable for best long term outcomes (Bykerk et al., 2004) Treatment involves a balance of rest and exercise, adequate nutrition, physical measures, drugs, and sometimes surgery (Altman, 2013). The present state of these interventions and delays in early intervention are discussed in the next two sections.

Though the focus of this study is on non-pharmacological management, background information is included in the next section to give a fuller understanding of the options available for treating RA. This provides a fuller clinical picture of what challenges may be facing the individual living with RA and compares the overall levels of evidence comparing pharmacological and non-pharmacological treatments currently available for RA.

1.3 Pharmacological RA management

Pharmacological agents to treat RA, must be approved for use with a federal licensing or approval body in most countries. To get this approval, medications must have completed an approved drug style study or multiple studies of this type, typically an RCT, in contrast to non-pharmacological interventions. These non-pharmacological agents may, or may not, require additional approval for use. In the United Kingdom, this includes the approval of NICE (National Institute for Healthcare and Excellence) if they are to be included in recommended disease treatment guidelines.

1.3.1 Anti-inflammatory medications

The management of RA via pharmacological means has advanced dramatically over the past two decades. Historically, treatments evolved from originally treating solely the inflammation of the joint, using anti-inflammatory medications, alone (Gabriel et al., 1999). In North America, non-steroidal anti-inflammatory (NSAID) medications are the most widely used, with some limited use of oral and injected steroid medications. Anti-inflammatory medications might include ibuprofen or naproxen (Radner et al., 2012). These medication pose potential risks and can have adverse effects including dependence, internal bleeding and increased risk of stroke (Lindhardsen et al., 2012). Cox-2 inhibitors

other than Celebrex have been removed from public circulation given the elevated risk they pose for cerebrovascular injury (Varas-Lorenzo et al., 2011).

In terms of steroid medications, injections cannot be done. There is an elevated risk of tendon rupture for up to two months after administration (Woon et al., 2010). These injections are done right into the joint, and they can be extremely painful for some patients. Oral steroids, something more commonly used outside of North America for treatment, may result in osteoporosis (Coulson et al., 2009), organ damage (Ruiz-Irastorza et al., 2014), and in some cases, cognitive issues (Fietta et al., 2009).

1.3.2 Disease modifying anti-rheumatic drugs (DMARDS)

As the disease mechanisms leading to inflammation and joint destruction in RA became better understood, the use of disease modifying anti-rheumatic drugs (DMARDS) became more commonplace. These drugs were prescribed with the intent of not solely treating the end result of the rheumatoid arthritis chemical cascade of reactions, the inflammation, but stopping or slowing the process of the disease. These drugs have included gold injections, sulpha based drugs such as sulfasalazine, Plaquenil and methotrexate.

These medications also come with potential adverse effects, some considerably more serious than those of the anti-inflammatory medications. Methotrexate, perhaps the most widely used DMARD in North America, has a variety of adverse effects. The clinician drug monograph notes that organ failure and even death are rare, but potential adverse effects, of taking this medication (Pfizer Canada, 2011). Monthly monitoring of liver enzymes and other blood work is done for at least six months with a varying level of monitoring for life. In the case of Methotrexate, better disease control is gained from weekly injections,

typically self-administered, versus taking the medication orally every day (Pfizer Canada, 2011).

1.3.3 Biologics

Biological medications are the newest form of pharmacological intervention for RA, and should be considered analogous to a person undergoing cancer treatment receiving chemotherapy with the primary difference being the person living with RA receives the intravenous treatment, presently on a once per month frequency, for life (Pfizer, Canada, 2011). These medications are purported for use in people with moderate to severe RA that has not adequately responded to other medications.

While some biologics, such as Xeljanz, may be also available in oral form, the vast majority are taken via an intravenous infusion, carried out in a clinic on a monthly basis, with the procedure taking anywhere from and hour to three hours (Pfizer, Canada, 2014). Current examples of biologics include: Actemra, Cimzia, Enbrel, Humira, Kineret, Orencia, Remicade, Rituxan and Simponi. Given their trademarked status, the cost of these, even in a socialized national healthcare system, can be prohibitive for many people. In Canada, the cost for a drug such as Orencia is 2000 Canadian Dollars, or 900 British Pounds, per month for individuals without a private drug plan (Patented Medicine Prices Review Board Canada, 2015).

1.4 Barriers to pharmacological management of RA

In addition to the cost and time taken for the monthly infusions when taking biologics, additional time must be taken to have blood work regularly checked, not only to look for markers of the drug effectiveness, but also potential harm. There is high risk of secondary infections as a result of significant immunosuppression, elevated risk of certain types of

cancers, such as lymphoma, and a need to ensure there has been no previous or current exposure to tuberculosis, involving additional testing prior to taking the medication as this type of medication may activate dormant tuberculosis (Pfizer, Canada, 2014).

It is further noted that many people diagnosed with RA may have a multitude of medications to address their disease. In this therapist's experience, it is not uncommon to have a person administer weekly injections of Methotrexate, take folic acid daily, report to an intravenous clinic once per month for their biological medication and also have prescription anti-inflammatory medication on hand in the event of a flare in symptoms. While there are a variety of growing and more clinically effective options available for people living with RA, it should be noted there are barriers to treatment outside of complexity of the therapeutic regimen as described here.

These barriers include the aforementioned medication costs, and time pressures for people of working age required to attend both blood draws and infusion appointments. In North American private drug plans will dictate whether or not they will cover one of the costlier biologic therapies, and often not fully. Furthermore, certain conditions must be met, such as only after a patient has failed on multiple DMARDs, typically a matter of months per medication trialled. All of these barriers can reduce the adherence to a prescribed medication protocol and reduce not only the effectiveness of the medication, but also fail in ever getting effective symptom control if the disease symptoms are not abated early and effectively enough. As previously noted by Bykerk et al. (2004), early intervention and symptom control is desirable given the early joint destruction and disability that can ensue in the earliest stages of RA.

Adding to these barriers is access to Rheumatologists, the internal medicine specialists most familiar with diagnosing and effectively treating RA. Though a Primary Care Physician can prescribe medications for RA management, the Rheumatologist typically will prescribe the biologics and come up with a combination of medications to form the proposed medical management of the person living with RA on a case-by-case basis. Though early intervention, including early access to Rheumatologists is recommended as a best practice (Bykerk et al., 2004), many people do not have access to such treatment for a variety of reasons.

In addition to there being a growing demand for Rheumatologists, there are a growing number of Canadians without a family physician (College of Family Physicians of Canada, 2007). The family physician and the emergency room are the two primary means of accessing the Healthcare system in Canada, meaning that without access to a family physician, most will either delay seeking treatment, or be turned away as a non-urgent case at a hospital. As a result of the current gatekeeping situation that exists, many do not get a rapid diagnosis and initiation of treatment of RA for a considerable amount of time from first symptom onset to diagnosis. Some sources indicate that this delay could lead to permanent, irreversible damage in a matter of months, and that the optimal time to commence with RA interventions is within the first two years of symptom onset (Emery, 2002).

1.5 Non-pharmacological management of RA

In contrast to pharmacological, non-pharmacological management of RA has not changed dramatically over the past two decades. Most interventions are outside the typical physician practice and include a variety of modalities and media. Most of these interventions are

provided via occupational therapists, physical therapists and in some cases, lay people. The one exception to non-pharmacological treatment of RA being outside of the typical physician range of practice is surgery. Subsections 1.5.1 through 1.5.13 describe the various non-pharmacological interventions presently available to people living with RA.

1.5.1 Surgery

Given the advent of biological therapies and increased treatment options, surgeries to address joint deformity and joint destruction are reported as becoming less prevalent in RA management (Goodman, 2013). Types of surgery to address joint damage secondary to RA includes removal of the synovium or synovectomy, joint resection, removal of part of a bone via osteotomy or repair of soft tissue structures via arthroscopic procedures (Altman, 2013). More severe damage may result in surgical fusion of an unstable joint via arthrodesis or conversely, the complete replacement of a joint via joint replacement or arthroplasty. It should be noted that surgery can be done while RA disease is active. However surgery will only be successful if disease activity can be eventually controlled.

1.5.2 Rehabilitative methods

The more common forms of rehabilitation for people living with RA include thermotherapy, laser, acupuncture, provision of assistive devices, provision of orthoses, mind-body approaches, dynamic exercise prescription, targeted hand exercises, hydrotherapy and cognitive-behavourial therapy. In a critical review of rehabilitative interventions for RA (Hammond, 2004), the most effective short-term interventions were comprehensive occupational therapy, orthoses and mind-body approaches in terms of maintaining function. Over a longer time, a one year period in this review, the following were found to be effective in reducing pain and maintaining function: patient education on

joint protection using behavioural approaches, dynamic exercise, targeted hand exercise, hydrotherapy and cognitive-behavioural therapy in those with poorer psychological status.

Critiques of many of the presently used interventions used in RA treatment are that they often have small sample sizes, most trials include only those with moderate to severe RA and that relatively little is known about those receiving earlier rehabilitation, which is becoming a more common practice (Hammond, 2004). Recommendations frequently include the need to conduct well-developed clinical trials with sufficient sample sizes as well as recruiting people with earlier disease and having patient-centred outcomes.

The following subsections include available evidence for commonly used rehabilitation modalities to treat RA, with a separate section regarding joint protection, as this is the primary of the focus of this study. What follows is a description of what is available as the bulk of the non-pharmacological treatment options for people living with RA. The following review briefly looks at the evidence supporting the use of these rehabilitative interventions, concluding that on the basis of the available evidence, there is perhaps the most favourable, though still limited, body of evidence supporting the use of joint protection techniques as a non-pharmacological intervention for people living with RA.

1.5.3 Thermotherapy

Thermotherapy, or application of heat or cold, has perhaps been one of the longest established means of treating RA symptoms. There are a multitude of studies published, arguing over the superiority of heat versus cold. Overall, it would appear that the bulk of the literature is quite inconclusive regarding this modality, particularly when considering the work of Robinson et al. (2002), undertaking a systematic review of the literature on thermotherapy use with RA. These authors conclude there is poor quality of available

studies. There is no long term benefit to this intervention, and in other studies reviewed, no statistically significant difference in measured outcomes, such as hand function.

1.5.4 Laser

Though a recent study by Carolina et al. (2013) states use of low-level laser therapy (LLLT) may be effective in reducing inflammation and inflammatory markers in people living with RA, it is noted that this was a histological study using animals. There is no mention in the study is functional measures were taken in terms of range of motion or other formal measures of function.

Older studies using human participants are less encouraging about LLLT use, but contain functional measures. A meta-analysis conducted by Brosseau et al. (2000) concluded that this therapy may be effective in addressing morning stiffness in the hand joints and could improve fingertip to palm range of motion. These were the only benefits seen with this meta-analysis. There were no other functional improvements. Brosseau et al. (2000) conclude that more study is needed to determine what best practices are in terms of laser application; dosage and duration, recommending that further randomised control trials (RCTs) need to occur.

This meta-analysis was repeated again in 2010, this time, Brosseau et al. (2010) concluded essentially the same findings, stating that there was still, a decade later, very limited evidence indicating that providing LLLT to people with RA was beneficial.

1.5.5 Acupuncture

Lee, Shin and Ernst (2008) conducted a critical review regarding the efficacy of acupuncture, stating that previous systematic reviews have been contradictory in their

conclusions and that in terms of RA, there has not been sufficient analysis specific to this diagnosis. A smaller scale review the same year, conducted by Wang et al. (2008) concluded that the evidence for efficacy of this modality was conflicting and both research groups recommend RCTs and rigorous control trials to further study this type of treatment. This sentiment is also reflected in cost-effectiveness studies of complementary medicine and RA. van Haselen (2000) indicates that though it is logical to show that complementary medicine is effective in clinical practice via RCTs, it may be advisable to collect observational data on costs, effectiveness and utility first, essentially making an argument for a pilot RCT before conducting a full RCT. The significance of a pilot study as suggested by Haselen (2000) is further discussed in section 1.9.3 of this chapter.

1.5.6 Provision of assistive devices

According to the American College of Rheumatology (2015), there are many competencies occupational therapists working in rheumatology are expected to be capable of, assistive device provision on a case-by-case basis being one of them as part of a treatment plan in working with a client living with RA. In an RCT Hammond, Young and Kidao (2004) found intensive occupational therapy did not improve health status, but improved disease self-management in people with early stage RA of 2.5 years or less duration. One modality used in this intensive occupational therapy was assistive device provision, but as participants received several interventions, the sole benefit of assistive device provision cannot be derived from this study.

Studies examining assistive device use indicate that the prescription and use of these may be effective in addressing not only specific functional complaints, but are also correlated with disease severity (Thyberg et al., 2004), (de Boer et al., 2009). In the Thyberg et al.

(2004) study, participants with more severe RA more likely to use assistive devices, and assistive device use remained stable for the year of follow up.

In the de Boer et al. (2009) study, findings included a low rate of abandonment of assistive device use and a high possession rate of assistive devices among participants living with RA. The rate of retention and abandonment was related to factors such as level of satisfaction and self-efficacy. These authors acknowledge that the definition and types of assistive devices are quite varied, in addition to their uses, and that more targeted studies on specific devices is required.

1.5.7 Orthoses

Provision of an orthoses, more commonly referred to as a splint or splinting, is a common intervention used in occupational therapy for clients living with RA. The American College of Rheumatology (2014) also recommends that occupational therapists providing interventions to people living with RA have competency in this area of practice.

Some studies have assisted in determining best practices in orthotic provision, such as an RCT recommending against resting splints as a routine treatment in patients with early RA (Adams et al., 2008). Conversely, other RCTs recommend use of working splints as a routine treatment to reduce wrist pain during activities (Veehof et al., 2008) and smaller scale studies on specific types of splints have been indicative of improved hand function (Zijlstra et al., 2004).

One of the challenges reviewing the evidence base of orthotics provision is the sheer variability of the type of orthoses available and the varying presentation of RA itself. In the Zijlstra et al. study (2004), there is no specific information provided as to the type of silver ring splint worn, or if all splints were from the same maker/manufacturer. Depending

on the source of the silver ring splint, there may be 40 or more permutations of the silver ring splint. Adding to this challenge is that many splinting studies contain small sample sizes, less than 15 in the aforementioned study, and most fail to include a control group. A few RCTs exist, looking at generically described working splints and resting splints (Adams et al., 2008), (Veehof et al., 2008) and at a more specific type of orthoses, such as foot orthotics. Woodburn et al. (2002) conducted a study of foot orthotics to address RA and conclude that these effectively reduce pain and increase functional mobility in people living with RA. Results were from over a 30-month period, considerably longer than most studies, including RCTs, regarding the efficacy of orthotic provision as an intervention for RA.

1.5.8 Mind-body approaches

These techniques may include meditation, yoga techniques, reflection and hypnosis. These also may include relaxation techniques, though several sources categorize relaxation as being more in line with the category of cognitive-behavioural techniques for treating RA.

Qualitative studies indicate that in self-management of RA, mind-body wellness contributes to effective self-management. These techniques are referred to by Shariff et al. (2009) as an important adjunct to biomedical care, and are acknowledged as part of broader concepts such as learning to live with an altered body, living with RA and feeling well (Sanderson et al., 2010). Given that when the concept of mindfulness is being studied, an individual experience, much of the work regarding this area of intervention with RA is from qualitative methods. In the case of a study via Loeppenthin et al. (2014), the authors studied the impact of mindfulness on physical well-being of people living with RA and found that mind body approaches were useful in not only maintaining a higher level of physical activity, but also

striving for what the authors describe as a transparent body and participation, pointing to experiences of sensations of wellbeing, liberation from restrictions and social participation on equal terms with non-arthritis populations.

1.5.9 Dynamic exercise prescription

Several studies appear to endorse a variety of different types of prescribed exercise protocols in people living with RA. Cardiovascular exercise is deemed not harmful and may have a modest benefit on outcome measures according to a recent systematic review (Baillett et al., 2010). More favourably, another systematic review on dynamic exercise and RA concluded that the majority of patients with RA should be encouraged to undertake aerobic and/or strength training exercise (Cairns and McVeigh, 2009). These authors further conclude exercise programs should be carefully tailored to the individual, particularly for patients with underlying large joint damage or pre-existing cardiovascular disease.

A recent review article by Cooney et al. (2011) goes further to support the use of exercise in client living with RA, stating that functional limitation, disability, comorbidities, and reduced quality of life are common in people living with RA, and that exercise training for RA patients has been shown to be efficacious in reversing cachexia, a form of involuntary loss of muscle mass in RA and is likely to reduce cardiovascular risk.

It should be noted, however, that not all forms of dynamic exercise receive support from the literature. Tai Chi is sometimes listed as a form of exercise suitable for clients with RA, but studies to date are limited in positive findings and have been critiqued for poor methodological quality. In a systematic review of the use of Tai Chi as a prescribed exercise for RA, Lee et al. (2007) conclude that available evidence is not convincing enough to

suggest that Tai Chi is an effective treatment for RA. According to these authors, the value of Tai Chi for this indication remains unproven.

A limited, and mixed methods study by Uhlig et al. (2010) claims that there were quantitative improvements in a small sample size of Tai Chi participants. The study of the efficacy of this form of exercise and its benefits may be more conducive to qualitative studies, such as has been done with mind-body modalities, than with RCTs and traditional qualitative studies.

1.5.10 Targeted hand exercises

Given that hands are both a frequently involved area of the body with RA and the hands are vital for interacting with the environment, targeted hand exercises are considered a specialized form of exercise in RA management. This intervention is largely supported by the literature, often with specific protocols being tested. For example, Manning et al. (2014) conducted an RCT and endorse a specific exercise program they report improves upper extremity disability, function, handgrip strength, and self-efficacy in people with RA, with no adverse effects on disease activity.

Likewise, a study supporting the use of targeted hand exercises was conducted by Robinson-Cima et al. (2013), and involved an RCT examining the efficacy on hand strengthening exercises on people living with RA related hand deformities. The conclusions of this study were that strengthening exercises for individuals with RA related hand deformity are beneficial to improve handgrip and pinch strength as well as function. Similar positive results on increased grip strength and function have be found in non-RCT studies comparing healthy participants and participants living with RA (Brorsson et al., 2009).

More dated critical reviews of the literature regarding targeted hand exercises for RA has called for randomized controlled trials with goal-specific exercise, measurement of outcomes appropriate to the goals, adequate sample size, and comparison with an appropriate control condition (Wessell, 2004). In contrast to this older review, not only have more recently conducted studies occurred that include controls and RCTs, but further studies challenging conventional approaches have been undertaken as well. One example is the work of Ronningen and Kjeken (2008) where it was concluded that compared with a traditional program, an intensive hand exercise program is well tolerated and more effective in improving hand function in comparison to traditional methods of hand exercise prescription in RA. Though an established form of intervention with a reasonable evidence base of efficacy on some outcomes, this still remains a means of non-pharmacological intervention that requires further study.

1.5.11 Hydrotherapy

The use of water as a means of exercise and pain management is another modality commonly used in the non-pharmacological treatment or RA. The hypothesized benefits of this particular modality include increased aerobic capacity, increased endurance, improved respiration and improved circulation (Salzman, 2009), though much of this has been shown to be anecdotal and earlier studies were short term, not specific to RA or lacking scientific rigour, such as having a control group.

More recent studies involving an RCT on hydrotherapy and RA concluded patients with RA treated with hydrotherapy are more likely to report feeling much better or very much better than those treated with land exercises immediately on completion of a treatment program. However, this perceived benefit was not reflected by differences between groups on mobility tests, functional scores, quality of life measures and pain scale scores

(Eversden, et al., 2007). This finding was also reflected in an earlier RCT study of hydrotherapy and RA (Bilberg et al., 2005). In this case hydrotherapy patients showed significantly greater improvement in joint tenderness and in knee range of movement in female participants. At follow up in this study, hydrotherapy patients maintained the improvement in emotional and psychological state only.

The European League Against Rheumatism (EULAR) recommendations for early intervention with RA concludes that in terms of hydrotherapy that there may be support for the use of hydrotherapy as a treatment adjunct to pharmacological interventions with RA, but this same group also concludes there is insufficient evidence to support a strong recommendation for the use of hydrotherapy to treat RA (Combe et al., 2007). To date, there is no conclusive quantitative evidence available examining the value of hydrotherapy for individuals with RA.

1.5.12 Cognitive-behavourial therapy

These methods of self-management use a variety of means to facilitate people living with RA to successfully manage the impact their disease has on their physical functioning, mental health, social life and ability to carry out their roles and preferred activities. These are often in the form of self-help and self-management programs that are offered in a group setting, such as via the Arthritis Association or Arthritis Society. These may also be offered through a specialized rheumatic disease service via the healthcare system. The primary difference in these programs is that lay people are most often used to teach classes via patient advocacy groups, versus therapists, if the program is being delivered via the healthcare system.

Many studies regarding arthritis self-management programs have been conducted, including studies of widely used self-help publications, such as “The Arthritis Helpbook” (Lorig and Fries, 2000). However, it should be noted that in reviewing much of the available literature, that the bulk of these resources are not wholly developed for RA management in isolation, with several prior studies looking at all forms of arthritis, mainly osteoarthritis as well as chronic pain conditions such as fibromyalgia (Solomon et al., 2002).

That being said, there are some targeted studies examining the impact of cognitive-behavioural therapies on those living with RA. Hammond et al. (2008) studied people with RA and Psoriatic Arthritis, a variant of RA, using a parallel group RCT design and found that a modular cognitive-behavioural program was more effective than a standard information only program in terms of managing pain, reducing fatigue, improved function and improved self-efficacy. It is noted that in addition to this program including individualized goal setting and individualized identification of barriers to effective RA management, the program also included some of the previously discussed modalities with some evidence base, such as provision of splints and participation in exercise, as well as those shown to have limited quantitative support, such as participation in Tai Chi.

More recent RCTs have targeted specific outcomes on specific common complaints of those living with RA. Examples include the impact of this treatment on fatigue (Hewlett et al., 2011), and finding that this is an effective means of treating RA related fatigue. Beltman et al. (2010) conducted a meta-analysis regarding the effectiveness of this intervention in dealing with depression in people with RA and also concluded that this is an effective intervention in this regard.

Sharpe et al. (2012) approach the endorsement of these types of interventions pragmatically, stating that cognitive behavioural therapies have both a cognitive and behavioural

component, that little is known about which of these components may be more effective in isolation and that these need to be studied in isolation, as well as in combination. These authors conducted a blind RCT, expecting to find that the combined form of intervention was superior to the isolated components, but did not have this result. Instead, the combined cognitive-behavioural treatment did not demonstrate the broader benefits to participants as expected, nor was there evidence that the behavioural component of treatment in isolation produced effects that were superior to cognitive therapy alone. In fact, cognitive therapy was superior on several scales. Effect sizes for the interventions examined in this study that included cognitive components were similar to those reported in the literature, according to these authors. These study results suggest that cognitive therapy is an effective treatment for RA and need not necessarily include behavioural strategies.

1.5.13 Joint protection for RA management: A modality of best choice?

One specific form of cognitive-behavioural therapy is joint protection techniques, which is the focus of this study and will be discussed in further detail in this section. This particular form of intervention is also sometimes labelled as an educational-behavioural technique in the literature as well (Hammond and Freeman, 2001). As an intervention for RA, it is one that has been participant to multiple RCTs, unlike some of the other interventions reviewed thus far. Additionally, these RCTs are also largely favourable in supporting the use of joint protection techniques in treating RA.

In 2001, Hammond and Freeman examined the outcomes of an RCT of a joint protection program for people living with RA, looking at outcomes a full year after program completion. These authors concluded that in comparison to matched controls in a standard program, those being taught joint protection techniques at one year follow up had significantly improved adherence to joint protection techniques ($p=0.001$), reduced hand

pain (p=0.02), reduced general pain(p=0.05), reduced morning stiffness (p=0.01), fewer self-reported disease flares (p=0.004), fewer visits to their physician (p<0.01) for arthritis related issues, and better scores on a standardized activities of daily living scale (Arthritis Impact Measurement Scale, version 2, or AIMS 2, p=0.04). Other positive indicators included physical and psychological benefits. A trend towards a reduced swollen joint count, indicative of reduced disease activity was observed. Psychologically, improved self-efficacy and perceived control was also reported by participants. In examining the differences between the groups, the authors also conclude that not only does this specific type of intervention benefit several areas of function, not typically seen with the other non-pharmacological modalities reviewed thus far, but that a joint protection program may slow the progression of the effects of RA over and above the effects of drug therapy alone.

More recent evaluations of joint protection programs have included the examination of variations on the means of teaching joint protection programs (Niedermann, et al., 2010) and developing more effective communication guidelines for occupational therapists teaching joint protection techniques (Niedermann, et al., 2011). There has been exploration of how to improve and tailor the programs offered, but little to challenge the multiple benefits of them as previously outlined several years ago by Hammond and Freeman (2001).

This general acceptance of joint protection programs is evident in one of the most recent and comprehensive systematic critical reviews of non-pharmacological interventions for RA (Brosseau et al., 2014). This study finds that joint protection education is one of a handful of modalities that has stronger evidence in the available literature to support its use in clinical practice. However, this same review is critical of the general overall lack of quality evidence to support the use of non-pharmacological treatments in RA.

The Brosseau et al. (2014) study also discusses that the operationalization of some interventions is difficult, or impossible, to overcome based on how studies to date have chosen to categorize certain interventions. For example, while Hammond (2004) is previously quoted as recommending intensive occupational therapy, the study by Brosseau et al. (2014) astutely points out that occupational therapy is not an intervention, but a profession, and as such, it may be difficult to ascertain specifically what interventions comprise intensive occupational therapy.

Likewise, one of the challenges in determining what constitutes a joint protection program is that there is no agreement on a standard package of content for a joint protection program for managing RA. While there are standardized programs offered by the Arthritis Society and Arthritis Foundation in North America, these are not solely joint protection programs and they are also not solely designed for the RA population and their unique demographics.

An example of this challenge includes comparisons between what are referred to as standard Arthritis Self-Management Programs (ASMPs) and specific joint protection programs (Hammond and Freeman, 2001). The standard 8 hour ASMP program has 2.5 hours labelled specifically as joint protection with other topics being covered, such as medication management and energy conservation. This ASMP was compared to a different 8-hour program, covering joint protection as the only topic. In this RCT, although both forms of intervention were effective, the joint protection only group had a greater comparative benefit. For example, within-group analyses showed significant improvements occurred in range of joint movement in the joint protection only group versus the standard ASMP group. On average, this improvement was 7° at the wrist (from 102 to 109°) and 5° at the metacarpal phalanges (from 77 to 82°) and proximal interphalangeal joints (from 94 to 99°) ($p < 0.05$).

In reviewing what goes into the standard ASMP, or even a diagnosis specific program offered by a dedicated rheumatic disease unit, it could be suggested that much of the content in an ASMP could be construed as joint protection, though not necessarily labelled as such. For example, a class on exercise may be primarily outlining exercise, but also include hands on application of joint protection techniques when discussion is included around exercises that are less stressful on the joints. Likewise, a class in an ASMP about assistive devices may, in fact, be more about using joint protection principles than the introduction of the assistive devices themselves.

To address this issue, in future studies of joint protection programs, it may be useful to employ more user driven techniques where clients were also treated as content experts in conjunction with the occupational therapists who typically delivered the content in the teaching of these programs. This could not only assist with operationalizing what may be considered joint protection while developing the program content, but also ensure that a variety of expert opinions are included as to what constitutes joint protection, possibly also providing a more robust content.

Overall, this section indicates that RA is chronic, lifetime condition. There are a number of physical and functional issues that accompany this diagnosis. Several different treatment options are available, the most evidence-based of which among non-pharmacological options are joint protection programs according to the literature reviewed.

1.6 Health education and chronic disease

Given the challenges with lifelong management of RA, people living with RA should be educated in joint protection. In order to determine what effective joint protection education may entail, one must understand what best practices may be in relation to health education

and chronic disease. This should include an examination of theories of adult learning, current theoretical and practical chronic disease management practices and a culmination in examining the current state of chronic disease management using eHealth.

Given the typical demographics of the client living with RA, one is typically dealing with an adult client. As such, adult learning theory must be integrated into instructional design if undertaking to teach clients living with RA about managing their disease. Sub-sections 1.6.1 through 1.6.11 discuss theories of adult learning, current means of chronic disease management used by adults as self-directed learners and current uses of e Health resources of adult learners for chronic disease self-management. The relevance to RA and joint protection education is discussed.

1.6.1 Theories of adult learning

According to Knowles (1980), adults know their needs and, in a pragmatic way, pursue knowledge according to their needs. Adult learning theory is more commonly referred to as andragogy and belongs to a long history of educational pedagogies. American educator and theorist, Malcolm Knowles, popularized andragogy and is credited with the development of this theory. However, this concept was first described by Alexander Kapp much earlier, in the 19th century (Knowles, Holton and Swanson, 2005). Andragogy as a study of adult learning originated in Europe in 1950s and was then pioneered as a theory and model of adult learning from the 1970s by Malcolm Knowles (Zmeyov 1998), Fidishun 2000). The term was revived in the early twentieth century, in 1921, but did not appear officially in a dictionary until the mid-1980s (Knowles, Holton and Swanson, 2005).

Presently, the terms adult learning or andragogy are used interchangeably and are generally considered separately from other pedagogies and distinguished by a focus on adult learners.

Part of the focus of andragogy is the belief that adults learn best in interactive classrooms or environments with an emphasis on practical application of learning concepts. Adults also have different roles and responsibilities than younger learners, and may desire learning that does not require a compromise of family or work responsibilities. Merriam, Caffarella and Baumgartner (2006) state that Knowles' concept was an attempt to build a comprehensive theory of adult learning anchored by the characteristics of adult learners. In contrast to pedagogy, andragogy was defined by Knowles (1980) as the art and science of helping adults learn. He labelled andragogy as an emerging technology, rather than a theoretical approach to learning, which facilitates the development of learning for adults.

Part of being an effective educator involves understanding how adults learn best (Lieb, 1991). Andragogy, whether a theory or an emerging technology, holds a set of assumptions about how adults learn. Andragogy emphasises the value of the process of learning. It uses approaches to learning that are problem-based and collaborative rather than didactic, and also emphasises more equality between the teacher and learner. This is important to consider in teaching joint protection to adult living with RA. The learner may present with unique needs, given the aforementioned variability of disease presentation. Additionally, the learner may have specific concerns they expect the ASMP to address.

Conversely, a pedagogical approach may be described as a teacher dominated learning situation. It deals more with the theories of learning to teach. In this approach, often times, and the teacher does all or most of the talking in order to provide the content, dictates the pace of learning and students are viewed as more passive. An andragogy based approach to learning places more emphasis on what the learner is doing. This approach is more learner-centred than teacher-centred, and it is believed by those who apply the work of Knowles that this is how adults mainly learn. Historically, andragogy has been hard to classify. It has

been referred to as a theory of adult education, theory of adult learning, theory of technological adult learning, method of adult education, technique of adult education and a set of assumptions.

In the development of the concept of further defining andragogy as helping adults learn, Malcolm Knowles, in addition to being frequently credited with coining the term, is also credited with proposing five factors involved in adult learning (Merriam, 2001). These five assumptions underlying andragogy describe the adult learner as someone who:

- Is capable of directing his or her own learning, so an adult needs to be involved in the planning and evaluation of their instruction. Essentially, this is predicated on the belief that as a person matures, they move from dependency to self-directedness. (Self-concept)
- Has accumulated life experiences that provide opportunities to enhance learning and experience, including mistakes, provides the basis for learning activities. Adults draw on experiences to aid learning. (Experience)
- Has learning needs closely related to changing or emerging social roles as adults are most interested in learning about participants that have immediate relevance to their job or personal life. The learning readiness of adults is closely related to the assumption of new social roles. (Readiness)
- Is problem-centred and interested in immediate application of knowledge, rather than concerned about learning content-oriented knowledge. As a person learns new knowledge, he or she wants to apply it immediately in problem solving. (Orientation)
- Is motivated to learn by internal, personally relevant, rather than external, or environmental factor. As a person matures, he or she receives their motivation to

learn from internal factors, versus a child, who may be more motivated by the environment. (Motivation)

These five assumptions of Knowles link to the learning theories of other educational theorists. Merriam and Caffarella (1999) discussed three keys to transformational learning: experience, critical reflection and development. Experience, which is the second assumption in andragogy, is significant according to Merriam and Caffarella (1999) as it creates an effective learning environment for adults. Argote, McEvily, and Reagans (2003) indicate that experience is a critical factor in developing the learner's ability to create, retain and transfer knowledge. Critical reflection is the second key to transformational and self-directed learning. Reflection is another essential principle for effective learning experiences. For example, Garvin (1993) shares the importance of fostering an environment conducive to learning including time for reflection and analysis. This is important in teaching joint protection as the learner would be expected to problem solve and apply information, not simply learn it by rote.

Adult learners need time to contemplate their learning experiences. The third key to transformational learning is development and this corresponds to the third assumption of andragogy, of readiness, specifically to learn how to cope with new roles and responsibilities and contemplate the implications of these life changes. Merriam and Caffarella (1999) state that the ability to think critically, mandatory for transformation, is in itself developmental. If development is the outcome of transformational learning, then an effective adult learning opportunity needs to be created that will take personal development into consideration.

Knowles used these principles to propose a program for the design, implementation and evaluation of adult learning. Since the development of his theory, Knowles has additionally

acknowledged that the aforementioned principles he outlined did not apply solely to adult learners. Knowles recommends that no matter what the age of the learner, that curriculum designers would be advised to involve learners in as many aspects of their education as possible. Instead of being passive recipients, he proposes the creation of a climate in which learners can most thoroughly learn by active participation (Merriam, 2001). In fact, Knowles' main focus with the development of andragogy was the notion of material being very learner centred and the learner themselves be self-directed, or responsible for a significant part of the learning via active, versus passive, participation. As an individual living with a chronic long term illness, the participant in joint protection education needs to actively involved in their learning and self-directed.

In applying the first principle, that the adult learner is capable of directing his or her own learning, an adult learner needs to be involved in the planning and evaluation of their instruction. This includes the content developer demonstrating respect for the adult learner. This may take the form of not only taking interest in the input the adult learner may contribute, but also acknowledging the wealth of experiences that the learner brings with them.

In order to achieve this creators of adult learning resources are encouraged to regard learners as a colleague who is equal in life experience while also encouraging expression of ideas, reasoning and feedback at every opportunity. However, it is important to keep in mind that the adult learner is taking on a learning opportunity for a reason, and as such, is still likely developing skills and knowledge at a more introductory level than the course leader. However, with the theory and principles of adult learning in mind, one can facilitate the learning approach of the learner to move from novice to more sophisticated learning methods. This approach facilitates greater integration of knowledge, information and

experience (Fidishun, 2000), (Lieb, 1991). One caveat by Fidishun (2000) is that as self-directed learners, adult learners may resist learning when they feel others are imposing information, ideas or actions on them (Fidishun, 2000).

In applying the second principle, that the adult learner has accumulated life experiences that provide opportunities to enhance learning and experience, which includes mistakes, and provides a basis for learning activities, means opportunities need to be provided for learners to use existing knowledge. Adults like to be given opportunity to use their existing foundation of knowledge and experience gained from life experience, and apply it to their new learning experiences. As a content developer for adult learners one may need to find out about targeted learners, such as their interests and past experiences, including personal, work and study related. A course or content developer may also assist them to draw on those experiences when problem-solving, reflecting and applying reasoning processes. Additionally, content developers for adult learners may also facilitate reflective learning opportunities which Fidishun (2000) suggests can also assist the learner to examine existing biases or habits based on life experiences and move them toward a new understanding of information presented.

In applying the third principle, that the adult learner has learning needs closely related to changing or emerging social roles as adults are most interested in learning about participants that have immediate relevance to their job or personal life, it needs to be emphasized that adult learners want to know the relevance of what they are learning to what they want to achieve. One way to help these learners to see the value of their observations and practical experiences throughout their learning opportunity is to ask the participant to reflect on what they expect to learn prior to the experience, on what they learned after the experience, and how they might apply what they learnt in the future, or how it will help

them to meet their learning goals. Another means of increasing the perceived practicality of adult learning opportunities include providing some choice of content by providing two or more options, so that learning is more likely to reflect the learner's interests.

In stating that adults are goal oriented, it is believed that adult students become ready to learn when they experience a need to learn it in order to cope more satisfyingly with real-life tasks or problems (Fidishun, 2000). This use of real-life tasks or problems is the domain of practice of occupational therapy. This focus on managing problems with real-life tasks would also apply to a person living with a chronic disease, such as RA. In using this real life, goal-oriented approach, suggestions by Fidishun (2000) include:

- That the learning environment provides meaningful learning experiences that are clearly linked to personal experiences
- Provide real examples of functional issues of relevance.
- Ask questions that motivate reflection, inquiry and further study or even research

In applying the fourth principle, that the adult learner is problem-centred and interested in immediate application of knowledge, rather than concerned about learning content-oriented knowledge, it is recommended that the learning experience promote active participation by allowing the adult learner to try things, rather than simply observe. The learning environment should also provide plenty of practice opportunities with the possibility of ample repetition in order to promote development of skill, confidence and competence in the participant matter or topic being studied. The ability to practice tasks, see real world application to joint protection principles and repeat tasks where the person feels less mastery would be important in a joint protection program according to this principle.

In applying the fifth principle, that the adult learner is motivated to learn by internal, personally relevant, rather than external, or environmental factors, it is recommended that the learning experience be explicit about how what the student is learning is useful and applicable to the client population with which one is working. Part of the role of the facilitator role of adult learning experiences may, therefore, need to include leading the learner through inquiry, versus spending a great deal of time on facts, moving from a more structured to less structured learning experience and moving from more to less supervision. This also may require the facilitator to determine what an adult learner's motivation may be for undertaking a learning activity. The purpose of these suggestions are not to provide a haphazard approach to adult learning, but to facilitate an adult learner's movement towards more self-directed learning while fostering and understanding what the internal motivation may be to learn. Part of fostering this intrinsic motivation includes not only providing tasks that reflect interests, but also regular opportunities to provide feedback about performance, as in a more traditional learning environment. If delivering specific content, such as joint protection education, one may need to consult others living with RA about their expectations for content, prior to developing learning materials.

Given the five aforementioned principles, it is important to acknowledge that learning opportunities for adults exist in a variety of settings including formal institutions, a place of employment, as a recipient of healthcare services or in-home. It is important to acknowledge prior knowledge and experiences of learners, including their ability to recognize their own skills as lifelong learners as well as the variety of settings that someone may partake in lifelong learning (Merriam, 2001).

Considerations for adult development and learning must also include biological and psychological development, such as potential deterioration and disease processes that may

occur, and sociocultural and integrative perspectives on development (Merriam, 2001). While the most common reason for adults to place themselves in a learning environment is a life-changing event, once in that environment there are many factors that affect the learning experience. The most significant are the prior experiences and learning brought with them. These experiences may include:

- Life experience (including life altering events that impact cognition and emotions)
- Work experience (both paid and unpaid work as well as patterns of work habits)
- Previous adult learning experiences (both good and bad experiences that may impact how receptive the learner may be in future learning environments)
- Performance effectors, (including not only the learner's cognitive abilities, but external distractions in their personal life and physical tolerances which may change with age)
- Time between learning interactions

Given the aforementioned experiences, common motivations for adult learners may include career shifts, such as trying to find more meaningful work, maintaining competencies at work, managing personal and family health issues, developing soft skills, such as interpersonal skills, developing skills to deal with new family, personal or social responsibilities or personal development, such as learning something new. Much of adult learning that has been formally studied has occurred in a corporate environment involving a variety of training processes. Trainers/facilitators in such environments need to have a working skill set to meet the demands of fast-paced, changing environments. Expectations are for trainers to arrive not only with delivery skills, but also with design experience and application of learning theories in a variety of settings (Meyer and Marsick, 2003). The most significant trend that continues to make an impact on facilitators is the demand for the

incorporation of technology into the content and delivery of professional development (King, 2003).

In developing materials for adult learners, the professional development toolkit for developers should include:

- Developing objectives, selection of appropriate activities and designing evaluation activities
- An understanding of diverse clients and their different learning styles
- The ability to read the context, assess needs, and select or create appropriate mini-learning sessions that are often delivered as just-in-time learning
- The use of reflective practice skills to make sense of their situation, tailoring learning solutions to their own and other local learning needs, developing and nurturing collaborative communities of practice

Training for designers of adult education content is critical in five areas (Riddle, 2000). These areas include stimulating creativity, assessing innovation options, focusing on the recipient or learner, designing new services, and implementing change, require a broad range of skills on the part of the trainer or developer. According to Riddle (2000), development of trainers should include demonstrating multiple approaches to delivering the same information. This includes a variety of different types of learning approaches, including Action Learning, Experiential Learning, Problem-Based Learning and Self-Directed Learning.

1.6.2 Action learning

Action learning is a commonly used term in many discussions regarding adult learning in a variety of business settings. Action learning has been compared with project work,

learning communities and various forms of simulation used in management development. It has been more widely used for organizational problems (Yorks, 2005). Action learning is defined as an approach to working with, and develop people. It is a method which uses work on a real project or problem as the way to learn. Participants work in small groups or teams to take action to solve their project or problem, and learn from that action. A learning coach works with the group in order to help them learn how to balance their work, with the learning from that work (O'Neil and Lamm, 2000).

Components of action learning include creating action groups based on expert knowledge and learning from real world experiences. These are small groups, often consisting on 3 or 4 people. Emphasis is placed on diversifying these small groups so that each group is best equipped to contribute to the learning community. A learning coach is designated for each group. Together, the learning coaches also form a group. From there, a project group leader is chosen. Both the project group leader and the learning coaches act as organizers, facilitators and overall motivators for the action groups (O'Neil and Lamm, 2000).

Action learning involves learning from experience through reflection and action with the support group. It is important that the groups remain constant and have duration, meaning the opportunity to establish themselves over a solid time period (Wade and Hammick, 1999). During learning activities the emphasis is to draw on a diversity of knowledge and skills in order to complete a project. The learning coach also acts as an expert as well as a motivator and organizer. Learning occurs through ongoing reflection and action of the group members.

Supporters of this type of learning approach claim the following strengths:

- It enhances the way people communicate and interact with one another

- It can weave quality tools and behaviours into the fabric of an organization
- Participants will develop and use problem-solving and coaching skills
- It will develop an environment of openness and trust, and get conflict on the table
- It promotes a process used in forming groups, which can be used in future projects
- It promotes the opportunity to form balanced and diverse groups, which enhances the learning process and allow significant contributions to the learning community

Despite these strengths with action learning, there are also several disadvantages and weaknesses in selecting this approach in adult learning. Given there is a specific task or project to complete, there may be an ongoing struggle for learners to find a balance between accomplishing their task and learning from it.

Given that groups are typically small, it may be difficult to ensure consistency across groups and across sessions of any program, particularly if different learning coaches are being used and a wide variety of skill sets are represented among a group of learners. Just as individual skill sets may vary, so can personalities, leading to the additional challenge of managing varying group dynamics. Overall, while action oriented learning may have many strengths for a business environment, it is not without multiple challenges and may not be the learning approach of choice if attempting to facilitate individual chronic disease management, such as RA.

1.6.3 Experiential learning:

Experiential learning is a learning theory that is learner-centred and operates on the premise that individuals learn best by experience. One way to describe this theory is learning by doing. Experiential learning thus has the learner directly involved with the material being studied instead of just thinking and talking about that material. This involves a cyclic

process involving setting goals, thinking, planning, experimenting and making decisions, and finally action, followed by observing, reflecting and reviewing by both the learners and facilitated by the instructor.

Experiential learning uses participants' own experiences and their own reflection about their experience, rather than a lecture as the primary mode of learning. Experiential learning theory allows for the generation of understanding and allows for the transfer of skills and knowledge. This type of learning is deemed as particularly effective in adult education as it is suggested that this type of learning addresses the cognitive, emotional and the physical aspects of the learner.

The strength of experiential learning is that it theoretically builds on experience. This is especially important in adult learning because simply by living, adults bring experience to every learning situation they face. Experiential learning theory is also considered a holistic learning approach and is most effective when the learning has intrinsic motivation which is a common characteristic in adult learning. As described, this type of learning could be of value in chronic disease management as these types of conditions would often call for a holistic approach, impacting physical, psychological and cognitive domains, and a variety of experiences in managing their conditions. This is particularly significant in self-management of RA and joint protection, as the disease is a chronic one, requiring lifelong management and a holistic approach.

However this type of learning comes with its disadvantages and weaknesses. One weakness is that experiential learning theory does not take into account differences in cultural experiences or conditions. What may matter very much in one part of the world or to one cultural group, may not matter at all to another. Additionally, it is less clear where elements of learning such as goals, purpose and intentions fit into experiential learning theory, and

though centred on learner experiences, it may not help us understand and explain change and new experiences.

1.6.4 Problem-based learning

In problem-based learning (PBL), sometimes also referred to project based learning, learners work in groups to solve challenging problems that are authentic, and often, interdisciplinary. Learners themselves decide how to approach a problem and what activities to pursue. In this type of learning approach, the participants are given a problem to solve, rather than a project to complete, in contrast to action-based learning. Learners in a PBL environment gather information from a variety of sources in order to synthesize, analyse, and derive knowledge from it.

Supporters of this type of learning claim that it is inherently valuable because it is connected to something real and involves adult skills such as collaboration and reflection. At the end of a PBL exercise the learners demonstrate their newly acquired knowledge and are judged or graded by how much they have learned and how well they communicate it. In contrast to action learning, throughout the PBL process, the group leader's role is to guide and advise, rather than to direct and manage work, as more frequently seen with a learning coach in an action-learning environment.

Supporters of PBL also claim that its advantages and strengths include giving the learner a chance to work on real-life scenarios that would be implausible on a real scale. This might include simulations in restructuring large corporations, clinical scenarios where practicing with a real patient may be too dangerous or rare and large scale situations such as responding to a natural disaster. Other claims include that PBL allows for cooperative

learning situations which build teamwork and collaboration skills important in many adult learning situations.

However, PBL might not always be the best learning method when dealing with many different cultures and backgrounds because problem solving methods vary from culture to culture. Additionally noted is that PBL, as with the other learning methods, requires group work, which may not be conducive to all adult learning situations.

1.6.5 Self-directed learning

Self-directed learning is also referred to as informal and incidental learning. Informal and incidental learning is at the heart of adult education because of its learner-centred focus and lessons that can be learned from life experience (Marsick and Watkins, 2001). It is defined as the process in which individuals take on the responsibility for their own learning process by diagnosing their personal learning needs, setting goals, identifying resources, implementing strategies and evaluating the outcomes. Some claim that self-directed learning has been a widespread means of adult learning. In 1999 it was claimed by Rager (2003) that more than 95% of adults participated in self-directed learning and that at that time typical adult learners were spending an average of 15 hours per week on some form of a self-directed learning project.

There are three categories involved with self-directed learning: the goals, the process, and the learner. In an adult learning context, the goals are generally self-determined, as is the process. Self-directed learning can be enhanced with facilitation, particularly through providing resources. Motivation is key to a successful self-directed learning experience. Adult learners, according to supporters of the self-directed mode of andragogy are motivated by the opportunity to gain new skills, knowledge, and attitudes to improve their

performance with productivity, improve family life and health, enjoy the arts and physical recreation, participate in a hobby, or simply increase their intellectual capital.

The advantages and strengths of using this approach include learning becoming integrated with daily routines, learning is triggered by either internal or external motivation, sometimes both, it is an inductive process of reflection and action and it may also be linked to learning of others. Conversely, the main disadvantage or weakness of this learning approach includes the variability of learners being self-directed depending on the situation. They will not necessarily be self-directed in all situations. Additionally, not all adults prefer the self-directed option, and even the adults who practice self-directed learning also engage in more formal educational experiences such as teacher-directed courses. As it is an unstructured teaching environment, learners may be distracted by their own needs, assumptions, values, and misperceptions. Some research has shown that some adults are unable to engage in self-directed learning because they lack independence, confidence, or resources (Song and Hill, 2007, Frambach, et al., 2012).

1.6.6 Challenges in working with adult learners

Despite the different approaches to andragogy available and the perceived flexibility of adult learning principles, there are some challenges in working with adult learners. One of these potential issues include the possible need to unlearn old knowledge. This might include not only outdated information, but also challenging habits that have developed, and would be of particular concern in self-management program focused on chronic disease.

Additional challenges include the need to adjust class format based on learning styles, the potential for learners to be unable to focus on topics, particularly if the leaner has not undertaken any type of study for a while, and the potential for weak study or critical

thinking skills. Furthermore, the adult learner may be unfamiliar with goal setting and set unrealistic goals while also facing a variety of time constraints and additional commitments not typically experienced by the traditional learners. These issues, coupled with a potentially lengthy duration since last in a learning environment may result in low self-esteem, and lower probability of success.

1.6.7 Theories of chronic disease management

In addition to theories of adult learning being relevant to RA and joint protection education, so are theories of chronic disease management. There is more than one theory of chronic disease management discussed here, noting that as RA is a chronic disease that requires lifelong self-management. In the past 30 years, the Stanford Patient Education Research Centre, originally named the Stanford Arthritis Centre Education Office, has developed, tested, and evaluated self-management programs for people with chronic health problems. The first program developed by this centre was the Arthritis Self-Management Course, also known as the Arthritis Self-Help Course or aforementioned Arthritis Self-Management Program (ASMP), which became the prototype for all of the self-management programs developed using the Stanford Model. All programs are designed to help people gain self-confidence, in their ability to control their symptoms and how their health problems affect their lives.

The ASMP, and most other programs, are small-group workshops that are generally six weeks long, meeting once a week for about two hours. These programs are often led by a pair of peer leaders, meaning that they themselves have the same or similar health problems of their own. Groups are limited to 16 in order to facilitate sharing and problem-solving. The meetings are designed to be highly interactive, focusing on building skills, sharing experiences and support. The program is offered throughout the United States by the

Arthritis Foundation as the Arthritis Self-Help Course. It has also been offered in Canada, the United Kingdom, Australia, New Zealand, South Africa, China, Scandinavia and St. Lucia.

Once the Stanford Patient Education Research Centre develops a program, it is evaluated for its effectiveness through a research study. Typically, an evaluation study is one to four years in length. It is only after a program has been shown to be safe and effective through these trials that the Stanford Patient Education Research Centre releases it for dissemination. In addition to programs developed and tested at Stanford, a Chronic Pain Self-Management Program (CPSMP) was developed and tested in Canada with close collaboration with Stanford. Stanford holds the copyright for the CPSMP, and the program is currently available as it has been through the evaluation process.

The CPSMP is a workshop where people with different chronic diseases attend together. It teaches the skills needed in the day-to-day management of treatment and to maintain and/or increase daily living activities. The program has been adopted by such groups as the National Health Service of England, the Diabetes Society of British Columbia in Canada, Kaiser Permanente, and Group Health Cooperative of Puget Sound. It has been translated into Arabic, French, Chinese, Vietnamese, Norwegian, Somali, Bengali, Dutch, German, Hindi, Korean, Welsh, and Italian.

Given the rise in prevalence of other chronic diseases, the Stanford Patient Education Research Centre has also developed a similarly structured Diabetes Self-Management Program. The Diabetes Self-Management Program is a 6-week workshop for people with type-2 diabetes. It teaches the skills needed in the day-to-day management of diabetes and to maintain and/or increase life's activities. Originally developed and evaluated in Spanish,

it was translated into English and tested in a randomized, controlled study. It is offered extensively throughout the United States.

Programs are usually offered outside of clinical settings and are typically held in community settings such as senior centres, churches, libraries, and hospitals. Likewise, the Positive Self-Management Program is a seven-week workshop for people with HIV. Programs are also usually held in community settings. Like the ASMP, and other programs, workshops are facilitated by two trained leaders, one or both of whom are peers with HIV. Participants covered during the small group meetings are also similar in theme to the ASMP and include: how to best integrate medication regimens into daily life, techniques for dealing with difficult emotions, exercise, nutrition, communication skills, evaluating symptoms and treatments.

The literature suggests that one needs to consider these components in effective management of chronic disease (Wagner et al., 1996):

- Collaboration
- Personalised care plans
- Self-management education
- Adherence to treatment
- Follow up and monitoring

The research also suggests that programs that are successful in improving self-management have the following characteristics:

- Targeting
- Goal Setting

- Planning

With the Stanford Programs, there is a noted emphasis on self-management, so this requires some consideration of what self-management involves. The definition of self-management as developed by the Centre for Advancement in Health (Centre for Advancement in Health, 1996) states that self-management involves the person with the chronic disease engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes. Lorig (1993) one of the leading researchers in arthritis self-management, also states that self-management is about enabling participants to make informed choices, to adopt new perspectives and generic skills that can be applied to problems as they arise, to practise new health behaviours, and to maintain or regain emotional stability.

Building on the adult learning priniciples discussed thus far, in conjunction with an individual's motives to manage chronic disease and current practices of chronic disease management, a framework of interacting systems emerges that also fits within the theoretical components of the Model of Human Occupations (MoHO). The MoHO is a model, developed initially by Keilhofner in the 1980s, that seeks to explain how occupation is motivated, patterned, and performed and is a broad view of human occupation. Since then, other occupational therapists have also been involved in its further development, revision and refinement of the concepts. With the MoHO, Humans are conceptualized as being made up of three interrelated components: volition, habituation, and performance capacities (Keilhofner, 2008). Volition refers to the motivation for occupation, habituation refers to the process by which occupation is organized into patterns or routines, and

performance capacity refers to the physical and mental abilities required for skilled occupational performance.

MoHO is intended for use with any person experiencing problems in their occupational life and is designed to be applicable across the life span, so it is applicable to the the adult learner and previously discussed priniciples of adult learning. MoHO has also been applied with adults with chronic pain, children with attention deficit hyperactivity disorder, persons with traumatic brain injury, older persons with dementia, persons living with AIDS, and adolescents with mental illness (Alcorn and Broome, 2014), (Dugow, et al., 2012). It is, therefore, applicable in chronic disease management too.

The MoHO's occupation-focused framework aims to explain aspects of engaging in occupations and how illness and disability related problems arise (Keilhofner, 2008). The MOHO puts more emphasis on occupational performance than on the three performance components. The MoHO also considers how the environment can demand and offer opportunities for occupational performance, which will be shown later to be applicable to virtual environments as well.

The focus of the MoHO includes considering:

- The motivation for occupation
- The patterning of occupational behaviour/ performance into routines and lifestyles
- The nature of skilled performance
- The influence of the environment on occupational performance

This model views the human being as a system and describes the human system using systems theories (Keilhofner, 2008). Per the dynamic systems theory interaction between

the human as a system, the task and the environment result in occupational behaviour. Occupational performance results in health, well-being, development and change, therefore making it dynamic. The human system is constantly changing, unfolding and reorganising itself through engagement. The MoHO, therefore, offers a theoretical framework from an occupational performance perspective about the motivation, or volition, to engage in self-management for a chronic disease, given the functional or occupational issues that may arise because of having a specific diagnosis.

The theoretical principles of self-management used in the popular Stanford approach, are also mimicked in other proprietary, for profit and trademarked programs, such as the Flinders programs offered in the United States. These principles state that in order for self-management of a chronic condition or disease to be effective across the lifetime, the recipient of a program must know what condition they are living with. Recipients also have knowledge of their condition, are capable of following a treatment plan, sometimes referred to as a care plan that is agreed upon with their health professionals and actively share in decision making with health professionals. Recipients are able to monitor and manage signs and symptoms of their condition, equipped with tools to manage the impact of the condition on their physical, emotional and social life. These principles encourage adoption of lifestyles that promote health, promote the learner to have confidence and the ability to use support and resources.

The rationale for including these key components of self-management include that it leads to an improved partnership between the client and health professional. Working collaboratively identifies problems. Better, or more successfully, targeted intervention is a motivational process for the client and will lead to sustained behaviour change. Additional rationale for this approach include that it may allow measurement over time and the ability

to track change or improvement in health, as well as the suggestion that this approach has a predictive ability. That is to say, improvements in self-management behaviour as measured by a validated tool or scale, related to improved health outcomes, will generally show improvement over time.

Both the Stanford and Flinders Programs consist of a set of tools that are completed by both the client and the health care professional, often working together as a team. Both types of self-management programs use their respective tools to provide a formal, systematic approach to assessing self-management capacity and care planning. There are a wide variety of these tools available for measurement and planning. An example of some of the more generic tools used to assess self-management capacity may include: a Partners in Health Scale, Cue and Response Interview, a Problems and Goals Statement, a Chronic Condition Management Care Plan. In contrast, some of the less generic tools, focus on a specific condition, such as the Readiness to Manage Arthritis Questionnaire (RMAQ) in the case of the ASMP. However, in the case of an apparently more specific tool, such as the RMAQ, it should be noted that this is still a generic form of arthritis questionnaire, so this is not a tool unique to RA, but all forms of arthritis.

Regardless of whether a generic tool or a more disease specific tool is used in the administration of a self-management program, use of these tools enables the health professional and the client to identify issues, form an individualised care plan and a system monitoring and reviewing progress. An additional potential advantage of them is that these tools are available in word and electronic versions, potentially making them easier to administer and disseminate. Additionally advantageous to having electronic forms of the tools is that this is conducive to eHealth forms of chronic disease management, as discussed in the next section. However, as discussed in section 3.3.7 of Chapter 3, one of the issues

with the use of tools and current ASMPs, is not selecting one from the sheer number available, or the issue of selecting a generic versus disease specific measure. The primary issue is that in many cases, a validated tool is not being used, and in some cases, as this study has found, no tools are used on ASMP follow-up.

1.6.8 eHealth and chronic disease management

The following section discusses the current trends and uses of eHealth among laypeople, with special consideration of those living with chronic conditions and potential challenges in reaching this audience. This section reviews representative studies on eHealth and management of chronic conditions and concludes with an examination of representative eHealth study designs to date, including successes and failures in previous eHealth studies, which influenced the preferred study design for the VW medium used in the pilot RCT.

1.6.9 Current trends in eHealth use amongst laypeople

As of the end of 2013, the percentage of Internet users in the population of North America was 84.9% and predicted to continue growing (www.internetworldstats.com, 2013). According to the Pew Research Centre, this number had already increased to 87% as of mid-2014 (Pew Research Centre, 2014). With the trend of increasing use of the Internet in North America, laypeople are using electronic information widely for health management. For example, 35% of American adults report they have gone online specifically to try to figure out what medical condition they or someone else might have.

Additionally, Pew Research Centre (2014) reports one in five Internet users have consulted online reviews and rankings of health care service providers and treatments. Up to 72% of Internet users say they looked online for health information within the past year. The bulk of these users, 77% of online Health seekers report that they began their last session at a

search engine such as Google, Bing, or Yahoo. Another 13% of this group report that they began at a site that specializes in health information, such as WebMD®, with only 2% reporting that they started their research at a more general site, such as Wikipedia®. A further 1% report that they started at a social network site, not an information site at all, like Facebook® (Pew Research Centre, 2014).

The most commonly researched topics by laypeople are regarding specific diseases or conditions, treatments or procedures and information about doctors or other health professionals. A total of 18% of Internet users, or 13% of all adults online, have gone online to find others who might have health concerns similar to theirs. People living with chronic and rare conditions are significantly more likely to do this, as discussed in the next subsection. Tracking of specific health indicators, such as symptoms or the significance of laboratory results, is a common occurrence in the United States as 7 out of 10 adults in that country have tracked a health indicator for themselves or for someone else. This information appears to be shared somewhat openly as well.

Of those tracking health indicator information, 34% share their health tracking records or notes with another person or group, with 26% of Internet users have read or watched someone else's experience about health or medical issues in the last 12 months and 3-4% of Internet users having posted their experiences with health care service providers or treatments (Pew Research Centre, 2014). It is also noted that adding a cost to access information may be prohibitive to seekers of online information as 26% of online health seekers state that they have been asked to pay for access to something they wanted to see online. Despite this proportion of requests to pay for information on some websites, only 2% report that they actually pay money for information provided via the Internet (Pew Research Centre, 2014).

Among the general population of individuals using the Internet in America to obtain health information a proportion of these are people who have gone through a recent personal health change. One in five American adults say they experienced at least one of the following changes in the past year: gaining or losing a lot of weight, becoming pregnant or quitting smoking. However, these adults having these specific experiences are no more likely than other people to track their weight, diet, or exercise routine. Conversely, adults who have gone through another significant health change in the past year, other than weight change, pregnancy or smoking cessation, are 10% more likely than other people to track another health indicator or symptom (Pew Research Centre, 2014).

Additionally noted is an increase in the use of not only the computer to obtain health information, but mobile methods as well. As of mid-2014, 31% of cell phone owners, and 52% of smartphone owners, report that they used their phone to look up health or medical information and 19% of smartphone owners have downloaded an application specifically designed to track or manage health. This finding is of particular interest to those interested in trends related to young people and visible minorities, since these groups are significantly more likely than other groups to have mobile Internet access. As of mid-2014, 12% of adults 65 years of age and older, and 32% of those aged 50-64 years old, own a smartphone, compared with 59% of adults aged 30-49 years old and 65% of adults aged 18-29 years old.

1.6.10 Current trends in eHealth use amongst people living with chronic conditions

Available literature indicates that use of eHealth resources occurs among people living with chronic conditions, but that this varies somewhat from the general population of users. This varied use needs to be considered in developing a study using electronic or online media to deliver health information on chronic disease management. In addition to the

aforementioned higher incidence of people living with chronic conditions looking online for others with the same diagnosis in comparison to the general population, there are a wide variety of people living with a number of chronic conditions. According to the Pew Research Centre (2014), and specific to the United States, online users accessing health information electronically had:

- High blood pressure (25%)
- Asthma, bronchitis, emphysema, or other lung condition (13%)
- Diabetes (11%)
- Heart disease, heart failure, or heart attack (7%)
- Cancer (3%)
- Living with another chronic condition (16%)

Additionally reported by this group is that 45% of adults in the United States are dealing with at least one chronic condition. Of those who are living with two or more conditions, 78% have high blood pressure and 45% have diabetes. Internet access is lower than that of the general population seeking health information.

Unlike the reported 87% of the general population having Internet access, only 64% of adults living with one or more chronic conditions have Internet access. This would be an important consideration in using eHealth as a medium as there would obviously be a number of people living with chronic conditions who would not have access to this information. Furthermore, given the disparity in Internet access between the general population and those living with chronic conditions, it would be a greater proportion of people missed, approximately 20-25% more, if eHealth were the only option available to those learning to manage a chronic health condition.

Despite this disparity in Internet access between the general population and those living with chronic conditions in the United States, 53% of adults living with one or more chronic conditions have reported that they looked online for health information. Additionally noted is that people living with one or more chronic conditions are no more likely than other American adults to track their weight, diet, or exercise routine. However, they are significantly more likely to track other health indicators or symptoms and this likelihood increases among those living with more than one condition.

In terms of how this is reflected among those living with chronic conditions, the Pew Research Centre (2014) currently reports that 19% of American adults reporting no chronic conditions say they track health indicators or symptoms online in comparison to 40% of American adults with 1 condition tracking indicators or symptoms online and 62% of American adults with 2 or more conditions tracking indicators or symptoms online. This is considerably higher than the general population reporting a health change in the past year, even when factoring out weight change, pregnancy and smoking cessation.

One of the issues with chronic conditions and diseases are that they may often lead to disability over time. According to the World Health Organization, disabilities are an umbrella term, covering physical and mental impairments, activity limitations, and participation restrictions. Evidence suggests that people with disabilities face barriers in accessing the health and rehabilitation services they need in many settings (WHO, 2014). In terms of people living with disability, the Pew Research Centre (2014) states, 27% of American adults report that they live with a disability which interferes with activities of daily living, including:

- Serious difficulty walking or climbing stairs (15%)

- Because of a physical, mental, or emotional condition, they have serious difficulty concentrating, remembering, or making decisions (11%)
- Serious difficulty hearing (9%)
- Because of a physical, mental, or emotional condition, they have difficulty running errands alone, such as visiting a doctor's office or shopping (8%)
- Are blind or have serious difficulty seeing, even when wearing glasses (7%)
- Have trouble dressing or bathing (3%)

Despite the indication from the WHO that a disability may result in participation restrictions, the Pew Research Centre indicates that 54% of people living with a disability in America use the Internet and that 42% of people living with a disability have looked online for health information. This is not only a lower number of users than those living with one or more chronic conditions. It is more than 30% lower than the general population. Again, this would be an important consideration in using eHealth as a medium, as there would obviously be a number of people living with a disability who would not have access to this information. Furthermore, given the even greater disparity in Internet access between the general population and those living with a disability, it would be a greater proportion of people missed if eHealth were the only option available to those learning to manage a disability.

Given that chronic diseases, and disease-associated disability, are issues across the lifespan once acquired, the demographics of Internet use for health information across the lifespan should also be considered. Additionally, since older adults typically face significantly more health challenges than younger adults, a closer look at the incidence of chronic conditions and Internet use is warranted.

According to the Pew Research Centre (2014), a higher proportion of older adults are living with a chronic condition in comparison to the general population with 75% of adults 65 years of age and older, and 60% of those aged 50-64 years old are living with at least one chronic health condition, compared with 34% of adults ages 30-49 years old and 20% of adults ages 18-29 years old. The general increase of chronic condition prevalence with age is inversely proportional in terms of Internet use, with use decreasing with increased age as 54% of adults 65 years of age and older, and 77% of those aged 50-64 years old, use the Internet, compared with 89% of adults ages 30-49 and 94% of adults ages 18-29 years old using the Internet.

Despite the higher prevalence of chronic conditions in older adults, there is not the same higher use of health tracking online, as used across all age ranges for those living with chronic conditions. In America, 30% of adults aged 65 years and older, and 54% of those aged 50-64 years old have looked online for health information in the past year, compared with 67% of adults aged 30-49 years old and 72% of adults aged 18-29 years old. Given the lower Internet use of older adults, and the lower Internet use of older adults living with chronic conditions in comparison to other ages, this would be a group for which eHealth may be appropriate. However, the older adult living with a chronic disease also runs the largest risk of missing opportunities to access information if online methods are used to deliver education. It would be most effective to target younger populations living with a chronic condition. Both being younger and living with chronic disease are associated with being more likely to use the Internet as well as using it to track a health condition online. While those living with a chronic condition were less likely to use the Internet, they were more likely to use it to track their health condition.

1.6.11 Current eHealth studies

An examination of representative eHealth study designs to date is summarized here, examining successes and failures in previous eHealth studies, which may influence the preferred study design for this type of medium in future studies using a novel form of eHealth. Given the rapid rise of a broad number of resources that offer information, advice and peer support, a number of concerns are raised, first, regarding the quality of such resources.

Potts (2006) questions if the area of eHealth is progressing faster than eHealth research. One of the core challenges proposed by Potts (2006) is that if the research has not been completed to support the use of a particular form of eHealth, healthcare professionals may not be encouraging patients to use eHealth resources if the safety or evidence-base behind it is not yet known. Furthermore, Potts (2006) suggests that many of the resources developed have not included input from health professionals and also places a larger amount of information available to health consumers. This is referred to by Potts (2006) as the democratization of health information and places the health consumer or patient in a more powerful position and the general public, according to this author, is typically not interested in evidence-based medicine and makes an argument for the de-emphasis of RCTs and the traditional definition of emphasis on empirical evidence in evaluating eHealth systems and services.

Despite Potts' view, earlier studies have evaluated eHealth systems and services. A preceding editorial opinion by Gustafson and Wyatt (2004) indicates that not only are efficacy and quality of eHealth resources issues, but that more pressing concerns, including

safety, testing for appropriateness and usability, as well as sociocultural considerations, are important in development of eHealth resources.

One of the criticisms put forth regarding eHealth is that it is not a cure all, or panacea (Boulos, 2008). What is proposed by Boulos (2008) is that a combination of development of health informatics, for laypeople, health professionals and as a field in itself, needs to occur, in addition to methodologically sound studies, including better eHealth tools and resources. Additionally, Boulos and Maramba (2009) advise that in the development of eHealth project evaluations of VWs, the media form discussed in the next section, that researchers avoid the trap of comparative drug style studies, comparing more traditional eHealth media with VWs. This is not a criticism by these authors regarding researchers developing well designed RCTs to evaluate eHealth media, but a recommendation to avoid comparing one form of eHealth media as being superior or more efficacious in comparison to another. The suggestion by Boulos and Maramba (2009) is to view varied eHealth media as complementary or synergistic, not as competing with each other for dominance as the preferred media.

Despite this recommendation by Boulos and Maramba (2009), some studies have attempted this style of comparison within non-VW media, strictly looking at Internet based eHealth resources. In 2008 Wang et al. compared the use of online websites and online discussion groups. The study focused on participant perceptions of credibility and perception of similarity the individual felt to the message source, or homophily. People living with cancer were surveyed and tools used measured the degree of perceived credibility and homophily by participants of Internet based information resources and discussion groups specific to cancer. While these authors claim that the more homophilus, or similar to the participant's own experiences, a resource was, the more likely the participant was to act on the advice of

the eHealth resource. Despite this conclusion, what is also evident in reviewing the results of this study is that in comparing the information based website and the online discussion groups, that there was virtually no difference found in the overall likelihood for the participant to act on the advice provided by either resource, correlations of 0.52 for the website and 0.53 for the online discussion group respectively, though there might be a number of different strengths each resource may provide to users.

Instead of comparing one form of eHealth against another, other studies have opted to examine the overall efficacy and feasibility of use of eHealth, including management of chronic conditions. In terms of feasibility, one hypothesis is that eHealth may involve a lower cost to the health care system. However, Jacklin et al. (2003) indicated that using teleconsultations for patients in the United Kingdom did not lower costs to the healthcare system, but reduce costs to patients.

Another means of reducing costs to the healthcare system was also undertaken by de Jong et al. in 2009, testing the feasibility of a web-based counselling program for occupational physicians focused on employees on disability leave due to non-specific back pain or neck pain. In this study, the investigators reported that the absence of personal contact between the health provider and the recipient as viewed as a major barrier to use of the program by the employees. Additionally reported was a relatively low use of the program by the employees. The methods of data collection were a combination of qualitative and quantitative and the authors conclude that the information obtained, though not indicative of endorsing such a program as an equivalent alternative, provides an opportunity to not only measure attitudes of users towards the program, but also make possible improvements to the program.

One possible issue with eHealth resources is that there is the risk of providing an inflexible learning experience, as opposed to wanting to be able to deal with an individual, as noted in the previous study. However, a personalized means of delivering health care is possible in some situations and this has been studied for some time now, including the results of a small trial by McGarry, Jones, Cowan and White, conducted in 1998. In this case, the authors studied a multimedia system for personalised treatment of anxiety, and this system was found to be effective in improving anxiety and depression scores. Furthermore, these authors conclude that, like the study by Jacklin et al. (2003), the data collected provides an opportunity to make improvements in the eHealth resource studied.

Studies such as the Jacklin et al. (2003) one are important for testing eHealth initiatives as they assist in identifying common barriers to using eHealth, but also assist as pilot studies in forming the basis for RCTs of eHealth. A future RCT is one of the recommendations from the aforementioned study by McGarry, Jones, Cowan and White (1998). Despite the recommendation by Potts (2006) that these are not necessary in eHealth, RCTs have been taking place, producing results and recommendations for the development and study of future eHealth focused studies.

Within the field of rehabilitation, Russell et al. (2011) completed a single blinded RCT and concluded that the outcomes of tele rehabilitation were no clinically different that conventional in-person therapy session attended with a physical therapist. In addition to the conclusion that this form of eHealth was effective, the authors suggest that this form of rehabilitation allows access to an alternative form of high quality rehabilitation, not often possible for individuals to attend living in remote or rural areas.

A Canadian RCT of individualized chronic condition support using eHealth was undertaken by Holbrook et al. (2009), investigating the efficacy of individualized electronic decision support and reminders on participants living with diabetes in the community. The results of this RCT found that not only was the process of care improved between the physician and the person living with diabetes, but that this form of eHealth also improved some of the clinical markers indicative of effective diabetes management.

Additional points made by this study's authors include that this RCT was an eHealth study taking place in the community, that at the time of writing there was very little research done to date on eHealth in Canada, and that overall, eHealth studies are complex to develop, to implement and to evaluate. Given the combination of the complexity of such studies and the authors' own reports of study limitations, such as improvements seen on only some clinical markers, but not others, these authors recommend proceeding with caution in using individualized electronic decision support and reminders in people living with diabetes in community settings.

This study's findings are generally positive, but appear to only weakly endorse the use of eHealth for this purpose. Potts' (2006) perspective that rigorous clinically based study of eHealth may prove stifling to the development of eHealth resources may still not be seen as advisable in a clinical sense, but can be appreciated more when comparing this study's results with the conclusions of Potts (2006).

Some RCTs have also indicated that some forms of eHealth initiatives are not feasible, but may still have use in specific circumstances, despite not testable using an RCT. In an Australian community based study, Bensink et al. (2008) describe two previously abandoned RCTs and instead conduct an acceptability study of the use of video telephony

to support paediatric oncology palliative support in the home. The authors examined two previous RCTs on the same topic, concluding that one of major issues with the two prior studies was with difficulty with recruitment of families to be participants.

Some of the proposed issues with recruitment included consideration of the acceptability, or lack of acceptability, of the use of the video telephone system itself. As an RCT type of study was not feasible, these authors instead conducted an acceptability study, using a smaller number of participants to determine whether or not this form of eHealth was an acceptable form of support for families with a terminally ill child. These authors were unable to complete an RCT, but were able to conclude that this was an acceptable form of eHealth based on their results. One possible criticism of this approach by these authors is that it may have been more effective to conduct an acceptability study first, or a pilot RCT before launching a full RCT. An argument for such an approach is summarized in section 1.9.3.6 of this chapter.

1.7 Virtual worlds

A virtual world (VW) is a not yet studied means of self-directed learning regarding self-management of RA. The following section describes the features of VWs and work to date studying these features.

Though considered by some a 21st century creation coming to mainstream online technology only within the past decade, VWs have been previously described in the popular literature as a successor to the World Wide Web in Neal Stephenson's Snow Crash (1992), including the conceptualization of the term Metaverse, the culmination of multiple VWs, a term in present use in the study of VWs. Authors, such a Douglas Coupland, also described a powerful programming language, object oriented programming, conceptualizing a

language allowing the user to use a limitless number of virtual Lego blocks to construct projects that would run on any computer platform to create virtual objects with ease in the novel, Microserfs (1995). This programming language is parallel to those presently used in more flexible VWs that permit users to create their own content. Even earlier works, such a William Gibson's Neuromancer (1984), described VWs as part of the technological landscape, albeit in a rather bleak future.

1.7.1 Features of VWs

Most accepted definitions of VWs require that it be persistent, the world must continue to exist even after a user exits the world, and user-made changes to the world, such as objects created and left behind, should remain, even after the creator has exited the VW. As defined by Bell (2008), a virtual world is a synchronous, persistent network of people, represented as avatars, facilitated by networked computers. While participants may interact in real-time, time consistency is not always maintained in online virtual worlds. For example, in some VWs, time passes faster than real-time despite using the same calendar and time units to present in-world time. In the case of some VWs, the environmental controls are such that the user may control the position of the sun, or set the environment to permanent day or night time.

Some suggest that in terms of a base definition, a VW must have, at a minimum: 1. A shared space allowing multiple users to use the world simultaneously. 2. Be visually represented in space via a graphical user interface, typically via a screen of some sort. 3. A sense of immediacy, allowing interaction with the VW to take place in real time as experienced by the user. 4. Interactivity allowing the users to alter the world, develop content and build objects. 5. Persistence of the world and its objects even after users log off. 6. Interactivity between users, allowing users to form social groups and communicate.

VW is a general term. The virtual environment supports varying degrees of play and gaming. Some uses of the currently used terms include:

- Massively multiplayer online games or massively multiplayer online role-playing game, which are games in which a large number of players interact within a virtual world. The concept of massively multiplayer online role-playing games has spread to other game types such as sports, real-time strategy and others.
- Collaborative virtual environments designed for collaborative work in a virtual environment.
- Massively multiplayer online real-life games, also called virtual social worlds (Kaplan and Haenlein, 2009) where the user can edit and alter their avatar, allowing them to play a more dynamic role, or multiple roles.
- Serious Virtual Worlds or Serious Social Games where the emphasis of the world, or at least parts of the world, are focused on specific teaching and learning activities, commerce or scientific research and development.

1.7.2 Differences from other forms of virtual environments

VWs differ from other forms of virtual environments. Virtual reality technologies are presently available in several formats. One of these formats includes multi-user virtual environments (MUVEs) or VWs, such as the widely available Second Life® platform, presently being used for research purposes at Plymouth University and other postsecondary institutions, and which are the focus of this study. Other forms of virtual technology involve fully immersive rooms, more commonly known as caves, where the user experiences the immersive environment fully surrounding them. Such environments can be accessed using single or multiple users depending on the size and configuration of them. Other options

include the use of haptic technology, where the user wears an item, such as a glove or head mounted goggles, which provides feedback to the user.

VWs themselves have a combination of features that set them apart from other forms of virtual environments. Though other forms of virtual environments may have some of these features, and there are overlaps in what one virtual environment may offer, VWs have a unique set of features for them to be considered a VW, and not a different form of virtual environment. While most virtual environments would be considered immersive, have some form of graphic user interface and degrees of responsiveness in terms of reacting to the virtual environment; there are also the features of permanence and social interaction not typically seen outside of VWs. In other words, most virtual environments do not allow for real time socialization between users and are designed for solitary use only.

Additionally, when the user of an environment outside of a VW turns off or ends the simulation, the objects used and/or created by that user are no longer available for other users to view or interact with in the environment. In a VW, there is the possibility of object permanence, meaning that objects can be left for others to use and interact with if the creator of these objects, and the Terms of Service of the VW in question allows this to occur. Depending on the robustness of the environment being used, this may be a simple polygon, such as an inverted green cone, to represent a tree. In more robust environments, this could be a fully interactive display that allows the user to perform a variety of actions depending on how the creator has programmed and rendered a number of linked polygons.

1.7.3 Current studies on uses of VWs

As an emerging medium, VWs have been researched from a multi-disciplinary approach, including the analysis of basic standards for VWs and what may be learned from VW

development to date and development of a variety of best-practice methods in the creation and use of a VW platform. Beyond the basic application of how to teach individuals to best design and use a VW, other studies have examined inquiries targeted on the social sciences, business applications and education of students as well.

1.7.3.1 Study of VW design and standards

Some of the literature to date on VWs has examined the basic standards of VWs and the development of a global standard for all VWs, the development of MPEG-V (Moving Picture Experts Groups Virtual Worlds Standard), as part of a large European study involving over 100 experts in VWs (Gelissen and Sivan, 2011), (Gelissen et al., 2011). This particular project, called Metaverse1, not only has proposed draft standards as to what aspects of a VW are targets for standardization, but also has identified future challenges as well. In terms of targeted standards, this would include things such as cross platform ability to take an object from one VW and place it in another and the ability to have some sort of standardization of sensory input from the user being applicable in more than one VW, such as three left mouse clicks carrying out the same command, or series of commands, no matter which VW was being accessed.

In addition to the design of VWs and VW standards, there have also been studies on end users, including the proposal of a User's Bill of Rights (Stanton, 2010) in VWs, which mirrors an earlier work regarding the rights of players in VWs (Koster, 2000), but is more in-depth regarding the rights of users in terms of research participation. While the Koster (2000) paper deals more with issues such as fair play, codes of conduct and the concept of sovereignty, the Stanton (2010) work is more concerned with the potential of VW researchers to fail to use basic standards of informed consent when approaching avatars in-

world for the purposes of research. Stanton (2010) not only reiterates what would be considered basic standards of practice for conducting research with human participants, such as reviewing benefits, risks, ability to contact the researcher in person and the right to drop out of the study, but additional rights of users unique to VWs, such as the right to teleport if wanting to leave the study, the right to have the researcher provide a reasonably representative avatar of themselves if interacting with a participant in-world and the right to know why their particular avatar was selected for a study if the recruitment was done in-world.

On the whole, a common theme in both the Koster (2000) and Stanton (2010) works, and alluded to in the MPEG-V overview is the issue of privacy. While the individual is afforded a degree of anonymity as they operate an avatar, there are still a number of potential privacy issues that have also been studied in the literature. Educase (2010) discusses the use of Web 2.0 technology as being valuable, but potentially problematic in terms of increasing researcher liability for a variety of privacy violations. Educase (2010) advocates use of this type of media, which would include VWs, by disseminating institutional policies regarding what may and may not be disseminated using this type of media. In addition to not including VWs in the discussion of types of media that may be used by educators and researchers, the authors also fail to acknowledge that many organizations, even at the time of writing, do not have specific social media policies, much less one pertaining to VWs (Kashani et al., 2010). Conversely, Pridmore and Overocker (2014) suggest that VWs have to be considered a special case in terms of privacy, not only considering the Terms of Service of the VW, but a country's privacy laws as well, in the case of this study, the United States. These authors not only admit that the policies and laws have not kept up with the technology, but they also propose areas for further study and development in this area of VW standards.

They further challenge the concepts of virtual versus real persona and virtual property, which will be further discussed in the following subsection.

While both the study of VW standards and privacy rights in VWs are important to consider if one is conducting a study using a VW, other literature has also examined some basic issues regarding programming challenges which are also significant if using this media. Some basic knowledge of how the VW works is required if one is going to be building in it. Some literature includes basic application of more interest to VW designers, such as best practices telecommunication infrastructure studies in VWs (Verdot et al., 2011) or the use of generic architecture to improve the reusability of graphics from one platform to another (Berthelot et al., 2011).

However, other studies have examined the limitations of VWs based on current limits on computers themselves, based mainly on CPU power limits (Koster, 2005) as well as frameworks for generation of commonly used virtual objects, such as houses (Rodrigues et al., 2010). These types of studies would be of particular interest to someone learning to use and create in a VW as some basic knowledge is required about how to create objects if the researcher is also responsible for building the reusable learning objects in the VW.

Additionally, though the VW may, at first viewing, appear to be a "limitless" platform, it is still participant to limits imposed by CPU power and Internet connection speeds, among other things. Moore's Law states that the processing speed of computers will double every two years, meaning that computers are getting faster and more powerful, but the other side of this observation is that there are still limits set on what the maximum processing speed is at a given point in time. Some familiarity with Moore's Law, which dictates the present limits of computer technology, and the limitations posed on VWs as described by Koster

(2005), are an important consideration in understanding the background of this medium before committing to use a VW for a study. Understanding Moore's Law will also lead to an appreciation that in VWs, there will be some limits placed on how fast the world may appear, how many objects can be placed in a given location and how many participants may be in a given area as well.

In addition to the studies of basic mechanics of VWs, and the improvement of them to specific standards, other studies have focused on the mechanics of the user experience in order to improve it. One author (Swink, 2006) describes in some detail, the various forms of virtual sensation, stating that if developers of VWs attend to the various aspects of virtual sensation, the overall sensation that one has been extended to being immersed in the VW, that this could be used as a tool to create better virtual experiences. What is described by Swink (2006) is a means of accounting for the replication of some basic laws of physics observed in the real world, as well as exaggeration of other aspects of the real world to increase the level of immersion experienced by the VW user.

Sometimes, this application may involve improving the user interface, versus the programming itself. In examining the representation of a 3-D image, such as a virtual globe, Boulos and Robinson (2009) account for the 6.5-centimetre discrepancy that exists between the pupils and the issues this poses when viewing a flat screen. In this study, these authors propose a variety of solutions to improve the end user experience so that a more stereoscopic, or 3-D experience is encountered in viewing virtual maps and globes. These types of basic application studies are useful for the researcher of VWs. Specifically, these studies indicate to the potential researcher of VWs what some of the unique challenges may be in attempting in getting the full 3-D experience, or perception of immersion in using a commercially available VW platform.

1.7.3.2 Studies in the social sciences

Some work from social sciences may be relevant to this study such as use of language among early adopters of VWs and the culture of VWs users to create a collaborative virtual environment (Grantham, 2010). Other studies include examination of language use and language translation scenarios in VWs (Bretaudiere et al., 2011).

Studying how early adopters of VWs interact and how users of VWs use language may be useful if attempting to teach users unfamiliar with a VW, as well as useful if conducting an internationally based study where real time translation may be necessary between users. The importance of how language is often used by VW world users while in-world, adds value in terms of details to include in the design of a VW study, such as knowing what terms, and even slang, may be required to access a VW effectively.

As communication occurs in VWs, some authors view digital natives as having a culture and language of their own (Bittarello, 2008). Additional study has suggested as societies move progressively towards a more computer mediated culture, that VWs and cloud computing will shape human sociology in general (Boellstorff, 2010), and studies such as underrepresentation of diversity of race, ethnicity and sex in VWs (Sanchez, 2010) and effects of avatar gender and appearance on social behaviour in VWs (Banakou and Chorianopoulos 2010) become relevant. Such studies may help researchers understand confounding variables and issues to be avoided. For example, if the focus of a VW study was to look at a topic that some may feel uncomfortable about discussing in a group setting, such as sexual health, the program could be designed to be more individually based, versus group based.

Several authors (Ortwein, 2010), (Vicdan and Ulusoy, 2010), (Dean, et al., 2009) have studied the sociology of the virtual body. While Ortwein (2010) proposes a more philosophical approach regarding the redefining of the real self, versus the extended, or virtual self in the VW, Vicdan and Ulusoy (2010) use what they describe as a netonographic approach to support their work, essentially a digital form of ethnographic research as described by Creswell (2013). In this study, the authors became VW residents and lived virtually among them, while capturing video and audio recordings of their research participants. Like Ortwein (2010), Vicdan and Ulusoy (2010) concluded that VW users, may view avatars as an extension of the physical body into the virtual world. They proposed that the real and virtual self can influence each other in many different ways and that the medium of the VW may be more than a communication platform or a novel medium for on line visual experiences. They concluded that while some chose to reflect their own life in a VW, others may select a completely different experience, but overall, the avatar used in a VW itself, becomes the experience of the VW and that these were inseparable, whether in carrying out a fantasy, such as choosing an non-human form of avatar, or selecting an avatar that was similar to the individual in real life. Vicden and Ulosoy (2008) label this extension of the real body to the avatar body, and their influences on each other, as symembodiment.

In addition to the overarching concept of symembodiment, this study also found that when avatars are in a VW, no matter what type of avatar is used, there are some behaviours that are consistently seen in the real world as well. Despite not being restricted by a physical body, avatars being operated by their human counterparts will maintain eye contact and keep a specific social distance between themselves and other avatars. These avatar behaviours, if the hypothesis about the real and virtual body influencing each other is

correct, could have some potentially beneficial effects. This potential is discussed in the following paragraphs.

Dean et al. (2009) supports the hypothesis of the qualitative study carried out by Vicdan and Ulusoy (2010). In a study of the influence of avatar appearance on real world weight, these authors noted that individuals whose avatars began to engage in virtual exercise were more likely to exercise outside of a VW. Additionally, this study indicated that those participants who were exercising in real life were more likely to engage in exercise in a VW. Participants using thinner looking avatars were also associated with having a lower weight in real life. The study authors were also able to manipulate their own appearance, and they were able to raise and lower the level of obesity of the avatar of the investigator. A heavier investigator had respondents report higher real world weights in comparison to a thin avatar. In other words, participants who believed that they were also dealing with an obese individual, even in avatar form, were more likely to report their actual, and more likely, heavier weight, than an idealized one.

What makes studies specific to the sociology of the body of particular interest is that if one were to design a VW program aimed at healthy behaviours, it appears that some work to date suggests that avatar behaviour may influence real world behaviour and vice versa. If one were to design a program where exercise was a component, then one would want to create a display or area where an avatar could actively participate in that activity. Additionally, future studies could evaluate if an avatar's appearance changed over time as specific behaviours were being engaged in, such as an avatar becoming less obese over time if a program has a weight management focus. Another useful suggestion from these focusing on the sociology of the body regards the presence of the investigator and the investigator's appearance. In some cases, it has been suggested that in some cases, the

investigator may not want to have a virtual presence as an avatar in their own study choosing to be in the VW during a study. In some cases, if a study's demographics are quite varied, or if the avatar appearance is too difficult to create so that it looks more like a typical participant, it may not be advisable for the investigator to appear in the VW during the study of a program.

Some sociological studies have explored the less-desirable, even potentially harmful, aspects of VWs. These include the study of online relationships that may develop in a VW, which has been the participant of criticism on television and in print news (Woods, 2008), (Canadian Broadcast Corporation, 2009). A correlational study conducted with a relatively large sample of 236 participants by Kolotkin et al. (2012) found that while having a virtual relationship may threaten a real world one, there may also some therapeutic benefits to couples having issues with communication and that the relationship novelty offered in a VW may also offer some therapeutic benefit as well. Though this study purposively selected individuals who were in a simultaneous real world and VW partnership with different people, it highlights some of the potential risks to participants if the focus of a study were to focus on group interactions, versus primarily individual experiences.

One major area of reporting in the Kolotkin et al. (2012) study results that is of interest is the considerable demographic information collected in the surveyed participants. Demographics, as a specialized branch of sociological study, are important when attempting to match a media form to a specific group. As outlined previously in section 1.2.5 of this chapter, if one were to select a VW for use with a population of people living with RA, this would need to be a VW where the users would typically be from 20-60 years of age, median age 40, with a mix of both females and males, and predominantly female users if best matching the demographics of a VW to those living with RA.

There are a number of studies examining the demographics of several VWs. In 2008 and during the planning of this study, Spence (2008) concluded that at that time that there were essentially 40 VWs in existence with an additional 50 in various stages of development. At the time of final writing in 2015, this has expended to over 200 VWs, not including some that have already disappeared. As VWs, much like various forms of social media and Internet service providers, such as My Space and America Online, can become defunct, this number has fluctuated greatly over time. Some VWs, such as There®, Metaplace® and OpenLife® have come and gone, arguably at a much faster rate in comparison to some other forms of media.

In selecting a VW for a study, one must not only consider what types of VWs are available, in terms of specific themes and purposes, but also the typical users they appeal to, such as average age of the user, and what the features of the world may be, such as allowing or prohibiting content creation. In selecting a VW for a study, one must consider basic attributes, such as some VWs may appeal only to children, and not be suitable or appealing to adult users, while other VWs may contain adult content in some regions and only be accessible to adults as part of the Terms of Service for accessing that VW. Additionally, if a VW has been developed primarily for sports simulations, gaming, or music, it may not be appropriate for a health education simulation. Likewise, if the intent of using a VW is the creation of a content driven educational experience, a VW that allows the most flexibility of original content creation is a necessity.

It would appear with the sheer number of VWs and the need to identify the appropriate demographics, overall purpose and features would be a daunting task in terms of selection of an appropriate VW for a study. Fortunately, given that there are commercial opportunities to be realized in VWs, this data is already compiled by some companies. At

this time, some of the most up to date and comprehensive tracking of the demographics of VWs comes from KZero Worldswide, a company that specifically looks at marketing and business in VWs.

An example of one of this company's VW universe charts from 2015 is included on the following page in Figure 1. The chart indicates there are a limited number of VWs that allow for content creation, that are used by an audience averaging 30 years of age and older and do not fall into one of the overly specific categories such as gaming, sports, casual gaming or a mirror world.

In fact, out of all VWs listed, only six or seven fit the required age demographic within the context of people living with RA as indicated by the innermost ring of the graph, and of these six or seven VWs, two are mirror worlds, essentially virtual copies of points of interest of the real world, and one is categorized as a socializing world, a non-modifiable chat room with graphics. Of the remaining three or four worlds, listing content creation and user generated content (UGC) as their key features, two are closed or no longer available.

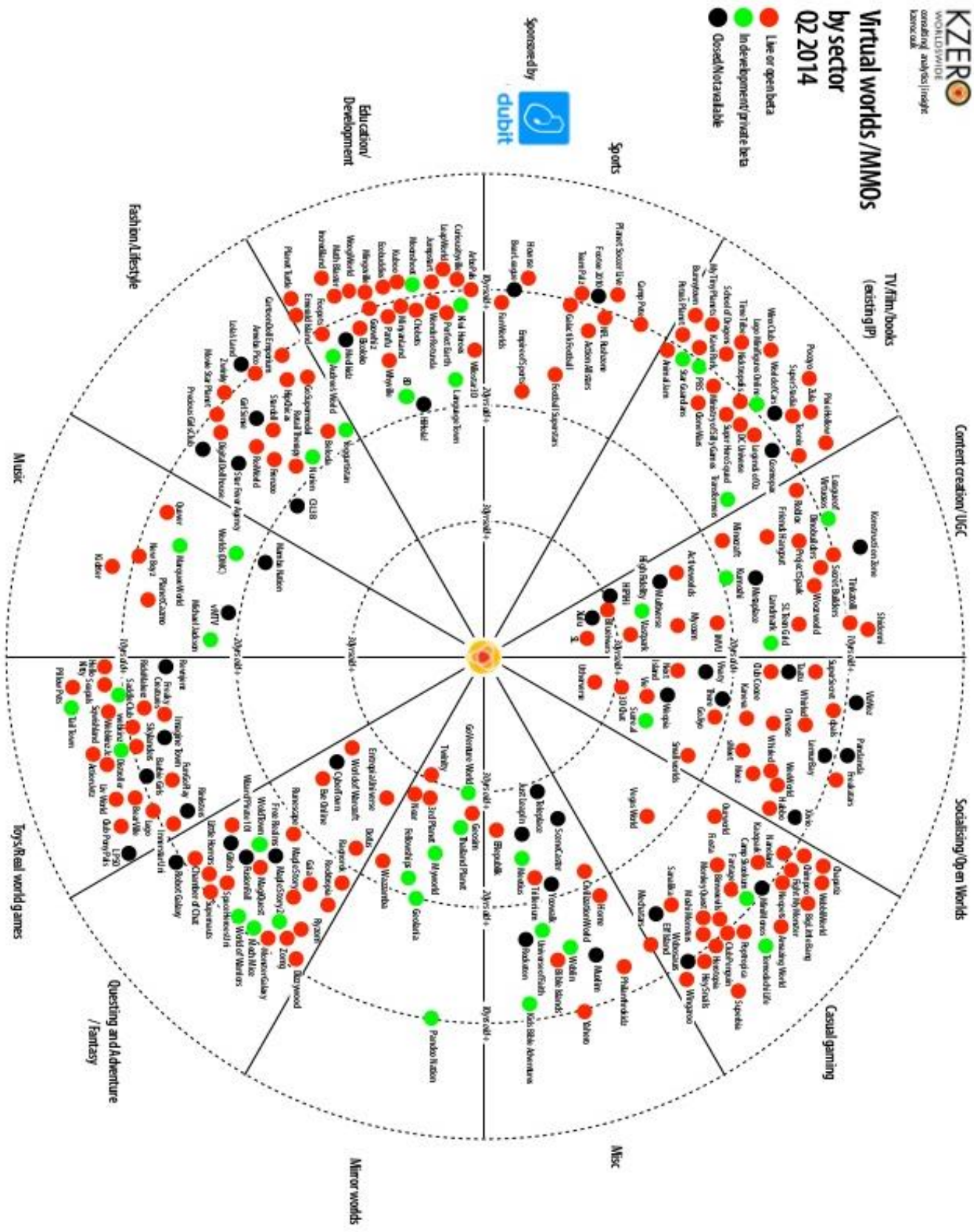

KZERO
WORLDWIDE
consulting | analysis | insight
kzero.co.uk
Virtual worlds /MMOs by sector Q2 2014
Live or open beta
In development/private beta
Closed/Not available
Sponsored by
dubit
TV/film/books (existing IP)
Content creation/ UGC
Socialising/Open Worlds
Casual gaming
Misc
Mirror worlds
Questing and Adventure / Fantasy
Toys/Real world games
Music
Fashion/Lifestyle
Education/ Development
Sports

Figure 1: Current VW Universe (KZero, 2014), reproduced with author permission

One of the most noticeable things in this graphic is that relatively few, if any, VWs allow for content creation. Additionally noted is that the demographics of most VW users tend to be younger, typically under 30 years of age. There is limited tracking in terms of which users are male and which are female, in part, because identifying sex is not a requirement in many VWs Terms of Service.

In selecting a VW with regard to most appropriate demographics and features as discussed here, the VW of choice would appear to be Second Life® (SL). This is one of the few VWs that allows content creation and has the very oldest demographics, which would most closely match those living with RA. The only other available VW matching these basic requirements is BlueMars®, though with a slightly younger average age. Both of these VWs were explored by this student researcher for suitability to use in a study regarding joint protection and people living with RA. This included using the VWs themselves and creating content in them. Given this exploration, there are additional factors, discussed in section 1.7.3.8 of this chapter that outline why SL is the present VW of choice for conducting the proposed study.

1.7.3.3 Studies of commercial and business applications

While some commercial and business studies of VW are more focused on economic aspects of VWs (Robinson, 2014), others that consider consumer behaviour and choices (Papagiannidis and Bourlakis, 2010) are relevant to this proposed study. For example, those that challenge the VW developer to create unique and tailor made consumer experiences not available in traditional retail environments could be transferrable to other VW scenarios, including customization of a virtual learning opportunity based on user

preferences. This is supported by others (Poncin and Garnier, 2012), (Peña, McGlone and Sanchez, 2012) which may be useful in avoiding potential pitfalls in the development of VW resources for end users.

The commerce sector has also proposed that if VWs are to be used, that some form of standardization also needs to occur. Studies have indicated that business training for a VW not only has to contain the requisite training that an organization, such as a business, would expect from an employee, but also the training to navigate, interact with and use the VW appropriately (Landers and Callen, 2012). Wurtz et al. (2013) go further, stating that in terms of standardization of practice in a VW, practices have to include not only real world applications, but also appreciation of rules, norms and relationship that exist in VWs. Essentially, these authors purport development of a hybrid of these two knowledge bases into a form of virtual management, or vManagement. Though these studies may appear to be solely business cases, they indicate that the user of a VW should not only be able to access that content programmed in the VW, they should also receive instruction on navigation and expected in-world content.

Commercialization of concepts developed in VWs also bears examination. VWs are being used by a number of companies for commercial purposes and government agencies also have a presence in VWs. Pre-experimental work to date includes, among many other commercial applications, the extraction of avatar facial gestures to create a commercially available, more interactive communication tool (Kamberi, 2012), the implementation of a Federal Transportation simulation that includes among its resources, the ability to simulate safety inspections (Schlicht and Schmidt, 2010) and in 2007 car manufacturer Mazda used a VW to launch a concept car.

In addition to real world business and government agencies having a VW presence, there are links between the real world and virtual economy. The global financial crisis in recent years has impacted the economy of VWs, particularly those with an economy and currency that can be purchased and exchanged for hard currency. A recent study involving business professionals previously involved in VW projects does not support the use of VWs in business, and possibly other areas. Respondents in this study indicated that VWs for business purposes might not be of particular use. The authors opine that these results may be reflective of economic conditions and may also be indicative of a level of disillusionment with VWs among experienced users (Bateman, et al., 2012). These authors indicate that while the majority of the 59 respondents in this study saw some value in using a VW for the purposes of conducting business, more than 41% indicated that they saw no value in using a VW in day-to-day practice. The suggestion made by Bateman, et al. (2012) is that VWs have never really lived up to their initial promises and references the Gartner hype cycle (Figure 2).

The Gartner hype cycle is represented by a graphic that depicts public expectations of new and emerging technologies in the form of a graph. Some of these are updated annually and produced by research and advisory company, Gartner Incorporated. Though there are several of these graphics available, the one depicted in Figure 2 is specific to VWs and indicates that the trough of disillusionment is in the past and the time at present is for a steady state of productivity. This would appear to contradict the 2012 study of Bateman et al. Although the participants in this study reported familiarity with VW use, there was no recording of how familiarity was measured. Further evidence that VWs are past the trough of disillusionment include the pending development of next generation VWs, such as project Sansar, to be discussed in Chapter 6. Additionally, Cearley, Burke and Walker

(2016) of Gartner Incorporated indicate that VWs will form at least part of the top ten technology trends for 2016 and Gilbert (2015) indicates that the rise of some adjunct technologies are occurring which will also support the steady state of productivity. These technologies would include 3-D printing and increased use of VR. Further evidence that this cycle is past the trough of disillusionment, in contradiction to Bateman, is suggested by the reduced, but stable populations, of more established VWs, such as Second Life®, as discussed in Chapter 6, Section 6.4.3.

This lack of familiarity is evident in summarizing issues with VWs as Bateman et al. (2012) report that the professionals consulted had, as their most significant complaint, that they had no control over anything that occurred in the VW, such as ability to deal with inappropriate behaviour. This is, in reality, one of the easier things to control as a VW administrator, depending on the VW being used, and indicative of a potentially low level of actual skills in using a VW. Though these participants indicate that in some cases, VWs might be of value if people with a business background were rebranding VWs so that they were more conducive to the business world, there also needs to be an acknowledgment that some background knowledge beyond the basics of navigating a VW should be possessed by a study investigator, and this is not done. However, this study serves as a reminder that a level of expertise in a selected platform is important prior to commencing a study using a VW. There needs to be attention paid to an organized approach to teaching and learning in VWs as well as what current educational practices are deemed effective by the current literature.

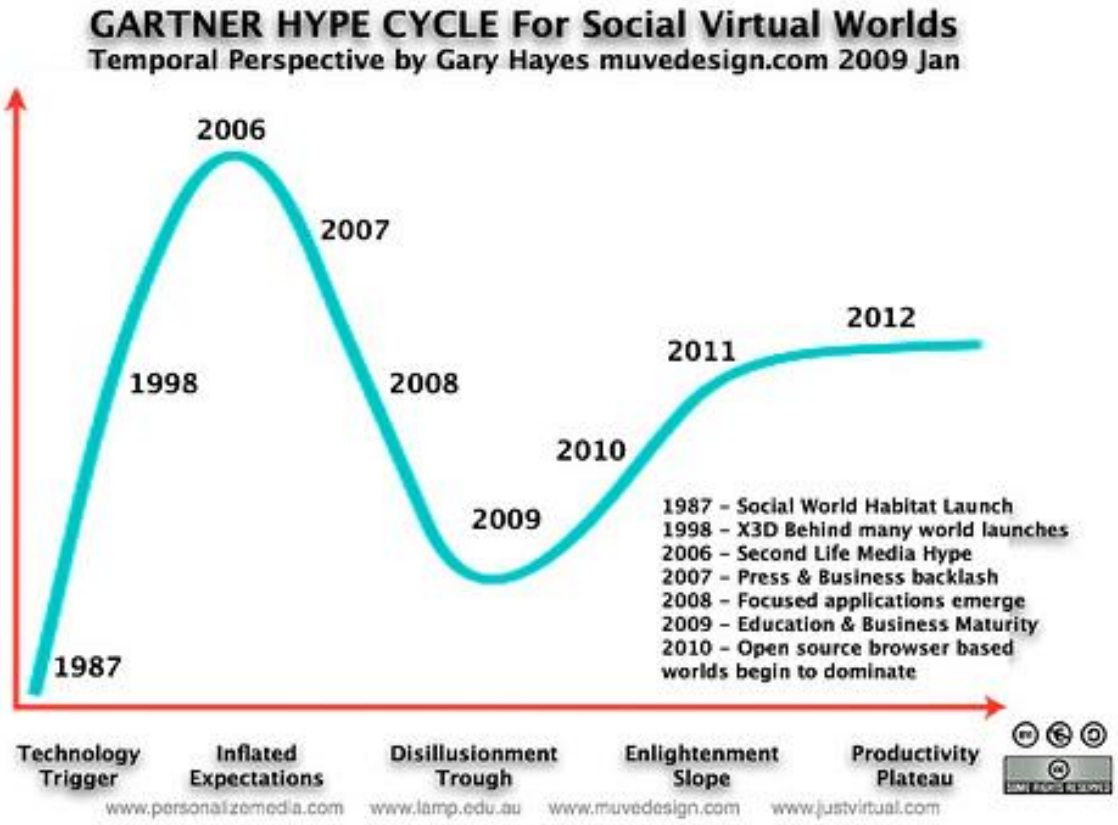


Figure 2 – Gartner Hype Cycle for Virtual Worlds, Gary Hayes (2009), permission via www.muvedesign.com/the-virtual-worlds-hype-cycle-for-2009, via Creative Commons

1.7.3.4 Educational uses of VWs

VWs have been studied for educational purposes and virtual learning has been supported in principle for enhancing student learning experiences for well over a decade (University of Holmberg and Huvila, 2008) as these experiences are purported as being more flexible and collaborative than more traditional learning experiences. Virtual classrooms have been investigated as a means of providing opportunities for students studying at a distance to become live participants in classroom discussions, even being able to demonstrate gestures such as holding up a hand to be answered via a live feed (Eastern Washington University, 2013).

A considerable amount of work in this area is critiqued as being primarily speculative and reporting what should happen in terms of research (de Freitas and Veletsianos, 2010).

However, other reviews of the literature in this area provide some examples of VWs offering opportunities for digital storytelling (Falloon, 2010), greater opportunities for experiential learning and improved contextualization of learning (Dalgarno and Lee, 2010) and leveraging authentic learning situations that may be impractical or impossible to create in a classroom setting (Dieterle and Clarke, 2007). In the following subsections on educational examples of VWs, what follows are a case studies, including proof of concept use of VWs in educational settings, assessment of educational initiatives in VWs and proposed frameworks for educational design in VWs.

1.7.3.5 Case studies and proof of concept use of VWs in educational settings

Though lacking in scientific rigour in comparison to RCT studies, many examples using a variety of VWs have been conducted to date indicating that a variety of projects in various stages of development exist in educational settings. These have not merely been presented as a new form of media without testing. Clarke et al. (2006) conducted an in-depth study on a VW called River City to teach middle school science in the United States. These authors use this case study to demonstrate not only is it possible to use this medium to teach, but also indicate that the design of the VW used must be sufficiently scalable to allow for curriculum changes and future growth.

An additional study using River City (Ketelhut et al., 2006) offers multiple suggestions as to how this particular case study not only resulted in a working VW for educational purposes, but several opportunities for assessment not typically observed in a traditional classroom setting, in part, because of the level of automatic recording afforded in this

environment. There is an attempt to quantify results by correlation, though is additionally noted that there is no control group for comparison.

Similar proof of concept simulations using VWs for educational purposes include case studies where NASA created a working library, the Neil Armstrong Library and Archives, in Second Life (Bohle, 2010), the creation of a virtual job interview scenario for students to practice skills in (Chodos et al., 2009) and a project named eLab City, designed as a platform for academics to carry out research in VWs (Novak, 2010). While much of this work involves primarily the creation of the program and some preliminary study of it, if any, it is still of use as part of a review of work to date in this area. Studies such as these indicate that it is at least feasible to provide specific, and in the cases reviewed here, widely varying content to varying audiences using a VW platform. Depending on the type of simulation being conducted, some of this work is amenable to further study, and this is suggested in some of the work cited, such as by Chodos et al. (2009) and Novak (2010).

1.7.3.6 Assessment of educational initiatives in VWs

Going a step further, and counter to the critique proposed by de Freitas and Veletsianos (2010), several other studies move beyond the construct and use stage of VW development and have tested educational outcomes in VWs. As education is a broad term, and in the case of formal education, spanning a number of years, what follows is a review of some of the studies to date involving educational setting studies using VWs from preschool students thorough to graduate level course work at the university level.

Hew and Cheung (2010) suggest in their review of empirical studies of VW use with students from kindergarten through grade 12 that though most studies to date have been purely descriptive, there was some evidence in the available literature to support the use of

VWs in education secondary to positive influences on self-efficacy, social interaction and specific learning outcomes. This finding is supported similarly in an additional study by Ketelhut (2007), particularly in the areas of self-efficacy and in examining specific learning outcomes.

An earlier descriptive study by Dede, Ketelhut and Ruess (2003) indicates that in middle school learners, pilot studies using lower achieving students and the VW to deliver science content were effective in achieving learning outcomes. More recent study by this same research group indicates that more robust investigations in the use of this particular VW has occurred (Ketelhut et al., 2010). The findings from this more recent study indicate that a VW can teach biology content infused with complex scientific inquiry skills as well, or even better, than traditional teaching methods at the middle school level. Additionally noted by these authors is that designers need to consider the purposes for designing a virtual environment and select a pedagogical approach that matches those purposes.

Studies involving slightly older participants, up to 18 years of age, also include positive findings to indicate that a VW may be a conducive environment to second language learning (Beals and Bers, 2010). In this case, a VW developed for use by youths, ClubZora®, was studied as students from 11 different countries used the world to participate in various learning activities. While the results of this study focused more on usage patterns, versus learning outcomes, the results indicate that usage patterns can be an important aspect in piloting a VW program and that this would also be useful information to include in a pilot study involving a VW.

This need to look at usage patterns during a piloting phase of a VW study is seen in the results of a study involving first year students at a polytechnic school in Hong Kong. In this

case, a VW was used to support first year orientation activities to new students (Penfold and Duffy, 2010). The program was not well received and the authors indicate that the orientation program was not as successful as envisioned, and in reviewing the methodology reported and issues listed, it is apparent that there was no piloting of this VW program prior to full scale use with an incoming class. Though essentially an unsuccessful venture, these authors suggest that this provided a valuable learning experience and feedback regarding why the program was not used by incoming students could be incorporated into future use, possibly creating a more positive user experience.

When piloting of a VW program has been conducted in educational settings, it appears to result in not only a better learning experience, but also adoption of the use of VWs by at least some first time users. In a qualitative pilot study by Campbell (2009) involving fourth year undergraduate students in an elective course, the use of a VW and a problem based learning were combined successfully by the investigator. Though a small pilot study as reported by the author, it is noted that half of the students, all of whom were new VW users, reported that they intended to use a VW, or similar medium in the future.

Likewise, a summative assessment using a VW in a post-graduate course in bioinformatics had similar findings involving a qualitative methodology and small number of participants (Olasoji and Henderson-Begg, 2010). In this study, students who elected to use a VW to complete their final project felt they had learned transferable skills, most indicated that they would continue to use a VW and all had positive comments about the process of using the VW. It is additionally noted that in this particular study, the students had no previous experience in virtual worlds, some having some limited experience in scripting, a form of programming behaviours into virtual objects, which will be discussed in further detail in the third chapter of this dissertation.

In terms of the bulk of the literature available on education and the use of VWs, it appears that most studies, though largely positive in their approach to VW use in education, are to date, pilot studies, and stand-alone qualitative studies examining a very specific aspect of education, or providing some descriptive data in isolation. This poses some challenges in examining what the proposed frameworks are for educational studies in VWs, which are briefly discussed in the following subsection.

1.7.3.7 Proposed frameworks for educational design in VWs

In discussing educational frameworks, it should be noted that these proposed frameworks are different than pedagogical approaches, as discussed in section 1.6 of this chapter. Frameworks, as discussed here, refer to overarching models of delivery of educational programs as they pertain to VWs.

Given the studies available on the use of VWs in educational settings, one would anticipate that the proposed frameworks for educational design in VWs may be quite varied, conflicting and lacking in specific recommendations. In some cases, this anticipation is warranted in reviewing the definitions provided regarding some the virtual learning models proposed. For example, in discussing virtually based learning Anderson, Annand and Wark (2005) refer to learning as being only offered as one of two models, cohort learning and learner paced. This is possibly an oversimplification of models of virtual learning, as this can also be modelled as synchronous, everyone showing up and learning at the same time, asynchronous, people showing up at different times and learning at different times, as well as a combination of these models, allowing some activities to occur at specific times while others can be paced to individual learning preferences.

Instead of taking this overarching approach of labelling e learning opportunities as one thing or another, more recent study has included the use of developing an educational framework examining specific educational constructs, such as task based learning in a VW (Bellotti, et al., 2009). In this case, Bellotti et al. (2009) support the use of VWs under a model of gaming while embedding serious, task-based learning experiences within the game. Much of this is predicated upon task-based learning theory, which will be discussed later as it falls under pedagogical approaches.

Other authors (de Freitas et al., 2010), build on the embedding of targeted tasks in a VW learning experience and propose a four-dimensional framework is required to appropriately design and evaluate learning experiences in a virtual world, with attention paid to lifelong learners in their work. The dimensions proposed by these authors include matching the learning activities and outcomes, considering current understanding of learner-centred theory, such as core principles of adult learners, the level of immersion required for the learner and the context of the learning itself, is it conceptual or applied, formal or informal? What is suggested by these authors is that more structured activities and more structured pedagogical approaches may be more effective in teaching and learning in VWs.

Other applied studies appear to support the theme of a problem-based learning (PBL) framework in designing of VWs for educational purposes. In a study using SL and a qualitative case study methodology, university students completed a PBL experience and had to then develop an activity that could be used with high school students (Campbell, 2009). Findings from this study indicated that some learners, all new to VWs, learned to use SL effectively and some indicated they would continue to use SL. All participants were able to complete the tasks assigned, indicating that PBL may be an effective framework for

use in a VW, though it is additionally noted that this was labelled a small pilot study by the author.

Likewise, O'Connell, et al. (2009) also appear to support a PBL framework in analysing collaborative behaviours of expert VW users, referred to as digital natives in this particular study. Participants were observed as they completed a puzzle task requiring collaboration. The authors were attempted to determine what skills and behaviours were unique to these experienced VW users that could be useful in future developments of VWs, concluding that the PBL experience observed could lead to better user led developments of specific VW features.

Given that the proposed study has an educational component, it is important to review what the current uses are of VWs in education. However, as this is also a study regarding a specific clinical population, and education regarding chronic disease management, it is also vital that studies regarding health education and VWs be reviewed as well. This was the focus of the previous section and indicates that various forms of andragogy as well as pedagogy are being considered in the present study of VWs for educational purposes, but that these are early studies, relatively few in number, and a consensus does not exist as to what the best fit may be with VWs, content and adult learners.

1.7.3.8 Current uses of VWs for health education

VWs have been used in novel ways to train future health care professionals, teach wellness strategies and address specific clinical questions with specific populations. Additionally, VWs have been studied for their potential deleterious effects as well as in innovative simulations that will be outlined in this section. This use of VWs differs in relation to how the older medium of VR was previously used, possibly because of the features of VWs that

VR does not have, as previously outlined in section 1.7.1 and 1.7.2 of this chapter. In order to appreciate these differences, a brief overview of some of the clinical and health educational uses of VR follows, prior to the review of current uses of VWs for health education.

1.7.3.9 Use of virtual reality (VR) in health education

In 2004, Weiss and Katz wrote about the potential of VR in rehabilitation. This was at the same time that VR was being critiqued by other authors as a potential research and rehabilitation tool, or possibly only a new toy (Keshner, 2004). It was during this time that video capture was being used as a rehabilitation tool (Weiss et al., 2004). While many studies reviewed by Weiss et al. (2004) had positive findings, it is noted that these authors do not acknowledge the methodological weaknesses of those studies, including a lack of control group, failing to control for internal threats, such as what might be considered normal recovery from a stroke in some studies and small samples. None appear to be RCT type studies and most are descriptive, looking for improvements in participants or comparing different forms of VR systems.

Despite the methodological weaknesses of the earliest studies and potential bias in reviews of these studies, many VR studies occurred in the years that followed, including multiple studies indicating VR would be of benefit in the treatment of stroke for functional rehabilitation (Oddsson et al., 2007), (Baheux et al., 2007), (Morganti et al., 2007), (Lamontagne et al., 2007), (You et al., 2005), (Stewart et al., 2007), (Subramanian et al., 2007). While some of these earlier studies included a control group, others continued to use very small sample sizes of one or two participants and some still did not have a control group and were mainly focused on comparing different types of VR systems or protocols

for using a specific VR system. A study by Das et al. (2005) included RCT design in analysing the effectiveness of VR and pain distraction in paediatric burn patients.

A systematic review of the literature focusing on the use of VR for upper limb rehabilitation (Mumford and Wilson, 2009) indicates that the results of studies to date are promising, but also cautions clinicians against adopting this technology before further higher quality studies are conducted. A more recent systematic review by Rahman and Shaheen (2011) indicates that the use of VR is supported in the treatment of both stroke and cerebral palsy, though notes that longer follow-up times are needed to better determine the duration of treatment effects, something still missing from the literature to date in this area.

In addition to a body of literature dedicated to the use of VR for stroke rehabilitation, there are studies on the use of VR and video capture for spinal cord injury rehabilitation (Kizony et al., 2005), rehabilitation of cognitive disorders in elderly patients (Cherniack, 2011) and multiple studies on the use of VR for pain distraction with burn patients (Hoffman et al., 2006), (Hoffman, 2004), (Hoffman et al., 2004). The bulk of the pain control studies were conducted by one research group and were conducted around the use of a VR program called Snow World, later revised to Super Snow World. Given the nature of the populations studied, spinal cord injury patients and burn patients, the ability to conduct a study beyond the descriptive level may not have been ethical or feasible. In a systematic review of the literature on pain distraction using VR with burn patients by Morris et al. (2009), the primary conclusion was that there were enough quality studies to indicate that this use of VR with this population could make the rehabilitation process less painful and could improve functional outcomes.

In addition to physical medicine, there are also some examples of applied clinical VR use in the literature regarding mental health. Phobia treatment studies were perhaps one of the earliest uses of VR as a therapeutic medium, and the use of VR to treat phobias continues to be studied. Examples of phobias treated with at least reasonably satisfactory results include fear of flying (Walluch and Bar-Zvi, 2007), arachnophobia (Opris et al., 2012), agoraphobia (Wiederhold and Wiederhold, 2003) social phobias (Price, Mehta, Tone and Anderson, 2011) and fear of heights (Rizzo et al., 2013).

This area of VR research is growing presently in treating post-traumatic stress disorder (Gerardi et al., 2010). Further examples of applied VR in this type of clinical setting have also included using VR to teach children with Fetal Alcohol Syndrome Spectrum Disorder fire safety (Padgett, Strickland and Coles, 2006) and assessing social competency skills in at-risk adolescents (Paschall, Fishbein, Hubal and Eldreth, 2005). More recent studies using VR in mental health include RCTs as well, such as a recent study using VR for exposure therapy to treat social anxiety disorder (Anderson, et al., 2013).

Another area of clinical application of VR includes the training of medical professionals as well. Examples of these uses have included practicing virtual surgical procedures, such as cataract surgery (Selvander and Asman, 2012), use of new surgical equipment, such as robotic arms (Lerner, Ayalew, Peine, and Sundaram, 2010) and training specific procedures to nursing students, such as catheter insertion (Jenson and Forsyth, 2012). One of the obvious advantages of using VR to teach these types of scenarios is that a certain level of proficiency would be expected prior to carrying them out on real patients. Increased success with clinical outcomes and patient safety are also proposed as potential advantages to using VR in these types of training situations as well.

However, in addition to the aforementioned methodological issues with several of the earlier studies of VR, there are some additional risks to using VR as a therapeutic medium as well. While it may be safer to carry out some tasks in a practice environment, where the patient is safely in a room and not facing a genuine phobia, or where a physician in training is not working on a real eye, VR has been found to not be hazard free. Motion sickness and unexpected elevations in heart rate have been documented as common problems with a variety of VR systems (Kiryu and So, 2007), (Keshner et al., 2007), (Sugita et al., 2007), (Watanabe et al., 2007). Both of these issues impact the potential risks to participants in carrying out a study using VR, as well as making some uses of VR potentially impractical, such as with individuals prone to motion sickness, or those with specific cardiac restrictions. These risks are considerably different than the ones to be discussed in section 1.7.4 of this chapter.

1.7.3.10 Use of VWs in health professional training

There are multiple examples of using VWs to teach procedural content in health professional training, such as emergency preparedness simulations and learning testable content on environmental health (Boulos et al., 2008), patient simulations involving standardized respiratory patients (Toro-Troconis and Boulos, 2009). A recent systematic review on VR in Medicine included many examples of VWs alongside VR, and indicates that while the use of both types of technology in the medical sciences is growing, there are limited protocols developed to date regarding the creation of VW resources for teaching in this capacity as well as testing effectiveness (Pensieri and Pennacchini, 2014).

In contrast to the use of VR for the training of health professionals to mainly learn and practice specific procedures, VWs appear to afford different types of learning opportunities.

While VWs can and have been used to teach more procedural types of clinical skills, such as clinical decision making (McCallum, Ness and Price, 2011), the types of learning these procedures takes on a new dimension in a VW, as social interaction is possible. For example, while one may learn cardiopulmonary resuscitation using VR, they could learn how to do this as a team, instead of as an individual in a VW (Creutzfeldt et al., 2010).

Given the level of VW multiuser interactivity that is possible between not only other health professionals and health professionals in training, but simulated patients, there are other aspects of health professional training possible in a VW not conducive to a VR environment. These are often referred to as soft skills, such as bedside manner, clinical interviewing skills and counselling skills. The use of a VW to develop these skills in health professionals in training has been discussed as feasible using SL (Danforth et al., 2009), (Johnson, Vorderstrasse and Shaw, 2009) and has been carried out in a variety of forms, the most frequently used to date also being SL.

Of these studies using SL, examples include the use of SL as a venue for interview skill development in nursing students (Sweigart et al., 2010), the development of the doctor-patient relationship (Gonzalez, 2009) and psychological counsellor skill development (Walker, 2009). What is suggested by these studies is that there exist opportunities where VW simulations can be used for development of skills in understanding and interpreting patient narratives, which is a key skill in the health professions. This is also the conclusion in an earlier study using a proprietary VW at the University of Edinburgh (Begg et al., 2007).

Given that, gaining this type of practical experience while in a health professions program is expensive to simulate in a traditional classroom environment, and in some cases, such as

with distance learning, impractical to carry out. It has been suggested that a VW could also be used to support an accelerated nursing program (Hansen et al., 2010) and physician continuing professional development sessions (Wiecha, et al., 2010). In both of these cases, the VW used was SL. A very recent study using SL to teach motivational interviewing using standardized patients concludes that though the use of a VW to create this simulation is supported by the results, budget and time constraints can be an issue in creating standardized patients in a VW as well and that comparison studies are needed between traditional and VW media (Czart, 2014).

One of the potential shifts that may occur if VWs are used more frequently in health professional education is a reduction in costs of real world simulations and a need to budget more for VW developers and technical support. A case is made for the need for this type of technical support in United Kingdom Universities by Kirriemuir (2010) as this author found that many academics gave up using VWs, frequently due to technical barriers and a lack of resources to overcome barriers to VW applications in academia.

1.7.3.11 Use of VWs to promote health and wellness

Just as a VW can be used for a wider variety of training opportunities with health professionals, they also serve a wider use for the health consumer. Annang et al. (2010) suggest that though a less familiar medium in comparison to text messaging, email and the World Wide Web, a variety of VWs, including SL, the River City Project and Whyville, afford opportunities for health promotion. Public exhibits themed around occupational therapy at the Jefferson Occupational Therapy Education Centre in SL serve as a proof of concept that not only can health and wellness exhibits be developed in a VW, but that they can also be evaluated. In this case, the authors surveyed users of the exhibits as to what they

found most useful regarding the interactive exhibits while also gathering demographic data about the users of the exhibits (Toth-Cohen and Gallagher, 2009).

A similar type of sexual health promotion display has also been developed in SL via Plymouth University, the Sexual Health SIM and evaluated via survey methods as being a useful resource for users, positively viewed by users and fostering a sense of community (Boulos and Toth-Cohen, 2009).

In addition to the use of a VW to provide health and wellness information to the general public, VWs have been used to address specific wellness initiatives, such as smoking cessation and weight management. Krebs et al. (2009) designed a simulation involving both virtual triggers and virtual coping strategies to prevent participants who had stopped smoking from relapsing. The prototype of this simulation was found to be effective with the small sample used, with the authors suggesting that a VW may be a low-cost and effective means of preventing former smokers from relapsing.

What is interesting in the case of Krebs et al. (2009) is that the behaviours and even the response to the triggers to smoking in the VW have a carry-over effect to the physical world. This behaviour is also seen in exercise programs and other wellness initiatives. In the case of a virtual exercise coach, Otte et al. (2011) suggest that the behaviours exhibited in a VW, such as engaging in exercise, will increase motivation to participate in exercise in real life. In this study, the activity was virtual bicycling, and participants reported that they were more motivated to participate in exercise after doing this virtually and being coached virtually as well.

Furthermore, studies on the ability of a VW to control weight has been discussed previously from a sociological perspective in section 1.7.3.2 of this chapter and this topic is being

revisited here as this effect has implications for this study. In addition to the previously referenced study by Dean et al. (2009), other studies indicate that VWs can be used for weight management, not solely influencing in-world behaviour and avatar size choices. For example, Taylor et al. (2013) indicate that VWs can be used as a tool to facilitate weight management in young people. Likewise, Siddiqi et al. (2011) suggest that a VW can be used as an obesity prevention intervention on an international scale.

However, it should be noted that in both cases, these studies were an initial evaluation of the effectiveness of the intervention and, similar to many other studies reviewed thus far, there was a lack of comparison or control group. Despite potential methodological issues with these studies, this type of effect, referred to more widely as the Proteus effect, as described by Yee et al. (2009) could be of interest if transfer of healthy in-world behaviours to the real world was the goal of a targeted VW program. With the Proteus effect, the hypothesis is that the sense of self is transformed in the digital environment or VW. This transformation results in a change in individual self-representation in both online and offline behaviour.

Given the differences in the types of interactions that can take place in a VW versus using VR, other uses for VWs in health have also been used to take advantage of concept of shared space, setting up virtual support groups, typically for people living with specific conditions. Norris (2009) describes the presence of a wide variety of health specific support groups in VWs, ranging thematically around a number of themes such as physical disabilities, mental health and bereavement.

While is it suggested that these groups may serve a purpose and that the literature is generally supportive of such groups, the efficacy of these is not known in many cases.

Likewise, those few VW studies that focus on specific populations, such as wheelchair users, discuss broad approaches in ensuring accessibility and offer opportunities for further research (Krueger et al., 2009), (Zielke, et al., 2009) but do not necessarily test a specific hypothesis regarding efficacy of the VW program itself.

A VW can afford several opportunities by removing many physical barriers for participation. A VW may allow for experiences impossible in the physical world. Some of these may include abilities not typically experienced in reality, such as instantaneous travel to distant regions. Additionally, the control over the environment can be significantly greater by the VW user who may be able to control the ambient environment, physical access to certain regions and even the social norms of privately owned areas that the user administrates. This has implications for the user interfaces being used if the individual using a VW has a physical disability that impedes their ability to access the VW using a traditional computer set up.

While accessibility standards in VWs are advocated for by some authors (Krueger and Stineman, 2011) and development of more inclusive user interfaces by others (Kashani et al., 2009), it appears that principles of Universal Design are not a priority for many VWs. However, many existing adaptive devices assist with a disabled user being able to access VWs. Given that there is no standard for Universal Design across all VWs, this remains a problem if the intent to use a VW to deliver health information is targeting a population with a specific set of physical, cognitive or affective limitations.

1.7.4 Potential risks to VW users

Just as VR has some risks to users in terms of motion sickness and unexpected heart rate increases, VWs are purported to have potential risks to users as well. VWs themselves are

frequently linked to and delivered over the internet. Use of the internet itself was reported at one time to have a causal link to depression (Kraut et al., 1998). However, a later study refuted these findings, indicating that online interactions supplemented and supported real world relationships (Hamman, 1999), (Wellman and Gulia, 1999). A causal link to Internet use and decreased depression via increased social support was also later suggested by Larose et al., 2001).

In terms of this particular form of media, VWs themselves have been characterized as potentially addictive (Cremorne, 2007) or having deleterious side-effects (Gorini et al., 2008). However, it is noted that often these claims in the literature are often without empirical data. For example, a lengthy paper by Young (2009) discusses the issue of online gaming addiction, including VWs in the paper, and relies primarily on clinical anecdotes, a single case study and a single paper by Yee (2006) to state that VWs are addictive. The bulk of the paper discusses how to recognize signs of gaming addiction and strategies, failing to acknowledge these signs and symptoms may also have differential diagnoses and root causes.

While there may not be conclusive studies indicating that VWs are inherently addictive to users, there appears to be a very real possibility of social risks in using a VW, even in comparison to other social media. Some of these social risks have been previously outlined in section 1.7.3.2 of this chapter. Sanders et al. (2010) indicate that there are additional social risks, such as revealing personal information, with many forms of social media, and suggest that this may be more frequently a risk observed in users of VWs. In this study, respondents indicated that they had not only often revealed personal data, but that they had done this in higher proportions in comparison to other forms of online media. This may be a function of the level of perceived anonymity to VW users.

What these authors propose is increased awareness of the social risks that VW users may encounter. Given that these social risks are potentially an elevated type of risk in using a VW, this may pose some unique ethical issues if using a VW in research. If developing a program, it would be prudent not only to inform participants that these risks may exist, but to also utilize features of the VW to minimize these risks, such as setting up a private area only accessible to study participants.

The proposed study is uses an electronically based form of media that is relatively novel and there is a very limited amount of research to date about its use with the population studied as per the current literature reviewed. In order to better determine the feasibility of such a study, it would be prudent to examine the current uses and methods of VW initiatives with chronic disease management, ideally including clients living with RA. The following sections examine current uses of VWs and a conclusion, based on studies to date, as to what the feasibility and challenges may be to design a VW program as a form of eHealth delivery.

1.7.5 Feasibility of VWs for chronic disease management

There are readily identifiable issues with content, cognitive load and access in using a VW in the manner proposed in this study. A VW, as both a novel media and an electronic one for delivering health education, is presumed to pose several challenges for potential users, particularly for those living with chronic disease, such as RA. To come up with content for every possible question a user may have about managing RA would be impossible. An all-inclusive means of delivering this content would make creating a program of this size impractical both for the developer, may overwhelm the user. At the other extreme, there may be issues with how useful the VW use may find the information if it is not disease specific enough, or sufficiently in-depth to be considered value added.

In addition to the need to deliver appropriate content, there is the added issue of cognitive load. This term is in reference to the amount of additional cognitive skills required to perform a task, typically more novel tasks requiring a higher cognitive load. It would be anticipated that many research participants may be new users to VWs. There would need to be sufficient orientation, support online, support offline, clear instructions as to how to access the VW and a minimum number of new skills to be learned. One potential means of addressing these issues, before even alpha testing of such a program commences, is to examine what the best practices in VW education are at present.

The use of secondary sources as a means of determining what might be most appealing includes the work of Aldrich (2009), Reeves and Read (2009) and Heiphetz and Woodill (2010) as providing useful templates to ensure that a VW program applies principle of adult learning as previously outlined, provides an experience that utilizing the properties common to VWs, such as notecards and landmarks and applying appropriate strategies for not only content development, but also data gathering regarding the users themselves in the earliest phases of program development.

Part of the rationale for the tracking of the early participants' demographic information in the alpha and beta testing of a VW program for RA would be useful as there may be a multitude of issues with access. There may be certain segments of the population, even with the RA population, who may be more or less prone to using a VW to learn about joint protection. This could be due to age, disease severity and physical inability to access a computer, sex, literacy, Internet availability or experience with using a computer. A potential worst-case scenario could be that the only potential research participants interested in using this education program are people living with RA who are also presently identifying themselves as SL users. This could indicate that the use of a VW in this manner

is not necessarily feasible. At the time of writing, this total is less than 100 individual accounts as registered with all current RA specific groups in SL.

Tracking initial demographics may assist with troubleshooting content appropriateness as well as overall usability and ease of navigation. Before this occurs, a few recommendations made by the VW developer resources, indicate that focus groups are useful before wider testing, such as a pilot RCT or other quantitative testing occurs (Heiphetz and Woodill (2010). There is also the need to consider that the development of the VW itself has to be cost-effective, not only for the user, but the developer as well as this is a student funded project lasting several months to several years. The development and programming of the VW content also needs to be simple enough for the student developer to understand and complete this phase of the study on his own.

Fortunately, the information provided by Heiphetz and Woodill (2010) and Aldrich (2009) provide recommendations regarding not only cost effective means of using VWs, such as SL, with a minimal amount of funding, but also recommended resources for learning content development skills in SL. There a standardized programming language in SL, Linden Scripting Language (LSL) to program custom scripts to program object behaviours. Building objects is also possible via purchased kits, from modifying purchased or free objects, from building objects using the online tools bar as an SL user in a sandbox or on one's own property or via hiring an SL user commissioned to complete specific objects or scripted object.

The building of objects is relatively simple for an experienced computer user and limited mainly by the artistic ability of the builder. However, the use of scripts is what makes these objects immersive and more interactive. LSL resembles an assembly style computing

language, dependent on specific commands and highly dependent on exact syntax, including placement of brackets to ensure a script works. This programming can be quite daunting to a non-programmer attempting to build a program with specific content in a VW. Fortunately, many of the scripts used contain common content, and scripts can be purchased from vendors, formally learned in SL classes, commissioned as part of other work and programmed via helper websites, such as www.3greeneggs.com, which generate a finite number of scripts.

Overall, the feasibility of the use of a VW, even at the pilot RCT phase of study is dependent on the ability to not only tailor the program itself to engage users with appropriate content, but also on the ability of the student researcher to construct a site that houses the objects and scripts so that the content is delivered in a logical and useable way. Fortunately, there are a number of resources available to VW developers so that a novice user can develop objects and scripts in order to deliver identified content. The use of focus groups during development is also a recommended practice as part of an alpha test, prior to wider beta testing, such as on a pilot RCT. The intent of this study is to use qualitative methods as a means of predetermining the feasibility of developing content in the VW program itself, prior to testing the feasibility of the pilot RCT itself.

1.7.6 Current methods for conducting research in VWs

VWs themselves are being studied using a variety of mainly qualitative and descriptive studies at present. As indicated in the work reviewed thus far, the use of RCTs and pilot RCTs has yet to be done. The research to date has also focused on training of various students, more than client populations, based on the balance of the literature reviewed in section 1.7.3.8. However, the use of VWs for research purposes is relatively new, and as

indicated in section 1.7.3, one critique of the general research in this area is that much of the conclusion reached to date are speculative and indicate what should be done in researching VWs.

The qualitative and descriptive studies themselves are useful in their methodology in the determining what methods can be used to inform a subsequent pilot RCT, or full RCT. Given that some studies reviewed built a program first, then received feedback that at times appeared to indicate that the program did not deliver the expected user experience, it may be more advisable to seek initial input from experts, build and test the program based on this input, and then release the program for wider testing, such as with a pilot RCT.

1.8 Outline of problem

Based on the information presented thus far, there are some issues with the present state of practice of RA management. RA is chronic, lifelong disease that typically strikes a population during a segment of the lifespan, which may be during the most productive years in terms of combined work and family roles. The disease, being both autoimmune and systemic, requires a multifaceted approach for lifelong management of the disease. Given a number of treatment options, the balance of the literature appears to support a combination of pharmacological and non-pharmacological interventions.

Information available regarding non-pharmacological interventions indicates that joint protection techniques are perhaps some of the most effective means of non-pharmacological management of RA. The literature indicates that there are challenges with getting this information to clients living with RA. One challenge is that ASMPs that are group taught combine people living with OA and RA (Brosseau et al., 2014), so content is not necessarily specific to those living with RA. Another issue is with access because of

geographic location and sheer distance from a major city (Niedermann et al., 2010a). A third issue is the ability to attend a program at a specific place and time, given demands of work and family.

Given that there may be issues with delivering disease specific content and access, an online option to deliver what is the most effective means of non-pharmacological management of RA may be a reasonable option. If a VW is to be used, the literature proposes principles of adult learning be incorporated as a pedagogical approach (de Freitas et al., 2010). Additionally, though a VW may offer opportunities not possible in traditional learning environments, there may be challenges with access and content development for both the user and the developer.

The use of a novel medium to deliver a program should be studied for a number of reasons, including determining if it is feasible to develop of the program content using this medium and testing its effectiveness. The overall reason for conducting this study was to determine if a pilot RCT was feasible. In order to develop the content a pilot RCT would need to initially include initial qualitative interviewing about content and platform expectations, piloting of the program once completed, interviewing participants for feedback, possible program modifications and analysis of feedback. If the use of a VW program and teaching joint protection is found to be feasible with a pilot RCT, this may provide the basis for determining effect size for a future full RCT. The feasibility of a full RCT would be dependent on the pilot study's selection of tools and collecting data regarding disease activity and function during the final phase of the study.

1.8.1 Formulation of proposed study plan

Given that there may be a means of delivering joint protection information using a VW to clients living with RA who are potentially unable to partake in traditional ASMPs, it would be potentially useful to deliver joint protection specific content using a VW as the delivery medium. Present ASMPs are also not specific to RA.

Occupational therapists are often the clinicians providing education on joint protection to clients. In the development of a VW program centred on RA and joint protection, these clinicians may be useful to interview about their expectations of program content, as well as being able to test the program and provide feedback. This may ensure that not only are content experts used in development, but also provide opportunities to focus on a more specific population of clients, given the relatively generic nature of many ASMPs. In this regard, it may be best to consult occupational therapists who have experience working with clients living with RA, having delivered classes on joint protection or taught some form of rheumatic disease self-management program.

As previously outlined, the population targeted in this study are adults. As such, not only would it be advisable to consider principles of adult learning for the end user of the program, but also at the development phase of the program. One of the primary principles as outlined by Merriam (2001) includes acknowledging the adult learner's prior experience. Specifically, that they have accumulated life experiences that provide opportunities to enhance learning and experience, including mistakes, provides the basis for learning activities. Adults draw on experiences to aid learning.

Given that peers frequently teach the ASMP, it would also be useful to have individuals living with RA who have either taken or taught in such a program to participate in the

development of the VW program as well. Like the occupational therapists with expertise in rheumatic diseases such as RA, this would include being interviewed about their expectations of program content, as well as being able to test the program and provide feedback.

Once the interviews regarding program expectations were conducted, the program developed and feedback provided, the program itself could be tested for its feasibility to be used with larger samples and potential effectiveness. The feasibility would depend on tracking and analysing noncompliance and completion rates.

Potential effectiveness would depend on tools to measure differences between groups of participants, such as those who used the program and those on a waitlist to use the program. These tools could measure a variety of outcomes, including knowledge transfer, perceived functional differences or clinical presentation differences between groups. It would be most effective to obtain feedback from both groups of content experts during the feedback part of the development phase of the VW program. Participants could indicate what they think the VW program may have an effect on after using the program, provide names of specific tools that measure these effects or may be able to select presented tools to measure perceived effects.

Once the program has entered the final testing phase, participants would be recruited, assigned to a group and complete the measures as determined by the first phases of the study with the content experts as participants. In addition to collecting demographic data, the groups would be analysed and compared in terms of their responses to the tools, as well as drop out and completion rate differences between the groups. This analysis would determine if the program was potentially effective, as well as inform the methodology for further study, including determining if a full RCT were feasible.

1.9 Evaluation methods

The previous section describes a combination of methods used in scientific inquiry. The first phases of this study are primarily qualitative and the final phase is quantitative. The following subsections describe the overall philosophies of both approaches. The first section is a general overview of the two approaches. The two sections that follow describe in greater detail the specific form of qualitative study and quantitative study that have been selected, and the rationale for both is provided.

1.9.1 Approaches to design and evaluation of a study

There are two overall approaches to guide study design and evaluation as described by Polgar and Thomas (2013). The primary philosophical differences between these two approaches are founded in epistemological assumptions about the nature of understanding reality. The qualitative approach is sometimes referred to as the subjectivist approach, and the quantitative approach is sometimes referred to as the objectivist approach. While there may be some truth to the belief that quantitative research is objectivist, confirmatory and deductive in nature and that qualitative research is subjectivist, exploratory and inductive in nature, this may be an oversimplification of the differences of the approaches (Trochim, 2006).

Qualitative researchers opine that the best means of understanding a phenomenon is to be able to study it within its context. Quantification is viewed as limiting and likely to result in the study of a phenomenon outside of the context in which it occurs. In the social sciences, or in studying the impact of a complex behavioural intervention, the qualitative researcher would be operating under a different ontological assumption, that reality as experienced by the individual is different from other individuals.

Quantitative researchers opine that the best means of understanding a phenomenon is to be able to study it within a controlled environment. Quantification and repetition of standard procedures is viewed as positive as it allows for consistent measurement and reproducibility of results. In studying a complex behavioural intervention, the ontological assumption is that there are experienced commonalities in reality that can be demonstrated and tested.

Given these differing epistemological and ontological differences, quantitative and qualitative research techniques may be more suitable in specific research scenarios. Quantitative research has the advantage of scale. It allows for large amounts of numerical data to be collected, and statistically analysed, from a large number of people or sources. Qualitative research, on the other hand, usually does not scale as easily. For example, it would be overly labour intensive to conduct in-depth interviews with thousands of participants, but relatively easier to analyse survey responses from thousands of people if the questions are closed-ended and responses can be mathematically encoded in rating scales or ranks.

Conversely, qualitative research is more suitable when it may not be possible to used closed-ended questions, such as in product or program design. Marketers often use focus groups of potential customers to try and gauge what influences brand perception, product purchase decisions, feelings and emotions. In such cases, researchers are usually at very early stages of forming hypotheses. They may not want to limit themselves to their initial understanding or assumptions. Qualitative research may open up new options and ideas that quantitative research cannot, due to its closed-ended nature.

For the purposes of this study, the nature of the research undertaken requires widely different approaches. The first phases involved examination of participants' expectations

and experiences. The latter part of the study, a pilot RCT, tested the potential effectiveness of the VW program. Overall, it would appear that if expert opinion for a product review, such as a VW program, were being developed, that qualitative methods would be preferable to inform the development and initial testing of the program. This would allow for more in-depth input from experts and follow the current practices of the business and marketing. The qualitative phases of development could then inform the final phase of the project, where quantitative methods could be used to determine effect, if any, and feasibility of a future RCT.

1.9.2 Qualitative methods and semi-structured interviews

There are a number of different means of both data gathering and analysis available to comprise the initial qualitative phases of this study. According to Creswell (2013), there are five main traditions, including biography, phenomenological study, grounded theory, ethnography and case study within qualitative methodology. By process of elimination, most of these would not be appropriate approaches, given the type of study being undertaken.

As the development and testing of the VW program is constrained to a specific product review, and the experiences of trying that product, all of these traditions may be inappropriate. The life history of the individual is not being studied, eliminating the appropriateness of the use of biography as a tradition of inquiry. Likewise, though one may be interested in the experiences of using the product, the study is not focusing globally on the participant, such as what their lived experiences are as a person living with RA, so phenomenology would not be appropriate either.

This part of the study would be far too short in duration and limited in scope to make the use of grounded theory an appropriate choice as well. Given that the focus of the population studied is people living with RA, ethnography is also not an appropriate form of inquiry as this is a diagnostic population, not a specific social group or culture. Case study may appear the most appropriate tradition, and the only remaining option, of qualitative inquiry. However, the duration of the study, and the use of participants to provide what is primarily a product review, indicate that while this may be the most congruent tradition with the design of this study, it is still not appropriate given the duration and limited depth required for this portion of the study. Thematic analysis is the method of choice given that what occurred was the extraction of themes from the data that would inform the latter parts of this research.

Thematic analysis, as described by Braun and Clarke (2006) supports the use of thematic analysis as a qualitative tradition in its own right and one that is conducive to flexibility over other qualitative traditions. This method is supported by these authors as useful for identifying, analysing and reporting patterns within qualitative data. Though critiqued as being unclear in methodology, Braun and Clarke (2006), propose that a step-by-step outline as to how to approach this form of qualitative analysis.

This outline, as proposed by these authors does not necessarily contain a process unique solely to the tradition of thematic analysis. This outline includes 6 phases described as: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report.

In the becoming familiar with the data, the researcher transcribes, reads and re-reads transcripts. Initial ideas may be written down as well. In generating initial codes, data may

be broken down into smaller units and coded, similar data may be collated or grouped. This is the stage at which sub-themes may emerge, leading to the development of themes that are searched for, reviewed and named in the next three stages. For the purposes of this study, the production of the report was considered to be a contribution to the third chapter of this dissertation, in addition to associated Tables and Appendices.

Additionally useful in the use of thematic analysis, as proposed by Braun and Clarke (2006) is a 15 point checklist that provides multiple checks to ensure that the coding process and extraction of themes is done completely and is interpreted, rather than paraphrased or described. The researcher actively seeks out themes, rather than having them haphazardly emerge.

The initial part of this study required qualitative methods to be used as the study design. What was proposed in the initial two phases of the study was that expert occupational therapists and clients living with RA with previous ASMP experience provide data via semi-structured interviews, have these interviews analysed via thematic analysis as described, and that member checks be used for study rigour.

1.9.3 Randomized controlled trials (RCTs)

In discussing the final phase of this study, a pilot study for a randomised controlled trial (RCT) is taking place as the culmination of the study. The preceding literature review has included a critique of the limited quantitative work that has occurred to date. The following sections will describe origins of the RCT, guidelines that exist with respect to RCTs, and options with respect to blinding, randomization and analysis. Included in this discussion of RCTs are criticisms of published RCTs and why some RCTs may fail or be abandoned.

The primary conclusion reached from this portion of the dissertation is that prior to commencing with a full RCT, a piloting of methods is necessary.

The RCT, by definition, describes a study in which participants are allocated at random to receive one of several clinical interventions (National Institute for Health and Care Excellence, 2014). At a minimum, one of these groups receives an intervention of interest and another group not receiving the intervention is used as a comparison or control. The control group receives an alternative treatment such as a standard practice, a placebo or no intervention at all. The overall motive for a RCT is to measure and compare the outcomes of participants receiving the intervention of interest versus the control group.

As medical researchers are involved with answering questions about specific topics in health, illness and treatment options, the evaluation of new interventions may involve research using RCTs. This involvement is necessary to ensure that the outcomes are determined by only the intervention under study, and no other factors, that could otherwise influence treatment assignment, such as aging, the natural history of a condition or being enrolled in a study itself influencing an outcome. In comparison, clinical trials are designed to answer a specific question about treatment, usually in regard to the safety and efficacy of a treatment.

1.9.3.1 A brief history of RCTs

Some authors have deemed the RCT as the most rigorous method of determining whether a cause and effect relationship exists between a specific treatment and outcome. This is due, in part, to some key elements of RCTs. These specific features include random allocation to intervention groups and the process of blinding participants and study staff as to whom is receiving the intervention. In the case of the RCT, participants are also typically analyzed within the group to which they were allocated (Sibbald and Roland 1998),

irrespective of whether they experienced the intended intervention or not. This is often referred to as intention to treat analysis (Fisher et al., 1990). The overall analysis is focused on estimating the size of the difference in predefined outcomes between intervention groups.

RCTs are a relevant participant of scholarly attention (Stolberg et al., 2004). Histories of medical information transmitted orally by those who remember the early clinical trials of Austin Hill were involved in the shaping of the present day RCT. Many of the earliest articles published on the RCT were written by physicians or statisticians and placed emphasis on randomisation. In particular, the work of Austin Hill, who introduced randomisation in the trial of Streptomycin in 1946 is highlighted (Stolberg et al., 2004), (Stolberg et al., 2004). This clinical trial is generally defined as the first correctly done RCT, with the RCT itself being deemed essentially British in origin given Hill's earlier work. Additional accounts by the physician, John Bull, medical statistician, Peter Armitage, and the epidemiologist, Abraham Lilienfield, have all become significant examples of early RCTs in history (Stolberg et al., 2004).

More recently, concern has arisen with how particular therapies have acquired cultural meanings. Scholars have produced historical studies of specific clinical trials, believing that they can be used to gauge the ethics employed by specific groups at a specific time in history (Hessenbruch 2000). The records of Daniel of Judah comparing vegetarian and omnivorous diets may be the earliest recorded comparative trial in human history (Stolberg et al., 2004). Bull himself is purported to state that clinical trials can be traced back to the ancient Egyptians, further claiming that experiments designed to assess the value of therapies on patients have always been an essential feature of medicine clinical trials (Stolberg et al., 2004). The Persian scientist Avicenna and his rules for testing drugs, Sir Francis Bacon's proposal to judge treatment efficacy via an expert committee, and James

Lind's comparative trials regarding peak efficacy for treatment of scurvy can also be considered earlier examples of less rigorous attempts at RCTs.

1.9.3.2 The origins of modern RCT guidelines

Several research organizations have deemed that clinical trials or RCTs are required to meet basic standards and principles of scientific research, and guidelines have been developed to ensure that RCTs meet specific criteria. One example is the consolidated standards of reporting trials (CONSORT) guidelines which seek to prevent bias in reporting on randomised trials (Schulz et al., 2010). As a set of guidelines, the CONSORT statement does not specify what should happen within a clinical trial. Rather, the guidelines provide recommendations that what is to be done or has been done in a clinical trial be fully reported (Altman et al. 2004), (Schulz et al., 2010). The CONSORT guidelines were originally developed in 1996 with revisions to the primary CONSORT guideline occurring most recently in 2010. The main product that CONSORT has produced is the CONSORT statement. This is essentially an evidence-based, minimum set of recommendations for reporting RCT findings. The statement itself is a 25 item checklist, previously updated from 22 (Schulz et al., 2010), and a flow diagram along with brief descriptive text, all available for free online (http://www.consort-statement.org/consort-2010).

The overall aim of CONSORT is to be part of a broader effort to improve the reporting of different types of health research, in turn improving the quality of research used in health care decision making. The checklist ensures that within each item several specific criteria are included. This means that at each stage of a study a particular checklist item can be rated as being present or absent and the quality of that particular item can be rated. For example, item twelve, which is statistical methods, includes both a description of the

statistical methods used to compare groups for primary outcomes and methods for additional analyses such as subgroup and adjusted analyses.

The authors of the American Psychological Association have deemed that these guidelines will allow readers to quickly understand exactly what happened in a RCT and more easily analyze a study's methods (Sharma, 2005). Likewise, readers will be able to judge the reliability and relevance of the study's findings by clearly spelling out the population examined and which findings are relevant. Other studies have found the CONSORT guidelines help improve readers' interpretation of RCTs, minimize biased conclusions, and standardize decision-making policies about treatment, including those within national public health policy guidelines (Altman et al. 2001).

CONSORT guidelines also contain a flow chart that can be used to determine what criteria have been met with respect to enrolment, allocation, follow-up and analysis. An extensive study from the Annals of Internal Medicine (Altman et al. 2001) discusses the CONSORT statement at length in terms of its ability to improve the quality of reporting on RCTs. This particular study includes discussion about the importance of randomisation, the use of the checklist items and the template of the CONSORT diagram, showing the flow of participants in a randomised trial. Examples and explanations are included for each item, providing an in-depth explanation to document the quality of a RCT.

Comments in the same study state that the assessment of healthcare interventions can be misleading unless investigators ensure unbiased comparisons are made. This study further states random allocation to groups remains the only method that eliminates selection and confounding biases. References are also made to previous RCTs where trials had been carried out improperly, or with inadequate or unclear allocation compared to those that used this procedure. One of the conclusions is that poorly executed trials exaggerate treatment

affects due to bias. The same authors also concluded that only high quality research in which proper attention has been given to RCT design will consistently eliminate bias.

Given that these guidelines have been developed for an idealized experimental setting, additional reporting criteria have been proposed (Zwarenstein et al., 2008) to potentially extend CONSORT to health care settings. Furthermore, given that sampling techniques can be varied, and at times be a potential methodological confound (such as with cluster randomized sampling), other groups, such as Campbell et al. (2004) have added further reporting criteria to the original CONSORT guidelines. To further extend the generalizability of these reporting guidelines, Boutron et al. (2008) have extended the guidelines beyond non-pharmacological treatments. In all of these cases, there has been an extension of the reporting guidelines to improve their applicability to scenarios outside of idealized experimental settings.

1.9.3.3 Options with respect to blinding, randomisation and analysis of RCTs

To meet ethical requirements in using human participants in any form of research, an informed consent process should include explaining the random treatment assignment as well as the risks and possible benefits of the trial. Blinding procedures are applied to protect against the influence of bias for or against the treatment being studied. In a double blind trial, neither the clinicians caring for the patient nor the participating volunteers know who has been assigned to the treatment group until the trial is concluded. In a single blind trial the investigators know the treatment assignments, but the participants do not. While Sibbald and Roland (1998) support the use of double-blinding methods, they also admit that this method of blinding may not always be available. With the proposed pilot study, a single blind method is being used as participants are being measured at either a baseline time, before being given access to the program proposed, or after using the program for 30 days.

A double blind method may be feasible, but would involve either the data gathering or the analysis of data collected being performed by another investigator.

There are a multitude of options with respect to randomization of this study. These are summarized in Table 1, based on information adapted from Trochim (2006).

Method	Utility	Advantage	Disadvantage
Simple random	Any study	Simple to use, and easily explained	Requires sampling frame
Stratified random	When wanting to ensure representation of smaller subgroups	Allows oversampling of minority subgroups to assure subgroup analyses	Requires sampling frame
Systematic random	When wanting to sample each n^{th} case in an ordered set	Saves time as there is no requirement to go through an entire sample to determine which were randomly selected	If the order of elements is nonrandom, there could be systematic bias
Cluster area random	Geographic organization of sample	More efficient way of sampling across a large area	Usually needs to be coupled with other methods
Multi-stage random	Any study	Efficient	Can be difficult to explain to lay people
Accidental/ Haphazard/ Convenience	Any study	Easy to use	Weak external validity and likely to be biased
Modal instance purposive	To sample a typical respondent	Easy to understand by lay people	Weak external validity
Modal purposive	Adjunct to other sampling methods	Experts can provide opinions	Limited external validity and likely to be biased
Quota purposive	To represent sub-groups	Allows for oversampling of sub-groups	Likely to have more bias than stratified random method
Heterogeneity purposive	To sample for diversity or variety	Easy to use, easy to explain to lay people, useful when sampling for variety instead of representativeness	Will not proportionately represent population
Snowball purposive	Difficult to reach populations	Can be used without a sampling frame	Low external validity

Table 1 Options for Randomisation for Proposed Study

Given the initially qualitative nature of the study proposed, the first two stages are dependent on expert clinicians and expert clients, also justifying the use of modal purposive sampling for these stages of the study. Methods of trustworthiness, such as member checks, will be used accordingly with the qualitative stages of this study. These are acceptable methods for qualitative methods as described previously by Creswell (2013). As there is a criticism of modal purposive sampling being potentially low in external validity for a quantitative study, simple random sampling can be used for this third stage of the study, where a sampling frame may be known.

As random assignment is being used in the control or treatment arm of the study, a randomized or true experiment design should be used in the development of this pilot RCT. One type of design in this category, the post-test only randomized experiment, appears to be very strong against all single group threats to validity simply by virtue of it not being a single group design. It can also be a strong design against repeated measures and testing threats as it does not use repeated measurements. Susceptibility to all of the social threats to internal validity may be a potential limitation of the use of this design. However, participants will not be seen in a specific institution or setting and will be receiving the intervention at a distance. This should typically prevent them from being seen by one another, so it is less likely that they will be aware of the status of their random assignment of treatment or control/waitlist condition.

Group differences will be compared using statistical tests to compare group means such as a t-test or one-way analysis of variance (ANOVA). Though the groups are both randomly selected from a sampling frame and then randomly assigned to one of two conditions, there still may be issues with the groups not being probabilistically equivalent. This implies testing differences such as age, sex, geographic location, perceived disease severity, years of computer use, use of disease modifying medications and length of time since initial

diagnosis will require analysis to determine equivalence of both groups. As a focus is to determine what sample size is required for a full RCT, there must also be a tracking of typical noncompliance rates and mortality of the groups to calculate this value.

1.9.3.4 Critiques of RCTs

Although there is considerable literature to support the use of RCTs and the accurate reporting of related findings using tools such as the CONSORT guidelines or one of its permutations, there is also literature demonstrating that there are times when RCTs fail despite the best intentions to carry out such studies with considerable scientific rigour. The issue with the studies is not necessarily that they show a null effect, rather that the attempts to carry out a RCT still resulted in biases or the RCT itself was abandoned. A review of the literature reveals that assessing the quality of reports of RCTs themselves sometimes yield results that are unexpected. For example, while assessing the quality of RCTs in comparison to non-randomised studies, Pibouleau et al. (2009) determined that when comparing reporting of the data itself, the quality of reporting and applicability of results of novel orthopaedic practices was relatively poor for the RCTs. Results from studies such as this one suggest that failure to report the characteristics of the design and execution of RCTs impact on the identification of potential bias, reproducibility and perceived application to clinical utility. If the CONSORT reporting guidelines had been followed in the RCTs reviewed, the knowledge translation may have had a more favourable outcome for the RCTs. If the CONSORT guidelines are being applied as developed, design data such as allocation, type of blinding and type of randomized trial should always be reported as a prerequisite to quality reporting of what is intended to occur in a clinical trial.

One study by Olivo et al. (2008) concludes that many scales used to evaluate the methodological quality of RCTs have not been adequately developed and have not been

adequately tested for validity and reliability. However, as a set of guidelines, the CONSORT statement itself has been demonstrated in the literature reviewed thus far to be modifiable to specific clinical settings and methodological variations.

In addition to the issues of quality and reporting that have been addressed, there are specific cases relevant to both rehabilitation and rheumatology that show that if a pilot study is not carried out, problems may arise with even the most rigorous RCT design. In Wolfe et al. (2004), RA treatment pharmacological cost effectiveness studies were stated to use a mixture of data from RCTs, observational studies and extrapolation. These authors state that almost no attention has been directed to an area of even greater importance: whether or not the participant's status at the onset of the RCT is a valid reflection of the actual status of RA patients who will receive the treatment. In this case, there is a threat to the generalizability of results. If the RCT is not reflective of those who may actually be receiving the treatment, there is a significant issue with the validity of the study itself. How can one make judgments on cost effectiveness when the sample used is not reflective of the people who will typically be receiving the treatment? How can one determine if the intervention is effective at all for that matter?

The issue of RCT applicability to RA management outside of a clinical trial has been examined by Strand and Sokolove (2009). Though primarily focused on pharmacological management of RA, the study acknowledges that RCTs must be extended to determine the long term safety and practical application of various types of treatment to the population at large.

Additional studies in the area of rheumatology also critique the overall methodology of specific RCTs. Recommendations from RCTs regarding the management of hip and knee osteoarthritis have been evaluated using a validated instrument (Zhang and Doherty, 2006). These RCTs show strength with respect to scope, rigour of development and clarity.

However, weaknesses with respect to stakeholder involvement, applicability and editorial independence have all been called into question as issues (Zhang and Doherty, 2006). The methods used to synthesize research evidence in this particular study included systematic review and expert opinion. Though demonstrating general adherence to the principles of RCTs, the need to involve stakeholders, such as those providing and receiving treatment, is a potentially overlooked means of intervention or program evaluation (Gaasterland et al., 2015)

Some studies relevant to rehabilitation actually document the complete failure of a planned RCT. Such a study is seen in the demise of a planned RCT in an urban aboriginal medical service (Sibthorpe et al. 2002). Although this study touts the RCT as the evidence gold standard for effectiveness of clinical interventions, what is documented is a failure to perform a RCT in such a setting. The key points that emerge from this study include that the sample population in focus was difficult to access, that the RCT would involve a complex study protocol which may not be adaptable or viable with this particular population, and that RCT evidence for effectiveness of this public health initiative may never be available, based on qualitative assessment of other populations and settings.

A follow-up RCT by Solomon et al. (2002) attempted to reproduce a prior study on RA self-management programs by Lorig et al. (1993). The study by Solomon et al. (2002) demonstrated that using RCT methodology, without considering appropriate reporting practices, may have deleterious results. While the authors of the follow-up RCT report a null result, in contrast to the earlier study, and attempt to explain aggressive recruitment as a potential issue, there were additional issues with this replication study. For example, a number of characteristics in each group compared make these groups non-equivalent to each other. Some immediately noticeable differences between these non-equivalent groups include the number of participants living with RA in each group, the average age of each

group and the employment status attributes of each group. Additionally, the combining of three broad diagnostic categories of two diseases (RA and osteoarthritis) and one condition (Fibromyalgia) is also not factored into what appears on the surface, to be a reproduction of an earlier RCT. As such, this study reports a null result, but the quality of reporting does not follow the CONSORT guidelines, and the methodological issues not raised in the discussion of the results raises many questions as to the validity of the results themselves.

Another example where a null result was obtained in an RCT, but where the validity of the measurement tools were questioned, is seen in an RCT examining the cost-effectiveness of RA self-management programs (Patel et al. 2009). In this case, the authors also got a null result. However, this null result was based on the reporting guidelines as purported by the current National Institute for Health and Clinical Excellence cost perspectives. These authors, in both their reporting and their discussion of results, look beyond the purview of the tools used, stating that there were other means of determining cost effectiveness not directly addressed by the study. A similar null result is also demonstrated in a study using tele-consultation for specialist appointments (Jacklin et al. 2003). In this case, other factors such as the reduced direct cost to patients was recorded, despite a hypothesis that the intervention under scrutiny would be cost neutral. The design of a methodologically sound RCT must contain the appropriate tools with some input by stakeholders in the appropriate measurement of the variables of interest. Failure to do so may result in a failed RCT as well.

Further to the issues with inconsistent reporting and tool selection, some question the use of a RCT when studying non-pharmacological interventions. In the case of a VW as a form of e-learning, it has been proposed that one cannot glean the full magnitude of the intervention effect if limiting oneself to the measurements typically seen in drug trial methodology (Boulos and Maramba 2009), (Cook and Triola, 2009). However, in

examining complex behavioural interventions with emerging media such as VWs, there is evidence to support the use of a well-developed RCT as an effective means of assessing such interventions.

An RCT examining the use of virtual applications as a means of delivering a pain symptom self-management program has been studied by Stephensen and Imrie (1998). RCT methodology has also been used to assess behaviourally based and education based initiatives via the Internet to determine adherence to self-management of congestive heart failure (Ross et al., 2004), as well as preferences for personalized computer-based information in cancer patients (Jones et al., 1999). As a relatively new form of widely available electronic media, VWs have not yet been studied as a means of self-management for patients with RA, but several studies involving virtual reality and pain reduction in patients living with burns have been published. A systematic review by Morris et al. (2009) indicates that there is a need to test this technology further, primarily due to a lack of RCT methods used in most studies. Though none of these studies involved VWs, all involved the use of some form of e-learning, environmental immersion, personalization, self-management of a chronic disease or condition, and a complex behavioural intervention. All of these parameters are relevant to the proposed study.

Design bias in new drug development has also come under some scrutiny with respect to RCTs. Even with drug studies, there appears to be a bias in scientific journals in favour of the registration or marketing of the sponsors' drugs. In a study by Fries and Krishnan (2004), 45 out of 45 results were favourable, indicating that 100% of the time results were favourable and could have only been predicted in advance by knowledge of sponsorship of the study.

In this case, these authors state that the uncertainty principle, that some negative findings would be inevitable based on the sheer probability alone was clearly being systematically

violated and publication bias appeared to be an incomplete explanation for this dramatic result. These authors also conclude bias occurs even after a study is completed and they hypothesize that design bias, in which extensive positive preliminary data are only used to design studies, is a major cause of asymmetric results. Furthermore, these authors conclude other issues were found with the uncertainty principle which discourages publishing of negative studies and ignores patient values, patient autonomy and social benefits.

Additional studies, which question the use of RCTs, include studies such as one by Sheppard et al. (2008). This study was carried out looking at the qualitative decision-making process in patients with early RA. Data was collected via three face to face and semi-structured interviews, and the sample size, as this was a qualitative methodology, was dependent on the concept of thematic development with recruitment of participants continuing until no additional themes emerged from the data. In this particular case the theme of "client is expert" showed that as a key message, many patients living with RA waited for long periods of time before seeking the advice of a health care professional and the lack of knowledge about RA is an important determinant of this delay. The data obtained was valuable and clinically relevant, though it did not use the methodology of an RCT. In fact, the authors state that to gain a full understanding of the behaviour behind delaying the initiation of early RA treatment, qualitative methods were preferable.

1.9.3.5 Studies specifically relevant to RA and RCTs

Despite these previous examples of literature not supporting the use of RCTs, the balance of the literature appears to support the use of such methodology, especially when testing an unproven form of treatment. If sponsorship from a particular product or drug is removed, the literature also supports the reduction or elimination of certain biases as seen with analyses of drug trials (Fries and Krishnan 2004). A meta-analysis conducted by Hammond

(2004) reveals that further study is needed in determining the most effective means of managing RA.

As previously indicated in the review of the literature with consultation with a research librarian, sixteen databases were searched, searches in Grey Literature and hand searching revealed that there were a few other studies examining rehabilitation interventions for people living with RA. The aforementioned study by Hammond (2004) identifies that many trials had methodological limitations, such as very short follow-up periods or small sample sizes. There have been few RCTs to date on non-pharmacological interventions and clients living with RA.

Based on the literature reviewed thus far, there is some evidence to indicate that symptomatic relief for clients living with RA resulted from thermotherapy, laser therapy, acupuncture and assistive devices, as well as short term comprehensive occupational therapy, orthosis and various mind-body approaches. However, these studies have been shown, on the whole, to be methodologically weak or limited in their findings.

Other findings supported that over a period of at least one year, patient education on joint protection training using behavioural approaches were effective in reducing pain and maintaining function. Hammond's study (2004) also reveals that relatively little is known about the long-term effectiveness of early rehabilitation, and that despite the increased availability of guidelines and systematic reviews, there is insufficient evidence for many areas of rheumatology rehabilitation. One of the final recommendations by Hammond (2004) is that further well designed clinical trials are needed, specifically those which recruit people with early disease and use patient-centred outcomes.

Some of the available studies have more systematically examined specific RA symptoms, such as fatigue levels, and efficacy of specific modalities, such as the clinical effectiveness

of static and resting splints for early RA (Adams et al., 2008) and have determined specific best-practice guideline, such as suggesting that splints should not be used as routine treatment of patients with early RA. Systematic comparison of fatigue levels reveals that those living with RA had similar levels to people in various stages of cancer and multiple sclerosis, possibly leading to the development of guidelines for prioritizing fatigue as a major symptom of RA, not solely pain symptoms.

As discussed in the literature review, the possible modality of choice best studied using quantitative methodology for efficacy is joint protection. Some of the literature indicates that educational/behavioural joint protection programs for people living with RA have varying positive outcomes of effectiveness, particularly the work of Hammond and Freeman (2001). These authors conclude that significant improvements in adherence to joint protection recommendations included a reduction in pain, improvement of disease status and increased functional ability. The methodology used by these authors is one of the few RCT based studies in the non-pharmacological management of RA. Hammond and Freeman (2001) also conclude that benefits of joint protection education became more apparent with time, and suggest that joint protection can help slow the progression of the effects of RA over and above the effects of drug therapy alone. In other words, the benefits of joint protection, as indicated by this RCT, potentiated the effects of medications alone with participants in this study.

1.9.3.6 Using an RCT to conclude this study

Given the information reviewed thus far, a case can be made for development of a pilot RCT to test a novel means of delivering a joint protection program to clients living with RA. If a RCT is to give unbiased results using the CONSORT criteria, one must first ensure that a pilot RCT is carried out as per the Medical Research Council (MRC) guidelines. As

a case can also be made for gathering of qualitative data using other methodological means, the use of qualitative methodology to induce appropriate selection of tools for the pilot and a future RCT is also warranted. This use of qualitative data from expert clients and clinicians also addresses some of the aforementioned critiques of leaving out stakeholders and relevance of tool selection to measure the sample studied in some of the RCTs reviewed.

The proposal in question is to perform a pilot study for a RCT using both the MRC guidelines for research and the current CONSORT guidelines. A combination of expert opinion pooled from clinicians and experienced clients will be utilized to pilot and develop treatment around a therapeutic modality that has already been shown to work in the clinical literature (Lorig et al., 1993). This use of participant informants and increasing the emphasis on the individual experience in health encounters is supported as one of the means of reconfiguring evidence-based practice in occupational therapy (Reagon et al., 2008). The experimental portion of this particular study will involve web-based delivery of a program using a VW platform for delivery of patient education instead of in person.

The overall conclusion is that careful methodological development and piloting of the RCT is required before starting a full RCT. This is required to avoid failures of previous studies with limited generalizability, as indicated in the literature survey. As VWs are a relatively novel form of eHealth and means of information delivery, delving into a full RCT may prove to be a significant issue, as the methodology for evaluating the intervention itself must be examined first. As qualitative work used alongside RCTs of behavioural health care interventions have been critiqued as often being poorly integrated into the final study (Lewin et al., 2009), the earliest phases need to clearly demonstrate how the proposed intervention was developed, refined and explored, as well as how the proposed measurement tools were selected.

As qualitative data will be used as the basis to create the VW tutorial and obtain initial feedback, it is anticipated that methodological issues seen in other studies using an electronically based health intervention, such as limited interactivity and user interface issues, can be avoided (de Jong et al., 2009). Such issues could be identified prior to pilot RCT implementation if the qualitative data is used to comprise the foundation for the latter parts of the study.

1.9.4 Web-based surveys and email

When recruiting to a study, individuals are typically from specific segments of the general population. The samples could theoretically be as large as sampling from everyone on a registered voters list or everyone with a registered Internet account. In sampling people from these segments of the population, assuming that it has been ethically approved to do so, recruiting would be from a large sample and potentially representative of the entire population.

Unlike general registers of voters, there is no registry of people living with RA. Theoretically, the provincial governments and dedicated rheumatic disease units in each province in Canada would have access to this data. However, this data would still be limited to those undergoing treatment for RA, assuming that a proportion of this population would not seek out treatment. Additionally, accessing a full registry of this information via a provincial government would prove very difficult given privacy legislation such as the Health Information Act and Freedom of Information and Privacy Protection Act.

Recruiting participants for a targeted health intervention, such as for those living with RA, would involve recruiting from much smaller samples given these issues. These samples would have to be accessed via a dedicated rheumatic disease unit or over the Internet, resulting in a potentially biased sample.

It has already been indicated in Section 2.4 that not all individuals diagnosed with RA seek out or have available treatment via a dedicated rheumatic disease unit. Given the demographic information provided in Section 2.4, reasons for not attending a specialised rheumatology service may include other commitments, such as work and family, or geographic location.

It is also indicated in Section 3.3.2 that not everyone uses the Internet, or uses the Internet for chronic disease management resources. However, as the intended audience for this study is people living with RA who may be interested in using an online resource, a sampling bias of this type may be desirable. If feasibility of an online program and disease management is the goal, this type of purposive sampling would seek out people living with RA who were also Internet users. If the initial study is deemed feasible, it makes the development of the resource worthwhile, and may help identify the types of people living with RA who may use the program.

1.9.4.1 Response rates

For data collection to be of value, there must be a reasonable response rate. For this study, this is a requirement of both those who agree to take part in the study as well as those who access the VW program as part of the treatment group. Earlier studies examining Internet based response rates to surveys indicate that mean response rates are comparable to more traditional means, such as via regular mail. A meta-analysis of Cook et al. (2000) indicated that at that time, the average response rate of Internet based surveys, 68 studies total, was 40%. Average response rates to postal style surveys was 47%. This difference across all studies was deemed not statistically significant in comparing overall responses rates. More recent analyses indicate that the difference has decreased and remains not statistically significant (Shih and Fan, 2008).

These meta-analyses indicate that a response rate meaningful enough for publishing a study is at least 40%. Additionally, response rates could be obtained with more variety in comparison to pen and paper mailed surveys. As an electronic medium is being used with this study, this could be via email, an online survey, and conversations between avatars in the VW in real time or objects left by participants, such as a virtual post-it note. This variety could increase response rates in comparison to other electronic media.

1.9.4.2 Quality of data collected via the Internet

One issue with a web based study is the validity of the questionnaire data compared with traditional methods. Several representative studies indicate that findings of electronically based surveys may not only be comparable, but there are advantages to collecting information electronically. For example, it has been proposed that a more anonymous means of submitting feedback, such as over the Internet, may result in more in-depth self-disclosure (Lee et al., 2008).

In terms of the ethical treatment of research participants, there may be a further advantage to using the Internet to provide feedback. Joinson (1999) found that participants using web-based resources in research studies reported lower social anxiety in comparison to using face-to-face methods. This finding, in addition to the possibility of more in-depth self-disclosure, may indicate that the quality of data collected via the Internet may be equivalent to, or superior, to paper based surveys.

1.9.4.3 Confidentiality and credibility in virtual environments

A significant concern in collecting data via both a VW and an Internet based survey is security and confidentiality. Participating in a health intervention program via a VW comes with potential added social risks as well. As some participants may require in-world

assistance or interaction with the principal investigator's avatar, guidelines are suggested in order to make participants comfortable and not feel deceived. As per the studies reviewed in section 1.7.3.2, the investigator avatar should be representative of the avatar, such as human adult male.

Additionally, information gathered about the participants themselves via the Internet should involve a secure survey, ideally outside of the VW program. Online surveys can be administered via a third party server. Access to the survey results would be password protected. In some cases, the survey information may be participant to The Patriot Act if administrated via a United States based company, such as Survey Monkey®. Access of this type by a government agency is unlikely given the type of study being undertaken and information being gathered.

To further ensure confidentiality, anonymizing participants will also occur in the VW program. Participants have individual accounts in the VW platform and these accounts are also password protected. Participants also select their own avatar name, further anonymizing themselves. The study area of the VW platform, the developed program itself, can also be set to private. In selecting this setting, only the investigator and participants involved with the study have access to the VW study area.

Additional security features to protect participant confidentiality include physical barriers, such as walls, sky boxes or privacy screens. Chat can also be blocked from neighbouring simulations. Land settings can be pre-programmed to ensure avatars of participants are also protected from encountering third party avatars not involved with the study. These land settings include prohibiting the use of scripted objects, such as weapons, limiting object entry into the study area, automatically returning objects left behind by participants and prohibiting bumping other avatars, as this can be a harassing behaviour in a VW. These measures will increase safety for virtual participants in addition to increasing

confidentiality. Such measures reduce the probability of harassment by non-research VW users and eliminate griefing, a form of virtual harassment and vandalism seen in several VWs.

With many interventions that involve online participation, direct observation is not possible unless watching the participant use a computer while accessing the resource of interest. This inability to readily observe may reduce the credibility of results of online study results. However, using less intrusive methods, it may be possible in a VW to accurately record visits to specific locations. Presently within the SL platform, it is possible to record the date and time a specific avatar visits a teleportation point or landmark. It is additionally possible to record local chat that occurs between avatars. These abilities are possible through the use of a combination of scripted objects, such as welcome mats and artificial avatars, which are both programmable in order to provide this type of data tracking.

1.9.5 Contribution to knowledge and understanding

This study will develop methods for development and piloting of VW content specific to joint protection and RA self-management which has not been attempted to date. The methodology and development of a pilot RCT using this content with this population has also not been attempted to date. A pilot RCT may determine if it is feasible to deliver joint protection information specific to RA management. Results of a pilot RCT may indicate what sample size may be required of a future full RCT. This pilot RCT may also determine if exposure to, and use of, the proposed VW program has a positive effect on RA management, based on the results of the outcome tools selected. This positive effect, if any, could also be tested via knowledge based questions of the participant area, in this case, joint protection.

Preliminary phases of the study determined the types of information content experts in this area expected to be included. Construction and tailoring of the program determined if it was possible to present this information effectively using this medium. The results of this study can provide a methodology for developing and testing other VW based programs for other populations. These populations could be those living with other rheumatic diseases or other chronic diseases.

Chapter 2 – Aims and Objectives of the Study

2. Aims

This study aimed first to develop a program using a VW platform over the Internet for people living with RA. The program aims to help patients learn about joint protection in self-managing RA. Second, once developed, the program was the focus of a pilot RCT in preparation for a possible future definitive RCT.

The study was in two parts. The first part was the identification of what was needed in the VW program and the development of the program. This involved an iterative process of user-led enquiry and design, including: A. the previous literature review, B. interviews with expert clinicians, C. interviews with expert clients, D. design and implementation of the VW environment and content and E. trial of the program by clinicians and clients for feedback prior to the pilot RCT. The second part was a pilot RCT to test the feasibility for, and design of, an RCT.

Primary questions to be answered in stage one, in conjunction with the initial development of the program, were:

1. What is the expected joint protection content in the VW program?
2. What features do users identify to make this media most useable?
3. What tools or instruments may be useful in determining measureable outcomes on management of RA?

In the second stage, the pilot RCT, the primary questions to be answered were:

1. Does the proposed RCT appear feasible?
2. Are we able to recruit and randomise participants? What rate of drop out do we have? Are noncompliance rates between intervention and control similar?

3. Given the tools or instruments selected via the expert input in the development of the program, is there evidence of clinical efficacy using this intervention as measured by these tools or instruments?
4. Given the results of this pilot RCT, and information about desirable effect sizes from literature or stakeholders, what would be an appropriate sample size for a future full RCT?
5. Is there any cost associated with using the program? Can we measure cost? This cost could be used to determine cost effectiveness in comparing treatment methods in future study.

2.1 Objectives and overall study design

This study was to develop a program using a VW platform over the Internet for people living with RA. The study culminated in the recruitment of individuals into one of two groups, those who were provided access to the VW program for up to 30 days, then completed an online survey, and those who completed the online survey and then were provided access to the VW program 30 days later.

The flow chart (Figure 1) indicates the overall structure of the first part of the research project, the initial development of the VW content. The VW was constructed based on initial participant input, tested and then the pilot RCT was carried out as the final phase of the project.

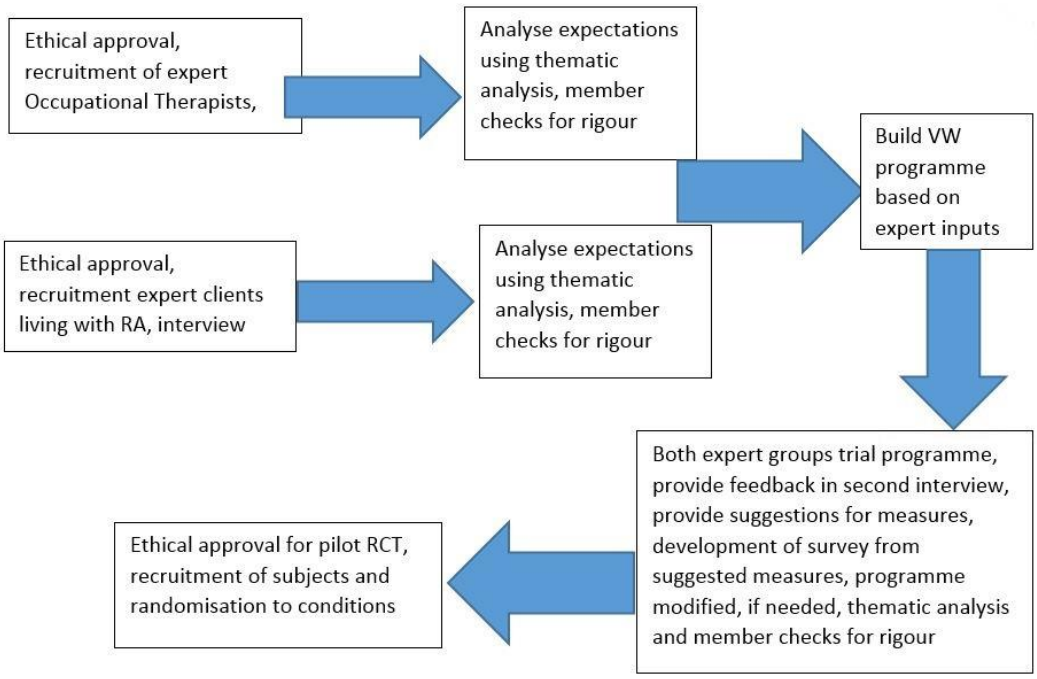


Figure 1 Structure of Project Methods

First, it was necessary to ensure that once the themes had been developed and confirmed via expert input, that the content for the VW was inclusive of the recommended content. In order to do this, a series of displays were built, one at a time, based on the input provided. This process was labour intensive, taking approximately a year to construct and followed the process as included in Figure 2. Details of the process are decribed in Chapter 3.

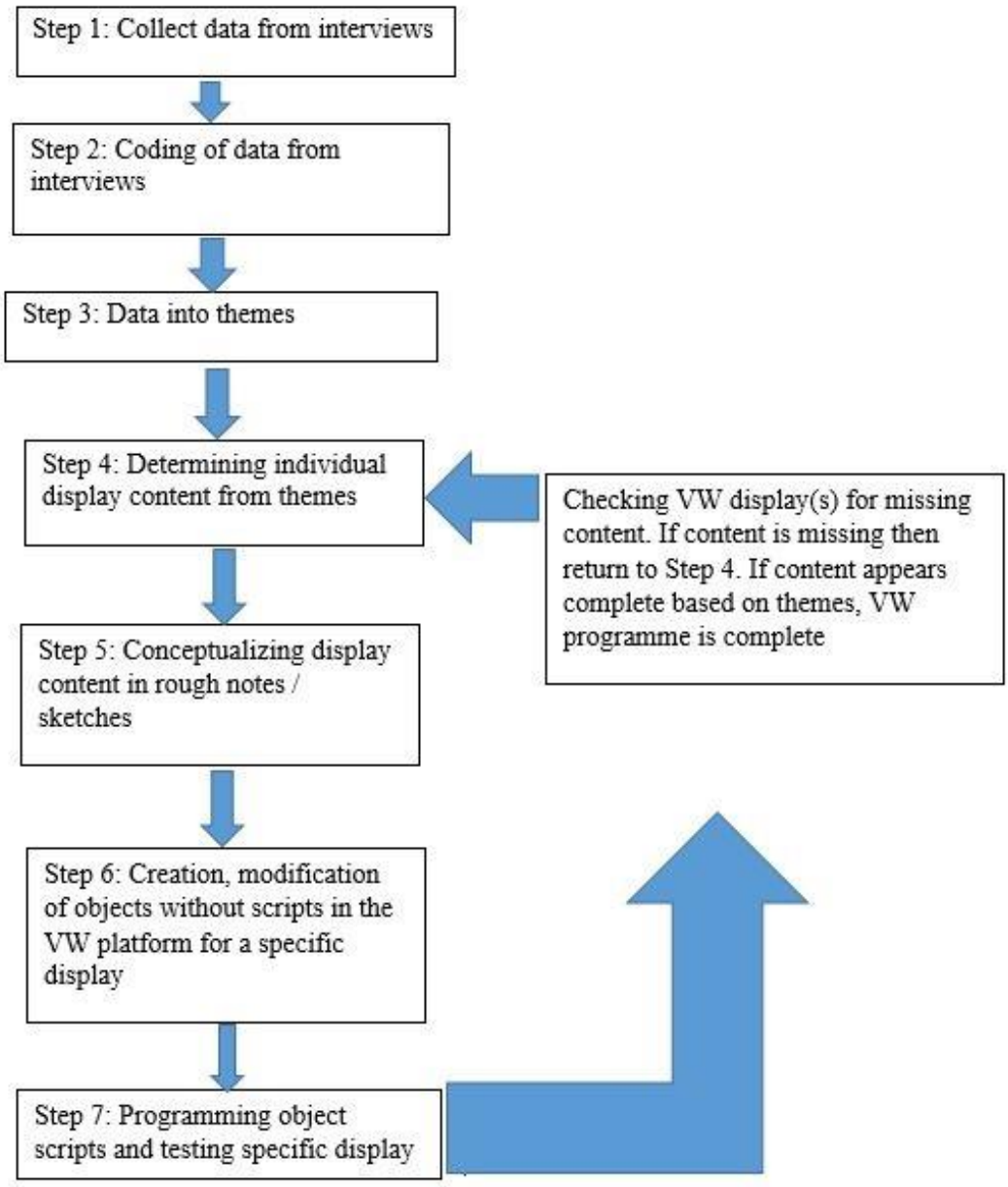


Figure 2 - Process of Developing VW Content

Several challenges in developing the VW program modules including limited programming experience in LSL, the need to purchase a section of land in SL large enough to hold all content and keeping track of the content itself. One means of maintaining the reproducibility of the program contents included the keeping of an inventory of objects and scripts, tabulated in the attached Appendix 1.

Additional data gathered during the program development included taking screen shots of work as it progressed. A sample of one display as it was developed is included in Figures 3, 4 and 5. Other examples of this development are included in Appendix 2. This information was useful in development of some of the later stations in the VW program as a more systematic approach to module development was possible with increased skills in building and scripting being achieved by the principle investigator. Few modifications were needed to the initially piloted program before undertaking the pilot RCT as described in Chapter 4.

Figure 3 Early Development of Gardening Display

Figure 4 Later Stage of Gardening Module

Figure 5 Gardening Module Completed with Scripted Objects

The pilot RCT undertaken involved sampling volunteers living with RA who had not participated previously in RA management programs, such as the ASMP as outlined in section 1.6.7 of Chapter 1. The pilot RCT involved recruiting via an ethics approved poster

invitation posted at a dedicated rheumatic disease service in Edmonton, Alberta, Canada and on variety of electronic bulletin boards, blogs and social media pages with web link to an online video invitation (www.screencast.com/t/w5BSzNw0).

Participants were invited to trial a VW program as part of a Plymouth University student study that was ethics approved without the offer of monetary compensation or other incentives. The Alberta Health Services Human Research Ethics Review Board granted approval for all three parts of the study on the conditions, among others, that potential participants would only be contacted once regarding participation and that the principal investigator would not be recruiting in person, such as at the rheumatic disease unit. Approval of the study was also participant to administrative approval, which was also obtained prior to the pilot RCT phase of study.

Potential participants who contacted the principal investigator were sent a reply via email, including an ethics board approved invitation and informed consent form for completion. Those who did not meet the inclusion criteria were excluded from participation and informed they did not qualify for the study. Those who completed the informed consent form and met the inclusion criteria were randomly assigned to one of two groups. Those who contacted the principal investigator but did not complete the consent form were sent one reminder via email 14 days after initial contact.

Those participants in the control group were invited to complete a survey pertaining to their present RA management, function and knowledge of joint protection principles. These participants, on completion of the survey, were granted access to the VW program. Participants in this group were sent a reminder after 14 days if they had agreed to participate and completed the informed consent form, but did not complete the survey.

Participants in the treatment group were provided with immediate access to the VW program. Participants in this group were sent a reminder email after 14 days to encourage them to access the VW at least once. These participants were requested to complete the same single survey 30 days after entering the study and being provided VW program access. Survey completion could be anytime within the 30 days after study entry and needed to be completed by the end of the 30-day study period. Participants were sent a single reminder after an additional 14 days after the 30-day period of VW access to if the survey had not already been completed. All data was collected via a Survey Monkey® account with unique survey identifiers. Figure 6 shows the overall design of the pilot RCT.

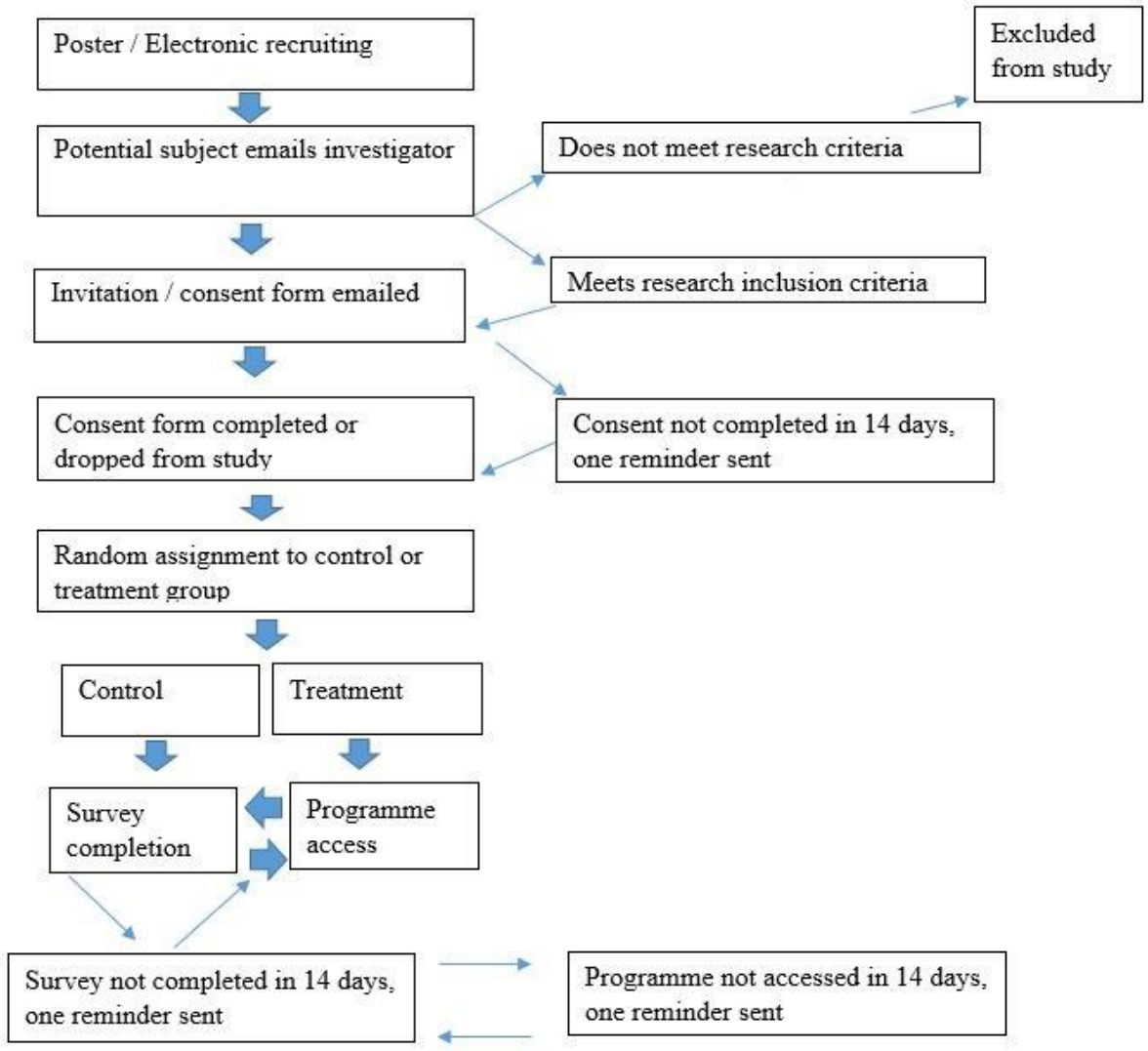


Figure 6 Overall Design of Pilot RCT

Demographic data was collected to determine the overall representativeness of the sample in comparison to information presented in section 1.2.5 of Chapter 1, while also allowing for examination of differences between groups. Parametric data were analysed between groups using t-tests to look for differences between the control and treatment groups. One-way Analysis of Variance was also used to examine mean differences between groups. For non-parametric data the Kruskal-Wallis Test was used to examine mean score differences between the treatment and control group. Chi-squared analysis was also used to assess

differences in proportions of each group. All analyses involved using a $p < 0.05$ in evaluating statistical significance. As the pilot RCT was intended to test the feasibility of a future full RCT, noncompliance rates were also tracked. Intention to Treat (ITT) Analysis was done in order to determine the sample size required of a full RCT.

Chapter 3 Development of VW Program Based on Expert Input and Piloting

As a VW program for teaching joint protection for RA did not exist prior to commencing this study, development of the program was a required early stage of this study. The literature review in Chapter 1, indicates that one of the more effective means of non-pharmacological management of RA is the teaching of joint protection techniques. These techniques are frequently taught via dedicated rheumatic disease units by therapists or via lay people living with a rheumatic disease. As both types of programs may vary in content, it was deemed prudent to include both input from therapists and lay people with experience taking and/or teaching joint protection content through an ASMP. As this was a new clinical application of a VW, and given the potential for gaps in current practice as per the literature review, it was deemed most suitable to use qualitative interviews for the development of the VW using both the therapist and client groups, versus looking at defining characteristics of a joint protection program and superimposing these on a scale using a VW. The rationale behind this selection of qualitative interviews during this stage of development included the need to better capture the user experiences and potential gaps in information that may be missed using a single opportunity for expert input. Allowing for a second, and potentially, third opportunity to provide less structured and restricted input was deemed a more labour intensive, but superior option for quality assurance in development of a client intervention using a novel medium.

3.1 Recruitment of occupational therapists (OTs)

As a VW program for teaching joint protection to people living with RA did not exist prior to commencing this study, development of this program was a required initial stage of this study. Recruitment of expert therapists was undertaken in order to obtain expert input to the development of the program. These therapists provided a considerable volume of input

into the overall content and design of the program. These therapist experts were recruited and interviewed, prior to the recruitment and interviewing of clients living with RA, as discussed in the following section of this chapter.

3.1.1 Qualitative interviewing of OTs

3.1.2 Study design

This portion of the study had a qualitative design. As described by section 1.9.2 in Chapter 1, the qualitative tradition most appropriate for this type of study is thematic analysis via semi-structured interviews. This part of the study involved program development and feedback, similar to product development and evaluation by users. Participants were purposively sampled from the Edmonton area and central Alberta for their expertise in rheumatic diseases as therapists.

3.1.3 Ethical approval

In order to recruit human participants for the study, the local health authority's permission needed to provide approval. Approval was applied for in March of 2010 via Alberta Health Services and the University of Alberta Human Ethics Research Board (HREB), the governing board where the participants were to be recruited from.

Four main ethical issues were addressed, confidentiality, informed consent, potential deleterious effects from participation and funding. Despite using regulated health professionals as participants, the local health ethics review board required an assurance of informed consent for all studies involving human participants.

All participants, via the information letter included in Appendix 3, were assured of confidentiality, received instructions regarding the nature and purpose of the study and were permitted to withdraw their permission to be tested at any time. Participants had the option

to request final study results as well. Participants were not deceived, misled nor received inducements to participate. They received a copy of the information sheet, reviewed and signed the consent form and received copies of both forms prior to data collection.

It was anticipated that participants would not experience pain or psychological distress. Deleterious effects of new interventions, treatment or unknown side effects are not a known issue. Some prior studies on the use of VR indicate potential issues with motion sickness (Finch and Howarth, 1996) and are outlined and previously discussed in section 1.7.3.9 of Chapter 1. However, this is with head mounted displays, which were not being used in this study. Participants were not expected to perform activity beyond a sedentary level of function and were performing non-repetitive tasks at a computer.

It terms of funding, the principle investigator was responsible for all costs, including postage, VW program development costs and VW program hosting costs and there was no financial gain for the investigator from the participation of therapist professionals in the study.

Application was conducted via an online submission to the committee and qualified for expedited approval as the study was deemed non-invasive and posed a minimal risk to participants. Ethics approval for this portion of the study was obtained in May, 2010 and is attached in Appendix 4.

3.1.4 Participant recruitment

Once ethics approval was obtained via the Health Research Ethics Board with Alberta Health Services and the University of Alberta, invitation letters were sent via email to six OTs who had specialized training in delivering an ASMP and / or had experience delivering a similar type of program while working on a dedicated rheumatic disease service.

Five participants expressed an interest in participation with no response being received from the sixth. Demographic information was collected in order to allow future studies to compare samples. The primary places of employment included acute care, community care, home care and a rehabilitation hospital. Of the five participants, three were actively involved with present delivery of an ASMP program, two of which were involved in delivering an ASMP dedicated to specific management of RA. All of the five participants were trained at the B.Sc.O.T. Level, with one recently completing a related non-Occupational Therapy Master's degree. The number of years of experience as a therapist ranged from 6-28 years. The range of experience of participants working in rheumatic disease education ranged from 1-20 years. One of the participants had also, coincidentally, been living with RA for just over 20 years. All participants were female. The age range of the participants was from 32-50 years of age.

3.1.5 Information and consent

Participants were provided with information about the study via the invitation letter. They were informed that they were being invited to participate in a research study. The letter indicated that the research conducted in this study complied with University of Alberta Standards for the Protection of Human Research Participants. This policy was available for inspection: www.uofaweb.ualberta.ca/gfcpolicymanual/policymanualsection66.cfm.

To participate, a signed Informed Consent form, explaining all benefits and risks, had to be completed prior to participation. The form, as attached in Appendix 5, explained potential risks and benefits, right to privacy, how information was kept secure and right to withdraw from the study at any time without risk or penalty.

As per the invitation letter, if potential participants were interested in participating in this research, or had further questions, they were encouraged to contact the principal investigator. If potential participants were not interested in participating, they were informed that they were under no obligation to respond and would not be contacted again.

For participants to be included in the study, they had to be a registered therapist in the province of Alberta and had previously or presently taught in an ASMP involving joint protection instruction. Participants had to have access to a computer and the Internet. Computers used had to meet the minimum system requirements for the program to run as per Table 1. The link to this information, including a test program to determine if their system met these minimum system requirements, was provided and participants were made aware that minimum system requirements were needed for the program to run.

Operating System	Windows	Mac OS X	Linux
Internet Connection	Cable or DSL	Cable or DSL	Cable or DSL
Operating System	Operating System: Vista, Windows 7 or 8 with the most up-to-date service pack installed	Mac OS X 10.7 or better	A reasonably modern 32-bit Linux environment is required, or a 32-bit compatibility environment if running a 64-bit Linux distribution
Computer Processor	CPU with SSE2 support, including Intel Pentium 4, Pentium M, Core or Atom, AMD Athlon 64 or later	1.4 GHz Intel based Mac	800 MHz Pentium III or Athlon
Computer Memory	1 GB or more	1 GB or more	512 MB or more
Screen Resolution	1024x768 pixels	1024 x 768 pixels	1024 x 768 pixels
Graphics Card	NVIDIA GeForce 6600 or better, or ATI Radeon 9500 or better, or Intel 945 chipset	ATI Radeon 9200 and above, or NVIDIA GeForce 2, or GeForce 4	NVIDIA GeForce 6600 or better, or ATI Radeon 8500, 9250, or better

Table 1: Minimum System Requirements for SL ® (Linden Labs, 2015)

As per Linden Labs' recommendations (2015), it was also noted that additional system requirements and restrictions may have been an issue. Specifically, SL is not compatible with dial-up internet, satellite internet and some wireless internet services. SL may also not run on some rarely used graphics cards other than the ones listed above.

Fortunately, no participants were excluded because of system requirements. All of the participants had to use a personal computer and were unable to access SL via a work computer. SL has been blocked from access on computers owned by Alberta Health

Services and this is the singular public health authority employing almost all OTs in the province of Alberta. The program has been deemed inappropriate for use at work by this health authority. It is noted that other blocked programs by this organisation at the time of writing include YouTube® and docstock.com which have proven useful in academic settings.

3.1.6 Confidentiality

The data included digital recording of interviews using Camtasia Studio software. Digital recordings included a single copy kept on a password-protected computer in a locked and alarm-protected office. A backup copy was kept on a password protected account. Digital recordings were anonymised, containing the date of interview as a file identifier. Identification of the participant was cross-referenced with a private calendar that contained the participant's initials. Digital recordings only included audio, there were no images that could identify participants.

3.2 Therapist interviews

Methods: Once participants agreed to participate and completed the informed consent form, participants were interviewed by the investigator in a private office, either the investigator's office at the Univeristy of Alberta in the Faculty of Rehabilitation Medicine, or the invesitgator's primary office at his private practice to ensure confidentiality, either provided by the investigator or at a place acceptable to the informant providing confidentiality could have been assured.

Interviews used a predetermined set of open-ended questions, included in Appendix 6, primarily centred on the participant's experiences delivering an ASMP and their expectations about the content that would be expected of such a program. These questions

had been derived procedurally via recommendations provided by Creswell (2013), including the number of questions, wording and use of probes, and were previously piloted with the investigator's supervisory team.

Interviews lasted from 60-90 minutes. Some of the interview included gathering information about how the therapist presently determined efficacy of their interventions and time spent dedicated to joint protection was also gathered. Interviews were recorded and transcribed by the investigator. Though it was initially intended to have these transcribed by a third party, it was deemed a more effective means to become familiar with the data if transcribed by the investigator. Transcripts were reviewed for accuracy while replaying recordings. As per the steps described by Braun and Clarke (2006), each interview was re-read several times to get an overall impression of the primary concerns and points that each participant was making.

After reading each transcript several times, preliminary thematic analysis was carried out manually. Several paper copies were made of each of the transcripts, and this information was highlighted manually and saved as a working theme within the data. For example, all information pertaining to any functional activity, regardless of what it was or how it may be classified, was highlighted as an initial working theme. As the data, rather than theory, drove the development of the theme, it was determined from development of this working theme that all informants identified specific activities that were critical in a joint protection program for clients living with RA.

Other working themes were developed using the same process, as decribed by Braun and Clarke (2006). Once no further working themes could be extracted, the data was reviewed again to determine if any of the statements made did not fit into another theme. Some statements fit into more than one theme. For example, an informant could have been

describing the activities discussed in their taught progam, while also discussing issues with clients accessing their program. This statement was incorporated into more than one theme. Once no further themes could be derived, it was concluded that no further themes could be extracted.

nVivo® software was then used to check the themes identified. This allowed for removal of overlapping themes. Data was cut and paste into a student version of nVivo® and these themes were then sought out in the transcribed interviews. While reviewing transcripts, several pieces of information were felt to be similar and requiring categorization. Becoming further immersed in the transcriptions revealed that not only was there some overlap in the working themes, but there was considerable overlap in several statements applying to more than one theme. Themes were condensed from their original working form given this overlap.

For example, statements about basic daily living activities were found throughout all the interviews as a theme. There were no transcripts where basic daily living activities, such as grooming, dressing and hygiene were not mentioned. Another theme emerged involving all informants, the difficulty of discussing some activities in groups. As per the options provided by the software, some data that did not appear to fit into a theme could be initially left as a free node, and reviewed later. For example, if the issue of paying for parking was raised by only one participant, and it was not obvious that this data indicated potential issues with existing program access and costs to participants, it could be incorporated later as this theme developed from the data.

Rigour needed to be addressed to ensure the data had been identified, driven the development of themes and the themes had been identified correctly. One means of ensuring this has occurred is via member checks, as described by Creswell (2013). This

has support as being one of the more rigourous means of determining the credibility of qualitative findings. Additionally recommended by Creswell (2013), is the use of at least two means of verification.

Once all themes were extracted, these were checked for trustworthiness with participants. All participants were first shown a transcript of their interview, and later, a copy of the extracted themes. These member checks were employed with all of the original five participants. None raised objections to the transcribed interviews. Three participants agreed outright with the thematic analysis. The remaining two agreed with the themes, but also had minor inquiries about specific content. For example, one informant had a query if covering avoiding positions of wrist flexion and ulnar deviation was going to be included. Though not a theme in itself, the participant was assured that this specific content would be included, and that this was not a theme in itself, but a data node which had appeared in several of the themes. The other participant indicated a desire to include a number of items pertaining to workers' rights, dealing with employment issues and disability rights. It was determined, on further follow-up, that this was a personal concern at the time for this particular participant. This participant agreed that the themes covered expectations regarding joint protection and RA when re-directed to the intended content, versus overall disability management and personal issues, which may have impacted initial feedback.

As the coding and data extraction was not something the participants were familiar with and this was perceived as a missing link in this part of the study, a peer review of this part of the study was included. A study supervisor well versed in thematic analyses provided a peer audit of two coded transcripts and the emerging themes. Initial feedback on the first transcript was that the data units could be broken down further to be less inclusive and more specific, which was corrected and deemed less of an issue with review of a subsequent

transcript. There were no issues raised regarding missing or confabulated themes from the data.

While social desirability may have been a threat to rigour, participants were provided the transcript via email. They did not have to immediately respond, nor respond face-to-face. Additionally, they were indirectly asked about their impressions of the interview transcipts and extracted themes, specifically, they were asked to provide feedback, versus leading and direct questions, such as if they agreed the information was complete. Indect questioning has been shown in the literature as an effective means of reducing the threat of social desirability bias (Trochim, 2006).

Results: Three primary themes were found from analysis of the transcripts:

- Challenges of balancing the role of educators while managing a caseload.
- Formal outcome measures are not being used to determine treatment efficacy.
- A VW based means of delivering joint protection information would complement existing programs.

One theme was striking a balance between fulfilling their role as educators while dealing with the demands of their caseloads. Therapists felt they have a significant role in teaching joint protection with a corresponding high volume of demands on their time in teaching RA self-management. This means that time spent specifically dedicated to joint protection may run through a program or one-on-one session, but specifically dedicated time on this topic may be 1-2 sessions of an hour each, at most.

Another theme was that though client education was deemed important, no formal outcome measures for existing programs are being used to determine efficacy. Most feedback collected presently is on client satisfaction and client reports regarding function.

A third theme was that clinicians viewed a VW based means of delivering joint protection information as a complement to their existing program, not a threat to it, allowing access to some who might not attend a self-management class. Reasons for not attending an ASMP were similar to those discussed in section 1.5.13 of Chapter 1, including being unable to take time off work or travel to a major urban area. Additional issues included hidden costs of attending an in-person program, such as paying for parking and costs of materials provided to participants.

In addition to these themes, there were five primary concrete content recommendations. Content recommendations were a significant source of information obtained through the transcribed interviews. Based on the thematic analysis of the transcribed interviews, participants identified the following content as required of a joint protection program:

- Activities to include home activities (such as basic mobility and transfers and housework), and leisure activities (such as community mobility, golf and gardening), and work (such as ergonomics with computer use and joint protection with activities such as lifting)
- Emphasis on avoiding deforming positions during daily activities
- Protection of hands, but also having whole body focus that explains the process of what is happening to the joint(s)
- Explaining why joint protection is important
- Linking joint protection to overall physical fitness.

Outside of the basic content, the informants also felt that a joint protection program ideally needed to have the following qualities:

- Be relatively easy to access

- Include elements of realism and ability to practice
- Have the option to combine individual and group elements, according to the topic
- An opportunity to discuss personal topics such as sexuality and peri-care

An unexpected result was a general lack of concern expressed by all participants, regarding online safety using this type of media for eHealth. This was despite a direct prompt asking the informant about concerns with safety. These findings are perhaps indicative of the need to continue to educate therapists about issues arising around the new social web and may need to be included as a preamble or introductory module in learning to use a VW program for client teaching. One of the participants stated that there may be some issue regarding ensuring confidentiality or privacy, though they were not aware of the security and privacy features available in a VW. None reported issues regarding social risks, issues regarding behaviours or the self or others in a VW or potential to be verbally or visually confronted in a VW. This may have been in part, because of a lack of familiarity with contemporary VW issues, though these can be common issues in many forms of social media. There may have been an assumption by participants that safety may have been defined in terms of physical harms only, given the musculoskeletal basis of the intervention proposed. This assumption, though not explicit, may have led participants to assume that a short duration sedentary task posed no major risk to users.

Overall, this finding was a concern for the principal investigator and it resulted in further discussion with colleagues regarding the rise of the new social web and the training of local occupational therapists. All participants had graduated from the local occupational therapy program over the past three decades. The reason for collecting this baseline demographic information was to allow for future studies to compare participant samples with this one. This discussion culminated in a study-related article being written, regarding more widely

used social media at present (Kashani, Burwash and Hamilton, 2010) and is included in Appendix 14. To date, this article has been cited in seven publications regarding guidelines and recommendations for more commonly used forms of the new social web. These are being deemed necessary to develop internationally in order to better educate OTs, given publicized issues with online privacy and safety for both themselves and their clients.

3.3. Recruitment of clients living with RA

People living with RA who had either taken or taught in an ASMP were recruited to obtain client or user input in the development of the program. These client experts provided a noticeably smaller volume of input into the overall content and design of the program in comparison to the therapists. These client experts provided some useful input that varied somewhat from what was provided by the expert OTs in both the program development and testing portions of this study.

3.3.1 Qualitative interviewing of clients living with RA

3.3.2 Study design

The design for this portion of the study was also qualitative, similar in overall design as outlined in section 3.1.1 of this chapter. As described by section 1.9.2 in Chapter 1, the qualitative method most appropriate for this type of study is again, thematic analysis via semi-structured interviews. This part of the study involved program development and feedback, similar to product development and evaluation by users. Participants were purposively sampled from the Edmonton area and central Alberta for their previous attendance to an ASMP program.

3.3.3 Ethical approval

Four main ethical issues were addressed, as was addressed similarly in section 3.1.3 of this chapter, confidentiality, informed consent, potential deleterious effects from participation and funding.

All participants, received the same information letter included in Appendix 5 as the therapists. Participants received the same type of treatment the therapists received as per section 3.1.5 of this chapter. Participants received a copy of the information sheet, reviewed and signed the consent form and received copies of both forms prior to data collection.

Participants had to be capable of giving informed consent to be included in the study or they were otherwise excluded as per the preceding inclusion and exclusion criteria.

In order to complete the ethics requirements for this stage of the study, the same minimal risks, proof of self-funding and local health ethics board approvals had to be met, as outlined in section 3.1.3 of this chapter.

3.3.4 Participant recruitment

Ethics approval was obtained from the Health Research Ethics Board with Alberta Health Services and the University of Alberta in September of 2011. Invitation letters were then sent to ten potential participants who had previously taken part in an ASMP. Demographic information was collected in order to allow future studies, if any, to compare similarities or differences between samples.

Seven participants expressed an interest in participation with no response being received from the remaining three identified individuals. The primary places of recruitment were from a rehabilitation service with a dedicated rheumatic disease unit and from a community based service that included an ASMP as one of the services. Of the seven participants, three

were from a health professional background (two nurses and a previous hand therapist), one participant was employed as an elementary school teacher and one was employed as an office administrator. The two remaining participants were not employed, one due to RA related disability and the other was beyond retirement age. Five of the participants had post-secondary education, one of whom had a Masters level degree. All participants were female and aged 24–72.

3.3.5 Information and consent

As per section 3.1.5 of this chapter, participants for this part of the study were provided the invitation letter, ethics approval was obtained via the Health Ethics Review Board (HREB) and invitation letters were sent to clients living with RA who had either taught an ASMP or had received education via a similar type of program.

Participants were identified via a hospital based rheumatology clinic or ASMP and provided an information flier, via an electronic bulletin board (www.edmontonrheumatology.com). The Arthritis Society of Canada, Alberta Division was also approached about posting a link to the study, but declined without providing a reason and did not contact the principal investigator. Participants who were interested in participating were sent an electronic copy of the invitation letter and then received a hard copy in person prior to consenting to the first interview.

For participants to be included in the study, they had to be an adult diagnosed with RA as a primary diagnosis, having previously received an ASMP program involving joint protection instruction. Participants had to be capable of providing informed consent. Participants were informed that they needed to have access to the Internet and were informed as to what the minimum system requirements were as per Table 2 in section 3.1.4

of this chapter. For this stage of the study, and to avoid excluding potential participants, the invitation letter indicated that access to a computer could be provided to participants if their system did not meet the minimum requirement as listed by Linden Labs (2015).

Participants unable to give informed consent, due to age or reduced cognitive capacity were excluded. This included, by definition, all persons under the age of eighteen. Participants who did not have access to the Internet would have also been excluded.

No potential participants were excluded based on the aforementioned criteria. All but one of the participants had a personal computer that could run the SL platform. This participant lived a considerable distance from Edmonton, 750 kilometres round trip. This distance posed a challenge with providing access to the program and follow-up interview, but was a condition of the ethics approved invitation letter. This participant was accommodated as computer access was stipulated as being provided to anyone who was unable to access the program via their own computer. The added travel by the principal investigator to northern Alberta in order to provide access and interview the participant took an additional two days of unanticipated travel.

Three of the participants were also employed by the provincial health authority, and like the expert therapists in section 3.1.4 of this chapter, were unable to access SL via a work computer. As previously noted, the program has been deemed inappropriate for use at work by this health authority.

3.3.6 Confidentiality

As per section 3.1.6 of this chapter, participants were provided information regarding confidentiality as per the invitation letter. Specifically, participants were informed that the information that they would provide would be kept anonymous and kept in a secure office.

This information will also be destroyed as previously outlined. The data was safeguarded as per the procedure outlined in section 3.1.6 of this chapter and was only digital recordings without images.

3.3.7 Client interviews

Methods: Both the methods for data collection via semi-structured interviews and thematic analysis was carried out as described in section 3.2 of this chapter.

Once all themes were extracted, these were checked for trustworthiness with participants. Member checks were employed with all seven participants. All participants agreed with the thematic analysis. It was noted that overall, there was a considerable difference in the robustness of the information provided by the therapist group and the client group. Fewer themes were found. Fewer specifics on the content were also found. Though some participants in the client group provided specific content suggestions, the amount of suggested content was more limited in comparison to the content suggested by the therapist participants. This comparison was achieved by analysing the specific content recommendations that emerged in the thematic analyses of the client interviews and the earlier therapist interviews. Overlaps in content recommendations between the two groups was first tabulated. Specific content that appeared in the therapist group was then tabulated. Scanning the data of the client group failed to reveal specific VW content recommendations that did not appear in the therapist group. Indications of which content was suggested by the therapists, versus both groups of participants, is included in Table 2.

Results: Three primary themes were found from analysis of the transcripts:

- None of the participants readily identified any of the specific priniciples of joint protection.

- Clients with RA notice that more generic ASMP are geared toward older clientele living with OA, versus younger clients living with RA.
- Barriers to attending traditional ASMPs exist, including travel time, time away from family, disruption of work and added expenses, such as paying for parking or room and board if living far away from a major centre.

Interviews identified that there may be some issues in the delivery of joint protection information to clients living with RA. One troubling finding from analysis of the interviews was that client participants during interviews were not relaying knowledge of the main principles of joint protection during interviews. This did not emerge from the interviews as they were read, re-read and coded. This is a core topic, and foundational material.

If the ASMP is geared towards a generic arthritic population, typically an older population living with osteoarthritis, most participants reported feeling that the information applied to someone older than themselves. This potential issue was raised in section 1.5.13 of Chapter 1.

Examples from the data supporting the development of this theme included a critique of information presently available as being geared towards older, often retired clients, such as use of mobility aides, and a focus on gardening, with less emphasis on work. Additional issues some participants raised included that work is sometimes not covered at all in the classes. Another potential issue raised by some participants included the experience of group ASMPs being dominated by one or two members, making the present format of group education less desirable for some participants.

A theme similar to one derived from the therapist interviews were potential reasons for not attending an ASMP. Again, these were similar to those discussed in section 1.5.13 of

Chapter 1, including being unable to take time off work, travel to a major urban area and remain apart from family during a period of a week or during several weeknights, having to choose between family time and disease management education. Additional issues included hidden costs of attending an in-person program, such as costs of materials provided to participants and paying for accommodation if having to travel from several hours away. Specific mention of these issues was found in the feedback from clients who had attended either an RA specific program and the more generic ASMP.

In addition to these themes, were a limited number of content recommendations. Based on the thematic analysis of the transcribed interviews, participants identified the following content as required of a joint protection program:

- Activities to include home activities (such as basic mobility and transfers and housework), and leisure activities (such as driving, golf, home workshop activities and gardening), and work (such as ergonomics with computer use and joint protection with activities such as lifting)
- Emphasis on avoiding deforming positions during daily activities
- Protection of hands
- Linking joint protection to overall physical activities that can and cannot be done

In addition to basic content, participants also felt that a joint protection program ideally needed to have the following qualities:

- Be relatively easy to access
- Be accessible at any time to fit their schedule
- Be flexible in order to allow participants to spend more time on specific topics, or only

review items of interest at a later time, if needed

- Provide information on personal topics, such as sexuality and peri-care

A similar theme between the therapist and client groups was that though joint protection education was deemed important, no formal outcome measures were identified client participants as being used to determine efficacy. They reported feedback collected presently was based on their reported satisfaction and self-reports regarding function. Most participants reported attending a follow up session with physical reassessment and subjective reporting, but could not recall if formal measures had been used before and after program other than a musculoskeletal assessment.

All participants in both groups indicated that the VW option may facilitate a more open discussion on several topics given the perceived anonymity in discussing issues they may not feel comfortable with in person. All participants in both groups also agreed that there needs to be more flexibility in the delivery of present programs and there are individuals who would benefit from another option to obtain joint protection information and RA management. The one overriding concern by both the therapists and the client participants was that there needed to be ease of use in accessing the program.

A summary of the three themes derived from the data analysis of both groups, with broad content categories, is included in Table 2.

Theme	Content Category
Role strain as an educator and clinician	Content should include basic principles of joint protection in order to address this issue as it can reduce role strain
Outcome measures lacking	Outcome measures should be used, including testable knowledge questions, VW should provide opportunities for application of principles and selection of outcome measures should reflect content (joint protection)
Complement existing program	Content covered should include a variety of self-care, productivity and leisure activities, as covered in existing ASMPs
No joint protection principles recalled	This is a potential issue with existing programs and should be presented explicitly and repeated / applied in presented content
Content to reflect RA specific demongraphics' primary concerns	Productivity outside the home will need to be emphasized more than in traditional ASMP, geared to older clients who may be retired or nearing retirement
Barriers to program access should be removed	Content should be easy to access. Many of the barriers to access will be removed by virtue of the program being offered online, though other barriers, such as ease of access and use, should also be addressed in the layout and design

Table 2 – Themes derived and links to broad content categories

3.4 Development of VW program

Based on the initial participant interviews with the therapists and the clients living with RA, the development of a VW program was undertaken. This development and initial testing took approximately a year to complete prior to commencing the pilot RCT. What follows is a description of the methods used to build and test the VW program.

First, a VW was selected based on the attributes of the participants and demographic information available on the average age of onset of RA as described in section 3.1. Second, an outline of what the specific content would need to be was created and tabulated later in this chapter, in section 3.4.2. The final VW content, to be tested by participants prior to the pilot RCT, was then developed, as outlined in detail in section 3.4.3 of this chapter.

3.4.1 VW platform selection

As previously outlined in section 1.7.3.3 of Chapter 1, there are several choices available for VWs. Given the type of study and the overall nature of the content required for this study, a VW that allows for original content creation is the most significant factor in VW selection. As per Figure 1 in Chapter 1, this limits the choices of VWs available for use in this study. Furthermore, if selecting a VW most appealing to potential users, the VW should best match the demographics of those living with RA. Age appropriateness would be another factor in VW selection. Based on these two criteria alone, there were two choices for VWs, Blue Mars® and Second Life® (SL) at the time of this study. It appears, based on Figure 1 from Chapter 1 that SL had a slightly older user base.

One additional factor in selecting the VW of choice included the literature on the VW itself. At the time of writing, a considerably greater number of studies had been published using SL compared to Blue Mars®. At the time of writing, a hand search of the Journal of Virtual Worlds Research reveals that Blue Mars® is referenced in two studies only, and no study with Blue Mars® as the sole platform studied, exists. That the VW itself had been used in other studies provided some indication as to its potential usefulness in this study. SL has a more established presence in the VW multi-verse and an economy that to present day is based on a unit of currency worth a higher real world value than bit-coin.

A third means of VW selection included the principal investigator exploring some VWs to determine the usability of the world for content creation and exploring the first-person user experience. It was determined that a high level of customized content creation was desirable, and not readily available on several of the VW platforms that were educational, such as Viviworld®. Though very easy to use and usable via a Smartphone, there is no opportunity for the user to create content. The investigator enrolled in, and explored, several

platforms, sampling those that would allow both open access, age appropriate and content creation. One world trialled in depth included MetaPlace®, which allowed from some basic content creation, but did not provide a very immersive experience. Additional issues with this VW were a lack of immersive graphics, a very young average user age and the overall stability of the world itself. The virtual economics of MetaPlace® were not sustainable, and it no longer existed as a VW a few months after beta testing was completed, as of December 2009.

Another factor in VW selection included the ability to purchase and use virtual land that could contain user-developed content relatively free from restriction. Again, SL was assessed as having an edge over many other VWs in this regard. Several of the other VWs investigated allowed only for communal sandboxes that could be accessed by anyone. These sandboxes are open access areas in a VW where content can be created and tested, but the area is not owned by the content creator, posing issues with storage, theft and ownership of content. Another issue was strict limitations on the size and amount of content a plot of virtual land could contain, without allowing linking of adjacent parcels of land, as is possible in SL.

Given the ability to create highly customized content, the need for age appropriateness and the need for a VW to have a track record of scientific inquiry and sustainability, SL was deemed the most appropriate choice for this study. The principle investigator purchased a plot of land after reviewing the terms of the purchase and visiting various locations in world. SL is divided into regions, some being part of a mainland area, some being on islands. Regions allow users some form of geographic orientation to other areas of the VW, while also providing a name address to places instead of a set of X, Y and Z-axis coordinates for SL addresses. Each region is divided into plots of land, typically 512 square metres each,

which can be subdivided or joined. There was an identified need to maximize privacy, which would be easiest if an island were purchased, but scalability was also an issue, making a mainland location more desirable.

The Boncarus region on the mainland was selected, as there were several vacant plots of land for sale in the area that could be annexed if the program content required a larger amount of virtual space and there were fewer users populating this area according to available land statistics, making privacy less of an issue. This lower user frequency was deemed desirable, as it would increase the privacy of the study area. The cost of the initial plot of land was 5000L (Lindens), which was approximately $12.50 Canadian at the time of purchase. As a premium account was required to make a land purchase, this entailed an additional cost of $80.00 Canadian per annum, but was offset with a 300L per week stipend, converting to $0.75 paid back to the investigator. This stipend is a deposit of virtual currency paid by Linden Labs into the user's online account, which can be used to make in-world purchases of virtual goods and services, or even converted into real world currency.

As the outline for content was developed, it was determined that more land was needed and further adjacent land plots were needed. This entailed further costs for both land purchase, as well as a monthly land maintenance and usage fee. By the end of the development of the VW program content, there were a total of 9000m of virtual land used at a purchase cost of 45 000.00L, approximately $333.33 Canadian total, and a monthly land usage and maintenance fee averaging $85.00 Canadian. At this time, this is the only ongoing cost, in addition to the annual account fee, to keep the VW program operating.

Part of the need for increasing the amount of virtual land arose from a limitation of SL known as prim limits. A prim limit is, by definition, a limitation on the number of primitive

objects or polygons that a specific region a VW can support and still operate. While there were attempts to use the most economical number of objects, including phantom objects, objects that appear visually as ghostlike on the user screen, with no impact on the number of objects in a region, there was still a need to expand beyond the allowable prim limit. Additionally, as there were a number of different displays, these needed to be spread out over an area large enough to allow avatars to interact with them.

3.4.2 VW content required

Based on the content suggestions provided via the transcribed interviews, several specific interactive displays were deemed necessary content in the proposed VW program. Below is a description of the method used to develop the displays based on participant input. Content required, based on participant interviews, is summarized in Table 3.

Principles of joint protection*	Anatomy comparing the normal and abnormal joint*	Computer work
Exercise*	Kitchen activities	Possible need for adaptive equipment*
Possible need for mobility equipment	Sexual activity	Social and leisure activity (not specified)
Golfing	Driving	Gardening
Home productivity	Footwear recommendations*	Bathing
Showering*	Grooming and hygiene activities	Toileting
Specific movements to avoid (ulnar deviation)	Heavier household and work activities involving lifting	Safety in transferring (bathroom)
Avoiding other joint harming conditions (including heat versus cold application)	Links to other resources, not just joint protection*	Application of principles*

*comparing the data between groups, these content recommendations were only obtained via the therapists interviews, all others were included in the data obtained from both groups.

Table 3 – Summary of recommended content as per participant interviews, combining both the therapist and client interviews

As a result of the themes derived and suggestions for specific content, as tabulated, there were a total of 24 “stations” deemed needing to be constructed and programmed in 3 virtual buildings with modular construction using the SL platform. The process of building involved the use of a premium user account in SL, purchasing 9000 square metres of virtual land over several months, learning both how to build objects, modify existing objects and creation of basic scripts using Linden Scripting Language (LSL). An example script is included in Appendix 1, in addition to an inventory of scripts and objects contained at each station.

A modular design, using a series of displays an avatar could walk through was deemed best, allowing the user to move from one display to the next initially, while also allowing the user to select a display they may want to review again. There were three areas developed to house displays: a main building at ground level with multiple display areas, a separate skybox, a floating room approximately 300 metres above the ground, providing a more private space for information about topics such as bathing, toileting and sexual activity and a third area as a “reward” for those who completed the joint protection program and contained extra resources that may have been of interest to people living with RA.

During module development, each station was checked against two primary criteria prior to being deemed completed. These criteria were: did the activity or display match the content that the clinicians and clients living with RA had recommended, did the activity or display cover one or more of the seven primary principles of joint protection? During construction, the participants’ expectations of a VW, in terms of ease of use, were also revisited during initial testing. Stations were set up so that a minimal amount of typing was needed in order to interact with them, for example. These checks for applicability to

expected content were tracked and included in Table 3. Some principles and content were repeated more than once, as some content, such as the basic principles of joint protection, needed to be included in more than one place.

Basic principles of joint protection included in: Station 1 Also included in every other station in the main display area and skybox	Anatomy comparing the normal and abnormal joint included in: Station 2 "Easter egg" area / social room	Computer work included in: Station 3
Exercise included in: Station 1 Station 5	Kitchen activities included in: Station 7	Possible need for adaptive equipment included in: Station 6 Station 7 Skybox "Easter egg" area / social room
Possible need for mobility equipment included in: Station 6 Skybox	Sexual activity included in: Skybox	Social and leisure activity (not specified) included in: Station 12 "Easter egg" area / social room
Golfing included in: Station 8	Driving included in: Station 4	Gardening included in: Station 11
Home productivity included in: Station 3 Station 7 Station 9	Footwear recommendations included in: Station 10	Bathing included in: Skybox
Showering included in: Skybox	Grooming and hygiene activities included in: Skybox	Toileting included in: Skybox
Specific movements to avoid (ulnar deviation) included in: Station 1 Station 3 Station 7	Heavier household and work activities involving lifting included in: Station 3 Station 9	Safety in transferring (bathroom) included in: Skybox – 2 stations
Avoiding other joint harming conditions (heat versus cold application as ADL) included in: Skybox	Links to other resources, not just joint protection included in: "Easter egg" area / social room	Application of principles: Included in every station, direct references being made in some displays in both main display area and skybox

Table 4 – Expected content and corresponding stations / areas presented in program

Displays included a gradual moving from typical web based displays, such as an introductory power point presentation, to more immersive displays that gave the user a printable or reusable note card, instructed the user to interact with objects and receive information on screen, or answer application questions about joint protection principles. Some of the objects were purchased through vendors in SL and modified, while others were originally created. Scripting and animations were limited by the principal investigator's programming ability, with the bulk of the scripts being limited to programming floating text messages, text responses from objects when touched or interacted with, providing note cards or images and opening linked web resources. One script that provided the user with the option to teleport to the elevated skybox in the main display area was repeatedly broken, shortly after initial creation, by multiple updates to the SL platform during the study. This was eventually replaced with a purchased script from the SL Marketplace and proved to be stable for the duration of the study.

3.4.3 Module development

Module development was themed centrally on joint protection principles and each module related back to the core concepts of joint protection principles. First, a brief overview of the main principles of joint protection and the development of the introductory display is presented. The subsequent sections discuss the development of additional display areas in terms of basic and instrumental daily living activities.

3.4.3.1 Core concepts

The principles of joint protection are predicated on seven primary principles. Though it was noted that these were familiar to the therapist participants to varying degrees, up to and

including some therapist participants knowing them verbatim, this was not the case with the participants living with RA, despite having recently undergone an ASMP. As core concepts of joint protection, it was deemed necessary to provide this information as early as possible in the VW program as all other displays would related back to these seven main principles of joint protection. As this is also standardized content in ASMPs, it would ensure some parity between the VW and traditional joint protection information.

As presented by Lorig et al. (2004), these seven primary principles of joint protection are:

1. Avoid positions that cause deformity
2. Avoid sustained positions
3. Use the strongest and biggest joints for heavy work
4. Pace activity and use energy conservation
5. Use the joint to its greatest mechanical advantage
6. Respect pain
7. Engage in appropriate exercise to increase strength of muscles to support joints

As these were the principles that all of the other modules were based on, it was determined that this should be the very first module or interactive display that the VW user should encounter. Early attempts included a basic note card that was provided as the user entered the display area. This was deemed problematic as it involved a considerable amount of reading basic text in a small white box, and little else. It also did not provide much in terms of immersive or visual input. This means of conveying this information was abandoned early in the development of the first display in the VW.

3.4.3.2 Basic daily living activity modules

A modular design, using a series of displays an avatar could walk through was deemed best, allowing the user to move from one display to the next initially, while also allowing the user to self-select a display they may want to review again. Earliest attempts to have a pathway in an open air setting resulted in too little a sense of privacy as the principal investigator's avatar moved from display to display. This also became quite visually confusing as well, such as having kitchen appliances appearing in the middle of an outdoor field, next to a series of adaptive aides and followed by a putting green for golf.

A central building was deemed more suitable after this initial arranging of displays along an outdoor path. A building was constructed with multiple display areas. A separate skybox, a floating room approximately 300 metres above the ground, was a readymade building solution to increasing usable display area and providing a more private space for receiving information about topics such as bathing, toileting and sexual activity. This is where the basic daily living activities stations were developed, and covered the full content that was suggested via the interviews from parts one and two of this study.

Each station was checked against criteria as it was constructed and completed as outlined in Tables 1 and 2. Displays also made use of graded activity, moving from simpler, less challenging, to more complex tasks, such as a gradual moving from typical web based displays, like passively viewing an introductory PowerPoint presentation, to more immersive displays that gave the user a printable or reusable note card, instructed the user to interact with objects and receive information on screen, or answer application questions about the principles of joint protection. The purpose of gradually moving from the more to the less familiar, was to minimize the problem of cognitive load in using a VW, as discussed in section 1.7.5 of Chapter 1. The printable or reusable note cards were a means of storing

information in electronic document form for later use or reference. Some of the objects were purchased through vendors in SL and modified, while others were originally created. The full listing of objects and modifiers, such as scripts, is included in the inventory in Appendix 1.

An example of the labour that went into building the portion of the program for basic daily living activities alone can be demonstrated in discussing the development of one object from start to finish and another where a readymade object was modified. In the skybox, there is an aerobic step under the claw foot bathtub. This was first a cube selected in the build mode of SL and dragged to the ground. This object was then edited, being flattened and sized using the edit tools in build mode. As this is a step, more than one cube underwent the same process. These were then oriented one on top of another and the entire selection was highlighted and linked together to move as a unit. Then a texture was selected and applied to the now linked units from a library containing a variety of colours and surfaces. Once an acceptable texture was chosen and applied, the object was then moved into position, partially under the bath.

To construct this single object, without a script, took 15 minutes. Adding a script to this object that provided a notecard when the object was clicked on added another 45 minutes of programming and testing time. This time, one hour in total was for a single scripted object created without initial errors.

As an example of modifying a readymade object, a programmable movie screen was purchased, first by an in-world search for this object and the user teleported to the shop offering the object. This was paid for in Lindens, the virtual currency previously referenced in section 3.4.3 of this chapter, and then put into the user inventory. Teleporting back to the work site, this object was taken out of inventory by dragging it out of the drop down menu

and placing it on the ground. The object was then opened and the components were placed on the wall using the aforementioned edit tools to move it into position. Once this was complete, individual slides were created, one at a time using Power Point, then saved as individual files (jpegs) and loaded into the virtual inventory one at a time as an individual texture. Each object has a unique identifier. This identifier was used with each uploaded slide to get them presented as a series of virtual pictures being presented as a slide show on constant loop. Some trial and error was involved. The means of uploading information was time consuming, and there is an element of timing uploads if the slides are to be presented in a particular order.

It was later deemed more appropriate to have this display at the very beginning of the program. This display was moved to the main area. The skybox was deemed more appropriate to present later in the program sequence, after some basic information on arthrology and the core joint protection principles had been presented on their own. The original screen was replaced with a static one that contained a basic chat script and a single slide instructing the user where to start reviewing the basic daily living activity stations.

The scripting language to allow objects to be more than inanimate displays is somewhat complex and sensitive to slight errors, so a computing science student was initially employed to assist with scripting of some objects. After two attempts at hiring computing science students with limited success, it was determined that the scripting language and requested programming may have been beyond a senior undergraduate student. There were issues with the quality of the scripts provided and many of them did not work, or contained errors so that they were only partially functional. This issue created delays in completion of several of the stations, as the basic daily living activities were the first displays constructed. The principal investigator began using the SL Wiki on scripts and learned the

use of simple scripts and how to use the SL scripting language through experimentation and consulting the SL Knowledge Base.

Additionally, a study supervisor suggested the use of the website www.3greeneggs.com as a means of getting simple scripts generated for the purposes of study completion. As the ability to build usable scripts was limited by the investigator's abilities, fewer programmable avatar animations were possible than originally planned. However, on completion of the program development, there were a total of six displays that could animate a user's avatar. These animations included sitting at a computer, hand washing, showering, bathing, gardening and performing various joint friendly exercises.

On completion of the basic daily living activities skybox, there were a total of seven displays, plus a greeting area and exit, that reviewed joint protection techniques while grooming, bathing, transferring to and from a bath and shower and issues of using heat versus cold. Though potentially seen as separate from basic daily living activities, the principal investigator's experience includes clients including application of thermal agents as part of morning or evening personal care. Additionally, ASMP encourage approaching cold and heat application as part of a daily routine, making it a basic daily living activity.

More personal issues, such as toileting and intimacy were also presented in the skybox. The displays were set up so the user is instructed to move from one display to the next. There was intent to set up the display content so that the user was not continuously reading, animated or receiving note cards. This intent was to provide variety in the program, so that there was a balance in watching the avatar perform activities, reading and interacting with displays. If this was not done, the user may have done nothing but read note cards for the entire program. The rationale for providing this variety was to keep the user engaged performing a variety of activities instead of one repeated activity, and to maximise the

interactive opportunities that are value-added in a VW, versus use of the traditional web page, as discussed in section 1.7.2 of Chapter 1. In the skybox display, three of the stations animate the avatar; one display opens a web page to a downloadable resource on intimacy and arthritis via the Arthritis Society; one display offers a note card.

In order to link the skybox with the main display area, a commercially available teleporter and a custom build from scratch one were used. The custom built one was a sign that automatically teleported the user up to the skybox. The commercially available one had programmable float text and opened a menu on the user screen. Part of the rationale for this choice was to determine if there was a preferred method that increased ease of use in moving from one geographic location to another in the VW. Ease of use was one theme raised in the thematic analysis of the preliminary interviews.

Sample screenshots of the skybox under construction and completed skybox are included in Figures 1 and 2. Screenshots of all of the individual display areas of basic daily living activities is included in Appendix 1.

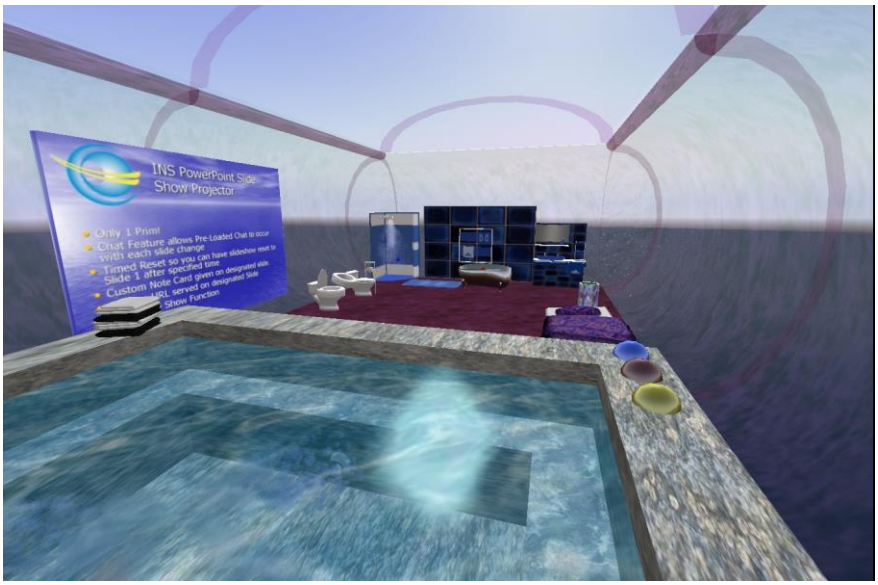


Figure 1- Skybox under construction with most displays not complete, including greeting screen

Figure 2- Completed skybox with all objects scripted and ready for use

3.4.3.3 Instrumental daily living activity modules

Other than the first and second displays in the main display area, the bulk of the main display area was dedicated to instrumental daily living activities. The first and second display areas included the aforementioned presentation on joint protection principles and some basic information on the differences between a healthy joint and one effected by RA versus one effected by osteoarthritis.

As outlined in the previous section, each station was checked against criteria, described in section 3.4.3 of this chapter and included in Tables 1 and 2, as it was constructed and completed. Displays also made use of graded activity as described in the previous section, and included a gradual moving from typical web based displays, to more immersive displays. Some of the objects were purchased through vendors in SL and modified, while

others were originally created. The full listing of objects and modifiers, such as scripts, is included in the inventory in Appendix 1.

Displays were organised in a pattern to essentially follow a circular pattern, noting that there were some space limitations with the golfing display, which altered this set up. On completion of the instrumental daily living activities display area, there were a total of 12 displays in the main display area, plus a greeting area and exit. This display area reviewed joint protection techniques while using a computer, during manual handling activities, driving, exercising, performing basic grooming and dressing, performing kitchen and household tasks, golfing, gardening, home workshop activities, sedentary leisure activities, such as reading, and decision making in selecting arthritis friendly choices, such as daily footwear.

The displays were set up so the user was instructed to move to the right to see the first display labelled as station 1, and then proceed to the next display labelled as station 2. Instructions were provided by first a greeting message on entering the main display area. Instructions to continue to the subsequent display were provided via instructions on screen at the first station.

Given the experience of setting up the basic daily living activities in the skybox, the display content was again created so that the user was not forced into continuous reading, animated or receiving note cards. In the main display area, four of the stations animated the avatar; two displays provided links to web pages for resources on work accommodation and arthritis friendly products for gardening. One display opens to a YouTube® video on managing household activities. Four of the displays offer note cards, mainly as printable resources that can be kept as a hard copy of information provided. Two of the displays offer diagrams that can also be kept as a hard copy of information pertaining to anatomy and

arthritis friendly footwear respectively. Again, part of the rationale for providing this variety was to keep the user engaged performing a variety of activities instead of one repeated activity, and to maximise the interactive opportunities that are value-added in a VW, versus use of the traditional web page, as discussed in section 1.7.2 of Chapter 1.

As this area was completed after the skybox area, construction occurred more rapidly than the earlier work and the combination of building, modifying and scripting was more efficient. As the intent was to also provide a gradual orientation to navigating the VW, as discussed in more detail in the following section, the requirements for interacting with the displays went from very structured and passive, to more complex and culminated in an unstructured opportunity to explore the VW outside the main display area. The avatar was guided via arrows on the ground to a welcome mat that not only greeted them by name, but also recorded the date and time of their visit and provided them with a note card. The avatar could opt to decline or ignore the note card, but the information would still be displayed on screen, indicating that they were in the study area, that they were to go to the display to their right marked with a "1". The note card also provided the investigator's avatar name and personal email address should assistance have been needed.

The content required, as summarized in Tables 2 and 3 of this chapter, was developed into the stations in the main display area as listed in Table 4. A detailed inventory of each station and corresponding screen shots of each station is included in Appendix 1.

Station 1	Seven principles of joint protection
Station 2	Anatomy of healthy / unhealthy joint
Station 3	Safer manual handling and computer work
Station 4	Driving
Station 5	Exercise
Station 6	Mobility equipment / Adaptive aides
Station 7	Kitchen activities / Housework
Station 8	Golf
Station 9	Heavier home activities
Station 10	Footwear
Station 11	Gardening
Station 12	Social and general leisure

Table 5 – Stations in main display area and corresponding description / main content

The first display, providing the principles of joint protection was initially set up to require some input from the user to start it. However, access would have been required to the controls and the screen had a controller with multiple buttons, which may have been confusing to the novice VW user. As cognitive load, as discussed in section 1.7.5 of Chapter 1 was a potential issue in using a VW, the initial display was left running on continuous loop with the slides changing every 30 seconds. This would require no active inputs from the user and they would be more likely looking at something familiar, a moving slide display, from previous web use.

As some studies suggest that social norms are frequently mirrored in VW, as outlined in section 1.7.3.2 of Chapter 1, the user was provided with the opportunity to sit, rather than only be permitted to stand, while viewing the first display. A chair was placed in front of the display with float text saying “Click on me”. When the user did this, a popup message provided information about how to use the chair. The user, while viewing the first display, also learned how to interact with an object and animate their avatar. These are requisite skills for interacting with a VW that are used in some form throughout the displays.

As the user moved from display to display, the information was presented in a variety of ways, but in all cases, required some form of input from the user, primarily from clicking on objects, allowing their avatar to be animated by an object or from typing a brief message into the chat window. There was minimal typing involved, in part, because of the population being studied. It was anticipated that frequent keyboarding could have been of potential harm to someone living with RA.

It was suggested by one study supervisor that in addition to knowledge testing questions, which are included in five of the stations in the main display area, there should be some additional reward or motivator for completing the program. Expedited, rather than full panel ethics reviews were sought out, in order to reduce required study time by a minimum of six months. As there could not be monetary, or equivalent, incentives used as per the expedited study ethics approvals, it was determined that a bonus area, often referred to as an "Easter egg" in gaming, should be including relevant to the study population. A third area that was linked via teleporter was provided to those who had completed all of the displays, including teleporting to and from the skybox displays.

This area was a house in a separate region and included an additional five displays. These included a two-minute description users could provide to others about what RA is, a list of arthritis friendly products that were extraneous to what information was thematically derived from the interviews, a link to what RA does to the body beyond joint involvement and a link to a video about a therapist living with RA. The house also provided a link to Ability Island, an area in SL set up specifically to be inclusive of all users of VWs living with a disability. Other resources included a message board users could leave virtual post-it notes on for others or for the investigator, furniture and a second floor free from RA related content. The welcome message in the house indicated that users were free to use the

displays, use the area to socialize or explore the area freely. A teleporter back to the main display area was also provided.

Sample screenshots of the main display area under construction and completed main display are included in Figures 3 and 4. Screenshots of all of the individual display areas of both the main display area and the Easter egg area are included in Appendix 1.

Figure 3 Main display area under early construction

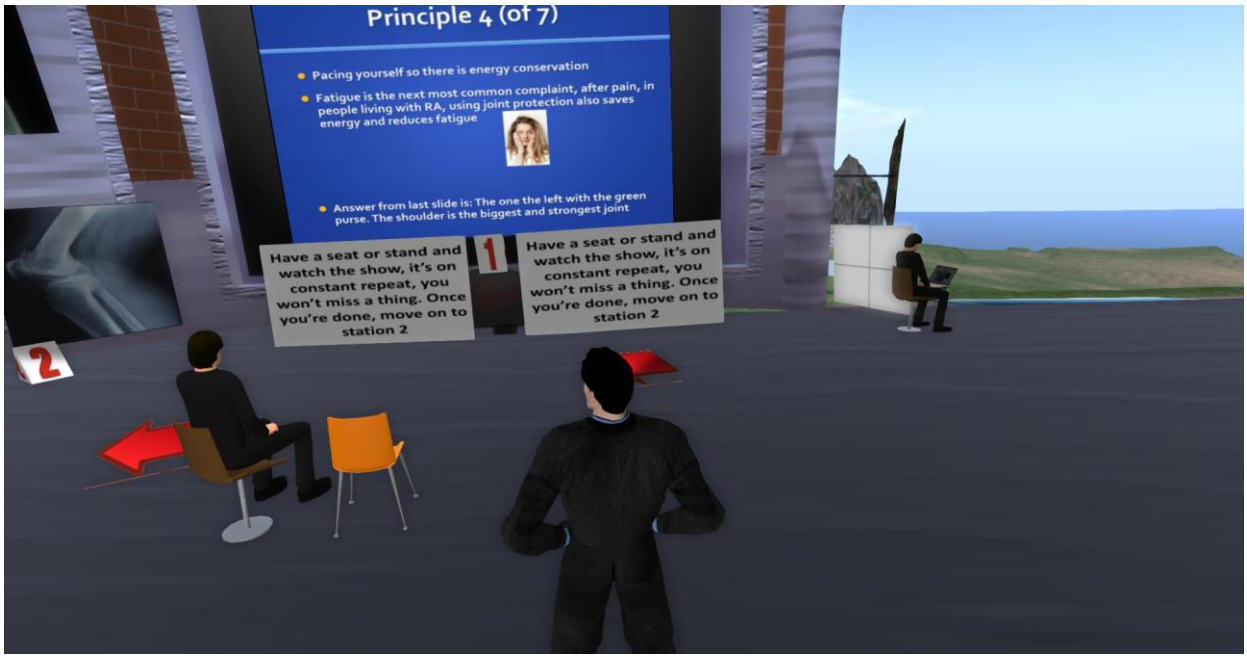


Figure 4 Main display area with completed stations, including scripted objects

3.4.3.4 Program orientation

Before the program could be tested out conceptually with the therapists and clients interviewed, the program needed to be tested technically, as described by Aldrich (2009). This technical testing included ensuring the SL program would run on different browsers, different security settings, and included stress testing of the VW, ensuring that a number of avatars could be on the site at the same time, without causing technical issues. The checklist of VW technical testing, as per Aldrich (2009), included ensuring that message boards were functional, instant messaging worked and application sharing, such as the YouTube® videos, loaded properly. Separate virtual rooms, in this case, other areas to teleport to, also had to have functioning teleporters. Some items, such as calendaring tools, were not applicable to the program developed.

Preliminary technical testing of the VW program, first by the principal investigator, and then by study supervisors indicated that the displays were functional. However, navigation and cognitive load remained an issue. Specifically, the visual feedback for navigating SL can be challenging and the user interface can sometimes have too many options. Information can pop up in any of the screen corners while the program is used. Combinations of auditory and visual cues are used by the VW platform, which may be overwhelming or distracting to novice users.

To increase the ease of navigation, several cues were provided in the displays themselves. Each display in the main area was distinctly labelled with a red number, 1-12 to indicate which number display the user was standing in front of. Second, a series of red arrows were uni-directionally arranged on the floor of the main display to indicate which direction the avatar was to move. These red arrows even led from the outside of the display to the welcome mat in case users wandered away from the display area. On entering the display, there were explicit instructions provided that indicated that the user is to go to the right and review the information at display number 1. This is in the form of a sign and a note card. At the bottom of the screen at station number 1 is a message, in duplicate, to move to station 2 when the presentation at station number 1 is completed.

Additional messages contained in the note cards and float text hovering above some displays indicated what was to happen next, in addition to the arrows and the sequentially numbered stations. This continued with the daily living activities skybox display, with instructions being provided as to which station the user was to start at first. The user is led in a circle, similar to the path in the main display area.

The golfing display was too large to fit inside the structure, and is actually not even on the same region of virtual land. It is on an annexed region, Milmerelda and had to be joined by

the investigator after purchase to the Boncarus region in order for it to link to the other displays. There was float text and an arrow indicating where to go to access station 8, the golfing display. The note card provided indicated that the user is to go back to the central displays and start with station 9 to complete the rest of the program. The arrows and sequential numbers are used to cue the user where to go next. At station 12, the final joint protection station, the user had the option of going to the Easter egg area, but the main displays regarding joint protection were completed at this point.

Even with these cues and graded use of learning to navigate SL from less interactive, to more interactive displays, there were still concerns regarding orientation. A newly downloaded SL viewer provides tips regarding basic navigation and communication, but this was not specific enough for the requirements of this study. As part of the orientation to the VW, and in order to provide assistance to new users, a fully narrated screen capture was provided as an optional orientation resource. This was a narrated video of an avatar entering the main display area, interacting with the displays as expected, teleporting to the skybox, reviewing the skybox displays, completing the main area displays and reviewing the resources in the Easter egg area. Explicit instructions were provided that included which mouse button to click and what each display would provide in terms of content or resources. This was completed using Camtasia Studio and was hosted via a private Screencast account of the investigator with the unique URL: http://www.screencast.com/t/JCRYqAyN2. Participants in both groups were provided this URL after they had provided consent and registered for a free SL account.

3.5. Pilot testing of VW program with expert OTs

Once the program modules were completed, the participants from the sample of expert therapists trialled the program and provided feedback. These were the same participants

initially interviewed regarding expectations of the VW program. All participants in this sample were occupational therapists with varying experience delivering ASMPs. None had dropped out from the initial interviews and were willing to trial the program. This trial occurred over a 30-day period, though the program itself appeared to take no more than 30 minutes to complete once, longer if the quizzes at checkpoints required the avatar to go back and repeat stations before continuing on to latter stations. Additional time may have been required if a participant opted to revisit a module or explore other areas of the VW. Access to the property and interaction with objects was limited to only those belonging to the study group. Overall, the therapist participants reported taking between 1-2 hours to review the program before feeling they were ready to provide feedback.

Participants were again interviewed by the investigator in a private office to ensure confidentiality, either provided by the investigator or at a place acceptable to the participant providing confidentiality and privacy could have been assured. Interviews were audio recorded using a predetermined set of open ended questions primarily centred on the participant's experiences in using the program. These questions are included in Appendix 6. Interviews were transcribed. Transcripts were reviewed for accuracy while replaying recordings. Each interview was re-read several times to get an overall impression of the primary concerns and points that each participant was making.

Preliminary thematic analysis was carried out manually as described in section 3.3.7 of this chapter. While reviewing transcripts, several pieces of information were felt to be similar and requiring categorization. Copies were made of the transcripts, and this information was highlighted and saved as a working theme within the data. Thematic analysis was then performed using the nVivo software previously referenced. Information was first coded into free nodes, grouped into sub themes and then organized into themes.

As this was primarily a product review, the follow up interviews were noticeably shorter in comparison to the initial interviews with the therapist participants. It appeared that no further information could be extracted, the data was reviewed again to determine if any of the statements made could fit into another theme. Once no further themes could be derived, it was concluded that thematic analysis was complete.

Once all themes were extracted, as presented in section 3.5.1, these were checked for trustworthiness with participants. Member checks were employed with all five participants. All participants agreed with the thematic analysis. There was more variability with specific content and usability recommendations after the OTs trialled the program in comparison to their recommendations made in the first interviews. Overall, there were more specific critiques of the program from the therapist participants in comparison to the client participants. This feedback was incorporated into the program prior to the pilot RCT phase of this study. Given the relative lack of outcome measures identified as in use in traditionally ASMPs, these participants were also asked to review four arthritis specific outcome measures presently used in the literature, one of which was the only measure identified by one participant in the initial interviews.

3.5.1 Findings

Based on thematic analysis of the second interviews with the expert therapists, there were three main themes that emerged. These themes were content versus expectations, flexibility of the VW as a learning environment, responses to VW layout/experiences with navigation. Some variation occurred within the themes, such as some participants preferring certain aspects of the content. A summary of themes and subthemes is included in Table 5.

Theme	Subthemes
Content versus expectations	Content met expectations Content exceeded expectations Some content in the VW had not been suggested by participant Some content exceeded what was typically taught in an ASMP
Flexibility of VW	Allows for access on demand Allows ability to choose what order information was presented Provided access in a suggested and logical order Ability to choose to interact or not interact with displays Allows for ability to do parallel play in-world Allows for ability to use VW to educate others
Responses to layout / experiences with navigation	Logical layout of program displays Ease of readability of displays Sense of familiar made VW easier to navigate and comprehend Confusion as to layout of displays being counter clockwise Aesthetic issue with colour theme Sensation of privacy Sensation of loneliness Cognitive load Learning new skills to navigate Allowed exploration away from the program area Wandered away from program and got lost Picture of ulnar deviation could be clearer Quiet, liked adding music/playing with radio

Table 6 – Summary of themes and subthemes from thematic analyses of second interviews with therapists

Theme one: content provided in VW compared to content expectations

In terms of content, all five therapist participants indicated that the content overall, met or exceeded their expectations for content. Some modules that appeared in the program were beyond what individual participants had suggested, as others had suggested them. There was no feedback to state that an area of content had been completely omitted. Likewise, there was no feedback to indicate that something was extraneous. Overall, the participants individually concurred the content met their expectations of an ASMP. The data obtained

from reviewing and coding each transcribed second interview indicated that the content met, or even exceeded, their expectations for content.

Theme two: flexibility of the VW

All participants in the group made varied positive statements regarding the flexibility of the VW. For example, two participants indicated that they appreciated being able to move from one station to another in a suggested order, but also had the flexibility to go back later and review some content at their own pace. One participant liked the ability to interact with the displays, including the ability to change the media player settings to add background music to the simulation. One participant, the therapist living with RA, reported she was able to complete the VW program with her young son, who was interested in learning more about his mother's job and was able to spend time learning about RA. She reported that she was able to access the program around other activities at home, but also found it a useful medium to engage and educate family members, even engaging in some parallel play and storytelling as she moved her avatar around the displays with another user involved in the study.

Theme three: responses to layout / experiences with navigation

Unlike the first two themes discussed, there was not the same level of concurrence between participants on the feedback regarding layout. Four of the participants reported that the layout was conducive to using the VW and had no issues with how the material was visually presented. One participant commented that the ADL skybox in particular, was set up to present the information that was particularly easy for her to process. Others commented that the number of pictures and videos used provided something familiar to keep the VW

itself from becoming overwhelming. One participant had a greater feeling of privacy in the ADL skybox where potentially more sensitive topics were presented.

One participant had a few issues with layout. She reported that she did not like the colour of the skybox, which was purple. She also reported that she did not know why the main display went counter clockwise instead of clockwise from station to station. It was explained, post-interview, that for the purposes of the skybox colour, this was actually programmable by the individual user, but left out of the instructions to reduce cognitive load and issues with navigation. In terms of the clockwise versus counter clockwise layout, it was further explained, post-interview, that this was, in part, imposed on the availability of the land and neighbouring parcels. The golfing display would not have been visible, would have involving having the avatar walk all the way around the display and back again and would have involved the displays facing a roadway. This set up, which was experimented with during the initial building of the program, was previously abandoned. While the post-interview explanation regarding the overall setup of the main displays was reported as satisfactory to this participant, she reported that she still did not like the colour of the purple skybox, which was duly noted. This participant agreed that this did not impact the content itself.

Navigation was the theme with the greatest number of presented issues. No participants reported that they were unable to navigate the VW. However, all participants were novice users and reported that they required a few minutes of practice in getting comfortable with navigation. Three participants wandered away from the RA simulation area and reported getting temporarily lost. Two participants reported that they had to learn to pay attention to looking at the entire screen as some popups and chat text appeared off centre on the screen and the avatar default position is at the bottom centre of the screen. Overall, there was a

report of increased cognitive load, as described as a possible issue in section 4.4 of Chapter 1, from all participants while using the program.

One participant reported that the lack of other avatars in the program area was an issue for her. She felt the VW was a lonely place with the lack of other avatars to interact with while she used the program. There was an initial plan to address this feedback and it was planned make program revisions to encourage more interaction, even incorporate social events, into the program, given this feedback. It was also planned to use the artificial avatars more in the main display area to provide some additional simulated interaction, such as having them named and provide scripted chat as an avatar approached them.

However, given that this was based on feedback from one therapist participant, combined with subsequent contradictory feedback from the client experts, as outlined in section 3.3.7 of this chapter, it was decided to not increase the level of social interaction, and leave the level of social immersion to the artificial avatars. It was also noted that as the program area was closed to only study participants, this may have been an unreasonable expectation of the program in the pilot RCT phase.

3.5.2 Revisions

With specific content, there was one participant who indicated that there needed to be some added clarity regarding ulnar deviation. This was an easily added modification, using a picture of the principle investigator's wrist in a position of extreme ulnar deviation using a Bennett Hand Tool Dexterity Test and placed on the appropriate slide within the content of the first station, illustrated in Figure 5. In the initial program, the photograph was not exaggerated enough for this to be clearly demonstrated. In terms of content, this was the only add-on from the therapist participants.

Figure 5 Demonstration of extreme ulnar deviation, as suggested by one participant

The participant who suggested the addition of music added music to the main display managed to add this media by altering the settings of the viewer at station 1 of the main display area. This created a problem as it also disabled the slide presentation, which was critical content for all subsequent displays. This incident resulted in two small modifications. The first was the addition of an instrumental FM station as the parcel media, which would play continuously, and could be blocked by muting the volume either in SL or on the user's computer. The second modification was the addition of a physical blocking of the first station screen control buttons and control box. This involved the addition of signage, which also indicated what to do at station 1, as shown in Figures 6 and 7.

Figure 6 - Station 1 with screen controls exposed, allowing users to stop, start and suspend presentation for other media, such as streaming radio

Figure 7 - Station 1 with screen controls covered and additional signage cuing users to proceed to the next station

Overall, the revisions required to the program were minor. The two participants that made suggestions requiring revisions were presented with these revisions and they agreed that these were satisfactory.

3.5.3 Tool selection based on feedback

As previously noted in section 3.2 of this chapter, none of the therapist participants reported using standardized or formal outcome measures to measure efficacy of an ASMP. One therapist identified the Readiness to Manage Arthritis Questionnaire as a familiar outcome measure, but they did not use this tool in their practice. As the initial interviews with this group of participants indicated a general lack of familiarity with or use of RA specific outcome measures, these were presented in conjunction with the follow-up and feedback interviews to assist with therapist-selected tools based on feedback. Specifically, participants in both groups were first asked what they thought may be the effect on someone using the program. After providing this information, participants were presented with four RA specific outcome measures. These were the: Arthritis Impact Measurement Scale Short Form II (AIMS2SF), Pain Self-Efficacy Scale (PSEQ), Readiness to Manage Arthritis Questionnaire and Health Assessment Questionnaire (HAQ).

All participants selected the PSEQ as one of their two choices for most appropriate outcome measure. Some participants had discussed that using the VW program may increase self-efficacy, but did not refer to the outcome measure itself. All but one participant selected the AIMS2SF, stating that it contained the highest number of daily living and functional activities as the primary reason for selection. One participant stated that it was the tool that had the most applicability to occupational therapy. One participant selected the Readiness to Manage Arthritis Questionnaire. Her rationale was that it was what the rheumatologists used and that she had some familiarity with it as a measure. Based on the feedback from

the therapist participants, the AIMS2SF and Arthritis Self-Efficacy Scale were held as the strongest possibilities for use as outcome measures. Samples of these tools are included in Appendices 9 and 10 respectively.

3.6 Pilot testing of VW program with expert clients living with RA

Once the program modules were completed, the procedure, as described on pages 204-206, is identical to what occurred at this stage of the study. The main difference is that the participants interviewed at this part of the study were the same participants from the sample of clients living with RA and previous ASMP experiences who were initially interviewed. These participants also trialled the program and provided feedback. It is noted that six participants were involved in this part of the study as one of the initial participants was lost to follow up. Several attempts were made to contact this participant by phone and via email. It is not known if this participant elected to drop out of the study, had moved or had health issues that prevented them from being contacted. This participant was dropped from the study after 90 days had passed since the start of the 30-day trial.

3.6.1 Findings

Based on the feedback from the clients living with RA and previous ASMP experience, there were three themes that emerged from the data analysis. These themes included content meeting expectations, flexibility of the VW as a learning environment and in-world experiences, again mainly focused on navigation. Again, some variation occurred within the themes. A summary of themes and subthemes is included in Table 6.

Theme	Subthemes
Content versus expectations	Content met expectations Content exceeded expectations Some content in the VW had not been suggested by participant (had been suggested by others) Some single station content never seen in an ASMP (driving, work, sexual activity) Several stations never seen in a previous ASMP Some content listed as a favourite by some (golfing, driving, footwear)
Flexibility of VW	Allows for access on demand Allows for ability to choose what order information could be presented Provided access in logical order Ability to log in and log out, reappear exactly where left off, was valued Ability to set own time to access content was valued Ability to review specific content additional times was valued Control of pace was with participant
In-world experiences	Cognitive load Needed practice to navigate Needed assistance to navigate Eventual comfort with navigation No comfort with navigation Valued privacy and did not want to interact with others Sense of privacy was valued Learning new skills to navigate Exploration away from the program Wandered away and got lost

Table 7 – Summary of themes and subthemes from thematic analyses of second interviews with clients living with RA

Theme one: Content versus expectations

In terms of content, all six participants indicated that the content overall, met their expectations. Some modules were highlighted as more important, or favourites, with some participants. There was no feedback to state that an area of content had been completely omitted.

Some participants reported that the content presented in the VW program was missed in the ASMPs that they had completed. Sexual activity was one area reported by three participants as completely unaddressed in the ASMPs that they had experienced. One participant

reported that they could not recall having previously seeing several of the topics, including driving, work and specific leisure activities.

Like the therapist participants, this group did not indicate that there was content deemed as extraneous. Overall, the participants individually concurred the content met, or exceeded, their expectations of an ASMP and joint protection content. It was noted in the earlier interviews with this group that there were not many specifics provided regarding content.

Theme two: VW flexibility

All participants in the group made positive statements regarding the flexibility of the VW. For example, one participant stated that they enjoyed being able to log off and them log back in again at a later time at the exact location they had stopped at previously. Another participant stated that they enjoyed the ability to access the program at any time, mainly because they wanted to use the program once everyone in the household had gone to bed. Three participants reported that they also felt relatively free to interact with the program at their own pace. The content, for the most part, was not being presented at a pace dictated by an instructor, but could be learned at a pace that the user could set, allowing for repetition of some content, or skimming other content deemed less interesting or less important. None reported that the program lacked cohesion or was too overwhelming in scope, a potential issue raised in section 4.4 of Chapter 1.

Theme three: In-world experiences

Navigation was the theme with the greatest number of presented issues, similar to the feedback from the expert therapists. No participants reported that they were completely unable to navigate the VW. However, two participants contacted the principal investigator for assistance in navigating the program when initially trying to use it. Again, all

participants were novice users and reported that they required a few minutes of practice in getting comfortable with navigation. One participant wandered away from the RA simulation area and reported getting temporarily lost. Like the therapist participants, there was a report of increased cognitive load from all participants living with RA with prior ASMP experience while using the program. Two participants stated that as they were not gamers, the navigation was overly difficult to them and that this was not an appealing medium for them, though they could see the value of the program for others.

Of the two participants requesting assistance with initial navigation, one needed some assistance that was provided via an email, essentially asking how to find her way back to the initial teleportation point, which had been saved as a landmark in their inventory. This was dealt with via a single email and the participant was able to find her way back to the requesting starting point with some simple instructions regarding how to find the landmark and use it.

The second participant required more assistance, having some difficulty with movement, interacting with the displays and reported feeling somewhat disoriented. The principal investigator stated they would be rendering assistance, and appeared in-world to guide the participant through some of the displays. On entering the program, this participant had made it as far as the third and fourth displays. She reported that she was both surprised at the appearance of another avatar in the region, and stated that she did not like the idea of a shared space with others in the program. She found this problematic as she wanted complete privacy, versus having to potentially interact with others in the program. As the artificial avatars had already been placed in the program, and appeared to be interacting as true avatars, she was under the impression that there were several other people in the simulation. When the principle investigator avatar appeared in the program, she found the information

and guidance helpful in order to navigate, but the overall experience was described as a negative one, as she felt that her privacy had been invaded.

Given the overall design was to test a new intervention, and the feasibility of the process, the results of this stage of the research indicated that it may be useful to include some questions regarding the user experience during the pilot RCT stage. The opportunities to provide this feedback were included in the survey in Appendix 11, as well as in-world while participants used the program. This feedback is summarized in Table 2 and Figure 1 in Chapter 6.

3.6.2 Revisions

In contrast to the therapist participants, none of the client participants had recommendations regarding specific content revisions. The only revisions were the ones presented in section 3.5.2 of this chapter.

3.6.3 Tool selection based on feedback

As previously noted in section 3.2 of this chapter, none of the therapist participants reported using standardized or formal outcome measures to measure efficacy of an ASMP. As the initial interviews with this group of client participants also indicated a general lack of familiarity with or use of RA specific outcome measures, these were presented in conjunction with the follow-up and feedback interviews to assist with participant-selected tools based on feedback.

Participants in this group were also presented with the same four RA specific outcome measures. These were the: Arthritis Impact Measurement Scale Short Form II (AIMS2SF), Pain Self-Efficacy Scale (PSEQ), Readiness to Manage Arthritis Questionnaire and Health Assessment Questionnaire (HAQ).

All participants from this stage of the study also selected the PSEQ as one of their two choices for most appropriate outcome measure. All participants selected the AIMS2SF. Based on the feedback combined both from the therapist and client participants, the AIMS2SF and PSEQ were held as the strongest possibilities for use as outcome measures.

3.7 Properties of selected tools

Both of the standardised tools are meant for measuring outcomes for people living with RA. The PSEQ asks participants to take pain into account when rating their self-efficacy beliefs. As outlined in Chapter 1, section 1.2, pain is typically the most significant complaint people living with RA report. This questionnaire has been examined on its psychometric qualities (van Der Maas et al., 2012) and indicates that self-efficacy as an independent predictor of outcome measures after controlling for pain intensity. Internal consistency has been rated as excellent, and test-retest reliability has been deemed adequate (Nicholas, 2007). Furthermore, the PSEQ discriminates between workers and nonworkers, and between patients who use medication and those who do not (van Der Maas et al., 2012), making this a more desirable tool if examining between group differences and potential confounds if working with a relatively small sample size, such as a pilot RCT. It has been used specifically with clients living with RA (Rahman, Daniel and Grahame, 2014) and has been validated in electronic form (Briet et al., 2014), as well as been translated and validated in multiple languages.

The AIMS2SF is specifically designed to measure the impact of arthritis on function. It has been studied in comparison to the longer form of the same tool, and showed substantial to near-perfect agreement in measuring more than 1000 people living with RA (Haavardsholm et al., 2000).

The AIMS2SF has been widely used across different types of arthritis diagnoses and exhibits good psychometric properties. It has been used in intervention research as a patient-oriented outcome and demonstrates comparable responsiveness and sensitivity to change as other disability and global health status measures. Use of the physical function sub-test of the AIMS2SF along with the other components allows the evaluation of pain and patient perceptions of the broad impact of arthritis on their lives (Gignac, et al., 2011).

Both of these tools are available free and can be downloaded from open access sources online. Both tools are self-administered. Neither tool was used novelly in this study.

Chapter 4 Pilot RCT

4. Study design

This portion of the study used a single-blind randomized study design, using a convenience sample. As the study measured the differences between two randomised groups following an intervention, the study design followed a two group, post-test only, randomized experimental design.

4.1 Ethical approval

Four main ethical issues were again addressed in this final phase of the study, (i) confidentiality, (ii) informed consent, (iii) potential deleterious effects from participation and (iv) funding. As per the summary provided on pages 162-163, all participants, via the information letter included in Appendix 3, were assured of confidentiality, received instructions regarding the nature and purpose of the study and were permitted to withdraw their permission to be tested at any time. Participants had the option to request final study results as well. Participants were not deceived, misled nor received inducements to participate. They received a copy of the information sheet, reviewed and signed the consent form and received copies of both forms prior to data collection. Anonymity was also ensured by the participants being able to select, and if desired, customize the appearance of their own avatar.

While authenticity of an investigator's or instructor's appearance has been discussed as important in Chapter 1, this was deemed less relevant in this study with the subjects as they were not expected to interact. While a subject could have dramatically altered their appearance from their real self, it did not pose an ethical issue in this study as the subjects were not interacting with each other. If the objective of the study was to simulate the lived

experiences of a person living with RA, this may have also been a potential issue, though for this educationally focused program, this was not an issue.

It was anticipated that participants would not experience pain or psychological distress. Deleterious effects of new interventions, treatment or unknown side effects are not a known issue. Some prior studies on the use of VR indicate potential issues with motion sickness (Finch and Howarth, 1996) and are outlined and previously discussed in section 1.7.3.9 of Chapter 1. However, this is with head mounted displays, which were not being used in this study. Participants were not expected to perform activity beyond a sedentary level of function and were performing non-repetitive tasks at a computer, thereby minimizing risk of repetitive strain, or similar injury.

It terms of funding, the principle investigator was responsible for all costs, including postage, VW program development costs and VW program hosting costs and there was no financial gain for the investigator from the participation of therapist professionals in the study.

As per the outlined process in Chapter 3, Section 3.1.3, the same process for ethics approval was followed for earlier phases of the study. Ethics approval for this portion of the study is attached in Appendix 4. Approval was granted in June of 2012, prior to completion of the first two phases of this study, so recruitment was delayed until the VW program had been developed, tested by both groups and minor revisions had been completed. Recruitment activities, as described in section 4.3.1 of this chapter, were undertaken for a period of one year, from April, 2013 to April, 2014.

4.2 Participant selection

4.2.1 Recruitment

Recruitment was via both an ethics board approved poster invitation and several forms of electronic media. The electronic media proved to be the more effective means of recruitment. This approval was extended to both the rehabilitation department at the University of Alberta Hospital and the Rheumatic Disease Unit at the Kaye Edmonton Clinic. Two posters were left in each area and remained up for 26 weeks. Copies of the poster were available to take from the Rheumatic Disease Unit. This means of recruitment resulted in a total of three study volunteers.

Electronic postings were more effective for participant recruitment, but also more labour intensive. A presentation was made in July 2013 at a citywide meeting of the Edmonton area Rheumatologists and an agreement was made that the paper form of the poster would be acceptable as well as an electronic version on www.edmontonrheumatology.com to support recruitment. Additional electronic bulletin boards used were the investigator's own Pinterest Boards on Occupational Therapy, Rheumatoid Arthritis Research and Virtual Worlds Research. A YouTube® video and Camtasia® account with a unique URL using the tags: Rheumatoid Arthritis, Research, Joint Protection and Occupational Therapy were also created as recruitment tools. Only the Pinterest boards resulted in recruitment of participants, with 8 potential participants identified.

The Arthritis Society of Canada, Alberta Division was again approached about posting a link to the study, but did not contact the principal investigator.

An attempt to find individuals using VWs and living with RA was also undertaken within SL. Similar strategies were used by Haque and Swicegood (2015). This revealed a very

limited number of individuals that identified themselves as living with RA, still less than 20 individual user accounts out of an estimated 36 million total accounts at the time of writing, many of whom were sent a private instant message and link to the study. Only two SL users responded to the invitation to participate. Only one person was eligible for the study as the other had previously participated in an ASMP. Other methods not thoroughly attempted, as described by Haque and Swicegood (2015), including using the New World Notes Blog, as posts were removed and an account suspension was threatened. It was additionally noted that other in-world recruiting by these authors included holding multiple hour long seminars, which would have been quite labour intensive and required further cooperation from the administrators of Ability Island in order to host seminars. Finally, it is noted that these seminars may have inadvertently introduced confounds, as the seminars provided by Haque and Swicegood (2015) provided disease management information to study recruits.

Twitter® was also used in an attempt to follow and send tweets out about the study. A separate account was created and used with the user name Arthritis Fighters. Despite following recommendations regarding time of day to post and use of hashtags: rheumatoid, arthritis, research, joint protection, virtual and Second Life, there were few respondents using this recruiting method. This method resulted in 6 volunteers expressing interest in the study. Tweets were sent out from November of 2013 to April of 2014 during this portion of the study. Figure 1 includes some of the tweets and information provided.

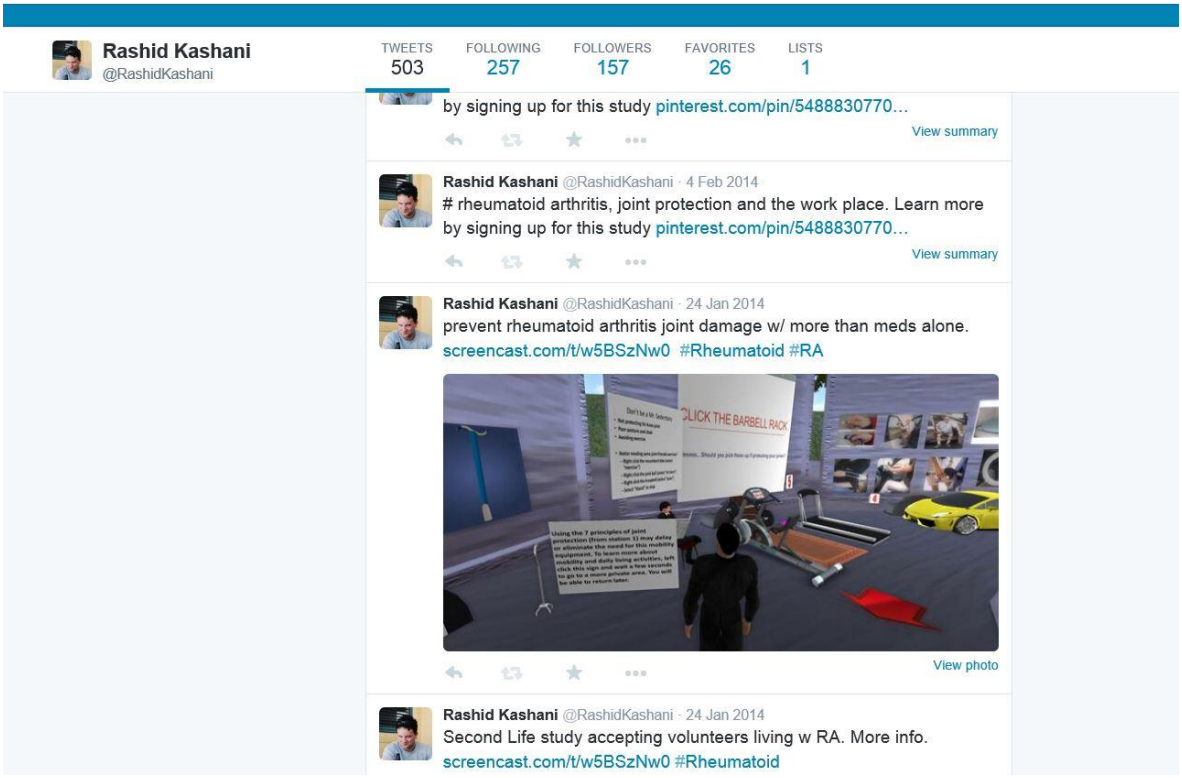


Figure 1 – Screen capture of use of Twitter and hashtags for pilot RCT recruitment

The Twitter® group, #OTtalk2US, also invited the principal investigator to be a presenter in April of 2013. This is an internationally broadcast series of moderated online discussions in various areas of clinical practice. Though the focus of the talk was private practice and the growth of this in Canada, part of the discussion included the development and funding of independent researchers as a form of private practice, so information about the present study was also presented. This event was attended by therapists in multiple countries who also agreed to post and re-tweet the link to the study. A screenshot of the Twitter® event summary is included in Figure 2.

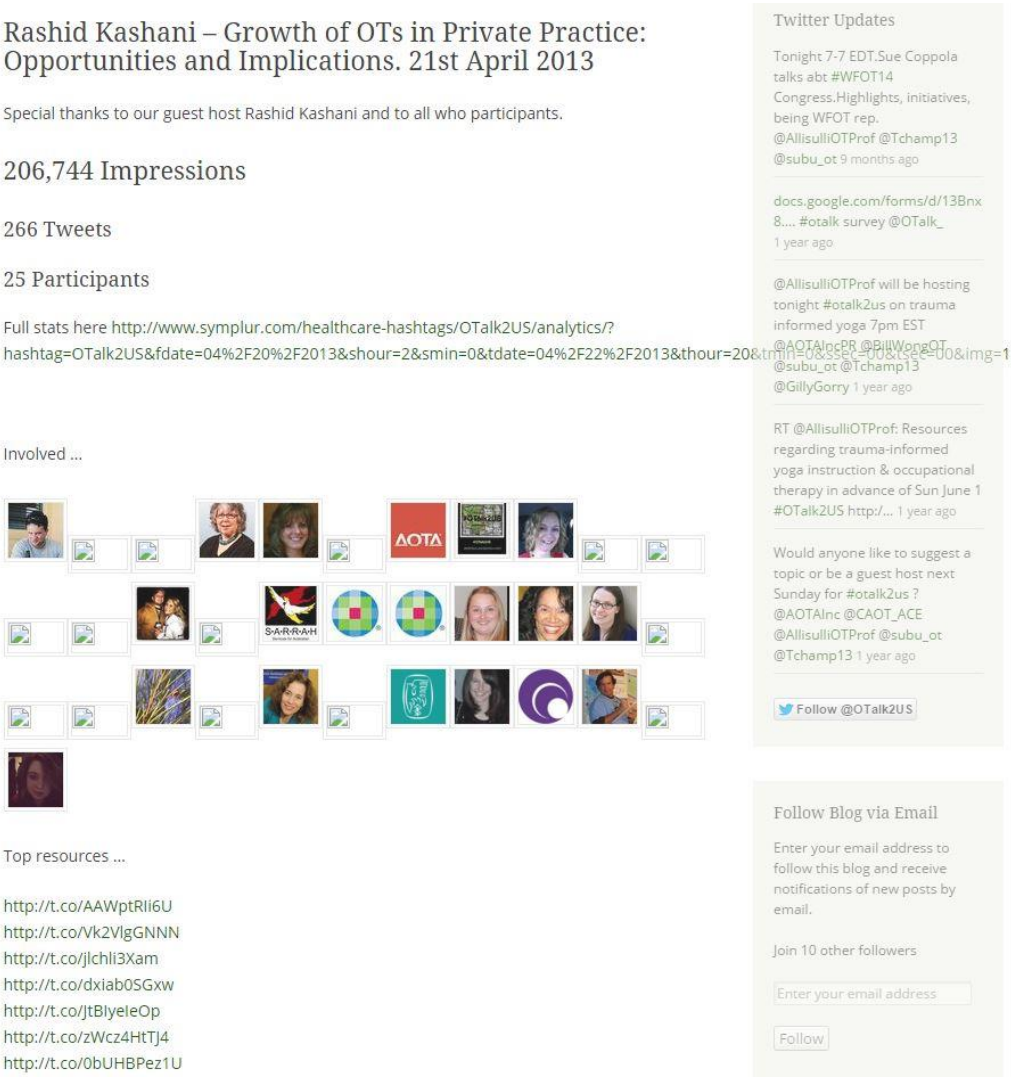


Figure 2 – Summary of statistics from #OTalk2US event

At the recommendation of one of the study supervisors, the search tool Followerwonk® was used in order to identify individual Twitter® user profiles who identified themselves as living with RA and either users of SL, or VWs or gamers. This method did not result in a significant number of identifiable potential participants and was time consuming. Search terms included rheumatoid, RA and arthritis. These terms were paired in permutations with Second Life, gamer and virtual. A very small number of accounts produced hits. This attempt to recruit resulted in no participants being directly recruited, but provided some useful information from those who responded to the invitation to participate. Two potential

participants indicated that they were quite particular with their VW choices, one stating a strong dislike for SL and a strong preference for only playing games produced by Blizzard Games®. Some participants recommended contacting other RA related Twitter® accounts that had a high number of followers, or RA influencers, on social media, for potential recruitment.

Given the limited number of individual online social media accounts identified for potential recruitment, and the suggestion RA influencers may be a useful source of participant recruitment, Followerwonk® was also used to identify users with high rated influence who were also tweeting to groups of online users about RA. These were individual Twitter accounts that groups of users would follow regarding the topic of RA. Other methods attempted for recruitment via groups included registering an account with Patients Like Me®, registering for a Tumblr® account and attempting to recruit via Facebook® Groups, such as Rheumato4OT, The Rheumatoid Arthritis Insomniacs Club and OT4OT. This recruiting via specific online groups was only successful via Facebook® and approaching high level influencers on Twitter® at getting potential participants. The Tumblr® and Patients Like Me® accounts resulted in no participant recruitment.

Approaching the accounts followed by groups on Twitter® and specific groups on Facebook® resulted in some inquiries from bloggers on disability. This resulted in a breakthrough in advancing recruitment. Some bloggers requested a brief interview or completion of a questionnaire that was broadcast to their audience via Twitter and also appeared in their corresponding blog. The blogger who edits The Seated View via Health Central interviewed the principal investigator and posted both the interview with the investigator and a link on her blog to the study, which resulted in multiple enquiries about the study, as well as the study being forwarded to others. The best estimate from this

recruitment strategy was that this resulted in at least an additional 35 volunteers for the study. The link to the interview on the Health Central RA page remains archived on this at: www.healthcentral.com/rheumatoid-arthritis/c/80106/164888/ra-protection. The study information was picked up and re-tweeted by other Twitter users, most notably, Rheumatology 2.0, Heal Click News and the Spoonie Rheum, all with a large number of followers.

Given this breakthrough with the use of bloggers in recruiting, the use of VW bloggers to assist with recruitment was also undertaken. Again using Followerwonk®, SL bloggers were also approached. The most influential SL blogger was Lutricia Roux, who publishes the SL daily newspaper and featured the study (http://paper.li/LutriciaRoux_SL/1355389270#!headlines) both in the technology section and as a headline in one issue. As with the RA bloggers and OT bloggers this author agreed to both publish to her blog and tweet about it as well, as per the screen capture in Figure 3.

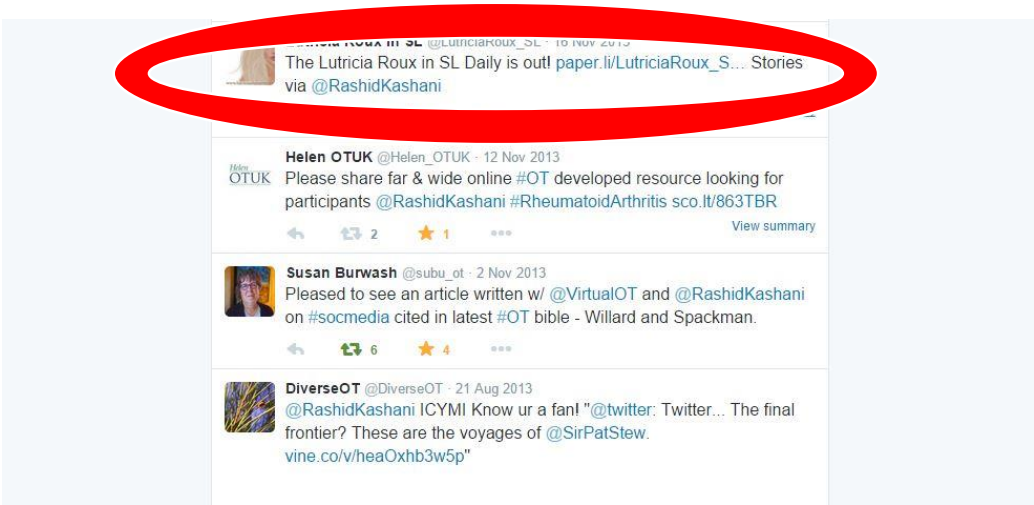


Figure 3 – SL Blogger, Lutricia Roux, Tweeting about the study in November, 2013

As the use of higher traffic sites, or targeting relevant websites with high traffic were successful at advancing recruitment, another high traffic health related website was thought to be a potential source of volunteers. The Surgery 101 website and YouTube® channel receive approximately 100 000 visits in a 6-month period, many of which are unique visitors. As of May, 2015, the Surgery 101 podcasts were the number 1 download in the Medical category of iTunes and the website itself had over 2 million downloads. It was deemed a potential source of considerable exposure to the study. The physician who created the Surgery 101 YouTube® channel was approached and agreed to provide a link to the study after reviewing the program with the principal investigator, posting a notice about the study included in Figure 4.

Figure 4 – Screenshot of link to study via Surgery 101 (www.surgery101.org)

A total of 108 individuals expressed initial interest in the study. Of the original 108, a total of 98 returned a completed consent form. Of the remaining 98 that completed the consent form, one participant was excluded for being under the specified age (18) to participate. Of the remaining participants not initially excluded, only 74 responded to the survey question regarding a previous ASMP. The study was aimed at providing this information to a sample who had not previously received this type of intervention. Of the remaining 74 potential participants, 8 indicated that they had, in fact, participated in a previous ASMP and were also excluded from the study. Of the remaining 66 participants, 15 were lost to follow up,

initially agreeing to be in the study but then dropping out before starting to participate in the study. One participant reviewed the main SL website and requested to be withdrawn from the study.

4.3 Sample size

A total of 50 participants who met the inclusion criteria were enrolled in the study and completed the full survey. There were two groups in the study design, a treatment group and a control group. The treatment group received immediate access to the VW and were to complete the survey, including measurement tools selected in Chapter 3, after 30 days of VW program access. The control group completed the survey first, then received access to the VW program after 30 days. Half of the participants (n=25) were randomly assigned to each group.

4.3.2 Information and consent

As per section 3.1.5 of the previous chapter, participants for this part of the study were provided information about the study via the invitation letter. They were informed that they were being invited to participate in a research study. The letter indicated that the research conducted in this study complied with University of Alberta Standards for the Protection of Human Research Participants. This policy was available for inspection at the previously listed link, also in section 3.1.3 of the previous chapter.

As per the previous stages of the study, a signed Informed Consent form, explaining all benefits and risks, had to be completed prior to participation. The form, as attached in Appendix 5, explained potential risks and benefits, right to privacy, how information was kept secure and right to withdraw from the study at any time up to study completion without risk or penalty. Participants could also contact the University of Alberta Health Research

Ethics Board at (780) 492 0302 should there have been any further questions regarding rights as a research participant.

As per the invitation letter, if potential participants were interested in participating in this research, or had further questions, they were again encouraged to contact the principal investigator. If potential participants were not interested in participating, they were informed that they were under no obligation to respond and would not be contacted again.

For participants to be included in this part of the study, they had to be aged 18 or older, diagnosed with rheumatoid arthritis as a primary diagnosis, and not have previously received an ASMP program involving joint protection instruction. Participants had to be capable of providing informed consent. Participants were informed that they needed to have access to the Internet and were informed as to what the minimum computer system requirements were as per Table 2 in section 3.1.4 of the previous chapter.

4.3.3 Confidentiality

As per section 3.1.6 of Chapter 3, participants were again provided information regarding confidentiality as per the invitation letter. This included the same information regarding anonymity, how information would be protected and destroyed as in the previous phases of this study.

The data was collected using a SurveyMonkey® account and users had to provide an electronic signature and had the option of providing an email address if they wanted to receive the final results of the study. These were the only two potential unique identifiers, which were removed prior to data collating and analyses. The SurveyMonkey® account was also password protected and this account could only be accessed by the principle investigator. One potential threat to confidentiality was that this webhosting service is

located in the United States, and as such, was participant to the Patriot Act. This legislation implied that the data could be participant to government scrutiny, or even confiscation. This was deemed a very remote possibility given the nature of the study that was being undertaken and deemed a minimal risk given the type of information being gathered and the very limited unique identifiers that would be available to a third party.

4.4 Measures

A sample copy of the completed online survey is included in Appendix 11. In addition to some demographic information, there were three primary measures incorporated into the survey. These measures were the short form of the AIMS II, the Arthritis Self-Efficacy Scale and 5 multiple-choice knowledge based questions about joint protection. Both the AIMS II and the Arthritis Self-Efficacy Scale are ordinal scales that are validated measures and self-administered. The 5 multiple choice knowledge based questions were based on information that users received while using the VW program. These were field tested prior to data collection, with 2 of the therapists from the first part of the study, a participant living with RA from the second part of the study and were also presented to the study supervisors.

4.5. Intervention procedure

The following subsections describe how individuals who volunteered for the study were enrolled, randomised to a group, the instructions they received about accessing the program and how data was collected. A diagram at the end of section 4.5.3 summarises this process, as per CONSORT guidelines.

4.5.1 Enrolment

In order to be in the study, potential participants had to be adult clients diagnosed with rheumatoid arthritis, not presently receiving or having previously received an ASMP program involving joint protection instruction. Participants had to have access to a computer and the Internet. Computers had to meet the minimum system requirements for the program to run, as outlined in section 3.1.4 in Chapter 3.

Participants unable to give informed consent, due to age or reduced cognitive capacity were excluded. This includes, by definition, all persons under the age of eighteen. Participants who did not have access to a computer and the Internet were also excluded. Participants who did not have the minimum system requirements were also excluded. A summary of the numbers recruited versus enrolled in the study is included in the diagram at the end of section 4.5.3 of this chapter.

The principle investigator was responsible for all costs involved in enrolment in the program, which was primarily VW program development and maintenance costs. The principle investigator was not paid to enrol participants in the study. Participants did not receive monetary incentives to participate in the study.

4.5.2 Randomisation and blinding

Of the 108 volunteers who identified themselves as willing to participate in the study, 76 completed the consent form. Other participants were excluded, as per Figure 5 at the end of this section, prior to being randomized using an online random number generator (Appendix 12), to either intervention or control. The intervention group immediately received information to orient them and allow access to the VW program. The control group completed the survey, including the AIMS2SF and PSEQ, waited 30 days to access the

program, and were then provided the same information as the intervention group about accessing the program.

All participants were given the survey once. This was in order to complete a one shot experimental design, the strengths of which are discussed in Chapter 6. Participants in the intervention group completed the same survey provided to the waitlist group after using the VW program for up to 30 days. Those in the intervention group were sent automatic reminders at 7 days and 21 days post-enrolment to try the VW program as the survey would be open to them after 30 days.

The study involved a single blind design. Participants were not informed what group they were in. However, the investigator was aware which email address was assigned to a specific group. However, there was no face-to-face contact between the principal investigator and the participants, and minimal electronic interaction with most participants.

4.5.3 Data collection

All data for the study was collected via the SurveyMonkey® site survey. In addition to the 3 main measures, some demographic data was gathered to determine if there were differences between groups. All participants were asked to provide any additional feedback they may have had about the study and the use of the VW program. This was within the survey, but was also possible via the VW itself in the form of an instant message (IM) to the principal investigator or via a note board in the previously discussed Easter egg area of the VW program, in section 3.4.2 of Chapter 3.

Upon study completion, participant data was downloaded from SurveyMonkey to Excel and on to SPSS. An example is shown in Table 1 on the following page. For those

participants who completed the full survey, this comprised 58 variables, not including any written feedback they may have provided.

The AIMS2SF and PSEQ required recoding and scoring as some of the items, are reverse scored. This involved using the scoring guidelines included in Appendices 9 and 10 for each data set collected per participant. Quality assurance to ensure accuracy was ensured via double data entry and comparing data sets for discrepancies.

country	age	school	sex	yrs RA	yrs dx	meds
1	61	6	2	3	3	1
1	60	5	2	15	4	1
1	54	4	2	2	0.3	1
1	42	5	2	20	5	1
2	73	6	2	34	8	1
2	46	6	1	35	35	1
1	35	3	2	15	15	2
1	48	5	2	23	14	1
1	52	4	2	20	10	1

Table 1 – Sample coding of survey data into Excel spreadsheet for export to SPSS

Participant recruitment, enrolment and randomisation, which culminated in the data collection is outlined in the following flowchart. Figure 5 includes numbers of initial volunteers, those lost due to exclusion, withdrawn and non-compliant participants.

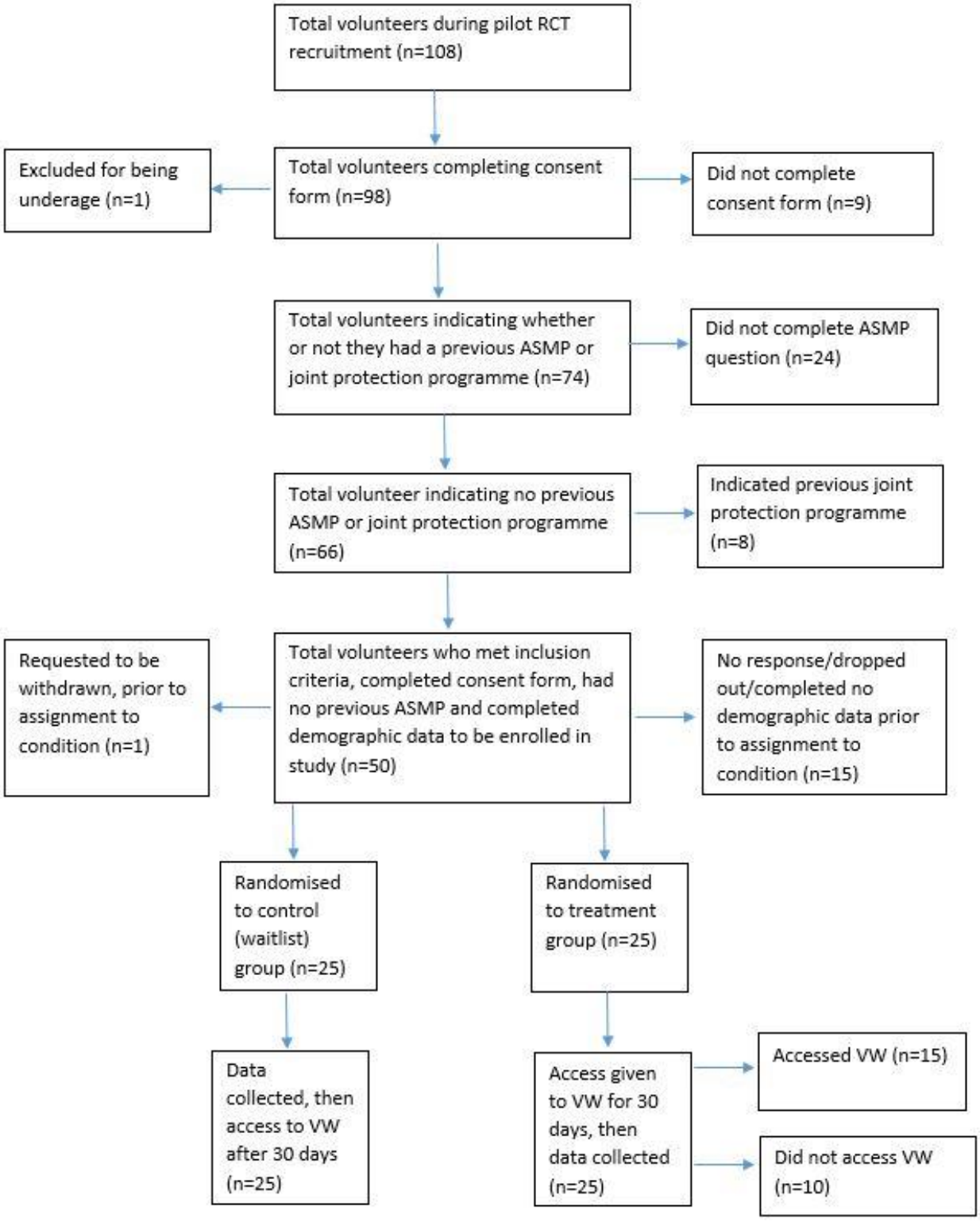


Figure 5 – Enrolment and randomisation of potential participants

4.5.4 Required follow up

Given the experimental design used, there was no follow up required of the participants upon completion of the survey. Only the aforementioned reminders were sent for those enrolled in the study to complete the survey if in the control group, or use the program, and then complete the survey, if in the treatment group. They were given the opportunity to follow up with the investigator, if needed, but this was not a requirement of the study.

Participants were also given the opportunity to request the results of the study, if interested. Eight participants expressed interest in receiving study results. These email addresses were stored in a password protected electronic list in order to provide these requested results upon dissertation completion.

A few participants indicated wanting to know the study outcome. An additional invitation will be sent out to all participants to an in-world event where the results will be presented live. A link via an interactive display will also be created in the main display area to present the results for those unable to attend the in-world event.

4.6 Statistical methods to analyse results

Prior to answering the research hypotheses, data was initially examined using descriptive statistics using a student version of SPSS 21. What follows is a description of the data obtained, tests used and analyses. Given that this was a pilot study, the sample size was small, but appropriate to test the feasibility of obtaining required data for a full RCT, and obtain information of the possible effects seen with a larger sample. Analyses were additionally needed to inform the sample size calculation for a full RCT. Though power calculations were included in the analyses, it was not anticipated that a pilot study would

have a sample large enough to detect statistically significant differences between the treatment and control groups.

4.6.1 Normality of data

It was necessary to determine if the groups analysed were normally distributed given the limited population data available for the measures and intervention used with which study data could be compared. The distributions of some variables could be checked for comparability between groups. Descriptive analyses of the data collected showed that the groups were normally distributed in age, sex and country of residence using independent samples t-tests for non-nominal level data, such as age, and Chi-squared analysis and Fisher's Exact Test for nominal level data, such as country of residence. Groups were also normally distributed for years diagnosed with RA, level of computer experience, level of education and prior VW experience. Groups were not normally distributed for only one variable, years reported living with RA.

4.6.2 Statistical tests

T-tests were used, where appropriate to determine if significant differences existed between groups for demographic data including age, years living with RA and years diagnosed with RA. T-tests were used to look for differences between groups on each measurement tool scores. A correlational coefficient was used to determine if data that was not normally distributed correlated with measurement tool scores.

Chi-Square analysis and Fisher's Exact Test were initially used to assess differences in proportions of attributes between groups. These proportions included demographic variables of sex, country of residence, medication use, knowledge of RA sub-type, level of computer expertise, level of education and previous VW use.

One-way Analysis of Variance (ANOVA) was used to examine the differences of scores on the three measurement tools between the groups. There was the potential for the sample used to be more appropriate for non-parametric analyses as the sample was small and contained outliers on most measures. An Independent Samples Median Test and Independent Samples Kruskal-Wallis Test was also used to examine the median differences in scores between the groups for non-parametric data. In all analyses, a level of $p<0.05$ was used in determining statistical significance.

4.6.3 Intention to treat analysis

As a pilot study, analysis for statistical differences is carried out mainly as a rehearsal for the subsequent definitive RCT to check that all the data has been collected appropriately and that the methods and data are robust. There are various ways of dealing with non-compliant participants from the study and with those who do not undertake the intervention. Intention to Treat (ITT) Analysis is one option. Using ITT analysis, non-compliant participants are not removed from the intervention group, maintaining randomisation of the original sample. One common issue is that non-compliant participants or non-users of the intervention can be removed from the treatment group and considered as part of the control group, or dropped from the study altogether, both manipulations reducing the effects of randomisation.

Options for dealing with missing values using ITT analysis for those who do not complete the intervention include treating non-compliant participants as treated, imputing values, such as the mean value of the treatment group, or carrying forward baseline values. This was less of an issue with this study as participants completed the survey, including those who did not access the VW during the 30-day enrolment in the study.

In the diagram included in section 4.5.3 of this chapter, there were a number of potential volunteers who were excluded prior to randomisation, which have also been recorded in order to determine the most inclusive sample size that may be required for a future RCT.

Ten of the 25 in the intervention group did not access the VW. Though this could be considered very high, it is actually low in comparison to typical drop out rates of up to 90% as reported by Zdanowski (2007) for new VW users. Follow-up regarding dropouts were not permitted as per the informed consent letter. In order to include non-compliant treatment group participants in an analysis, outcome data could have been imputed, which would have involved making assumptions about the outcomes in these participants. In this case, the assumption is that had these non-users of the VW program actually used the VW, their scores on the AIMS2SF, PSEQ and joint protection knowledge would be similar to the mean scores of those participants in the treatment group who accessed the VW program.

For those who did not use the VW program, instead of reassigning the non-compliant participants to the control group, and losing randomisation between the groups, survey scores could have been imputed with the mean scores of the treatment group participants who completed the program. This was not required, in this case, as the participants in the treatment group completed the questionnaire, but did not access the VW program. For these few missing values, this data was imputed using the mean score of those who indicated they accessed the program. They were included as treated and remained in the treatment group, despite not accessing the VW program. However, for the measurement tools used, the data was otherwise there, though participants had not used the VW program. As such, these participants were considered as treated, despite not accessing the intervention.

4.6.4 Analysis

The objectives here were to test the procedures that would lead to an RCT, estimate drop-out rates, determine effect size and enable an estimate for the sample size of an RCT. Outcomes analysed here needed to include: 1- numbers recruited into the study from the initial group of volunteers, 2- numbers in the intervention group who actually accessed the program and, 3- comparison of the group outcomes on the tools selected using Intention to Treat Analysis to estimate effect size for a future RCT.

In this study, there was a proportion of 40% of the data could be considered as missing or not representative of being in the treatment group. By adopting the ITT strategy, this data was used to keep 25 randomised participants in each group.

Though some of the differences between groups, discussed in the next chapter, were not statistically significant, results are useful in determining the sample size required given the size of difference between groups. Additional analysis, as discussed in the next two chapters, included identifying problems encountered in the recruitment process, which would be useful to avoid prior to planning a full RCT.

Chapter 5 Results of the Pilot RCT

The overall response rates to the types of invitations used, and the demographic characteristics of the participant sample are detailed in the following sections, before presenting the results of the outcome measures of the pilot RCT. Outcome measures are analysed later in this chapter, comparing the control and treatment groups. Mean differences are compared between groups and analyses are included on whether the size of such differences between the groups are statistically significant. Individual feedback and potential improvements on outcome measures are also examined.

5 Recruitment and response rates

The total sampling frame for this study was not known. What was known were a few key demographic points about the population that was being sampled, as per the information provided in section 1.2.5 of Chapter 1. It was known that a representative sample of people living with RA include a 4:1 ratio of females to males, and that the mean age of participants would be expected to be over 40 years of age, given an average age of onset of 20-60 years, and a frequent delay in onset of symptoms and time to diagnosis, as discussed in section 1.2.5.2 of chapter 1.

All participants in the study identified that they were living with RA and reported that they resided either in Canada or the United States. Of those who indicated an interest in the study (n=108), 9 were ineligible to participate as per Figure 4.5.3 in Chapter 4. Of the remaining participants who answered the question regarding attending a previous ASMP and completed the consent form, a total of 50 participants were randomised to the control or treatment group with 25 in each arm.

The number of views of the YouTube® clip and posts on the aforementioned blogs as outlined in section 4.3.1 of Chapter 4 was known to be well over an estimated 2000 views combined during the recruitment phase of this study. This would, potentially, lower the response rate to 4.8%. Some viewers may not have been eligible to participate in the study or viewed the online video or a related blog post several times. Given the information available, the response rate could have potentially been anywhere from an estimated minimum of 4.8% to a maximum of 15.5%. As the sample frame was not accurately known in two of the recruitment methods, an accurate response rate was not possible to calculate. Estimates have been provided using what data was available.

5.1 Paper invitation

In order to increase recruitment, an information poster and copies of this poster were made available at the local dedicated rheumatic disease unit as described in section 4.3.1 of Chapter 4. This was extended to the rehabilitation department at the University of Alberta Hospital and the Rheumatic Disease Unit at the Kaye Edmonton Clinic. Two posters were displayed in the central waiting room and 100 colour copies were made available for 26 weeks for potential participants to take with them. As not everyone attending these services has RA, and patient numbers can be quite variable, the number of new referrals of new patients living with RA from one unit to the other averages 200 per annum presently. The estimated number of newly diagnosed patients living with RA would be 100 in the 26 week period of recruitment.

At study conclusion, it was apparent that no more than 37 people had taken paper invitations as 63 remained at study completion, and assuming no paper invitations were wasted. Of the 37 potential participants who took a copy of the poster, 3 participants identified themselves as having been recruited through this method, or an estimated response rate of 8.1%. An

accurate response rate using paper invitations was difficult to determine as it was not known how many people actually read the poster, how many were eligible for the study and how many invitations were taken versus destroyed. The rheumatic disease unit was in agreement with displaying the materials, but did not actively distribute the paper invitation to individuals. This was due to administrative approval stating that staff onsite were not to be used to recruit to the study. The principal investigator was also not permitted to recruit participants in person on site. This restriction was put in place via the Health Ethics Research Board in order to protect potential participants from feeling pressured to participate in the study.

5.2 Email invitation

Individual email invitations were sent to 58 individuals. Of these individuals, 12 were recommended via a healthcare provider who was aware of the study, including 11 occupational therapists and 1 registered nurse. The remaining 26 individuals were invited using the Followerwonk® and Twitter® sites as outlined in section 4.3.1 of Chapter 4. Of these 58 potential participants, a total of 9 were recruited to the study. This could be interpreted as a response rate of 15.5%. As individual emails and responses could be tracked, this method of recruitment was easier to determine what the response rate was in comparison to other recruitment methods.

5.3 Electronic bulletin board invitation

The remaining potential participants (n=96) were recruited from the blogs and online forums, including directly from SL users, as outlined in section 4.3.1 of Chapter 4. Though the total number of individual viewers is not exactly known, some of the websites had data to indicate the total number of views or visits over the recruitment stage. These numbers, where available, are included in Table 1.

Web site / resource	Views or visitors / followers during recruitment
YouTube and Camtasia video	67 views
Seated View (Arthritis Central)	144 followers
Second Life (Arthritis groups / profiles)	16 members
Surgery 101	2000 views and 454 subscribers
SL Daily	Unknown

Table 1 – Web Resources used for recruiting and known views or site visitors

These numbers do not necessarily reflect accurate numbers of unique viewers, as previously outlined in section 5 of this chapter. Additionally noted is that individuals may have viewed the study on more than one site, further obscuring the response rate using this medium. There is also no way of knowing if those who viewed the invitation met the eligibility criteria to be included in the study. The response rate using this method of recruitment, previously reported as 4.8%, is likely an underestimation of the true response rate in considering these other factors.

This recruitment method yielded the highest number of potential participants, though it also had the least certain sampling frame in comparison to the other recruitment methods. Table 2 below indicates the recruitment strategies used, and the number of participants recruited relative to estimated or known sampling frame.

	Paper invitation	Email invitation	E-bulletin board
Number invited	37 (estimated)	58 (known)	2000+ (estimated)
Number recruited	3	9	96
Response rate	8.1%	15.5%	4.8%

Table 2 – Response rates based on recruitment methods used

5.4 Retention and noncompliance rates

There were a total of 50 of the original 108 participants who met the eligibility criteria and completed the consent form to participate in the study. There were 15/25 participants in the

treatment group who completed the VW program. All participants randomly assigned to the control group were required to complete the initial survey, including the outcome tools. All participants (n=25), completed this initial survey after providing consent and being admitted to the study. This difference in completion rates represents a noncompliance rate of 40% in comparing the treatment and control groups.

There were few differences between groups in terms of the demographic data as outlined in Table 3. T-tests were performed with the non-nominal level data, which included age, years living with RA and years diagnosed with RA. All other demographic data was nominal and analysed via Chi-squared analysis, or Fisher's Exact Test for those analyses where data sets contained cells with less than 5 data points, which was all nominal level data other than country of participant.

The treatment and control groups only varied in the years living with RA with statistical significance ($p < 0.05$). There were no statistically significant differences in the other demographic parameters listed between the control and treatment groups in analysing the data using SPSS 21.0. The uneven distribution of the years living with RA was a confounding variable as it was found to be a weak, but statistically significantly, positively correlated variable with joint protection scores as indicated in section 5.7.3 of this chapter. Those participants living with RA longer were found to score better on joint protection knowledge. Though the control group had the higher mean number of years living with RA, the control group also had lower scores on the joint protection knowledge questions, with statistical significance.

Parameter	Control group	Treatment group	Significant difference
Age	Mean = 48.5 years	Mean = 47.3 years	No
Country	Canadian, n=13 United States, n=12	Canadian, n=10 United States, n=15	No
Sex	Male = 6 Female = 19	Male = 6 Female = 19	No
Education	High school to partial post-secondary education, n=14 One or more degree, n=11	High school to partial post-secondary education, n=11 One or more degree, n=14	No
Medication use	Yes =19/25 No = 6/25	Yes = 22/25 No = 3/25	No
Years living with RA	Mean = 15.1 years	Mean = 8.3 years	Yes
Years since diagnosis	Mean = 11.3 years	Mean = 7.1 years	No
Know sub-type of RA	Yes = 2/25 No = 23/25	Yes = 1/25 No = 24/25	No
Level of computer expertise	Poor/Fair = 3/25 Average - Expert = 22/25	Poor/Fair = 1/25 Average - Expert = 24/25	No
Previous VW experience	Yes = 4/25 No = 21/25	Yes = 2/25 No = 23/25	No

Table 3- Demographic data of the control and treatment groups

As the groups varied with statistical significance in terms of years living with RA, part of the subsequent analyses included determining if these variables correlated with the participant scores on the tools used. As previously noted, though those living with RA longer were correlated with higher joint protection knowledge. The control group, with a significantly higher average of years living with RA was not found to have higher joint protection scores than the treatment group. This is further discussed in section 5.7.2 of this chapter.

5.5 Missing data

As per section 4.5.3 of Chapter 4, a number of potential participants did not participate in the study prior to randomisation to condition (n=58/108). Of those who did not comply with the treatment after randomisation (n=10/25), there was no data generated for VW use or

experiences. This missing data is discussed as part of the intention to treat (ITT) analysis in section 4.6.3. It was also noted that 3 participants did not indicate if they were taking medications for their arthritis. This data was imputed as a negative response. The bulk of participants surveyed stated that they did not know what sub-type of RA they had (n=47).

This missing data regarding medication use and sub-type of RA was not a significant issue as it was being collected as a means of determining, as much as possible, what the overall demographics were of the sample. This was done in order to compare samples in future studies, rather than for the purposes of statistical analyses. It can be stated that at least 84% of all the enrolled participants indicated use of RA specific medications. It can also be stated that 94% of the enrolled participants could not, or did not, indicate knowledge of having a specific type of RA. This information may be useful in comparing overall attributes of future samples in further studies.

For the tools used, no participants failed to provide answers to every question. This result was part of the forced choice structure of the online survey format, requiring an answer to each question before being able to move on to the next section or exit the survey. Overall, a total of 60 data points was collected on each participant, as per Table 4. Of the total data points collected across the 50 participants (n=3000), this represents a total of 2.9% of missing data (n=88).

Country	AIMS scores (27 data points)	Issue with using SL (missing for 10 participants)
Age	Self-efficacy score (11 data points)	Cost of using program
Education level	Joint protection knowledge (6 data points)	Time in SL (missing for 10 participants)
Sex	Level of computer use	Frequency of SL use (missing for 10 participants)
Years living with RA	Prior VW use	Medication use for RA (missing for 3 participants)
Years diagnosed with RA	SL use (missing for 10 participants)	Subtype of RA (missing for 45 participants)

Table 4 – Data collected in each participant survey

5.6 Characteristics of respondents

The mean age of all respondents was 47.5 years with a range of 24 to 73 years. The total numbers of female to male participants was 38 to 12. This was a representative sample of the expected average age, over 40 years, as well as female to male ratio approximating 4 females per male, based on the information presented in section 1.2.5 of Chapter 1. These were typically known demographic attributes of people living with RA, so this information was useful in determining the representativeness of the sample, compared to the overall population of people living with RA. As discussed in section 5.4 of this chapter, the randomized groups did not vary significantly on these characteristics.

Factors that may have influenced the use of the VW, or correlated with performance on the tools used, were also collected. Participants also provided information on their country of residence, education level, years living with RA and time since diagnosis, computer expertise, prior use of VWs, use of medications and sub-type of RA. As discussed in section

5.4 of this chapter, the randomized groups varied with statistical significance on the number of years living with RA.

Descriptive statistics for the respondent characteristics are summarized in Table 5. SPSS 21.0 was used to calculate these findings and the original outputs for these calculations are included in Appendix 13.

Characteristic	Statistic or Nominal data (for 50 participants)	Comments
Age	x = 47.5 years, sd = 11.5 years	Mean age should approximate over 40 years of age given an expected median of 40 at diagnosis
Sex	Females: n = 38 Males: n = 12	Approximates a sample of 80% females and 20% males
Country	Canada: n = 23 United States: n = 27	Recruitment was internationally open to any country
Years diagnosed	x = 9.2 years, sd = 9.0 years	Significant difference between groups
Years living with RA	x = 11.8 years, sd = 9.7 years	Significant difference between groups
Education level	High school to partial post-secondary: 25 One or more post-secondary degree: 25	No participants had less than high school or high school equivalency
Medication use	Yes: n = 41 (84%) No: n = 9 (16%)	Missing data for 3 participants included as a negative response
Subtype RA	Aware of type: n = 3/50 (6%)	Discussed in section 3 of this chapter
Computer use	Poor to minimal abilities: n = 4 Average, high or expertise: n = 46	All participants had to be on the Internet, indicating both familiarity and access
Prior use of VWs	Yes: n = 6 No: n = 44	Very few participants had prior VW experience

Table 5 – Characteristics of Respondents

5.7 Study outcome variables

The following section will discuss the comparison between the control and treatment groups, and the varying scores between the two groups. In comparing groups, possible confounds are also analysed to explain differences in scores on the tools used.

Non-compliant participants, or those who did not use the VW program at all, were not removed from the treatment group or added as control group participants by reassigning them. This does not comply with ITT analysis as per CONSORT guidelines. Groups were compared on their overall scores on the AIMS2SF outcome measure (26 items and a multiple domain scores), PSEQ (10 items and a composite score) and knowledge based questions on joint protection (an overall score on 5 items), including content presented in the VW program.

5.7.1 Scores

Overall scores are included in Table 6. Outputs for these scores were calculated using SPSS 21.0 and are included in Appendix 13.

Measure	Mean score	Standard deviation	Significance (two-tailed)
AIMS2SF (lower score = less disability)	Control: 24.8 Treatment: 26.6	Control: 8.6 Treatment: 8.5	No (p=0.480)
PSEQ (higher score = higher self-efficacy)	Control: 33.6 Treatment: 35.4	Control: 12.6 Treatment: 13.0	No (p=0.621)
Joint Protection Knowledge (higher score = more knowledge of joint protection principles)	Control: 24.0 Treatment: 52.8	Control: 15.3 Treatment: 27.6	Yes (p=0.000)

Table 6 – Scores between groups on measures used

5.7.2 Mean difference between groups

The mean score for the AIMS2SF was 24.8 for the control group and 26.6 for the treatment group. With this measure, a higher score is associated with a higher level of disability in

terms of perceived function. The mean score in the control group was actually lower than the treatment group, indicating a more favourable mean score for the control group. Non-compliant members of the treatment group, those who did not use the VW program in the treatment group, were kept in the treatment group as per CONSORT guidelines for ITT analysis. Keeping the AIMS2SF scores of the non-compliant subjects with the originally assigned treatment group resulted in the differences between the two groups not being statistically significant (p=0.480).

The mean score for the PSEQ was 33.6 for the control group and 35.4 for the treatment group. With this measure, a higher score is correlated with a higher level of confidence, or self-efficacy in terms of pain management and functional abilities. The mean score in the treatment group was higher than the control group on this measure, indicating a more favourable mean score for the treatment group. Again, non-compliant members of the treatment group were kept in the treatment group as per CONSORT guidelines for ITT analysis. Keeping the PSEQ scores of non-compliant subjects with the originally assigned treatment group resulted in the differences between the two groups not being statistically significant (p=0.621).

The mean score for the joint protection knowledge questions was 24.0% for the control group and 52.8% for the treatment group. With this measure, a higher score would be indicative of a higher level of knowledge with the joint protection information presented in the VW program. The mean score in the treatment group was higher, more than double, of the control group on this measure, indicating a more favourable mean score for the treatment group. Again, non-compliant members of the treatment group, those who did not use the VW program in the treatment group, were kept in the treatment group as per CONSORT guidelines for ITT analysis. Keeping the joint protection knowledge scores of

the non-compliant participants with the originally assigned treatment group resulted in the differences between the two groups being statistically significant (p=0.000) while maintaining the original random assignment to condition.

As the groups were not evenly distributed for years living with RA as per the findings reported in Table 3 of Section 5.4 of this chapter, correlations were calculated to determine if these had a potential effect on scores. Given the level of data of the tools used was interval and ratio, a Pearson correlational coefficient was calculated for each. In all cases, the years living with RA was not correlated with the overall scores on the three tools used to measure differences between the treatment and control groups. These results are in included in Table 7 below.

Measure	Calculated (r)	Significance
AIMS2SF	0.06	No, two-tailed
PSEQ	-0.16	No, two-tailed
Joint Protection Knowledge	0.37	Yes, two-tailed Significant at $p < 0.01$

Table 7 – Correlations between measures used and non-equivalent group characteristics

Given the higher number of years living with RA correlating with joint protection knowledge, it would be anticipated that the control group, with a statistically significantly greater number of years living with RA, would have superior joint protection scores. Though not even distributed between groups, this did not appear to impact the study results as the intervention group, with the statistically significantly lower number of years living with RA, had higher joint protection scores than the control group with statistical significance.

5.7.3 Mean difference between groups and tool subsets

In examining differences between the treatment and control groups, and using the ITT analysis as outlined in the previous section, it was possible to perform a subtest analysis on the AIMS2SF scores based on the subsections or subtests it can be broken down into several domains, measuring x, y and z subscales, according to Meenan, Gertman and Mason (1980). This tool was designed to be analysed as a whole, or along specific domains as per the tool's scoring instructions. It was also possible to examine individual items on the other two measures and determine if there were differences between the groups on specific items. There were differences on several items as summarized in Table 8.

Sub-test	Mean treatment group score	Mean control group score	Significance ($p<0.05$)
AIMS2SF – Physical domain	3.5*	3.9	No, two tailed
AIMS2SF – Symptom control	6.0	5.3	No, two tailed
AIMS2SF – Affect	4.8	4.4	No, two tailed
AIMS2SF - Social	5.2	4.5	No, two tailed
AIMS2SF - Work	7.1*	6.7	No, two tailed
PSEQ – Pain	4.3*	3.7	No, two tailed
PSEQ – Housework	3.8*	3.6	No, two tailed
PSEQ – Social	3.5	3.8	No, two tailed
PSEQ – Coping	4.3*	3.9	No, two tailed
PSEQ – Work	4.0*	3.5	No, two tailed
PSEQ – Hobbies	3.6*	3.4	No, two tailed
PSEQ – Medication	1.9	2.4	No, two tailed
PSEQ – Goal achievement	3.3*	3.1	No, two tailed
PSEQ – Normalize lifestyle	3.3	3.3	No, two tailed
PSEQ – Increased activity	3.5*	3.4	No, two tailed
Joint protection – Positioning	3.2	3.2	No, two tailed
Joint protection – Principles	11.2*	4.8	Yes, two tailed
Joint protection – Activities	12.0*	6.4	Yes, two tailed
Joint protection – Application	12.0*	1.6	Yes, two tailed
Joint protection – ADL	14.4*	8.0	Yes, two tailed

*favourable score for treatment group

Table 8 – Differences between groups for AIMS2SF subsections, individual items on the PSEQ and individual joint protection knowledge items

On 13 of the 20 subtests, the treatment group had scores suggestive of better outcome than the control group. However, this was statistically significant on only 4 of the subtests, all of these being items pertaining to joint protection knowledge.

A one-way ANOVA test was also done across both groups in comparing the scores on the three measures used for the study. The results of the ANOVA test are summarized in Table 9. As with other measures, the level of statistical significance was $p < 0.05$. The only significant difference between groups was on the Joint Protection Knowledge questions.

Measure	F value	Significance
AIMS2SF	0.5	0.5
PSEQ	0.2	0.6
Joint Protection Knowledge	20.8	0.00* ($p < 0.05$)

Table 9 – One-way ANOVA comparing group scores across measures

Two concerns raised during initial analyses were with the uneven distribution between the groups with years living with RA and the large standard deviations of several group demographics and group means on measures used. The uneven distribution of the years living with RA was a confounding variable as it was found to be a weak, but statistically significantly, positively correlated variable with joint protection scores. However, the control group had the higher mean number of years living with RA, but had lower scores on the joint protection knowledge questions, both with statistical significance.

Despite the years living with RA being an unlikely confound given the analyses performed, the groups were not completely evenly distributed. The large standard deviations obtained on the demographic data and some measures, as well as the relatively small sample size were deemed as indicators of need for further analyses. As a precaution, additional statistical analyses were performed. These analyses included an Independent-Samples

Median Test and Kruskal-Wallis Independent Samples Test to compare median scores across the three measures for each group.

The results were the same as the assumed normal distribution of the groups as summarized in Table 10. There was only a significant difference in the means between the treatment and control groups on the measure of joint protection knowledge.

Null Hypothesis	Test	Significance	Decision
Medians of the AIMS2SF are the same across groups	Independent-Samples Median Test	1.00	Retain the null hypothesis
The distributions of the AIMS2SF are the same across groups	Independent-Samples Kruskal-Wallis Test	0.56	Retain the null hypothesis
Medians of the PSEQ are the same across groups	Independent-Samples Median Test	1.00	Retain the null hypothesis
The distributions of the PSEQ are the same across groups	Independent-Samples Kruskal-Wallis Test	0.92	Retain the null hypothesis
Medians of the Joint Protection Questions are the same across groups	Independent-Samples Median Test	0.00	Reject the null hypothesis
The distributions of the Joint Protection Questions are the same across both groups	Independent-Samples Kruskal-Wallis Test	0.00	Reject the null hypothesis

Table 10 – Nonparametric tests of medians and distributions of test groups and scores on measures used. Asymptotic differences are displayed. Significance level is $p < 0.05$.

5.7.4 Cost of using the program

Given the non-compliance of 10 participants from the treatment group, data was only available for 15 of the 25 participants, the total number who reported using the VW program. Of these 15 participants who used the VW program, none reported realizing financial a cost for using the program. Examples of costs were provided in the questionnaire, the exact wording being:

"Q24: Did the virtual program (US spelling) cost you anything? (This includes anything you may have had to purchase to use the program, time away from work, travel time, etc.)."

The program for this sample appeared to be cost neutral to those who used it. If considering the aforementioned ITT analysis, the imputing of the mean score for the missing data would still result in an overall cost of zero as there were no responses that indicated otherwise. However, hidden costs on time and resources, such as time away from more meaningful activities, or increased wear and tear of a personal computer, may have been present, and difficult to calculate. Overall, the data appears to support that this is a resource, that when used, does not entail a cost to the user.

5.7.5 Sample size for a future RCT

Though there was a statistically significant difference between groups on the joint protection measure, the sample size for the study was small. The study had weak statistical power for the AIMS2SF and PSEQ, as indicated in Table 11. A larger sample would be required for a full RCT with higher power. A power calculation was performed, based on the effect size seen between the treatment group and the control group, for each measure used. These were calculated using an effect size(b) of 0.8 and significance (p) of 0.05 The proposed sample sizes are included in Table 11, indicating that at a minimum, participants would need to be randomized to one of the two groups, to a maximum of 1250 participants total, if a full RCT using the same measures was to be conducted. The power calculations for both this study, as well as the calculations to determine the proposed sample size for a full RCT were conducted using an online power calculator at: https://www.dssresearch .com/KnowledgeCentre/toolkitcalculators/

Measure	Power calculation		Power for this study, with n=25 in each group, two-tailed (%)	Proposed sample size (n) per group for full RCT
AIMS2SF	Mean 1 = 24.8 Mean 2 = 26.6 p(0.05) b(0.80)	s.d. 1 = 8.6 s.d. 2 = 8.5	11.5	279
PSEQ	Mean 1 = 33.6 Mean 2 = 35.4 p(0.05) b(0.80)	s.d. 1 = 12.6 s.d. 2 = 13.0	7.9	625
Joint Protection Knowledge	Mean 1 = 24.0 Mean 2 = 52.8 p(0.05) b(0.80)	s.d. 1 = 15.3 s.d. 2 = 27.6	99.5	7

Table 11 – Proposed sample sizes based on power calculation and measures used

Chapter 6 Discussion

6. Synopsis

Aims of the study were presented in Chapter 2. To remind the reader, the overall aim of this study was to develop a VW program designed to teach people living with RA about joint protection and through a pilot study determine if a definitive RCT was feasible and if so what form it should take. Subsidiary aims for the development of the program included determining what was the expected joint protection content in the VW program and what features users identified to make this media most useable. Subsidiary aims of the pilot RCT included identifying, what tools or instruments may be useful in determining measureable outcomes on management of RA with the program, determining if one could recruit and randomise participants, determining rate of drop outs, measurement of clinical efficacy, if any, using this intervention, calculating appropriate sample size for a future full RCT and calculating cost of program use, which could be used to determine cost effectiveness in comparing treatment methods in future study.

Outline of this chapter: The main study aim, to conduct a pilot RCT to inform the methodology of a future full RCT, is discussed. The results relating to subsidiary aims are also discussed, including reviewing findings by measure. Several methodological findings and issues are presented. These issues include discussing response rates, recruitment methods, completion versus noncompliance rates, feasibility of using a VW in health education, feasibility of an RCT using a VW and limitations of the study. Suggestions to improve methods are also presented at the conclusion of this chapter.

6.1 Feasibility of an RCT study of a VW

While few, if any RCTs exist using VWs and health initiatives, as discussed in section 1.7.3.1 of Chapter 1, this study demonstrates, that though challenging, it may be feasible to conduct a full RCT with the program developed. As previously indicated, barriers to

recruitment, a more thorough cost/benefit analysis and limitations of the VW platform capabilties would need to be addressed prior to conducting a full RCT. However, this study moved beyond the proof of concept phase, seen with most other VW studies discussed in section 1.7.3 of Chapter 1.

A full RCT, using the measures tested in this pilot study, would vary considerably in size and feasibility depending on the measures selected for a future RCT. For example, the PSEQ, if used as a measure in a future study, would require a much larger sample size (n=1250), and would reduce the feasibility of a future RCT. This relatively large sample may make a preference study more favourable as a future study. Conversely, dropping the PSEQ reduces the required RCT sample size, increasing the feasibility of a future RCT.

An additional consideration about future RCT feasibility is that the total number of participants who were randomised and assigned to a condition (n=50) was no where near the actual number of individuals who indicated initial interest on the study (n=108). If the same proportion (54%) of potential participants were anticipated to drop out before random assignment in a full RCT, the numbers required to recruit would be higher than indicated based on the power calculations in section 5.7.5 of Chapter 5. These number are compared and summarised in Table 1.

Measure	Proposed sample size based on power calculation	Numbers needed to recruit if same proportion drops out prior to random assignment
AIMS2SF	558	1213 (655 drop out)
PSEQ	1250	2717 (1467 drop out)
Joint protection knowledge questions	14	30 (16 drop out)

Table 1 – Assuming similar drop out prior to random assignment, actual sample sizes required per tool used

While feasible, the numbers needed to recruit to a full RCT could take a considerable time. Even limiting the recruitment of a full RCT to the recruitment numbers needed for the AIMS2SF and joint protection knowledge questions would require up to 1213 potential participants. Recruitment for the present study required an intensive and widespread recruitment of participants, as discussed in section 4.3.1 of Chapter 4. Though labour and resource intensive, it may be feasible to recruit much higher numbers of participants. If recruitment was done over a matter of years, instead of months, and used suggestions as outlined in the next chapter to improve the methods of a future RCT, this sample size may be acheivable. Overall, recruitment for a sample of 1250, with a very conservative global recruitment of 1-1.5 participants per day would take up to 3 years to complete a full RCT. Accounting for the numbers recruited, versus the numbers who actually enrolled in the study, this number could be close to double and may double this time, taking up to 6 years to complete. A lack of endorsement of the study by a national association, such as The Arthritis Society of Canada, remains a major barrier to a future full RCT.

As with the feasibility of the use of the VW and health education, the RCT would potentially only recruit individuals with specific attibutes, as outlined in the previous section. This may only include people already using the Internet, people of a specific age range, people with high school education or higher and people with an average level of reported computer skills or greater. However, based on the sample attibutes of this pilot RCT, this could potentially represent a broad segment of the population. Further discussion addressing feasibility issues is presented in the next section, regarding limitations of this study.

6.2 Feasibility of using a VW in health education

The feasibility of using a VW in health education needs to also be evaluated to determine if this medium is a realistic alternative to existing ASMP. Both the practical limitations and

possible advantages a VW may have over traditional, in-person ASMPs needs to be considered.

A VW is visually markedly different than an in-person interaction, particularly for those who are new users to VWs. This difference may have proven to be a barrier to some users, who provided feedback on the survey, via email and on the note board in the Easter egg area discussed in section 3.4.3.3 of Chapter 3. Cognitive load, discussed in section 1.7.5 of Chapter 1 may have been quite high for some users, making this medium feasible for some users, but not the medium of choice for others. The characteristics of the sample indicate that the vast majority of people had rated themselves as having at least average computer skills, or better. Participants also all had high school education, or greater. This may put some limitations on the generalisability on how feasible it may be to use a VW in health education of this type.

The VW itself is not always a stable environment, and like other Internet based sites, it is participant to crashing, performance issues and can take several seconds, to even minutes, to load onto a computer. The need to download the viewer from the SL website was a reported barrier for some in this study and would be an issue for someone concerned about downloading malware. Five of the 15 participants who used the VW reported issues with accessing SL. Two of the non-compliant participants had an issue with SL and provided feedback as well. Outside of the formal survey, participants could email and leave messages in SL regarding the program. Feedback from participants that would negatively impact the feasibility of the use of a VW for health education is included in Table 2 and Figure 1.

Issue type	Example statement(s)	Number reporting this issue
Navigation	"I wandered away and didn't know how to get back" "I didn't know where to go after number 8" "I keep getting lost"	3
VW performance	"The videos don't load" "It takes a very long time to log in and see the displays"	2
Suspicion about the VW	"It looks like a dating site" "I don't want to download software"	2

Table 2 – Feedback from participants about SL issues

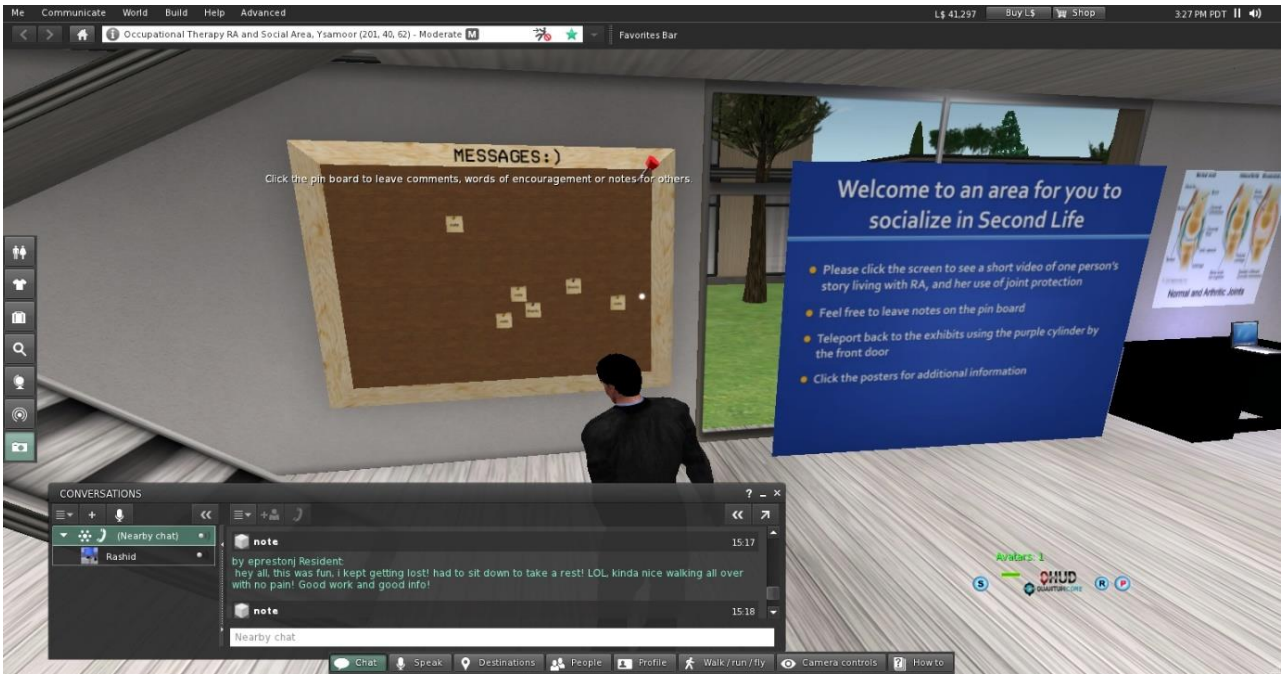


Figure 1 – Sample feedback on SL access issue left by participant in "Easter Egg" area

In addition to considering the VW, and how it is operated and designed posing some barriers to use, there is also the issue of the VW being dependent on Internet use. As presented in

section 1.6.9 of Chapter 1, there is a high level of Internet use among the general North American population and there is also a high frequecy with which people living with chronic disease use the Internet for accessing health information, up to 53%, as presented in section 1.6.10 of Chapter 1.

However, it has also be concluded in some studies that using related eHealth initiatives may not always reach the intended audience. This issue has been documented by Jones (2009). In this study, the author suggests that the use of electronic means of delivering health information is more successful if the rationale for use of the medium is clear, that user feedback is incorporated into improvements in the use of the medium, and cultural and socioeconomic factors may result in some segments of the population being underserved. Compounding this potential limitation of failing to reach the intended audience are limitations in Internet use not being uniform across the entire population, some still do not have access to high speed connections and minimum system requirements may become a larger, rather than smaller issue over time with increased use of smartphones and tablets.

Conversely, there are a number of factors which support the feasibility of the use of a VW for delivery of health education. In addition to the flexibility of use, reported cost neutrality, reported content matching participant expectations and suggestion of knowledge transfer in this study, there are additional benefits. A taught program run by professional staff, at a minimum, would cost the health care system of $50.00 Canadian per hour. This is a bare minimum, and grossly underestimates a number of costs. The current budget for the rehabilitation staffing of the rheumatology service is $550 000.00 Canadian. The RA specific program, offered by the local rheumatic disease service would take up roughly one third of this budget, or over $183 000.00 Canadian. At last count, the program is offered 10 times per year, in conjunction with other disease specific programs, roughly 200 referrals are made to this program, at a cost of $900.00 per referral.

Not all referred clients attend prescribed ASMPs, often due to reasons outlined in section 1.2.5.2 of Chapter 1. While this type of program provides in-person options, such as one-on-one therapy, not all who attend require treatment. Presently, physical resources and staffing would not allow for additional programs in a calendar year, nor greater numbers of attendees per class. The cost per referral remains relatively static, rising modestly with increasing compensation to professional staff. The VW offers an option that could be more cost effective to the health care system for some who do not require one-on-one teaching or hands on interventions from a physical or occupational therapist.

If an AMSP is taught by lay people, instead of professional staff, the costs of running the program may be lower, but are still more expensive and resource contrained than the VW option. There is still a per attendee cost for rented or leased space to hold the program, even on a per use basis. Presently, per use space to hold a meeting would be least expensive in a community hall in the Edmonton area, costing $500.00 Canadian per evening, plus tax of 5% and deposit. If running a 6 week, once per week course, this is $3650.00 Canadian for rent alone, not including a $50.00 honorarium often paid to each of 2 laypeople per session, cost of liability insurance and increased use of adminstrative staff needed to book appointments and provide printed resources. It is further noted, as discussed in section 1.5.13 of Chapter 1, that such an ASMP it not specific to RA, but all forms of arthritis. This type of program was critiqued by some of the participants interviewed in section 3.6.1 of Chapter 3 as possibly not being specific enough to their issues, strenthening the argument for VWs as feasible for delivering health information.

Literature reviewed in section 1.7.3.11 of chapter 1 indicated that a VW has the potential to foster a sense of community among users, particularly those with a specific condition or health concern (Boulos and Toth-Cohen, 2009). Additional literature reviewed in this same section indicated that the use of VWs, as a medium delivered over the Internet, could be

one means of addressing social isolation, a common issue for those living with chronic disease, though there have been other studies that suggest VWs may increase social isolation. As previously noted, use of the Internet itself was reported at one time to have a causal link to depression (Kraut et al., 1998). However, a later study refuted these findings, indicating that online interactions supplemented and supported real world relationships (Hamman, 1999), (Wellman and Gulia, 1999).

In terms of this particular form of media, VWs themselves have been previously characterized as potentially addictive (Cremorne, 2007) or having deleterious side-effects (Gorini et al., 2008) on socialisation. However, it is noted that often these claims in the literature are often without empirical data. For example, a lengthy paper by Young (2009) discusses the issue of online gaming addiction, including VWs in the paper, and relies primarily on clinical anecdotes, a single case study and a single paper by Yee (2006) to state that VWs are addictive. The bulk of the paper discusses how to recognize signs of gaming addiction and strategies, failing to acknowledge these signs and symptoms may also have differential diagnoses and root causes.

While this study's primary focus was not on social dimensions of isolation or engagement, the results do not conclusively indicate that this was an issue, based on the results of standardized outcome measures as well as qualitative feedback from subjects engaged in the pilot RCT. This may be another area for further exploration in a future, larger scale study. The more current literature indicates that a VW may be a low cost means of modelling healthy behaviours (Otte et al., 2011), provide social support (Norris, 2009) and create the aforementioned sense of community among users with common health issues or interests (Boulos and Toth-Cohen, 2009).

The current cost of hosting the VW program is $100.21 Canadian per month. The present limits of the SL platform allow for 40 avatars to be present in any single parcel of land at a time, so an estimated 40 avatars per hour could theoretically access and complete the program, with 24 hour per day access. Comparitively, if only 40 avatars completed the program, the cost per participant would be less than $3.00 Canadian. While joint protection is only one aspect of a typical ASMP, other display areas could be developed as modules. Even if up to 12 modules were developed, providing 12 or more hours of ASMP information, similar to the number of hours provided in most present 6 week ASMPs, this would still be a per participant cost of $36.00 Canadian, assuming 40 users per month. Overall, the VW offers a lower cost option to some living with RA, and may be an option for those who cannot attend a program due to other commitments or time constraints.

6.3 Findings by measure

6.3.1 Joint protection knowledge questions

The joint protection knowledge questions selected and piloted for the study, as discussed in section 4.6.3 of Chapter 4, when ITT analysis was used, revealed a composite score that was statistically significant between the treatment and control groups, with the treatment group scoring better than the control group ($p < 0.05$). On an item-by-item analysis of the joint protection knowledge questions, the treatment group also scored better than the control group on 4 of 5 of the items with statistical significance. The differences between the treatment and control groups were large enough to result in a high power statistic (99.5%), indicating a very low probability of incorrectly rejecting the null hypothesis.

The primary purpose of the VW program was to deliver information on joint protection specific to management of RA. It would appear, based on the results obtained with this

sample, that there is some preliminary evidence that this may be a reasonably effective medium for delivering this type of information to people living with RA.

Despite these positive findings, there are some limitations to concluding that the results of the joint protection knowledge questions are indicative of the VW program used being effective. Though statistically significant, this is an original study, testing both the medium content and a novel measure. Though the development of the medium content was rigorous, as outlined in Chapter 3, there is the possibility, though remote, that the content was not congruent with what was needed in a joint protection program. This possibility was minimized using a variety of checks, including interviews, member checks, testing the program with participants and checking the content against the seven main principals of joint protection, presented in most ASMPs.

A more significant, and likely, limitation of the findings of this measure was that the joint protection knowledge questions, though developed and piloted with input from both study supervisors and expert OTs, were not a standardized measure, unlike the AIMS2SF and PSEQ. However, though both the AIMS2SF and PSEQ are standardized measures, neither is specific to joint protection knowledge. At this time, there are no standardized measures of joint protection knowledge specific to RA. In addition to the piloting of the VW program, this study should also be considered a pilot of the measurement of joint protection knowledge.

6.3.2 AIMS2SF

The AIMS2SF selected for this study, as discussed in section 3.5.3 and 3.6.3 in Chapter 3, when ITT analysis was used, revealed a composite score indicative of a worse (higher) outcome for the treatment group over the control group. Though not statistically significant,

the overall scores being higher for the treatment group indicated a lower level of overall reported functional ability.

One of the benefits of the AIMS2SF was that it could be analysed further in specific functional domains. This 26 item survey was additionally broken down and scored as per the instrument instructions by Quality of Life Group in Rheumatology (1995) into the following domains: physical, affect, symptom control, social and work. Despite the non-significant and negative findings of the composite score of this measure, the domains, as subtests, revealed that the treatment group scored more favourably on the physical function and work domains, in comparison to the control group, as presented in Table 8 of Chapter 5.

One of the disadvantages of the use of this outcome measure is that though it may measure function and and symptom control, it does not specifically measure joint protection. There is a connection between self-management, exposure to joint protection information and ability to retain joint protection knowledge, as indicated by the pilot RCT findings on joint protection knowledge as a measurement tool. However, this may not necessarily be the case with the AIMS2SF. While not necessarily an incorrect tool to measure joint protection knowledge, it may not be the most effective tool. This tool was selected by therapists and clients who also informed the content of the VW program. It was previously noted that these participants did not report much use of, or exposure to, outcome measures in evaluating existing ASMPs. Use of a more specific tool regarding joint protection only, may have yielded results requiring a much smaller sample size for a full RCT.

The negative overall effect, but small positive effect on some domains, may be attributed to the program selectively impacting functional domains, or could be a spurious finding. The literature presented in section 1.5.13 of Chapter 1 stated that joint protection training may result in lower levels of disability. The literature presented in section 1.7.4 of Chapter

1 also suggested that the use of online social media, such as a VW, could potentially lead to feeling more socially isolated and depressed. The existing literature may explain why a small, but measurable, negative effect was seen in the social and affect domains of this measure.

The sample size was small and the statistical power low (11.5%) in this pilot study. One cannot conclude the results would be the same in a larger scale study. However, determining differences in power obtained in pilot studies on measured used may be useful in determining appropriateness for larger scale studies. A larger sample size using this measure, as presented in section 5.7.5 of Chapter 5, may clarify if this effect is significant and if the direction of this relationship is positive or negative. One of the advantages of the AIMS2SF is that it has been developed to find scores on specific domains that may be differentially influenced by an intervention. It would be unusual for a specific intervention, like a VW program, to uniformly impact all five of the domains, as outlined, positively or negatively simultaneously.

6.3.3 PSEQ

The PSEQ selected for this study, as discussed in sections 3.5.3 and 3.6.3 in chapter 3, when ITT analysis was used, revealed a composite score indicative of higher levels of self-efficacy for the treatment group over the control group. Like the AIMS2SF, this was not statistically significant. Also similar to the AIMS2SF, this was also not significant in breaking down the measure further, in this case, an item-by-item analysis.

The ten items on the PSEQ included the following items: pain control, housework completion, socialisation, coping, work participation, hobby participation, medication dependence, goal achievement, ability to normalise lifestyle and ability to increase activity. Though the overall PSEQ score was favourable (higher) for the treatment group, some areas

were indicative of lower self-efficacy on item-by-item analysis. The areas of socialisation, medication use and normalisation of lifestyle were more favourable for the control group than the treatment group on this measure. Similar to the findings of the use of the AIMS2SF, these differences could be due to the use of the VW itself, as suggested by some of the aforementioned literature. It is further observed that the treatment group had less favourable scores regarding socialisation, but better scores regarding managing work, on both measures.

Despite the overall positive findings using this measure, the sample size required, as per section 5.7.5 of Chapter 5, would need to be extremely large for a full RCT. It is also noted that the PSEQ does not have the same multi-item domains as the AIMS2SF, so breaking down the PSEQ into an item-by-item analysis, results in an analysis of a single data point provided by each participant. The PSEQ also had the lowest ability to predict a statistical difference of the three measures used in this study (power calculation of 7.9%). The PSEQ may not be a favourable measure on a future RCT given the suggested sample size is 1250 participants, which is far larger, and potentially less feasible, sample size in comparison to the other two measures used in this study.

Like the AIMS2SF, ne of the disadvantages of the use of this outcome measure is that though it may measure self-efficacy with function and and symptom control, it does not specifically measure joint protection. While not necessarily an incorrect tool to measure joint protection knowledge, it may not be the most effective tool. This tool was selected by therapists and clients who also informed the content of the VW program. It was previously noted that these participants did not report much use of, or exposure to, outcome measures in evaluating existing ASMPs, identifying a gap in practice. Use of a more specific tool regarding joint protection only, may have yielded results requiring a much smaller sample size for a full RCT.

As the principal investigator of the study is an Occupational Therapist, self-efficacy of the individual is a significant clinical practice concept. Given the practical issues with the PSEQ, requiring a very large sample to ensure an RCT of acceptable power, this may be better measured via other tools in an RCT study. One could suggest the AIMS2SF could be similar to the PSEQ, given the overlap of some of the domains, such as socialisation and work. However, the AIMS2SF, is more a measure of reported functional ability, and not reported confidence in a specific area. Regardless of the potential hindrance of using the PSEQ as a measure for a full RCT, the findings of this pilot RCT indicated a measurable, non-significant overall positive effect on self-efficacy with low power.

Though a statistically significant difference was seen using one measure, and non-significant effects were seen with the other two measures, it may not be practical to a measure a true clinical effect, unless significant alterations are undertaken in future studies. In order to measure a clinical effect with RA, the bulk of the literature discusses measurement of disease activity, presented in section 1.2.2 of Chapter 1. Typically, the determination of clinical effect on RA interventions is mainly focused on efficacy of new medications. These measures of clinical effect would include comparisons of specific blood test results, diagnostics imaging and active versus damaged joint counts via physical examination. From an occupational therapy perspective, this could also include measurement of grip strength, hand function tests, range of motion assessments or a full functional capacity evaluation. While such testing could verify that a clinical change had taken place, it may not be practical, particularly for a full RCT.

There are a few studies, presented in section 1.5 of Chapter 1, pertaining to non-pharmacological interventions for RA self-management, which include measures pertaining to clinical effectiveness as defined here. Such measures could be added to future permutations of a pilot RCT or full RCT. In addition to increasing the need for further

resources to carry out this research, there would also be reduced anonymity, as participants would need to be assessed face-to-face if measuring clinical effects as described. There would, therefore, a need to introduce further blinding for data collection, particularly collection dependent on human rating, such as interpreting functional test scores, or recording values with some degree of variation, such as range of motion values. In this study, there was a single blind where the participants were unaware if they were in the treatment or control group. If direct clinical measures are involved a separate investigator, perhaps carrying out standardised assessments, would have to be blinded as well, in order to set up a double blind experimental condition and reduce the possibility of a Rosenthal effect, as discussed in section 1.9.3.3 of Chapter 1.

If choosing to operationalise a clinical effect as one defined by broader terms, it could be argued that there are indications of a positive clinical effect in this study. Expanding clinical effect to include increased knowledge of chronic disease management, increased or altered forms of reported function and reduced subjective complaints that cannot be easily measured, such as pain, might lead to the conclusion this study demonstrates the VW program had some clinical effect. Overall, this expansion of the definition of clinical effect to include self-reports of function, subjective complaints and increased knowledge of diagnosed condition appears to have been the norm on most studies to date on joint protection and RA self-management, given the literature findings reported in section 1.5.13 of Chapter 1.

6.3.4 Clinical effect by measures

Though a statistically significant difference was seen using one measure, and non-significant effects were seen with the other two measures, it may not be practical to a measure a true clinical effect, unless significant alterations are undertaken in future studies. In order to measure a clinical effect with RA, the bulk of the literature discusses

measurement of disease activity, presented in section 1.2.2 of Chapter 1. Clinical responsiveness of the AIMS2SF is better than most other generic and disease-specific measures including the Sickness Impact Profile, Health Assessment Questionnarie, Functional Status Index and MacMaster Health Index. Clinical response means for changes in AIMS2SF scores over a 3-month range from 0.36 (small) to 0.8 (high) on subscales, according to Carr (2003). This would translate to a minimum of 5 times this range, given the 5 subscales for the AIMS2SF, or 1.8 – 4.0, in order to observe a clinical effect. In terms of clinical effect, and chronic conditions like RA, a meaningful clinical change after a self-management program addressing chronic pain would require a raw score of 11 out of a total of 60 on the PSEQ (Nicholas 2007). Given these are a 6-fold increase in magnitude in mean differences between groups for the PSEQ and up to a 2-fold increase in the magnitude in the mean differences between groups using these validated outcome measures, a clinical effect study may not be practical using these measures, given the sample sizes and power calculations presented in Table 11 of this chapter.

Typically, the determination of clinical effect on RA interventions is mainly focused on efficacy of new medications. These measures of clinical effect would include comparisons of specific blood test results, diagnostics imaging and active versus damaged joint counts via physical examination. From an occupational therapy perspective, this could also include measurement of grip strength, hand function tests, range of motion assessments or a full functional capacity evaluation. While such testing could verify that a clinical change had taken place, it may not be practical, particularly for a full RCT.

There are a few studies, presented in section 1.5 of Chapter 1, pertaining to non-pharmacological interventions for RA self-management, which include measures pertaining to clinical effectiveness as defined here. Such measures could be added to future permutations of a pilot RCT or full RCT. In addition to increasing the need for further

resources to carry out this research, there would also be reduced anonymity, as participants would need to be assessed face-to-face if measuring clinical effects as described. There would, therefore, a need to introduce further blinding for data collection, particularly collection dependent on human rating, such as interpreting functional test scores, or recording values with some degree of variation, such as range of motion values. In this study, there was a single blind where the participants were unaware if they were in the treatment or control group. If direct clinical measures are involved a separate investigator, perhaps carrying out standardised assessments, would have to be blinded as well, in order to set up a double blind experimental condition and reduce the possibility of a Rosenthal effect, as discussed in section 1.9.3.3 of Chapter 1.

If choosing to operationalise a clinical effect as one defined by broader terms, it could be argued that there are indications of a positive clinical effect in this study. Expanding clinical effect to include increased knowledge of chronic disease management, increased or altered forms of reported function and reduced subjective complaints that cannot be easily measured, such as pain, might lead to the conclusion this study demonstrates the VW program had some clinical effect.

Overall, this expansion of the definition of clinical effect to include self-reports of function, subjective complaints and increased knowledge of diagnosed condition appears to have been the norm on most studies to date on joint protection and RA self-management, given the literature findings reported in section 1.5.13 of Chapter 1.

Section Summary: Effect sizes were seen with all three measures. The joint protection knowledge questions were indicative of statistically significant differences between treatment and control groups. There were limitations with each measure used in isolation. The AIMS2SF and PSEQ, selected by participants during the earlier stages of the study, may be suboptimal measures of joint protection knowledge. The lack of clinician and

layperson led use of outcome measures with current ASMPs indicates a gap in present clinical practice. Other measures focusing specifically on joint protection, may be preferable in a full RCT.

6.4. Methodological issues

As a pilot study, the purpose of this research was not only to test the feasibility of a future RCT, but also develop, and improve upon, the methodology used to develop and test a VW program, recruit participants and measure differences between test conditions. What follows is a discussion of methodological issues including response rates to the study invitation, recruitment methods used, and completion versus noncompliance rates. The concluding discussion points of this section include supporting the use of VWs in health education with this population and stating that an RCT is possible to conduct with a VW study, with a few caveats.

6.4.1 Response rate

Response rates to the various means of recruitment outlined in sections 5.1-5.3 of Chapter 5, section are indicative of relatively low response rates to the invitation to the study in all forms used to recruit participants. The lowest response rates were from the web based forms of recruiting. The highest response rates were from the direct referral of potential participants via other healthcare professionals and directly contacting potential participants via Twitter®, yielding the most accurately known response rate (15.5%). The remaining recruitment methods did not yield known response rates, as discussed in Chapter 5, as the number of eligible participants who saw the invitation to the study is not definitively known.

Despite the uncertainty of the sampling frame viewing the invitation to the study in either the paper or electronic form, conservative estimates of 4.8% for the paper invitation and

8.1% for the online invitation have been proposed as plausible response rates to the various means of recruiting, given the exact sampling frame was not known. Overall, the response rates are low in comparison to those in the literature, as outlined in section 1.9.4.1 of Chapter 1. In the referenced studies, response rates were as high as 60%, much higher than what was seen in this study. The electronic invitation method, posting to relevant websites, provided the highest number of potential participants. While most of these websites were selected as the target audience was VW users, such as the SL Daily, or people living with RA, such as The Seated View blog, others were selected for different attributes. Surgery 101 was deemed a useful site as it was health focused and frequently visited by both healthcare professionals and laypeople. As an estimated 1% of the population is living with RA, as presented in section 1.2.5.1 of Chapter 1, it was anticipated that a larger audience would have approximately 1% of the viewers living with RA. In this case, it may have been a proportion of an estimated 200 out of 2000 viewers who would have been eligible for the study.

In comparing the methods for recruitment, what could be considered more active recruitment, such as emailing invitations to known individuals via referral, and using Twitter® and Followerwonk®, as outlined in section 4.3.1 of Chapter 4, was time intensive and not particularly effective. More passive forms of recruitment varied in the ability to obtain potential research participants. The traditional paper invitation method was not particularly effective. This may have been more effective if participants could have been recruited via the rheumatic disease unit staff, or if mailing lists of patients newly diagnosed with RA were made available. Neither of these suggestions were an option as per the administrative and ethics approvals obtained for this study. Conversely, the more passive means of using electronic forms of the poster and the Camtasia® based video clip were

deemed more effective in recruiting participants, despite this yielding the lowest response rate of the three methods used.

Given that the type of medium used in this study is a VW, it is reasonable to conclude that those who responded to the study invitation would be more appropriate to recruit via online means. This conclusion was tested during recruitment using the aforementioned Twitter® and Followerwonk® combination, in determining who might be a potential participant based on their Twitter® account description. Ideally, the user profile would have included example terms such as “arthritis”, “virtual world”, “rheumatoid” or “gamer”. As a Venn diagram, this would be expressed as indicated in Figure 2.

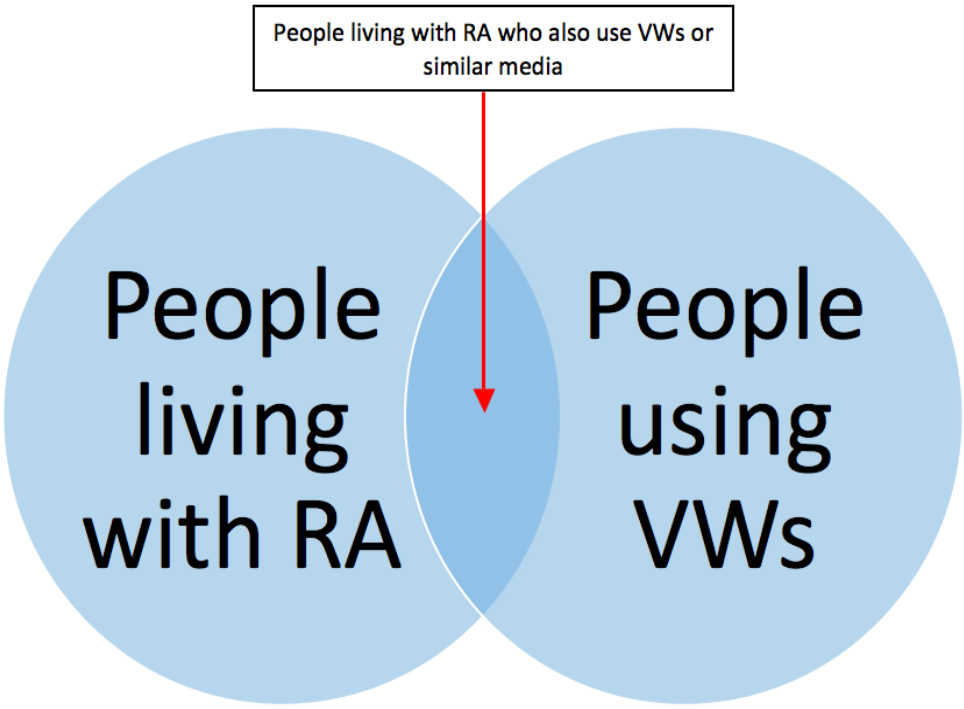


Figure 2 – Proposed population of participants sought out during initial recruitment

Although this may be a very large theoretical pool, only a very small number of participants were found using this recruiting method. There was not a large intersection between those living with RA and those who engaged in VWs, or related media. Additionally, the use of Twitter® may have indicated a willingness to use online resources, but not necessarily the new social web in more immersive ways, such as a VW. Overall, it appears that the most effective means of recruiting numbers of participants to the study would be use electronic bulletin boards, with the knowledge that response rates may be much less certain, but a potentially more receptive audience may be reached, and in higher numbers.

6.4.2 Subject characteristics and contribution to knowledge for future recruitment

Recruitment methods are outlined in the previous section. It was reported in section 4.1 of Chapter 4 that incentives were not used to obtain potential research participants. This was a condition to getting ethics approval for this part of the study. While incentives were not a part of the study for the purposes of recruitment, an "Easter egg" area was created as an in-program bonus offered to participants already enrolled in the study. Though no monetary value was attached to the ability to access the area, it could be seen as an incentive to complete the study. This was not advertised as a potential incentive to participants. It could also be suggested that the opportunity to use a novel program, and the exclusive use of the study area by participants, could have been an incentive as well. This may be a sufficient incentive for someone intrinsically motivated to better manage their RA.

In terms of subject characteristics, not everyone living with RA actively manages his or her RA (WHO, 2014). Some individuals may be aware of their diagnosis, but not do anything to manage their disease, including taking medications as prescribed. Clinical experience with this client population on the part of the principal investigator indicates that others diagnosed with RA might be accepting of the diagnosis, and will take medications, but do little else to manage their symptoms. Others may take a more active role in their chronic

disease management, participate in rehabilitation, education or be proactive in their disease management. These individuals may go on to feel more in control of their RA and realize functional benefits to this active participation in their medical care. This behaviour change may translate into improved health, quality of life and self-efficacy.

As previously introduced in Chapter 1 as being applicable to this study, the components of the MoHO can be used to explain how the overarching priniciples of adult learning and chronic disease can be used to explain the results of this study. The volition to participate in the study, or desire to learn how to better manage RA would be dependent on what opportunities could be afforded in the learning environment, in this case a VW. Participants would have been motivated by not only their potential roles and habits as adult learners, but also had volition to better manage RA to possibly improve their performance of various occupations as they carried out these roles and habits. Performance could be measured by the outcome tools used, particularly the performance of participants on the joint protection knowledge measure. While all four of the main components are significant in the interaction between the participant, the VW and performance, the volitional subsystem of the MoHO is of particular interest as it can be further examined to determine what the personal causation, values or interests a participant may have to motivate them to manage their RA using different means of self-management.

The model in Figure 3 and Table 3 suggests a novel conceptualization of a continuum of disease management, including where the VW program might fit as an intervention method, and includes the expected means of measuring outcomes of various forms of intervention. The expected outcomes, from varying levels of intervention, are also included, assuming that higher levels of intervention and active disease management are associated with more effective self-management of RA. Further study may be needed to include targeting individuals living with RA who may be predisposed, or more likely to, be interested in

managing their chronic disease at a level on the continuum proposed most congruent with the area pertaining to the VW as an intervention.

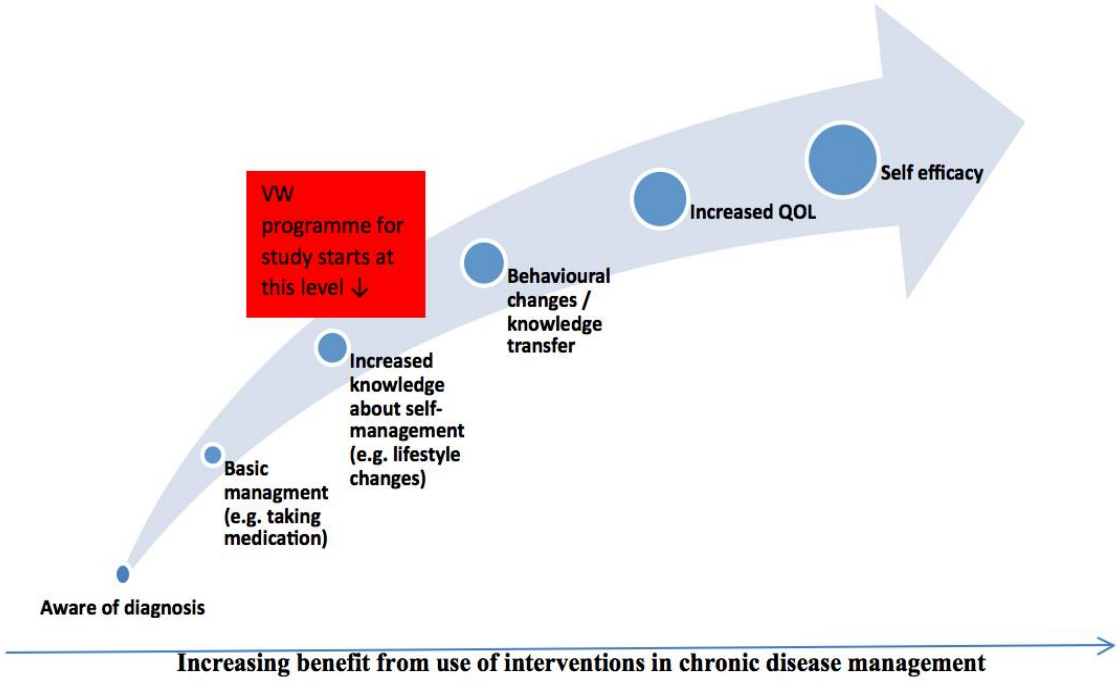


Figure 3 – Proposed continuum model of chronic disease management, such as RA, with increasing positive impact and higher levels of self-management

Level of impact	Possible measure(s)
Awareness of diagnosis	Client able to identify self as having diagnosis
Basic management (e.g. taking medications)	Pill counts, blood tests, journals, reduced disease activity
Increased knowledge about self-management (e.g. lifestyle changes)	Quiz basic knowledge*
Behavioural changes/knowledge transfer	Reduced symptoms, direct observation, indirect observation (video or motion capture)
Increased QOL	AIMS II, Arthritis Readiness Questionnaire*
Self-efficacy	Self-efficacy scale*

Table 3 – Possible measures of outcomes, as per the continuum presented in Figure 3

Though no monetary incentives were approved for use in this study, a small incentive, such as a donation on behalf of the participant to the Arthritis Society, or a small honorarium, may have modestly improved recruitment, as suggested by Lee, Lenert, Weisman, and Kavanaugh (2005). This incentive may have resulted in some initial issues with obtaining

ethics approval, and added costs to the principal investigator. However, if the amount were small enough, and paired with the relatively low risk of participating in the study as outlined in section 4.1 of Chapter 4, it may have still been feasible to obtain ethics approval for this study. This would have extended the time to complete the study by a minimum of an additional six months, likely longer, as the full ethics panel does not sit every month and full panel reviews, defended in person, typically do not occur during summer months.

It was previously noted that the Arthritis Society of Canada did not want to support the study, despite showing the local chapter representative the ethics approvals for the study and cooperation of the local rheumatic disease unit. The request made of the Arthritis Society was similar to that of the rheumatic disease unit, to leave a poster and paper invitations in the reception area of the local office in Edmonton. Failing this approval, a request was also made to be permitted to post a link to the study on their website. Both requests were refused in person and follow up emails were not returned. If other organisations that provide support to people living with RA could be identified and accessed, or if the Arthritis Society of Canada were willing to support studies such as this one, recruitment could potentially reach a much wider audience.

6.4.3 Completion, dropout and non-compliance rates

Ideally, all participants participating in a study, once assigned to a condition, would complete the intervention and measures used. Realistically, a number of participants would not complete the intervention, drop out during the trial or withdraw from a study. It is useful in determining the feasibility of a future RCT to find out why participants may have dropped out of a study or look at noncompliance rates to determine what it might be in repeat studies.

There were a high number of potential participants who dropped out prior to assignment to conditions. This may have been due to the explanation of what the VW program was, the need to download software or the indication regarding the time to complete both the VW program (an hour) as well as the survey (another 10-15 minutes). For some potential participants, this may have been deemed too long. These potential participants may have opted to withdraw prior to consenting to the study, though initially expressing interest in it. A total of 58/108 did not complete the consent form after initially expressing interest, as per section 4.2 in Chapter 4. This attrition occurred prior to randomisation to a condition, and may be indicative of barriers to recruitment. Suggestions for improvement in this area are included in section 6.6 of this chapter. Additionally, the survey for the treatment group could have been potentially completed anywhere from 1-30 days after exposure to the intervention. This is a possible study weakness and suggestions for improvement in this area are also discussed in section 6.6 of this chapter.

Fifty participants were enrolled in the study. The noncompliance rate for the treatment group was 40% (10/25). Some participants provided reasons for not completing the SL based program. This information is included in Table 4. The primary reasons were issues with using the VW itself, such as too much cognitive load, as discussed in section 1.7.5 of Chapter 1, time available to use the program and lack of desirability of the program itself. For example, one dropout contacted the principal investigator via email, stating that the SL website “looked too much like a dating site” and reported that he would not be using the program.

Dropout numbers	Reason for withdrawing	Example statement (if applicable)
3	Time	"Haven't used it yet"
2	Trust	"Don't like downloading software"
2	Difficulty	"I found it hard to use"
8	Unknown/not specified	N/A

Table 4 – Dropout participants and reasons for dropping out

Though a 40% noncompliance rate for the treatment group may appear high, it does meet the 60% completion rate as presented in section 1.9.4.1 of Chapter 1. Furthermore, the 40% noncompliance rate is much lower in comparison to the noncompliance, or novel users who quit rates, of SL users as presently measured. This rate is as high as 90% within the first 30 days of signing up for a SL account (Zdanowski, 2007), (Fulton, 2007), (Urriah, 2011).

Similar to the difficulty in calculating actual numbers of people potentially recruited to this study, many of the present SL user statistics, now mainly coming from third parties and not the VW providers themselves, have accuracy issues. For example, there is no accounting for people with multiple accounts. These multiple account users could be inflating user numbers and retention rates, or lower noncompliance rates. Though this is highly unlikely in this study, it is possible participants could have created multiple accounts and participated in the study more than once.

More up to date statistics on non-compliant participants from SL are not presently available via the owner of SL, Linden Labs, as they started reporting their usage statistics differently once the world size and user base became smaller, though considered to be sustainable, in 2011. Login concurrency appears to be continuing to peak at roughly 50 000 users in a 24-hour period (Korolov, 2014a). However, despite getting 9000-13 000 new signups per day, active members continue to decline, but remain at a maximum of 40 000 to 50 000 daily users (Korolov, 2014b). Overall, a retention rate of 60% is much higher than even the most liberal estimates of SL noncompliance and retention rates, all typically indicative of a

greater than 50% noncompliance rate for new SL users. Future studies would have improved retention rates by offering incentives to participants, and could yield superior data if non-compliant participants could be approached for feedback.

Summary: If several barriers are addressed, a future RCT may be feasible using a VW Caution is recommended in addressing these barriers prior to moving forward with a full RCT. Barriers include addressing the very large sample size required, recruitment efforts and tool refinement, or more appropriate tool selection, noting this is presently also an identifiable gap in clinical practice. If tools more specific to only joint protection were selected, a smaller sample size may be required. Larger study samples may also test the limits of VW platform hosting as well, such as SL limits on concurrent avatar use in a specific region.

Despite some issues with the VW selected, SL appears to be an acceptable medium for delivery of joint protection information. The purpose of the program was to deliver joint protection information and there was a significant difference in the scores achieved, with the treatment group scoring higher than the control group, even with ITT analysis. The completion rate of 60% meets a reasonable completion rate, higher than that of current SL noncompliance rates of up to 90%. Recruitment methods used were varied, with online methods being the more effective means of generating numbers of potential participants. However, the response rate to the study invitation was much less certain using this recruitment method. Further recommendations regarding a future full RCT are included in section 6.6 of this chapter.

6.5 Limitations of the study

The following section discusses limitations of the study and provides suggestions to improve the methodology of pilot RCTs using similar types of participants and VWs to

deliver patient education. Overall the external validity of this study's findings are limited given the small sample of participants, all of whom were people living with RA, recruited from North America. Participants were recruited from primarily anonymous means. Even those directly referred, and then emailed, or contacted via Twitter®, were never met face-to-face. The result was a low recruitment rate.

Findings were also based primarily on self-reported data, which can be difficult to validate. The intervention period and reported time using the program was also quite limited, no more than 5.5 hours maximum, according to what was reported by participants who accessed the VW, and limited to a 30 day period. A one-shot experimental design was used, so long term effects of the VW program on function, self-efficacy and joint protection knowledge are unknown.

In reviewing the types of tools selected and resultant effect size, the statistical power of this study varies considerably. All of the instruments used for measuring outcomes had floor and ceiling effects. Though not documented in the literature, as it is a non-standardized measurment tool, the joint protection knowledge questions would be expected to have a minimum score of 20%, assuming that with even guessing all answers, the average person would get approximately a quarter of the multiple choice questions correct. All of these limitations restrict the generalisability of this study to the larger population. More joint protection knowledge questions could be developed and posed in a future survey, though this might also have resulted in a higher noncompliance rate if the survey was deemed too long by participants.

The variablity of RA as a chronic disease, as discussed in section 1.2.3 of Chapter 1 also limits the generalisability of this study. The relatively small sample was not evenly distributed for all demographics collected. Some variables within this data collected showed large standard deviations and some variables, such as education level, had to have

categories combined to ensure there were enough participants per cell in Chi squared analysis. Both the disease variablity and the small sample size may have limited the effect size seen in the measures, particularly when non-compliant participants comprised 40% of the treatment group.

The focus of this VW program was solely on joint protection to manage RA. Though one of the more effective means of non-pharmacological management of RA, as presented in section 1.5.13 of Chapter 1, it is only one form of RA self-management. The results of this study would only apply to the joint protection portion of an ASMP, and not necessarily other forms of RA self-management.

This study used SL as the platform of choice for several reasons, initially presented in section 1.7.3.3 of Chapter 1. There are a multitude of VWs, some of which may be more appropriate. Alternate VWs may yield different results. The results of this study may not necessarily translate to similar findings using other VW platforms.

6.6 Suggestions to improve methods of pilot RCTs

This study could be considered ambitious in its multiple aims of interviewing and analyses of two groups of expert for opinions regarding expectations of VW content, development and alpha testing of the VW content and then conducting a pilot RCT, even with a topic as specific as joint protection. The additional aims to select appropriate measurement tools, recruit participants for a pilot RCT and determine if there were any measureable effects were considered tasks that would not be as time consuming as they turned out to be in carrying out the study.

The sheer amount of time to learn the skills to build and script in the VW selected, in addition to the time required to carry out the other aims, was challenging to complete within the limits of a PhD study time frame. Unanticipated time demands, such as the 750-

kilometre trip for one participant in the second phase of this study, added a full day of unanticipated travel time. A future pilot RCT would be more efficiently conducted if individuals who do not have access to a computer failing to meet the minimum system requirements are also excluded from the initial phases of the study as well. This would eliminate the possibility of long distance travel being required, though it may reduce the number of potential participants providing recommendations regarding content.

Given the timing limitations, the selected period of one month of exposure to the VW program may not have been sufficient for some to try the program. Additionally, those who used the program did not use the program for very long. As mentioned in section 6.4.3 of this chapter, the time of exposure to the treatment could have been as little as a day, or as much as 30 days. A future study may need to block access to the survey until 30 days of enrolment, or track individual user's exposure time from first VW access until survey completion to address this possible weakness.

While this study's findings may be suggestive of a powerful means of delivering this information, requiring not a considerable amount of time to learn new information, it may also be indicative of limited opportunities to access the VW. An additional issue is that the 30-day period given prior to measurement may have not been sufficient time to effect changes in function, self-efficacy or joint protection knowledge. In order to see behaviour change, Lorig et al. (2004) advocate a program exposure of at least 6 weeks.

Length of exposure to a novel medium, such as a VW, may have to be even longer, lasting 90 days, or perhaps greater to allow for mastery of basic skills in navigating a VW. A potential concern in making the exposure period to the VW longer would be that it may increase the noncompliance rates. However, this could be reduced somewhat if those identifying that 30 days was not enough time to access the VW even once, were provided with more time to start using the program. Further reduction of non-compliant participants

could also be realized by the use of more frequent reminders about the study, allowing the participant to answer parts of the survey in isolation, such as provide their demographic data, prior to commencing with the forced choice measurement tools. The aforementioned use of small incentives for study completion may also offset noncompliance rates, even if length of exposure were increased.

The option to contact potential participants more than once for initial recruitment would likely increase response rates and may have resulted in a greater number of the initial 108 potential participants being retained for study enrolment. The ability to recruit over a longer time frame, up to a year, may have minimised seasonal variation in recruitment, done partially over the year-end holiday season for this study, and further develops the argument that a pilot RCT would be best conducted over a longer time, making a study such as this ambitious to complete with the timeframe for a PhD study.

Data collection for this study occurred via the Internet for the final stage. This lack of face-to-face contact may have resulted in more honest feedback on the use of the VW program. This was also a more convenient way for the participants to access both the VW and survey, both being accessible 24 hours per day. Using a web based approach, it may still be possible to be more vigorous in collecting data about participants' use of the VW displays. For example, a welcome mat and artificial avatar greeter, shown in Figure 4, were placed at the entrance of the main display area. The welcome mat informed the principal investigator that someone had entered the program area, including the avatar name, via email. This information could be used in a future pilot study as a virtual roll call. This would be dependent on all participants being required to register their avatar name prior to accessing the program.

Figure 4 – Highlighted welcome mat and artificial avatar, recording attendances

During this study the artificial avatar greeter also recorded the name of each avatar as it entered the display area as well as the date and time of entry, while providing a note card to the entering avatar. These artificial avatars can be modified so that all chat that occurs in a region is recorded. This recording could lead to more robust data collection about participants' behaviour while using the program.

However, this level of observation could also lead to ethical and privacy issues, particularly if participants were unaware their entire conversations were being recorded. Similarly, one issue validating the reported amount of time participants used the VW program could be addressed by programming each station to record the amount of time an avatar spent at each station. This is possible, but would be quite time consuming to set up, would require the participant to register their avatar name prior to being granted access to the VW study area and may further reduce anonymity as surveys would also need to be matched to a known avatar and email address. While increasing the ability of the investigator to validate participant reports, privacy and anonymity is diminished. In a most extreme form of

validation, the principal investigator could limit access to specific times of day, and be present as an avatar observer, even as an invisible avatar. This scenario would not be ethical, particularly if participants were unaware they were being directly observed when they may have reasonable expectations of privacy.

Given the types of measurements used in this study, it may have been useful to not only pilot the joint protection knowledge questions prior to the pilot RCT, but also the standardized tools, so that the amount of time to score them could be determined as well. Though the testing references for both the AIMS2SF and PSEQ state an overall score for each can be hand calculated in under 10 minutes, this time did not include scoring of individual domains with the AIMS2SF or the item-by-item analysis of the PSEQ. This scoring took considerably longer than 10 minutes per tool, per participant. Specific formulae were applied to the AIMS2SF and there was additional reverse scoring required of half of the 26 items, further adding to the scoring time and analyses. Future use of the AIMS2SF in particular should involve setting up the online survey so that reverse scoring of items and application of the various weighted formulae are via macros in an Excel spreadsheet, or at the time of input by the participant. Overall, this could potentially save several hours of analysis time. Assuming a similar number of participants in a repeat pilot RCT, this could reduce analysis time by 17 hours and would reduce the likelihood of human error from fewer manual calculations being required. As previously noted in section 6.3 of this chapter, these measures may need to be reconsidered and others, more specific to joint protection, could be piloted and used instead of the AIMS2SF and PSEQ.

6.7 Suggestions to improve methods of a future RCT

Methods recommended in the previous section to improve a pilot RCT would apply to conducting a full RCT as well. In addition to the possibilities already suggested regarding incentives, more than one contact with potential participants, longer exposure time to the

treatment condition, more intrusive methods of validating participant reports of VW use and increases automation of scoring measures via piloting even standardized measures, there are further recommendations to improve methods for a future RCT.

Given the sheer number of tasks involved in the pilot study, and the variety of them, both potential repeat studies and a full RCT would be best and most efficiently undertaken by a team of researchers involved in participant recruitment, VW content development and analyses. Even if working full time on the development of the VW content and the initial program testing, the combination of time required for recruitment for the much larger RCT sample, and longer time of VW exposure before measurement, would take one person several years to complete alone. At least one expert in VW content creation, one expert in conducting RCTs and one expert acting as principal investigator would be recommended at a minimum. In order to increase the speed of some stages, additional supports would be required for transcription, data analyses, recruitment and in-world support as needed by some participants.

In order to speed up recruitment, there is the option of hiring a third party, such as Survey Monkey® to market the study to a specific audience. SL also offers the possibility of commercially boosting a listed business or service for a fee, which may increase numbers recruited more rapidly. A more international focus on recruiting participants may also reduce the amount of time required for recruiting participants. The added challenge would be to either make a specific level of proficiency in English a requirement, or to add instructions about, and make available, a universal translator that can be worn by an avatar in SL. Such an item already exists and is commercially available at a nominal cost via the SL marketplace. This may increase the cost of a future RCT slightly. The addition of further instructions and requirements of participants may further increase cognitive load on new VW users. Further efforts may need to be undertaken to gain the endorsement of other

groups if the Canadian Arthritis Society remains unwilling to assist with recruitment in a future RCT. One further consideration is that SL has a typical limit of 40 avatars per land parcel, meaning that other VWs may need to be considered, allowing up to 100 avatars per land parcel, or that several areas may need to be set up simulatanuosly, allowing no more than the maximum number of avatars that the platform can tolerate at a time to access a study area.

Summary: Overall, there were methodological issues, which would inform a future pilot of full RCT, several options are available to address these issues. These issues, if addressed could improve the methods of a repeat study or a full RCT. A full RCT is feasible, though at considerable investment of time and potentially high cost given the numbers of subjects needed to recruit for a full RCT. This would be a labour and resource intensive undertaking that require the identified barriers to a full RCT be addressed prior to commencing a full RCT study. Given the size of the undertaking, would be best carried out by a team and additional administrative supports as suggested.

Chapter 7 Conclusions and Implications for Future Study

7 Conclusions

This chapter outlines some recommendations for further study, after first reviewing the study hypotheses proposed in Chapter 2. Implications of this study's findings and opportunities specific to occupational therapy are discussed, as well as future clinical research pertaining to VWs and related media.

7.1 Study objectives

For the pilot RCT, the primary objectives, restated here, were:

1. A pilot RCT of a VW program to teach people living with RA about joint protection was feasible.
2. One could recruit and randomise participants for a pilot RCT of this program.
3. It would be possible to track the noncompliance rates between intervention and control groups during a pilot RCT of this program.
4. During the pilot RCT, noncompliance rates between the intervention and control groups could be compared.
5. Using tools or instruments selected during earlier stages of the study, there would be evidence of clinical efficacy using this program.
6. From the pilot RCT a power calculation would be possible to estimate sample size for a future full RCT.
7. Cost associated with using the program during the pilot RCT could be measured. This cost could be used to determine cost effectiveness in comparing treatment methods in future study.

All of the objectives were addressed in this study. The pilot RCT was feasible. It was possible to recruit and randomise participants. It was possible to track and compare

noncompliance rates between the two groups. There may be some evidence of effect, which was measureable. Further discussion of effect versus clinical efficacy is discussed in section 7.3.1 of this chapter. This effect size varied based on the measure used. It was possible to calculate a sample size for a future RCT. There were no reported costs by participants to access the program, and it was possible to compare estimated costs between treatment methods, which could be used for further study.

7.2 Improvements in measures

The statistically significant difference between the control and treatment group was using a non-standardized measure that requires further piloting and development. However, the focus of the VW program developed for this study was to teach joint protection information using an andragogy congruent with principles of adult learning presented in section 1.6.1 of Chapter 1. Treatment group performance on the joint protection knowledge questions suggest that the VW may be an effective means of delivering joint protection information to people living with RA.

Both improvements on some subtests of the AIMS2SF, and the overall negative effect in comparing the treatment and control groups were not statistically significant. Some relationships on subsections indicated a positive outcome in favour of the treatment group, while others did not. The use of subtests, examining specific domains of reported function, may be appropriate to show both potential positive and negative effects on areas of function in future studies.

The PSEQ showed an overall non-significant improvement in comparing the treatment and control groups in favour of the treatment group with some concurrent findings with subscales of the AIMS2SF, such as work and social indices on item-by-item analysis. Improvement was smallest in effect size between the control and treatment groups in

comparison to the two other measures used. This finding does fit with the proposed model in section 6.6 of Chapter 6. Self-efficacy is further along the continuum proposed and would be anticipated to be changed the least, if at all, given the limited amount of time participants were enrolled in the study.

7.3 Use of a VW as a health education medium

Literature supporting the use of VWs as a health education medium was presented in section 1.7.3.8 of Chapter 1, though the scientific quality of these studies is often critiqued as being limited. This type of learning environment fits with trends seen in studies of management of RA and eHealth as presented in sections 1.7.3.8 and 1.7.3.9 of Chapter 1 and principles of adult learning.

Furthermore, the use of Internet based resources as health maintenance for those living with chronic disease is more frequent than the general population, as presented in section 1.6.10 of Chapter 1. The primary content of this program was health education, rather than social experiences or skill development. Based on data that was obtained, it would appear that a VW could be acceptable for use as a medium for health education. A specific VW was used in this study, so other VWs may need to be tested, or have very similar attributes to SL, in order to achieve similar results. Other VWs may need to be tested prior to making broader generalisations about the use of a VW as an acceptable health education medium.

7.3.1 Clinical effect

Given this study's parameters and selected measurement tools, measuring clinical effect may not be practical, as presented in section 6.3.4 of chapter 6. As previously noted, if choosing to operationalise a clinical effect as one defined by broader terms, it could be argued that there are indications of a positive clinical effect in this study. Expanding clinical effect to include increased knowledge of chronic disease management, increased or altered

forms of reported function and reduced subjective complaints that cannot be easily measured, such as pain, might lead to the conclusion this study demonstrates the VW program had some clinical effect. Overall, this expansion of the definition of clinical effect to include self-reports of function, subjective complaints and increased knowledge of diagnosed condition appears to have been the norm on most studies to date on joint protection and RA self-management, given the literature findings reported in section 1.5.13 of Chapter 1.

7.3.2 Cost

As per the results presented in section 5.7.4 of Chapter 5, none of the participants in the treatment group indicated that the program cost them anything to use. It is noted that the time to use the program itself could be considered a cost to the user in terms of loss of time for leisure, ability to perform extra paid or unpaid work or other leisure activities. However, no participants indicated that they had lost time from regularly paid work or had to spend additional monies to use the program. This finding is in contrast to both the information presented in Chapter 1, section 1.2.5.2 and the information from the client participants in the first stages of this study, such as presented in section 3.6.1 of Chapter 3. Both the literature reviewed and the participants used for program development indicated that there is often a monetary cost to attending a traditional, in-person ASMP, including additional travel time, parking, time off work, periods of time away from family, and in some cases, paying for accommodation if not living near a major urban centre.

The implications for this study indicate that the VW program may be a cost-effective alternative to traditional ASMP. The results from this sample indicate that that the participants considered the use of the program to be cost neutral. This finding has positive implications for individuals living with RA who may find the hidden costs of attending a traditional ASMP prohibitive. In North America, and in Canada in particular, having a

population density averaging less than 10% of the United States and even larger land mass, this may mean increased opportunities to partake in self-management education, reported by the participants in this study to be cost neutral and available in-home.

Costs of running and maintaining a full VW based ASMP have been estimated to be considerable lower than present options in section 6.2 of Chapter 6. Future cost comparison studies could accurately track not only costs to participants in terms of less tangible costs, such as loss of reported leisure time or social time, but also real comparative costs to the public health care system or non-profit organisations, such as the Arthritis Society. The current hypothesis is that a future study would find that the VW program would have the lowest cost and a dedicated rehabilitation unit, staffed with professionals, would be the most expensive. Volunteer based ASMPs offered through the Arthritis Society would fall somewhere between the other two options for overall costs to both consumers and the health care system. While all three types of self-management programs have their individual strengths and weaknesses, cost per user, based on what information is available and can be estimated, where needed, is the lowest with the VW option.

7.3.3 User acceptance

While feedback collected about the program content and aim was mainly positive, there were a number of criticisms about the VW platform itself as per Table 2 in Chapter 6. Overall, several participants during the pilot RCT reported that the SL platform was difficult to use or navigate.

The critiques of SL being difficult to use are not new and indicate that the user interface may be too complex for some people. The concerns about cognitive load potentially reducing user acceptance has also been discussed in section 1.7.5 of Chapter 1 and summarised for this study in section 6.4 of Chapter 6. The recommendations to increase user acceptance from the referenced literature remains valid. VW developers need to

consider creating less complex and more interactive user interfaces to increase acceptance of VWs.

There were no reports by participants of incidents of griefing, a form of virtual vandalism, or trolling, a form of virtual harassment. Both of these behaviours of some VW users are ongoing issues with the social web and can take on unique forms when using avatars in a VW. These behaviours can include, are not limited to, pushing, use of weapons or other forms of visual and auditory assault not possible in flat web environments. Given the pre-emptive security measures taken by the principal investigator, as presented in section 3.4.1 of Chapter 3 by selecting a private area in a VW, there were a number of steps taken to ensure that participants were not at risk of encountering others who may attempt to grief or troll them while accessing the VW study area. Such experiences may have significantly impacted user acceptance of VWs as a medium.

Of the two potential issues that may have negatively impacted user acceptance of this novel medium, the safety of participants was under control of the principal investigator and did not result in any reported issues of negative experiences with other avatars in the VW. While generally accepted, the VW posed some issues with cognitive load and this issue, not under the control of the principal investigator, remains in the hands of VW developers.

7.4 Methodological conclusions

The use of occupational therapists with expertise in rheumatology and people living with RA with previous ASMP experiences was effective in informing the development of a VW program to teach people living with RA about joint protection. The occupational therapist participants were considerably more adept at providing recommendations for program content.

The VW program to deliver joint protection content was initially constructed as a proof of concept, prior to testing with the therapist and client participants. The creation of this content demonstrated that it was possible for a clinician with entry level programming skills to independently construct content as recommended by participants. This content was testable and modifiable, as further recommended by participants, demonstrating further feasibility of the content being adaptable to other experimental conditions.

During the pilot RCT, electronic bulletin board postings were far more effective at generating potential participants though the response rate, as estimated, was much lower than the other methods used for recruitment. Use of incentives to complete the study may have held up initial ethics approval, but may have aided in both recruitment and reduction of non-compliant participants.

The issues of accessibility and acceptability could be limiting the overall audience for studies using this medium. As VWs continue to increase in mainstream use, such as primary school classes, acceptability may increase with the general population. Accessibility may remain an issue with some users, such as those most socioeconomically disadvantaged. No participants reported issues with access secondary to physical consequences of living with RA, such as markedly altered hand function. Navigation of the VW and displays were created by an occupational therapist with the intent of minimal keyboarding being required. No reporting of physical access issues could also be indicative of more mainstream use of adapting human computer interfaces, an overall improvement in RA medications or a selection bias, where those who had the most difficulty using a computer did not participate in the study, or even were among those who dropped out prior to randomisation. Overall, functional abilities of the participants should be a consideration in other studies so that it does not negatively impact user acceptability. With the proliferation of both increased VW

use and increased variation of readily available human/computer interfaces, such as adapted mice, these potential acceptability issues should decrease in the future.

7.5 Future research recommendations

Previous recommendations have been suggested for general studies of this type, and future RCTs using a VW. These have included using a team approach, using the services of a VW developer and increased time for recruitment and exposure to the treatment condition. Though security around the study area was deemed sufficient, as there were no issues with griefing or trolling, future research on a private SL island could be of benefit, depending on the scope of the study and the sensitivity of the information being shared in the study.

7.5.1 Use of a VW for teaching chronic disease management

The methods used in this study could transfer to the development of VW programs for other aspects of RA self-management and management of other chronic diseases. For example, the content in this study, focusing on joint protection for RA, the materials developed would also be mostly applicable to a person living with myositis, a much rarer, but also potentially debilitating rheumatic disease.

Such development would require similar steps of initial development and testing of content specific to the topic and condition. It may be theoretically possible to develop a module specific to RA and exercise with animations and virtually presented recommendations. Other modules could include a program addressing energy conservation, sleep hygiene, relaxation, and in-depth simulations focusing on taking care of hands and feet, two areas most commonly impacted by RA.

Development of enough of these modules could evolve into a series equivalent, or greater in content, to present ASMPs. Future development of a social component could also address the potential issue of isolation some may report while using this medium, and could be a

potential strength, as there is a level of anonymity and privacy that would not be possible with traditional in-person classes.

Future development of chronic disease management specific to VW research would need to further explore the social benefits of a VW, in addition to the possibility of increased anonymity, such as the ability for those living with rare diseases to meet others. People living with these conditions are less likely to be able to share their experiences in the real world, or may be limited to flat web chatrooms or forums. The social aspects of using the VW was not part of this study, as presented in section 3.6.1 of Chapter 3, given feedback during the development of the VW content. It was also deemed a potentially confounding variable within the design of a pilot RCT.

Social interactions, if part of a future study, may alter the experimental design required considerably, as complex behavioural interventions that include these types of interactions may not be conducive to RCTs (Boulos and Miramba, 2008). However, the initial development of VW resources for rarer chronic diseases, such as myositis, could follow the methodology undertaken with this study, developing at least some evidence-based and peer reviewed core content. Development of qualitative studies could be undertaken in order to determine perceived benefits of VW use, and could be measured from a different research perspective, as outlined in section 1.9.2 of Chapter 1.

7.5.2 Recruitment

In order to recruit the highest number of participants, recommendations have been provided in section 6.6 of Chapter 6. This study may also have had better recruitment at a different time in history, such as during the peak of the Gartner Hype Cycle, presented as Figure 2 in Chapter 1, section 1.7.3.3. There would have been a higher number of active users, new accounts and there were previously nearly 100 SL users who previously had active accounts

who identified themselves as living with RA, but now appear to be mainly inactive accounts.

This study may additionally have to be considered a methodology developed prior to the creation of the next generation of VW users who are living with RA. Presently, lower resolution, and less immersive VWs than SL, such as Minecraft®, are now being used as an educational medium in primary and secondary school classrooms (Short, 2012). The next generations of people who are yet to be diagnosed with RA are now being raised with VWs as a teaching medium, but have not yet reached the age where they develop RA, given the age of onset of 20-60 years, presented in section 1.2.5 of Chapter 1. Recruitment in future studies may be easier if the overlap between the populations of those living with RA who already use VWs, or have been previously exposed to VWs, increases.

7.5.3 Clinical research

In addition to recommendations for future research with VWs, additional clinical research is required regarding the long term benefits, if any, on several of the existing non-pharmacological interventions for management of RA, including the additional benefits of combining such interventions with medication use. These non-pharmacological interventions are numerous and discussed in sections 1.5-1.5.13 of Chapter 1, indicating that quality evidence in favour of using most of these interventions is limited. Though joint protection techniques are one of the few approaches with some evidence of efficacy, literature remains limited, particularly at the level of a pilot or full RCT.

The cause of RA remains unknown. Further clinical and epidemiological studies are required to not only better determine correlation with risk factors for development of RA, but also geographic representation of RA, in order to better deploy resources. Early detection and diagnosis have been deemed valuable in preventing disability and disease progress. As a highly variable disease, or group of diseases, epidemiological RA studies

could optimize treatment options available based on how RA more commonly manifests itself in certain parts of a country.

The primary focus of most RA studies using RCTs is medication efficacy and safety. The same RCT methods could be applied not only to VW based research, but all forms of non-pharmacological means of managing RA to improve the evidence base for using, or not using, these modalities. A second means of improving the evidence base of RA interventions would be to pool epidemiological studies, or conduct large scale epidemiological studies to examine how RA presents itself across the global population, such as variations in disease severity, presence of sub-types of RA, as well as incidence and prevalence rates. By obtaining this information, epidemiology could drive future research by indicating what the most needed variables may be for future RCTs.

7.5.4 Future study design

This pilot RCT was a two group post-test only randomized experimental design which does eliminate several, but not all, threats to internal validity, such as most social threats, like imitation of treatment effects or demoralization. It does eliminate all internal validity single group threats by being a two-group design. It does eliminate several two-group threats to internal validity, such as maturation, testing and selection. It may also be argued, that as an Internet based study, not all social threats to internal validity apply, as participants were very unlikely to interact face-to-face. However, any design has some weaknesses and a one shot design's primary weakness is the inability to control for selection-mortality threats (Trochim, 2006). This was an issues with the differential noncompliance rates between the control and treatment group. This was addressed by using ITT analysis.

Another study design issue with this pilot RCT is the small sample size. A full RCT with a sample size of strong power has been proposed as a feasible option in section 6.1 of Chapter 6.

Other study designs to determine the effects, if any, of the VW program in isolation could include a switching replications design where the VW is withdrawn and clinical effects are measured after withdrawal and re-introduction of the VW access or a full RCT where all participants enter the treatment arm of the study and are measured a second time after program exposure. Given the variability of the sample from this study, if a smaller scale study is needed, a matched sample non-random quasi-experimental design may be required to ensure that groups are equivalent in terms of age, sex ratio, years living with RA and other factors accounted for as per section 5.6 of Chapter 5.

In addition to the variation of experimental design using the VW alone in comparison to various forms of control and treatment group comparison studies, comparison against other treatment studies are also recommended. This would result in a number of intriguing possibilities for further study, including, but not limited to, comparison of VWs and traditional ASMP to deliver patient education, comparison of different VWs to deliver patient education, comparison of different components of patient education for the same condition, in this case RA, and comparison of similar VW content for different conditions, such as joint protection for RA versus osteoarthritis. As with the variation of experimental design for other RCTs, pilot studies would be recommended in order to avoid potential abandonment of larger scale studies.

7.5.5 Future VW programs

Issues with user acceptance have been presented in section 7.3.3 of this chapter. Future study may include using a different VW that may be more user friendly. At this time, Linden Labs is in the process of creating a new VW platform that will co-exist with SL, but may replace it entirely. This new platform is called Sansar® and is, thus far, claimed to be an easier to use VW than SL. It is scheduled for release in late 2016 (Linden Labs, 2015). Handheld devices, such as smart phones, and wearable technology are also driving some of

the development of VWs away from computers and this may be an additional factor in future study design. This move towards devices such as smart phones may positively influence recruitment of future studies if VWs are readily accessible to people from an object carried frequently carried with them.

While other conditions have been alluded to previously as possible developments in VW program studies, this is only one aspect of future VW development. VW content could be developed with specific cultural inclusivity as a focus. For example, some First Nations peoples in Canada live with inflammatory arthritis subtypes that are higher in comparison to the general population (El-Gabalawy, et al., 2009), but access to treatment remains an issue. A further issue is that traditional ASMP presently does not necessarily include culturally relevant information for First Nations populations, for example, the use of traditional medicines in conjunction with manufactured medications, or the incorporation of daily living activities that may be more culturally relevant, such as participating in traditional hand games, fishing practices or dances. The flexibility of a VW, with the ability to create customised content and manipulate the environment, may offer a culturally relevant, and more readily accessible means of accessing this information.

As the types and numbers of VWs proliferate, there may be VWs created with specific user groups in mind. Though the feasibility of an RA world is unlikely in the near future, some VWs may be developed solely for consumers of health and disability information. This concept has been developed as an Island in SL, Virtual Ability, and less successfully as the now defunct Health Info Island Kiosks. As a novel medium, future uses of VW programs will have to justify the value added in using them, beyond their novelty, to ensure users continue to access them. Future VW development would be advised to attend to factors such as flexibility of use and level of immersive experiences. The ability to have

experiences that would be difficult, expensive, or even dangerous to experience otherwise should also be a value added point, while also addressing current issues of acceptance.

7.5.6 Future use for RA management education

The future potential for specific VW content for other aspects of self-management of RA has been presented in section 7.3. It may be possible to develop specific content that goes beyond what is taught in current ASMP, tailoring specific exercise programs, medication decision making and adherence simulations, mental health resources and even more client specific programs on core concepts, such as joint protection and energy conservation. These could be picked out by a therapist from a series of developed activity modules, assessed as specific to the recipient, and dropped into place in a virtual region.

The previous recommendation of comparison studies also presented in section 7.3 was not to eliminate current methods of delivering ASMP, but to determine comparative effectiveness, and ideally, provide an equivalent evidence-based option for obtaining health education. In the future, this could allow people living with RA the option of attending a synchronous, in-person ASMP as currently used, or several other options for program delivery. Though this study was an asynchronous use of a VW, a synchronous, virtual option is plausible, with class participants attending virtually at designated times. Presently being explored at the University of Alberta Hospital in Edmonton, some attendees to the RA education program are opting to use Telehealth links to avoid travelling long distances. Participants attend by travelling to their local health unit. A blended option of attending a class occurring in real life while attending in avatar from any place, as needed, may also be a future use of offering more flexible ASMPs where a VW could be an adjunct medium. Other future programs may include a combination of synchronous and asynchronous use of VWs. Learners could complete the various modules on their own, but would have designated times to discuss topics, or interact with an expert layperson or clinician in-world.

Each of these scenarios, in the interest of evidence-based practice, should be developed and piloted prior to implementation. This would ensure that the technology is developed to serve the user, versus the health system. A critique of the current exploratory of the use of Telehealth, as it is currently being explored in Edmonton, is that the focus has been on the feasibility of use to the presenting therapist finding the technology acceptable, versus how effective the medium is at delivering the patient education content. Further study would be more evidence based if focusing on the recipient's acceptance of virtual media, in addition to determining clinical efficacy.

7.6 Implications for occupational therapists

The current status of technology use in Canadian Occupational Therapy is limited, despite its utility and increasing popularity among commercial system users for home entertainment. In 2005, Reid stated that most virtual technology was underutilized in Canada in the training of new occupational therapists and also was not commonly used in the clinical setting. Over a decade later, this situation is still the norm, though some studies have been published using video games, such as the Wii, with very small samples and no control group. Immersive and responsive environments, which are safe for client use, such as VWs should be of significant interest to occupational therapists given theoretical models of practice, such as the Canadian Model of Occupational Performance and Enablement (CMOP-E) (Polatajko et al., 2007), the Model of Human Occupations (MoHO) (Kielhofner, 2008) and the Kawa Model (Iwama, 2006). All of these theoretical models include consideration of how the environment influences client function or dysfunction.

At this time, a VW based alternative to a full ASMP program is not available. This study developed one aspect of a full ASMP, the joint protection content. Virtual means of accessing health education is becoming more available, indicating that it may be time to look at development of a full ASMP alternative using virtual means, including VWs.

Though there are a variety of electronic means of delivering rheumatic disease specific patient information now available, such as via www.edmontonrheumatology.com, or via consumer/patient blogs, such as via www.rheumatoidarthritiswarrior.com and CD ROMs for managing ankylosing spondylitis (Trofimuk et al., 2004), there are issues with available resources.

Issues with what is presently available using these media include limited interactivity, especially in real time, and limited flexibility in content. The content of a CD ROM or DVD is relatively inflexible and cannot be changed, even if expense is relatively low, it must be repurchased in the event of updated information. Additionally, both of these media forms are now considered by many consumers as archaic, although clinicians may still distribute them.

The VW medium may hold several advantages over what media is presently available. Although blogs are resources that can be updated and changed, there still may be some issues, especially with content. In the case of the patient mediated blogs, there may be a lack of clinical accuracy of content. With the rheumatologist run website, content may be accurate, but there are virtually no ways of interacting with a clinician, or other patients. Level of immersion is also one major advantage that a VW would have over currently used methods in terms of interactivity compared to blogs.

Additionally, though only the DVD or CD ROM has a cost directly associated with it, the intent with a VW was to create a resource that would be openly accessible to anyone with Internet access without additional cost to the user. In the future, creating a full ASMP in a VW program in conjunction with expert clinicians and clients could meet the needs of clients seeking strategies for self-management in a more time and cost effective way. This study has developed the joint protection content of a full ASMP. Additionally, as there is an element of serious or educational gaming involved in this study. Some studies indicate

this has been shown to have some long-term effectiveness with retention of information (Roberts, 1993), (Shute et al., 2009), (Mislevy et al., 2003), (Young et al., 2012). Potential advantages of a VW, over other web-based methods include:

1. An ability to be more easily updated than some web based methods presently being used.

2. VWs offers interaction that is not possible with some web based methods.

3. VWs, like other web-based methods can be accessed by anyone with Internet access and does not require distribution of materials, such as CDs or paper resources.

The present state of use of technology in Canada has three main implications for occupational therapy practice. The first implication is the growing area of virtual occupations. Educators of future occupational therapists need to be cognizant that in addition to the basic curriculum covering traditional activity analyses and discussions around hygiene, transfers and return to work, that accessing virtual occupations is increasing as a daily living activity. The theoretical bases of occupational therapy need to consider the virtual environment as a legitimate environment within the CMOP-E and the MoHO in application to practice. Likewise, the Kawa Model in application could also examine the interaction that exists between the virtual and real world environments, as well as how trading time between the virtual and real environments can affect groups of people and how VW use may be a potential asset or liability. Such theoretical considerations may afford occupational science as a discipline to develop a branch of study solely in virtual occupations.

In addition to opportunities for further study and development of curricula, there is also a second implication for practicing clinicians. Clinicians could expand the use of therapeutic media and their repertoire of client-centred goals. Clients may expect to be able to resume

accessing a VW as a therapeutic goal, or to start accessing them as a new meaningful occupation. Practical application of knowledge regarding adapted equipment to access computers, modifying seating and customized set up of VW viewers are some examples of skills that could be used more often in practice, if VW use is an occupation identified as meaningful by clients, or a future therapeutic modality used in clinical practice.

Given the present state of VWs, there is a third implication for occupational therapy practice. In addition to needing to re-consider, and adapt what may be considered basic knowledge for entry to practice competencies, occupational therapists may also be in a position to work as VW developers. Occupational therapists are frequently content experts in health education they deliver to clients, are adept at analysing activities and consider the environment in relation to the client. These attributes make them ideal consultants in this capacity. This consult role could be of considerable value to future users of VWs in the interest of inclusivity. If the VW is easier to use and more inclusive of people living with disabilities, this could also have positive commercial outcomes for proprietors of VWs, reducing rates of abandonment and increasing longer term paid subscribers.

Both the growth of virtual occupations, including VWs, and the proliferation of ebased forms of health education, will afford students, educators and practicing therapists opportunities for professional development, application of existing skills to new media and further research, both theoretical and applied. As of late 2015, there have been no other published studies on rheumatoid arthritis and occupational therapy using RCT study design in a VW. At this time, there is one occupational therapy based study examining knowledge translation of evidence-based practices and social benefits in using SL with amputees (Winkler et al., 2015). All other studies involving occupational therapy have been focused on students. As most virtually based studies, including those using gaming systems, have

involved small samples, and no control group, future research opportunities in this area are numerous, and could contribute significantly to the evidence base of occupational therapy.

7.7 Benefits of use of a VW

A VW may offer free, no cost access to patient education materials and may potentially be effective as an educational tool, even clinically effective, depending on how this definition is operationalised as discussed in section 7.3.1 of this chapter. In terms of health behaviour and long-term benefits, the Proteus Effect, as discussed in section 1.7.3.2 of Chapter 1 could be a benefit with other form of health promotion yet to be explored.

Additional potential benefits to clients using VWs, from an occupational therapy or science perspective, includes clients living with a specific conditions supporting one another in a more immersive environment than a chat room, including opportunities for socialisation and new virtual experiences, even ones not possible in the real world, such as flying, or as one participant in this study reported, feeling that they were walking without pain. These activities could be considered diversional activities for pain control, substitute activities for ones no longer possible, posing just right challenges for skill development and even graded use of activity to regain functional skills.

7.8 Future of the profession

As per section 7.6 of this chapter, as the VW medium grows as part of an emerging group of virtual occupations, activities that people participate in, typically online, to fulfil any number of roles and needs, therapists will need to be familiar with basic skills required to navigate VWs in order to help clients continue to access them, or learn to access them. Therapists will also need to appreciate the value some clients may place on the ability to access VW as a goal of therapy.

VWs may also offer alternate means of delivering health education, as indicated by the results of this study. Occupational therapists, in the interests of concepts such as occupational justice, emphasizing the right to experiences, and appreciating the importance of the social environment on client health, should be aware of barriers to accessing VWs, and could be instrumental in design of VWs to reduce these inequities.

Conversely, despite the positive outlook for increased opportunities for clients, clinicians and researchers, there are additional issues that may come with the use of increased proliferation of VWs, including professional liability and issues surrounding ownership of virtual property. Both of these issues will create some professional ambiguity in the profession that will need to be addressed by legislation and regulatory bodies.

As self-regulated professionals, including the province of Alberta, and governed by the Health Professions Act, occupational therapists are responsible for all professional activities, including those that occur virtually, even in another jurisdiction. The only case law concerning this issue to date involves a music therapist conducting a telephone based intervention from one province to another. However, this was a Supreme Court ruling, stating the therapist needed to hold a licence in both provinces and is used to guide the rulings of the Alberta College of Occupational Therapists. Though not presently being extended to VWs, but including both phone consultations and Telehealth, this could eventually be extended to VWs. This could lead to a need to carry multiple licenses, particularly in Canada and the United States, where jurisdiction over health practices are typically governed by provincial, territorial or state laws, not federally. International collaborations could have similar challenges, noting that at this time, SL is an illegal program in some countries.

Virtual property issues could also pose a challenge to the profession, both in research and clinical practice. Unlike written work, there is no specific delineation between what may

be considered as original work, modified work or an original work with some elements essentially quoted from elsewhere. For example, if a reusable learning object is created by one therapist, then copied with a few minor changes for use by another therapist, it may be questionable if the intent of the second therapist was to plagiarize the work, or simply improve on the design. The modifications may be limited, but may completely change the usefulness of the object. However, if a colour change was all that occurred, it may be considered intellectual theft. This is part of the need to develop the VW standards as presented in section 1.7.3.1 of Chapter 1. This modification of existing work is much better defined with written works or real world commercial products. Virtual plagiarism may be much more difficult to prove, depending on how the original creator of a reusable learning object protected themselves, such as creating no copy, no modification objects, the equivalent of creating a copyrighted and protected page on the flat web. These are objects that are scripted as locked by the creator, prohibiting others from altering or copying, then reselling them. Again, this highlights the need for therapists to be familiar with some basic skills pertaining to VWs as a potential necessity. Further complicating this issue is the possibility of others reverse-engineering a virtual product. If recreated with a few, or even no modifications, there are few resources available to protect the original creator.

In both the professional liability and intellectual property ownership issues presented, the law and regulatory bodies have not kept up with the technology. Occupational therapists will need to be aware of these potential issues in the future as self-regulated health professionals.

7.9 Outlook

The overall outlook for VWs is favourable. The pending re-release of the home based VR viewer, Oculus rift®, proliferation of MMPORGs, growth of social media and serious social games, and current use of Minecraft® in mainstream elementary and junior high

education are all favourable signs of increased VW presence. There is a strong indication that new social media, including VWs, are a growing medium. People living with RA in another 10 years may be expecting the ability to use this medium as an instrumental daily living activity, an activity that is typically performed to fulfil various roles that goes beyond providing basic needs to maintain health, including how they access health information, as suggested in section 7.6 of this chapter.

Despite some favourable trends, some view the outlook of VWs as unfavourable. The hype cycle as discussed in section 1.7.3.3 of Chapter 1, may indicate the impending end of VWs, especially long existing VWs, such as SL. However, SL has existed for 12 years with a stable economy and user base that has remained relatively static (Korolov, 2014b). SL may not exist years from now, but several others do, as indicated in Figure 1 of section 1.7.3.3 of Chapter 1, which may prove to be suitable, pending a similar study.

As an extremely flexible media form, VWs have been explored for a variety of properties, in both educational and business settings. Whether VWs continue to develop in serious applications that may improve users' quality of life, or simply be used as social gaming platforms, will depend on early adopters' experiences in these VWs, and their ability, or lack thereof, to be able to use them effectively.

People living with RA do require earlier intervention and increased options than what is available presently for ASMP. VWs may offer an option that serves a portion of the population, who cannot typically attend a traditional ASMP, which they can access on their own schedule, an important feature in examining principles of adult learning, not presently offered via existing ASMPs.

Without developing a greater number of treatment options, clients living with RA are presently limited in their ability to access ASMPs. Without the ability to access this information, there is the increased risk of disability and reduced function that can come

with untreated or undertreated RA. Long-term implications could include increased costs to both individuals and the healthcare system. Presently 47% of the provincial budget in Alberta is for running the healthcare system. The remaining 53% is for running all other government services. Providing earlier access to low cost interventions could be one means of curtailing future health care costs while potentially improving health to a measureable portion of the population.

If the present state of RA management continues, the healthcare system may find itself progressively less capable of providing even the existing level of service to what may be deemed small groups of patient populations. At this time, the dedicated rehabilitation service via the Rheumatic Disease Unit at the University of Alberta Hospital is the only service of its kind, serving a population of 6 million people. Over the past 2 years, it has been operating with reduced staffing, has been subjected to staffing layoffs and been operating as an unfunded program. This service may be completely eliminated in the future. Increasing options, including virtual options, may decrease the burden on what resources remain available to clients living with RA via this local specialised rheumatic disease service as well as the healthcare system as a whole. Failing to explore alternate avenues to deliver patient education with this population may result in further reductions to existing services, fewer options for people living with RA and downstream increased costs to society as a whole.

7.10 Final study conclusions and contribution to knowledge

In completing the aims and objectives of this study, this research has contributed to the development of an evidence-based online resource that demonstrates preliminary evidence of the ability to effectively teach people living with RA about joint protection principles. This study has also developed a methodology for conducting pilot RCTs in virtual worlds as a further contribution to knowledge. A third contribution includes identification of gaps

in clinical practice, such as a lack of client input into the content of ASMPs specific to RA and a lack of use of outcome measures.

Final conclusions regarding this study include that the reusable learning objects created in the program used can benefit others living with RA and that future patients may now have more options for non-pharmacological interventions for RA management. The methodology developed for conducting pilot RCTs can be replicated, with fewer errors as outlined in this dissertation, and improved upon in future studies. Current gaps in clinical practice identified may also be of interest to adminstrators and health care improvement consultants as an area of practice to address.

Bibliography (works consulted but not cited)

1. Brace N Kemp R and Snelgar R. SPSS for Psychologists, 5th edition, Rutledge, 2012.
2. Phillips E and Pugh D. How to Get a PhD: A Handbook for Students and Their Supervisors, 3rd edition, McGraw-Hill, Berkshire, 2005.
3. QRS International. nVivo for Mac Tutorials, accessed from: www.qsr international.com/support_tutorials.aspx?productid=28, 2009
4. Rudestam K and Newton R. Surviving Your Dissertation: A Comprehensive Guide to Content and Process, 3rd edition, Sage, 2007.
5. TechSmith. Camtasia Studio Tutorials, accessed from: www.techsmith.com/ tutorial.html?gclid=CPqlgfyS4scCFUdhfgodLa0NcQ, 2010.

References

1. Adams J, Burridge J, Mullee M, Hammond A and Cooper C (2008). The clinical effectiveness of static resting splints in early rheumatoid arthritis: a randomized controlled trial. Rheumatology, 47(10), 1548-1553.

2. Alcorn K, Broome K (2014). Occupational performance coaching for chronic conditions: A review of literature. New Zealand Journal of Occupational Therapy, 61(2), 49-56.

3. Aldrich C (2009). Learning Online with Games, Simulations, and Virtual Worlds: Strategies for Online Instruction. San Francisco: Jossey-Bass.

4. Altman DG, Schulz KF and Moher D (2004). Turning a blind eye: testing the success of blinding and the CONSORT statement. British Medical Journal, 328(7448), 1135.

5. Altman DG, Schulz KF, Moher D, Egger M, Davidoff F, Elbourne D and Lang T (2001). The revised CONSORT statement for reporting randomized trials: explanation and elaboration. Annals of Internal Medicine, 34(8), 663-694.

6. American College of Rheumatology (2015). The Role of the Occupational Therapist in the Management of Rheumatic Disease. Retrieved from: http://www.rheumatology. org/I-Am-A/Patient-Caregiver/Health-Care-Team/Occupational-Therapist on March 18, 2015.

7. American College of Rheumatology, Aletaha D, Neogi T, Silman AJ, Funovits J, Felson DT, Bingham CO III, Birnbaum NS, Burmester GR, Bykerk VP, Cohen MD, Combe B, Costenbader KH, Dougados M, Emery P, Ferraccioli G, Hazes JMW, Hobbs K, Huizinga TWJ, Kavanaugh A, Kay J, Kvien TK, Laing T, Mease P, Ménard HA, Moreland LW, Naden RL, Pincus T, Smolen JS, Stanislawska-Biernat E, Symmons D, Tak PP, Upchurch

KS, Vencovsky´ J, Wolfe F and Hawker G (2010). 2010 Rheumatoid Arthritis Classification Criteria. Arthritis and Rheumatism, 62(9), 2569-2581.

8. Anderson T, Annand D and Wark N (2005). The search for learning community in learner paced distance education: Or, 'Having your cake and eating it, too!' Australasian Journal of Educational Technology, 21(2).

9. Anderson PL, Price M, Edwards SM, Obasaju MA, Schmertz SK, Zimand E and Calamaras MR (2013). Virtual reality exposure therapy for social anxiety disorder: A randomized controlled trial. Journal of Consulting and Clinical Psychology, 81(5), 751.

10. Annang L, Muilenburg JL and Strasser SM (2010). Virtual worlds: Taking health promotion to new levels. American Journal of Health Promotion, 24(5), 344-346.

11. Argote L, McEvily B and Reagans R (2003). Managing knowledge in organizations: An integrative framework and review of emerging themes. Management Science, 49(4), 571-582.

12. Baheux K, Yoshizawa M and Yoshida Y (2007). Simulating hemispatial neglect with virtual reality. Journal of NeuroEngineering and Rehabilitation, 4, 27.

13. Baillet A, Zeboulon N, Gossec L, Combescure C, Bodin LA, Juvin R, Dougados M and Gaudin P (2010), Efficacy of cardiorespiratory aerobic exercise in rheumatoid arthritis: Meta-analysis of randomized controlled trials. Arthritis Care Research, 62, 984–992.

14. Banakou D and Chorianopoulos K (2010). The effects of avatars' gender and appearance on social behaviour in online 3D virtual worlds. Journal of Virtual Worlds Research, 2(5).

15. Bateman J, Allen ME, Kidd J, Parsons N and Davies D (2012). Virtual patients design and its effect on clinical reasoning and student experience: a protocol for a randomised factorial multi-centre study. Bio Med Central Medical Education, 12(1), 62.

16. Beals L and Bers MU (2010). Evaluating participation in an international bilingual virtual world educational intervention for youth. Journal of Virtual Worlds Research, 2(5).

17. Begg M, Ellaway R, Dewhurst D and Macleod H (2006). Virtual patients: considerations of narrative and game play. In: Digital Game Based Learning, Proc. of the 4th International Symposium for Information Design, Stuttgart Media University (pp. 101-113).

18. Bell MW (2008). Toward a Definition of "Virtual Worlds". Journal of Virtual Worlds Research, 1 (1).

19. Bellotti F, Berta R, Gloria AD and Primavera L (2009). Enhancing the educational value of video games. Computers in Entertainment, 7(2), 23.

20. Beltman MW, Voshaar RCO and Speckens AE (2010). Cognitive–behavioural therapy for depression in people with a somatic disease: meta-analysis of randomised controlled trials. The British Journal of Psychiatry, 197(1), 11-19.

21. Bensink ME, Armfield NR, Pinkerton R, Irving H, Hallahan AR, Theodoros DG and Wootton R (2008). Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study. Palliative Medicine, 23(3), 228.

22. Berthelot RB, Duval T, Royan J and Arnaldi B (2011). Improving reusability of assets for virtual worlds while preserving 3d formats features. Journal of Virtual Worlds Research, 4(3).

23. Bilberg A, Ahlmén M and Mannerkorpi K (2005). Moderately intensive exercise in a temperate pool for patients with rheumatoid arthritis: a randomized controlled study. Rheumatology, 44(4), 502-508.

24. Bittarello MB (2008). Another time, another space: Virtual worlds, myths and imagination. Journal of Virtual Worlds Research, 1(1).

25. Boellstorff T (2010). A typology of ethnographic scales for virtual worlds. In Online Worlds: Convergence of the Real and the Virtual. London: Springer, 123-133.

26. Bohle S (2010). The Neil A. Armstrong Library and Archives: That's One Small Step for a Virtual World Library, One Giant Leap for Education! Journal of Virtual Worlds Research, 3(1).

27. Boulos MNK (2008). Principles and techniques of interactive Web cartography and Internet GIS. Manual of Geographic Information Systems. Bethesda, Maryland: ASPRS–American Society for Photogrammetry and Remote Sensing, 935-74.

28. Boulos, MNK and Maramba I (2009). Pitfalls in 3-D Virtual Worlds Health Project Evaluations: The Trap of Drug-trial-style Media Comparative Studies. Journal of Virtual Worlds Research, 2(2). Retrieved from http://dx.doi.org/10.4101/jvwr.v2i2.669 on December 10, 2010.

29. Boulos MNK, Ramloll R, Jones R and Toth-Cohen S (2008). Web 3D for public, environmental and occupational health: early examples from Second Life®. International Journal of Environmental Research and Public Health, 5(4), 290-317.

30. Boulos MNK and Robinson LR (2009). Web GIS in practice VII: stereoscopic 3-D solutions for online maps and virtual globes. International Journal of Health Geographics, 8, 59.

31. Boulos MNK and Toth-Cohen S. (2009). The University of Plymouth Sexual Health SIM experience in Second Life: evaluation and reflections after 1 year. Health Information and Libraries Journal, 26(4), 279-288.

32. Boutron I, Moher D, Altman DG, Schulz KF and Ravaud P (2008). Methods and processes of the CONSORT Group: example of an extension for trials assessing nonpharmacologic treatments. Annals of Internal Medicine, 148(4), 60-66.

33. Braun V and Clarke V (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77-101.

34. Bretaudière T, Cruz-Lara S and Rojas Barahona L (2011). Associating automatic natural language processing to serious games and virtual worlds. Journal of Virtual Worlds Research, 4(3).

35. Briet J P, Bot AG, Hageman MG, Menendez ME, Mudgal CS and Ring DC (2014). The pain self-efficacy questionnaire: validation of an abbreviated two-item questionnaire. Psychosomatics, 55(6), 578-585.

36. Brorsson S, Hilliges M, Sollerman C and Nilsdotter A (2009). A six-week hand exercise program improves strength and hand function in patients with rheumatoid arthritis. Journal of Rehabilitation Medicine, 41(5), 338-342.

37. Brosseau L, Welch V, Wells G, Tugwell P, De Bie R, Gam A and Morin M (2000). Low level laser therapy for osteoarthritis and rheumatoid arthritis: a meta-analysis. The Journal of Rheumatology, 27(8), 1961-1969.

38. Brosseau L, Welch V, Wells GA, de Bie R, Gam A, Harman K and Tugwell P (2010). Low level laser therapy for rheumatoid arthritis. The Cochrane Library.

39. Brosseau L, Rahman P, Poitras S, Toupin-April K, Paterson G, Smith C and Mc Ewan J (2014). A systematic critical appraisal of non-pharmacological management of rheumatoid arthritis with Appraisal of Guidelines for Research and Evaluation II. Public Library of Science: Retrieved from: http://www.ncbi.nlm.nih.gov/pmc/articles /PMC4026323/ on April 23, 2015.

40. Bykerk VP, Baron M, Boire G, Haraoui B, Khraishi M, LeClercq S and Keystone EC (2004). Canadian consensus statement on early optimal therapy in early rheumatoid arthritis. Journal of the Canadian Rheumatology Association, 14, 11-3.

41. Cairns AP and McVeigh JG (2009). A systematic review of the effects of dynamic exercise in rheumatoid arthritis. Rheumatology International, 30(2), 147-158.

42. Campbell M (2009). Using 3D-virtual worlds to teach decision-making. Same places, different spaces. Proceedings, Auckland 2009. Retrieved from: www.ascilite. org.au on September 15, 2013.

43. Campbell MK, Elbourne DR and Altman DG (2004). CONSORT statement: extension to cluster randomised trials. British Medical Journal, 328(7441), 702-708.

44. Canadian Broadcasting Corporation (2009). Strangers in Paradise: A Documentary about Second Life Couples (video). The Fifth Estate. Retrieved from: http://www.cbc.ca/fifth/2008-2009/strangers_in_paradise/video.html , January 12, 2010.

45. Carolina A, Alves A, de Paula Vieira R, Leal ECP Jr., dos Santos SA , Ligeiro AP, Albertini R, Silva JA Jr. and de Carvalho PTC (2013). Effect of low-level laser therapy on the expression of inflammatory mediators and on neutrophils and macrophages in acute joint inflammation. Arthritis Research & Therapy, 15, 1-11.

46. Centre for Advancement in Health (1996). Washington D.C. (Decommissioned as of 2014, confirmed via: http://www.cfah.org/ on March 18, 2015).

47. Cherniack EP (2011). Not just fun and games: applications of virtual reality in the identification and rehabilitation of cognitive disorders of the elderly. Disability and Rehabilitation: Assistive Technology, 6(4), 283-289.

48. Chodos D, Stroulia E and Naeimi P (2009). An integrated framework for simulation-based training on video and in a virtual world. Journal of Virtual Worlds Research, 2(1).

49. Clarke J, Dede C, Ketelhut DJ, Nelson B and Bowman C (2006). A design-based research strategy to promote scalability for educational innovations. Educational Technology. New Jersey: Saddlebrook 46(3), 27.

50. College of Family Physicians of Canada (2007). Vision Statement on Inter-professional Care. Retrieved from: http://www.cfpc.ca/uploadedFiles/Resources/ Resource_Items/CFPC-CNA20Vision20ENG.pdf on December 10, 2010.

51. Combe B (2007). Early rheumatoid arthritis: strategies for prevention and management. Best Practice & Research Clinical Rheumatology, 21(1), 27-42.

52. Cook DA and Triola MM (2009), Virtual patients: a critical literature review and proposed next steps. Medical Education, 43, 303–31.

53. Cook JV, Dickinson HO and Eccles MP (2009). Response rates in postal surveys of healthcare professionals between 1996 and 2005: an observational study. Bio Medical Central Health Services Research, 9(1), 160.

54. Cooney JK, Law RJ, Matschke V, Lemmey AB, Moore JP, Ahmad Y and Thom JM (2011). Benefits of exercise in rheumatoid arthritis. Journal of Aging Research, 2011.

55. Coulson KA, Reed G, Gilliam BE, Kremer JM and Pepmueller PH (2009). Factors influencing fracture risk, T score, and management of osteoporosis in patients with rheumatoid arthritis in the Consortium of Rheumatology Researchers of North America (CORRONA) registry. Journal of Clinical Rheumatology, 15(4), 155-160.

56. Coupland D (1995). Microserfs. Toronto: HarperCollins Publishers Ltd.

57. Cremorne, L. (2007). Addiction – SL as the Double-Edged Sword. The Metaverse Journal. Retrieved from http://www.metaversejournal.com/2007/01/10/addiction sl-as-the-double-edged-sword/ on January 22, 2009.

58. Creswell JW (2013). Qualitative Inquiry and Research Design: Choosing Among Five Approaches. London: Sage Publications Inc.

59. Creutzfeldt J, Hedman L, Medin C, Heinrichs WL and Felländer-Tsai L (2010). Exploring virtual worlds for scenario-based repeated team training of cardiopulmonary resuscitation in medical students. Journal of Medical Internet Research, 12(3).

60. Cyphert D, Wurtz MS and Duclos LK (2013). Curricular Implications of Virtual World Technology: A Review of Business Applications. Business Communication Quarterly, 73, 434-438.

61. Czart M (2014). Using 3D Virtual Standardized Patients to Teach Motivational Interviewing. Journal of Virtual Worlds Research, 7(2).

62. Dalgarno B and Lee MJ (2010). What are the learning affordances of 3-D virtual environments? British Journal of Educational Technology, 41(1), 10-32.

63. Danforth DR, Procter M, Chen R, Johnson M and Heller R (2009). Development of virtual patient simulations for medical education. Journal of Virtual Worlds Research, 2(2).

64. Das, D. A., Grimmer, K. A., Sparnon, A. L., McRae, S. E., & Thomas B. H. (2005). The efficacy of playing a virtual reality game in modulating pain for children with acute burn injuries: A randomized controlled trial. BioMed Central Pediatrics, 5(1):1.

65. Dean E, Cook S, Keating M and Murphy J (2009). Does this avatar make me look fat? Obesity and interviewing in Second Life. Journal of Virtual Worlds Research, 2(2).

66. de Boer IG, Peeters AJ, Ronday HK, Mertens BJA, Huizinga TWJ, and Vlieland TV (2009). Assistive devices: usage in patients with rheumatoid arthritis. Clinical Rheumatology, 28(2), 119-128.

67. de Freitas S, Rebolledo-Mendez G, Liarokapis F, Magoulas G and Poulovassilis A (2010). Learning as immersive experiences: Using the four-dimensional framework for designing and evaluating immersive learning experiences in a virtual world. British Journal of Educational Technology, 41(1), 69-85.

68. de Freitas S and Veletsianos G (2010). Editorial: Crossing boundaries: Learning and teaching in virtual worlds. British Journal of Educational Technology, 41(1), 3-9.

69. de Jong T, Heinrich J, Blatter BM, Anema JR and van der Beek AJ (2009). The feasibility of a web-based counselling program for occupational physicians and employees on sick leave due to back or neck pain. Bio Medical Central Medical Informatics and Decision Making, 9(1), 46.

70. Dede C, Ketelhut D and Ruess K (2003). Designing for motivation and usability in a museum-based multi-user virtual environment. (Available via Chris_Dede @harvard.edu).

71. Dieterle E and Clarke J (2007). Multi-user virtual environments for teaching and learning. In M. Pagani (Ed.), Encyclopedia of Multimedia Technology and Networking (2nd edition). Hershy, PA: Idea Group Inc.

72. Dugow H, Connolly D and Yuen, HK (2012). Exploring impact of independent living programme on activity participation of elderly people with chronic conditions. International Journal of Therapy & Rehabilitation, 19(3), 154-162.

73. Educase (2010). Online Horizon Report. Retrieved from: http://www.educause .edu/library/resources/2010-horizon-report on March 18, 2011.

74. El-Gabalawy HS, Robinson DB, Hart D, Elias B, Markland J, Peschken CA and Oen K (2009). Immunogenetic risks of anti-cyclical citrullinated peptide antibodies in a North American Native population with rheumatoid arthritis and their first-degree relatives. Journal of Rheumatology, 36(6), 1130-1135.

75. Emery P (2002). Evidence supporting the benefit of early intervention in rheumatoid arthritis. The Journal of Rheumatology, 66, 3-8.

76. Eversden L, Maggs F, Nightingale P and Jobanputra, P. (2007). A pragmatic randomised controlled trial of hydrotherapy and land exercises on overall well-being and quality of life in rheumatoid arthritis. Biomedical Central Musculoskeletal Disorders, 8(1), 23.

77. Falloon, G. (2010). Using avatars and virtual environments in learning: What do they have to offer? British Journal of Educational Technology, 41(1), 108-122.

78. Fidishun D (2000). Andragogy and Technology: Integrating Adult Learning Theory as we Teach with Technology: 5th Annual Instructional Technology Conference: Extending the Frontiers of Teaching and Learning, Middle Tennessee State University, Proceedings, retrieved from http://frank.mtsu.edu/~itconf/proceed00/fidishun.htm on January 19, 2012.

79. Fietta P, Fietta P and Delsante G (2009). Central nervous system effects of natural and synthetic glucocorticoids. Psychiatry and clinical neurosciences, 63(5), 613-622.

80. Fisher LD, Dixon DO, Herson J, Frankowski RK, Hearron MS and Peace KE (1990). Intention to treat in clinical trials. In: Peace KE, editor. Statistical issues in drug research and development. New York: Marcel Dekker, 331–50.

81. Frambach JM, Driessen EW, Chan LC and van der Vleuten CP (2012). Rethinking the globalisation of problem-based learning: how culture challenges self-directed learning. Medical Education, 46(8), 738-747.

82. Fries JF and Krishnan E (2004). Equipoise, design bias, and randomized controlled trials: the elusive ethics of new drug development. Arthritis Research and Therapy, 6(3), 250-255.

83. Fulton III S (2007). How many users does Second Life really have? Retrieved from: http://betanews.com/2007/05/07/how-many-users-does-second-life-really-have on April 30, 2015.

84. Gabriel SE, Crowson CS and O'Fallon M (1999). The epidemiology of rheumatoid arthritis in Rochester, Minnesota, 1955-1985. Arthritis & Rheumatism, 42(3), 415-420.

85. Garvin DA (1993). Manufacturing strategic planning. California Management Review, 35(4), 85.

86. Gaasterland CM, Jansen-van der Weide MC and van der Lee JH (2015). Development of a method to involve patients in the determination and appraisal of outcomes in clinical trials. Trials, 16(Suppl 1), p15.

87. Gelissen JH, Preda M, Cruz-Lara S and Sivan Y (2011). Special Issue on MPEG-V and Other Virtual Worlds Standards. The Journal of Virtual Worlds Research, 4(3).

88. Gelissen JH and Sivan YY (2011). The Metaverse 1 Case: Historical Review of Making One Virtual Worlds Standard (MPEG-V). Journal of Virtual Worlds Research, 4(3).

89. Gerardi M, Cukor J, Difede J, Rizzo A and Rothbaum, BO (2010). Virtual reality exposure therapy for post-traumatic stress disorder and other anxiety disorders. Current Psychiatry Reports, 12(4), 298-305.

90. Gibson W (1984). Neuromancer. New York: Ace Publishers.

91. Gignac MA, Cao X, Mcalpine J and Badley EM (2011). Measures of disability: Arthritis Impact Measurement Scales 2 (AIMS2), Arthritis Impact Measurement Scales 2-Short Form (AIMS2-SF), The Organization for Economic Cooperation and Development (OECD) Long-Term Disability (LTD) Questionnaire, EQ-5D, World Health Organization Disability Assessment Schedule II (WHODASII), Late-Life Function and Disability Instrument (LLFDI), and Late-Life Function and Disability Instrument-Abbreviated Version (LLFDI-Abbreviated). Arthritis Care and Research, 63(11), 308-324.

92. González VG (2009). Towards a virtual doctor-patient relationship: Understanding virtual patients. Journal of Virtual Worlds Research, 2(2).

93. Goodman SM (2013). Rheumatoid arthritis: preoperative evaluation for total hip and total knee replacement surgery. Journal of Clinical Rheumatology, 19(4), 187-192.

94. Gorini A, Gaggioli A, Vigna C and Riva G (2008). A second life for eHealth: prospects for the use of 3-D virtual worlds in clinical psychology. Journal of Medical Internet Research, 10(3).

95. Grantham J (2010). Didn't you say that: digital discourse, digital natives and gameplay. Journal of Virtual Worlds Research, 3 (1).

96. Gustafson DH and Wyatt JC (2004). Evaluation of ehealth systems and services: We need to move beyond hits and testimonials. British Medical Journal, 328(7449), 1150.

97. Haavardsholm, EA, Kvien TK, Uhlig T, Smedstad L M and Guillemin, F (2000). A comparison of agreement and sensitivity to change between AIMS2 and a short form of AIMS2 (AIMS2-SF) in more than 1,000 rheumatoid arthritis patients. The Journal of Rheumatology, 27(12), 2810-2816.

98. Hamman RB (1999). Computer networks linking network communities: Effects of AOL use upon pre-existing communities. Retrieved from http://www.socio. demon.co.uk/cybersociety/ on September 14, 2009.

99. Hammond A (2004). Rehabilitation in rheumatoid arthritis: a critical review. Musculoskeletal Care, 2, 135-151.

100. Hammond A, Bryan J and Hardy A (2008). Effects of a modular behavioural arthritis education program: a pragmatic parallel-group randomized controlled trial. Rheumatology, 47(11), 1712-1718.

101. Hammond A and Freeman K (2001). One-year outcomes of a randomized controlled trial of an educational–behavioural joint protection program for people with rheumatoid arthritis. Rheumatology, 40(9), 1044-1051.

102. Hammond A, Young A and Kidao R (2004). A randomised controlled trial of occupational therapy for people with early rheumatoid arthritis. Annals of the Rheumatic Diseases, 63, 23–30.

103. Hansen D, Shneiderman B and Smith MA (2010). Analyzing Social Media Networks with NodeXL: Insights from a Connected World. Morgan Kaufmann. Retrieved from: http://nodexl.codeplex.com/ on May 15, 2011.

104. Haque SN and Swicegood J (2015). Lessons from recruiting Second Life users with chronic medical conditions: Applications for health communications. Journal of Virtual Worlds Research, 8(1), 1-16.

105. Heiphetz A and Woodill G (2010). Training and Collaboration with Virtual Worlds: How to Create Cost-Saving, Efficient and Engaging Programs. Toronto: McGraw-Hill.

106. Hew KF and Cheung WS (2010). Use of three-dimensional (3-D) immersive virtual worlds in K-12 and higher education settings: A review of the research. British Journal of Educational Technology, 41(1), 33-55.

107. Hewlett S, Ambler N, Almeida C, Cliss A, Hammond A, Kitchen K and Pollock J (2011). Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. Annals of the Rheumatic Diseases, 70(6), 1060-1067.

108. Hoffman HG (2004). Virtual-reality therapy. Scientific American-American Edition, 291, 58-65.

109. Hoffman HG, Richards TL, Coda B, Bills AR, Blough D, Richards AL and Sharar SR (2004). Modulation of thermal pain-related brain activity with virtual reality: evidence from fMRI. Neuroreport, 15(8), 1245-1248.

110. Hoffman HG, Seibel EJ, Richards TL, Furness TA, Patterson DR and Sharar SR. (2006). Virtual reality helmet display quality influences the magnitude of virtual reality analgesia. The Journal of Pain, 7(11), 843-850.

111. Holbrook A, Thabane L, Keshavjee K, Dolovich L, Bernstein B, Chan D and COMPETE II Investigators (2009). Individualized electronic decision support and reminders to improve diabetes care in the community: COMPETE II randomized trial. Canadian Medical Association Journal, 181(1-2), 37-44.

112. Holmberg K and Huvila I (2008). Learning together apart: Distance education in a virtual world. First Monday, 13(10).

113. Internet World Stats: Usage and Population Statistics (2013). Miniwatts Marketing Group. Retrieved from http://www.internetworldstats.com/stats.htm on January 30, 2013.

114. Iwama MK (2006). The Kawa Model: Culturally Relevant Occupational Therapy. Toronto: Elsevier Health Sciences.

115. Jacklin PB, Roberts JA, Wallace P, Haines A, Harrison R, Barber JA and Wainwright P (2003). Virtual outreach: economic evaluation of joint teleconsultations for patients referred by their general practitioner for a specialist opinion. British Medical Journal, 327(7406), 84.

116. Jenson CE and Forsyth DM (2012). Virtual reality simulation: using three-dimensional technology to teach nursing students. Computers Informatics Nursing, 30(6), 312-318.

117. Johnson CM, Vorderstrasse AA and Shaw R (2009). Virtual worlds in health care higher education. Journal of Virtual Worlds Research, 2(2).

118. Joinson A (1999). Social desirability, anonymity, and Internet-based questionnaires. Behavior Research Methods, Instruments, & Computers, 31(3), 433-438.

119. Jones R (2009). The role of health kiosks in 2009: literature and informant review. International Journal of Environmental Research and Public Health, 6(6), 1818-1855.

120. Jones R, McConville J, Mason D, Macpherson L, Naven L and McEwen, J. (1999). Attitudes towards, and utility of, an integrated medical-dental patient-held record in primary care. British Journal of General Practice, 49(442), 368-373.

121. Kamberi, S. (2012). A Cross-Case Analysis of Possible Facial Emotion Extraction Methods that Could Be Used in Second Life-Pre Experimental Work. Journal of Virtual Worlds Research, 5(3).

122. Kaplan AM and Haenlein M (2009). The fairyland of Second Life: Virtual social worlds and how to use them. Business Horizons, 52(6), 563-572.

123. Kashani R, Burwash S and Hamilton A (2010). To be or not to be on Facebook: That is the question. Occupational Therapy Now, 12(6), 19-22.

124. Kashani, R., Roberts, A., Jones, R., & Kamel Boulos, M. (2009). Virtual Worlds, Collective Responses and Responsibilities in Health. Journal of Virtual Worlds Research, 2(2).

125. Keshner EA (2004). Virtual reality and physical rehabilitation: a new toy or a new research and rehabilitation tool? Journal of NeuroEngineering and Rehabilitation, 1(1), 1-2.

126. Keshner EA, Streepey J, Dhaher Y and Hain T (2007). Pairing virtual reality with dynamic posturography serves to differentiate between patients experiencing visual vertigo. Journal of Neuroengineering and Rehabilitation, 4(1), 24.

127. Ketelhut D (2007). The impact of student self-efficacy on scientific inquiry skills: An exploratory investigation in River City, a multi-user virtual environment. Journal of Science Education and Technology, 16 (3), 99-111.

128. Ketelhut D, Dede C, Clarke J, Nelson B, Bowman C (2010) Studying situated learning in a multi-user virtual environment. Retrieved from: ketelhdi@gse. harvard.edu on March 12, 2012.

129. Ketelhut DJ, Nelson B, Dede C and Clarke J (2006). Inquiry learning in multi-user virtual environments. National Association for Research in Science Teaching, San Francisco.

130. Kielhofner G (Ed.) (2008). A model of human occupation: theory and application (4th edition). Philadelphia. Lippincott, Williams & Wilkins.

131. King KP (2003). Learning the new technologies: Strategies for success. New Directions for Adult and Continuing Education, 2003(98), 49-58.

132. Kirriemuir J (2010). UK university and college technical support for Second Life developers and users. Educational Research, 52(2), 215-227.

133. Kiryu T and So RHY (2007). Sensation of presence and cybersickness in applications of virtual reality for advanced rehabilitation. Journal of NeuroEngineering and Rehabilitation, 4(34), 1-5.

134. Kizony R, Raz L, Katz N, Weingarden H and Weiss PLT (2005). Video-capture virtual reality system for patients with paraplegic spinal cord injury. Journal of Rehabilitation Research and Development, 42(5), 595.

135. Knowles MS, Holton EF and Swanson RA (2005). The Adult Learner: The definitive class in adult education and human resource development (6th edition). Huston: Gulf Publishing Company.

136. Knowles MS (1980). The Modern Practice of Adult Education: From pedagogy to andragogy. Englewood Cliffs: Prentice Hall/Cambridge.

137. Kolotkin RA, Williams MM, Lloyd C and Hallford EW (2012). Does Loving an Avatar Threaten Real Life Marriage? Journal of Virtual Worlds Research, 5(3).

138. Korolov M (2014a). 18 OpenSim grids doing a better job at retention than Second Life. Retrieved from: http://www.hypergridbusiness.com/2014/07/18-opensim-grids-doing-a-better-job-at-retention-than-second-life/ on August 1, 2015.

139. Korolov M (2014b). CasperVend releases Second Life Business Statistics. Retrieved from: http://www.hypergridbusiness.com/2014/07/caspervend-releases-second-life-business-stats/ on August 1, 2015.

140. Koster R. (2000). A Declaration of the Rights of Avatars. Retrieved from: http://www.raphkoster.com/gaming/playerrights.shtml on January 19, 2009.

141. Koster R (2005). A Theory of Fun for Game Design. Retrieved from: http://www.theoryoffun.com/ on January 19, 2009.

142. Kraut R, Patterson M, Lundmark V, Kiesler S, Mukophadhyay T and Scherlis, W (1998). Internet paradox: A social technology that reduces social involvement and psychological well-being? American Psychologist, 53(9), 1017.

143. Krebs P, Burkhalter J, Lewis S, Hendrickson T, Chiu O, Fearn P and Ostroff J (2009). Development of a Virtual Reality Coping Skills Game to Prevent Post-Hospitalization Smoking Relapse in Tobacco Dependent Cancer Patients. Journal of Virtual Worlds Research, 2(2).

144. Krueger A, Ludwig A and Ludwig D (2009). Universal design: Including everyone in virtual world design. Journal of Virtual Worlds Research, 2(3), 4-9.

145. Krueger A and Stineman MG (2011). Assistive technology interoperability between virtual and real worlds. Journal of Virtual Worlds Research, 4(3).

146. Lamontagne A, Fung J, McFadyen BJ and Faubert J (2007). Modulation of walking speed by changing optic flow in persons with stroke. Journal of Neuroengineering and Rehabilitation, 4(1), 22.

147. Landers RN and Callan RC (2012). Training evaluation in virtual worlds: Development of a model. Journal of Virtual Worlds Research, 5(3).

148. LaRose R, Eastin MS and Gregg J. (2001). Reformulating the Internet paradox: Social cognitive explanations of Internet use and depression. Journal of Online Behaviour, 1(2).

149. Law M, Stewart D, Pollock N, Lette L, Bosch J and Westmorland M (1998). Guidelines for Critical Review Form – Quantitative Studies. Hamilton: McMaster University.

150. Lee DH, Im S and Taylor CR (2008). Voluntary self-disclosure of information on the Internet: A multi-method study of the motivations and consequences of disclosing information on blogs. Psychology & Marketing, 25(7), 692-710.

151. Lee SJ, Lenert L, Weisman S and Kavanaugh A (2005). Factors affecting rheumatoid arthritis patients' decisions to participate in clinical trials. The Journal of Rheumatology, 32(12), 2317-2325.

152. Lee MS, Pittler MH and Ernst E (2007). Tai chi for rheumatoid arthritis: systematic review. Rheumatology, 46(11), 1648-1651.

153. Lee MS, Shin BC and Ernst E (2008). Acupuncture for rheumatoid arthritis: a systematic review. Rheumatology, 47(12), 1747-1753.

154. Lerner MA, Ayalew M, Peine WJ and Sundaram CP (2010). Does Training on a Virtual Reality Robotic Simulator Improve Performance on the da Vinci® Surgical System? Journal of Endourology, 24(3), 467-472.

155. Lewin S, Glenton C and Oxman AD (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: methodological study. British Medical Journal, 339, 732-34.

156. Li LC, Adam P, Townsend AF, Stacey D, Lacaille D, Cox S, McGowan J, Tugwell P, Sinclair G, Ho K and Backman L (2009). Improving healthcare consumer effectiveness: An animated self-serve, web-based research tool (ANSWER) for people with early rheumatoid arthritis. BioMed Central Informatics and Decision Making, 9(40).

157. Li LC, Adam PM, Backman CL, Lineker S, Jones CA, Lacaille D, Townsend AF, Yacyshyn E, Yousefi C, Tugwell P, Leese J and Stacey D. (2014). Proof-of-concept study of a Web-based methotrexate decision aid for patients with rheumatoid arthritis. Arthritis Care Research, 66(10), 1472-81.

158. Lieb S (1991). Principles of Adult Learning. VISION journal [electronic version]. Fall. Retrieved on April 14 2010 from Honolulu Community College intranet from http://honolulu.hawaii.edu/intranet/committees/FacDevCom/guidebk/teachtip/adults2.htm

159. Linden Labs (2015) Minimum System Requirements. Last retrieved from: https://secondlife.com/support/system-requirements/ on September 1, 2015.

160. Linden Labs (2015b) Linden Labs invites first group of creators to new Sansar platform.

161. Retrieved from: http://www.hypergridbusiness.com/2015/08/linden-labs-invites-first-group-of-creators-to-new-sansar-platform/ on August 18, 2015.

162. Lindhardsen J, Ahlehoff O, Gislason GH, Madsen OR, Olesen JB, Svendsen JH and Hansen PR (2012). Risk of atrial fibrillation and stroke in rheumatoid arthritis: Danish nationwide cohort study. British Medical Journal, 344, e1257.

163. Loeppenthin K, Esbensen BA, Ostergaard M, Jennum P, Thomsen T and Midtgaard J (2014). Physical activity maintenance in patients with rheumatoid arthritis: a qualitative study. Clinical Rehabilitation, 28(3), 289-299.

164. Lorig K (1993). Self-management of chronic illness: a model for the future. Generations, 17(3), 11-14.

165. Lorig K and Fries JF (2000). The Arthritis Helpbook: a tested self-management program for coping with arthritis and fibromyalgia (5th edition). Stanford:Da Capo Press.

166. Lorig KR, Ritter PL, Laurent DD and Fries JF (2004). Long-term randomized controlled trials of tailored-print and small-group arthritis self-management interventions. Medical Care, 42(4), 346-354.

167. Manning VL, Hurley MV, Scott DL, Coker B, Choy E and Bearne LM (2014). Education, self-management, and upper extremity exercise training in people with rheumatoid arthritis: a randomized controlled trial. Arthritis Care & Research, 66(2), 217-227.

168. Marsick VJ and Watkins KE (2001). Informal and incidental learning. New Directions for Adult and Continuing Education, 2001(89), 25-34.

169. McCallum J, Ness V and Price T (2011). Exploring nursing students' decision-making skills whilst in a Second Life clinical simulation laboratory. Nurse Education Today, 31(7), 699-704.

170. McGarry E, Jones R, Cowan B and White J (1998). A multimedia system for personalised treatment of anxiety in primary care. Current Perspectives in Healthcare Computing, 277-288.

171. Meenan RF, Gertman PM and Mason JH (1980). Measuring health status in arthritis. Arthritis & Rheumatism, 23(2), 146-152.

172. Merriam S B (2001). Andragogy and Self-Directed Learning: Pillars of Adult Learning Theory. New Directions for Adult and Continuing Education, 89, 3–14.

173. Merriam SB, Caffarella RS and Baumgartner, L. M. (2006). Knowles's andragogy, and models of adult learning in McClusky, Illeris, and Jarvis. Learning in adulthood: A comprehensive guide (3rd edition), 83-104. San Francisco: John Wiley & Sons Inc.

174. Merriam SB and Caffarella RS (1999). Learning in Adulthood: A Comprehensive Guide (2nd Edition). San Francisco: Jossey-Bass.

175. Meyer SR and Marsick VJ (2003). Professional development in corporate training. New Directions for Adult and Continuing Education, 2003(98), 75-82.

176. Mislevy RJ, Chudowsky N, Draney K, Fried R, Gaffney T, Haertel G and Wilson M (2003). Design patterns for assessing science inquiry. Principled Assessment Designs for Inquiry (PADI) Technical Report, 1.

177. Morganti F, Carassa A and Geminiani G (2007). Planning optimal paths: A simple assessment of survey spatial knowledge in virtual environments. Computers in Human Behaviour, 23(4), 1982-1996.

178. Morris LD, Louw QA and Grimmer-Somers K (2009). The effectiveness of virtual reality on reducing pain and anxiety in burn injury patients: a systematic review. The Clinical Journal of Pain, 25(9), 815-826.

179. Morris Z, Whiteley WN, Longstreth Jr WT, Weber F, Lee YC, Tsushima Y and Salman RAS (2009). Incidental findings on brain magnetic resonance imaging: systematic review and meta-analysis. British Medical Journal, 339, 547-550.

180. Mumford N and Wilson PH (2009). Virtual reality in acquired brain injury upper limb rehabilitation: Evidence-based evaluation of clinical research. Brain Injury, 23(3), 179-191.

181. National Institute for Health and Care Excellence (2014). Glossary. Retrieved from: https://www.nice.org.uk/glossary?letter=r on May 15, 2014.

182. Nicholas MK (2007). The pain self-efficacy questionnaire: taking pain into account. European Journal of Pain, 11(2), 153-163.

183. Niedermann K, Forster A, Ciurea A, Hammond A, Uebelhart D and de Bie R (2011). Development and psychometric properties of a joint protection self-efficacy scale. Scandinavian Journal of Occupational Therapy, 18(2), 143-152.

184. Niedermann K, Hammond A, Forster A and de Bie R (2010). Perceived benefits and barriers to joint protection among people with rheumatoid arthritis and occupational therapists. A mixed methods study. Musculoskeletal Care, 8(3), 143-156.

185. Norris, J. R. (2009). The growth and direction of healthcare support groups in virtual worlds. Journal of Virtual Worlds Research, 2(2).

186. Novak TP (2010). eLab city: A platform for academic research on virtual worlds. Journal of Virtual Worlds Research, 3(1).

187. O'Connell TA, Grantham JD, Workman KA and Wong W (2009). Leveraging game-playing skills, expectations and behaviors of digital natives to improve visual analytic tools. Journal of Virtual Worlds Research, 2(1).

188. Oddsson LI, Karlsson R, Konrad J, Ince S, Williams SR and Zemkova E (2006). A rehabilitation tool for functional balance using altered gravity and virtual reality. Journal of Neuroengineering and Rehabilitation, 4, 25-25.

189. Olasoji R and Henderson-Begg S (2010). Summative Assessment in Second Life: A Case Study. Journal of Virtual Worlds Research, 3(3).

190. Olivo SA, Macedo LG, Gadotti IC, Fuentes J, Stanton T and Magee DJ (2008). Scales to assess the quality of randomized controlled trials: a systematic review. Physical Therapy, 88(2), 156-175.

191. O'Neil J and Lamm SL (2000). Working as a learning coach team in action learning. New Directions for Adult and Continuing Education, 2000(87), 43-52.

192. Opriş D, Pintea S, García-Palacios A, Botella C, Szamosközi Ş and David D (2012). Virtual reality exposure therapy in anxiety disorders: a quantitative meta-analysis. Depression and Anxiety, 29(2), 85-93.

193. Ortwein M (2010). The Essence of Virtuality: Exploring the Digital Body. Journal of Virtual Worlds Research, 2(5).

194. Otte M, Roosendaal L and Hoorn JF (2011). Teleportation of objects between virtual worlds: use case: exer-gaming. Journal of Virtual Worlds Research, 4(3).

195. Padgett LS, Strickland D and Coles CD (2006). Case study: using a virtual reality computer game to teach fire safety skills to children diagnosed with fetal alcohol syndrome. Journal of Pediatric Psychology, 31(1), 65-70.

196. Papagiannidis S and Bourlakis M (2010). Staging the new retail drama: At a metaverse near you!' Journal of Virtual Worlds Research, 5, (2), pp. 3-17.

197. Paschall MJ, Fishbein DH, Hubal RC and Eldreth D (2005). Psychometric properties of virtual reality vignette performance measures: a novel approach for assessing adolescents' social competency skills. Health Education Research, 20(1), 61-70.

198. Patel A, Buszewicz M, Beecham J, Griffin M, Rait G, Nazareth I and Haines A (2009). Economic evaluation of arthritis self-management in primary care. British Medical Journal, 339, b3532.

199. Patented Medicine Prices Review Board Canada (2015). Government of Canada website information retrieved from: http://www.pmprb-cepmb.gc.ca /en/home/ on March 18, 2015.

200. Pearson, A., Wiechula, R., Court, A. and Lockwood, C. (2005). The JBI model of evidence-based healthcare. JBI Reports. 3:8, 207- 216.

201. Peña J, McGlone MS and Sanchez J (2012). The cowl makes the monk: How avatar appearance and role labels affect cognition in virtual worlds. Journal of Virtual Worlds Research, 5(3).

202. Penfold P and Duffy P (2010). A Second Life first year experience. Journal of Virtual Worlds Research, 2(5).

203. Pensieri C and Pennacchini M (2014). Overview: Virtual reality in medicine. Journal of Virtual Worlds Research, 7(1).

204. Pew Research Centre (2014). Health Fact Sheet. Retrieved from: http://www.pewinternet.org/fact-sheets/health-fact-sheet/ on February 13, 2015.

205. Pfizer Canada (2011). Methotrexate drug monograph for professionals. Retrieved from: http://www.pfizer.ca/sites/g/files/g10017036/f/201410/Methotrexate_0.pdf on May 2, 2012.

206. Pfizer Canada (2014) Xeljanz drug monograph for professionals. Retrieved from: https://www.cadth.ca/media/cdr/monograph/Xeljanz_Product%20Monograph.pdf, March 18, 2015.

207. Pibouleau L, Boutron I, Reeves BC, Nizard R and Ravaud P (2009). Applicability and generalisability of published results of randomised controlled trials and non-randomised studies evaluating four orthopaedic procedures: methodological systematic review. British Medical Journal (Clinical research edition), 339, b4538.

208. Polgar S and Thomas SA (2000). Introduction to Research in the Health Sciences (fourth edition). Toronto: Churchill Livingston.

209. Poncin I and Garnier M (2012). Immersion in a new commercial virtual environment: the role of the avatar in the appropriation process. Advances in Consumer Research, 40, 475-483.

210. Porter R and Kaplan J (2013). The Merck Manual Online – Professional Edition. Retrieved from: http://www.merckmanuals.com/professional/musculoskeletal-and-connective -tissue-disorders/joint-disorders/rheumatoid-arthritis-ra on March 18, 2015.

211. Potts HW (2006). Is e-health progressing faster than e-health researchers? Journal of Medical Internet Research, 8(3).

212. Price M, Mehta N, Tone EB and Anderson PL (2011). Does engagement with exposure yield better outcomes? Components of presence as a predictor of treatment response for virtual reality exposure therapy for social phobia. Journal of Anxiety Disorders, 25(6), 763-770.

213. Pridmore J and Overocker J (2014). Privacy in virtual worlds: a US perspective. Journal of Virtual Worlds Research, 7(1).

214. Radner H, Ramiro S, Buchbinder R, Landewé R, Van Der Heijde D and Aletaha D (2012). Pain management for inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and other spondyloarthritis) and gastrointestinal or liver comorbidity. The Cochrane Library.

215. Rager KB (2003). The self-directed learning of women with breast cancer. Adult Education Quarterly, 53(4), 277-293.

216. Rahman S and Shaheen A (2011). Virtual reality use in motor rehabilitation of neurological disorders: A systematic review. Middle-East Journal of Scientific Research, 7(1), 63-70.

217. Rahman A, Daniel C and Grahame R (2014). Efficacy of an out-patient pain management program for people with joint hypermobility syndrome. Clinical Rheumatology, 33(11), 1665-1669.

218. Reagon C, Bellin W and Boniface G (2008). Reconfiguring evidence-based practice for occupational therapists. International Journal of Therapy and Rehabilitation, 15(10), 428-436.

219. Reeves B and Read JL (2009). Total Engagement: Using Games and Virtual Worlds to Change the Way People Work and Businesses Compete. Boston: Harvard Business Press.

220. Reid, DT (2005). Virtual occupations create opportunities. Occupational Therapy Now, 7(1), 10- 11.

221. Riddle J (2000). Crisis or Turning Point? The Frustrations and Transformations of the Mid-Life Education Doctoral Student. ASHE Annual Meeting Paper.

222. Rizzo A, John B, Newman B, Williams J, Hartholt A, Lethin C and Buckwalter JG (2013). Virtual reality as a tool for delivering PTSD exposure therapy and stress resilience training. Military Behavioural Health, 1(1), 52-58.

223. Roberts AEK (1993). An evaluation of the effectiveness of educational gaming as a teaching method for therapists. British Journal of Occupational Therapy, 56(10), 371-375.

224. Robinson E (2014). The Aspatial Economics of Virtual Worlds. Journal of Virtual Worlds Research, 7(1).

225. Robinson V, Brosseau L, Casimiro L, Judd M, Shea B, Wells G and Tugwell P (2002). Thermotherapy for treating rheumatoid arthritis (Cochrane Review). The Cochrane Library, (4).

226. Robinson-Cima S, Barone A, Porto JM and de Abreu DCC (2013). Strengthening exercises to improve hand strength and functionality in rheumatoid arthritis with hand deformities: a randomized, controlled trial. Rheumatology International, 33(3), 725-732.

227. Rodrigues N, Magalhães L, Moura JP, Chalmers A, Santos F and Morgado L (2010). ArchHouseGenerator–A Framework for House Generation. Journal of Virtual Worlds Research, 2(5).

228. Rønningen A and Kjeken I (2008). Effect of an intensive hand exercise program in patients with rheumatoid arthritis. Scandinavian Journal of Occupational Therapy, 15(3), 173-183.

229. Ross SE, Moore LA, Earnest MA, Wittevrongel L and Lin CT (2004). Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. Journal of Medical Internet Research, 6(2), e12.

230. Ruiz-Irastorza G, Danza A, Perales I, Villar I, Garcia M, Delgado S and Khamashta M (2014). Prednisone in lupus nephritis: how much is enough? Autoimmunity Reviews, 13(2), 206-214.

231. Russell, TG, Buttrum P, Wootton R and Jull GA (2011). Internet-based outpatient telerehabilitation for patients following total knee arthroplasty. The Journal of Bone & Joint Surgery, 93(2), 113-120.

232. Sanchez, CD (2010). My Second Life as a Cyber Border Crosser. Journal of Virtual Worlds Research, *2*(5).

233. Sanders B, Furnell S, Dowland P and Atkinson S (2010). Massively Multi-Player Online Role Playing Games: What's the Risk? Journal of Virtual Worlds Research, 3(3).

234. Sanderson T, Morris M, Calnan M, Richards P and Hewlett S (2010). Patient perspective of measuring treatment efficacy: the rheumatoid arthritis patient priorities for pharmacologic interventions outcomes. Arthritis Care & Research, 62(5), 647-656.

235. Salzman AP (2009). Evidence-Based Case for Aquatic Therapy for the Patient with Arthritis. Retrieved from: http://www.aquaticnet.com/Article%20-%20Evidencebased%20case%20for%20aquatic%20therapy%20for%20rheumatic%20disorders.htm on May 15, 2010.

236. Schlicht A and Schmidt T (2010). Trucking Towards a Virtual World: The Development and Implementation of FMCSA's Transportation Nation Second Life Island. Journal of Virtual Worlds Research, 2(5), 1-17.

237. Schulz KF, Altman DG and Moher D (2010). CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. Bio Medical Central Medicine, 8(1), 18.

238. Selvander M and Åsman P (2012). Virtual reality cataract surgery training: learning curves and concurrent validity. Acta Ophthalmologica, 90(5), 412-417.

239. Shariff F, Carter J, Dow C, Polley M, Salinas M and Ridge D (2009). Mind and body management strategies for chronic pain and rheumatoid arthritis. Qualitative Health Research, 19(8), 1037-1049.

240. Sharma M (2005). Reporting of Randomized Controlled Trials: The CONSORT Statement. Journal of Alcohol & Drug Education, 49(4), 1.

241. Sharpe L and Schrieber L (2012). A blind randomized controlled trial of cognitive versus behavioural versus cognitive-behavioural therapy for patients with rheumatoid arthritis. Psychotherapy and Psychosomatics, 81(3), 145-152.

242. Sheppard J, Kumar K, Buckley CD, Shaw KL and Raza K (2008). I just thought it was normal aches and pains: a qualitative study of decision-making processes in patients with early rheumatoid arthritis. Rheumatology, 47(10), 1577-1582.

243. Shih TH and Fan X (2008). Comparing response rates from web and mail surveys: A meta-analysis. Field Methods, 20(3), 249-271.

244. Short D (2012). Teaching scientific concepts using a virtual world-Minecraft. Journal of the Australian Science Teachers Association, 58(3), 55.

245. Shute VJ, Ventura M, Bauer M and Zapata-Rivera D (2009). Melding the power of serious games and embedded assessment to monitor and foster learning. Serious games: Mechanisms and effects, 2, 295-321.

246. Sibbald B and Roland M (1998). Understanding controlled trials. Why are randomised controlled trials important? British Medical Journal, 316(7126), 201.

247. Sibthorpe BM, Bailie RS, Brady MA, Ball SA, Sumner-Dodd P and Hall WD (2002). The demise of a planned randomised controlled trial in an urban Aboriginal medical service. The Medical Journal of Australia, 176(6), 273-276.

248. Siddiqi S, Mama SK and Lee RE (2010). Developing an obesity prevention intervention in virtual worlds: The international health challenge in Second Life. Journal of Virtual Worlds Research, 3(3).

249. Solomon DH, Katz JN, Jacobs JP, La Tourette AM and Coblyn J (2002). Management of glucocorticoid-induced osteoporosis in patients with rheumatoid arthritis: Rates and predictors of care in an academic rheumatology practice. Arthritis & Rheumatism, 46(12), 3136-3142.

250. Solomon DH, Warsi A, Brown-Stevenson T, Farrell M, Gauthier S, Mikels D and Lee TH (2002). Does self-management education benefit all populations with arthritis? A randomized controlled trial in a primary care physician network. The Journal of Rheumatology, 29(2), 362-368.

251. Song L and Hill JR (2007). A conceptual model for understanding self-directed learning in online environments. Journal of Interactive Online Learning, 6(1), 27-42.

252. Spence J (2008). Demographics of virtual worlds. Journal of Virtual Worlds Research, 1(2).

253. Stanton JM (2010). Virtual Worlds, the IRB and a User's Bill of Rights. Journal of Virtual Worlds Research, 3(1).

254. Steinman L, Ousman SS and Robinson WH (2011). Alpha B-crystallin as a therapy for rheumatoid arthritis. U.S. Patent No. 7,875,589. 25.

255. Stephenson N (1992). Snow Crash. New York: Bantam.

256. Stephenson J and Imrie J (1998). Why do we need randomised controlled trials to assess behavioural interventions? British Medical Journal, 316(7131), 611-613.

257. Stewart JC, Yeh SC, Jung Y, Yoon H, Whitford M, Chen SY and Winstein CJ (2007). Intervention to enhance skilled arm and hand movements after stroke: A feasibility study using a new virtual reality system. Journal of NeuroEngineering and Rehabilitation, 4, 21.

258. Stolberg HO, Norman G and Trop I (2004). Randomized controlled trials. American Journal of Roentgenology, 183(6), 1539-1544.

259. Strand V and Sokolove J (2009). Randomized controlled trial design in rheumatoid arthritis: the past decade. Arthritis Research and Therapy, 11(1), 1-11.

260. Subramanian S, Knaut LA, Beaudoin C, McFadyen BJ, Feldman AG and Levin MF (2007). Virtual reality environments for post-stroke arm rehabilitation. Journal of Neuroengineering and Rehabilitation, 4(1), 20.

261. Sugita N, Yoshizawa M, Abe M, Tanaka A, Watanabe T, Chiba S and Nitta SI (2007). Evaluation of adaptation to visually induced motion sickness based on the maximum cross-correlation between pulse transmission time and heart rate. Journal of NeuroEngineering and Rehabilitation, 4(1), 1-6.

262. Sweigart L, Hodson-Carlton K, Campbell BR and Lutz DR (2010). Second life environment: a venue for interview skill development. Computers Informatics Nursing, 28(5), 258-263.

263. Swink, S. (2006). Principles of virtual sensation. Gamasutra. Retrieved from:http://www.gamasutra.com/view/feature/1781/principles_of_virtual_sensation.php on September 12, 2009.

264. Taylor MJ, Taylor D, Kulendran M, Gately P and Darzi, A (2013). Virtual worlds as a tool to facilitate weight management for young people. Journal of Virtual Worlds Research, 6(1).

265. Thyberg I, Hass UA, Nordenskiöld U and Skogh T (2004). Survey of the use and effect of assistive devices in patients with early rheumatoid arthritis: A two-year follow-up of women and men. Arthritis Care & Research, 51(3), 413-421.

266. Toro-Troconis M and Boulos MNK (2009). Musings on the state of 3-D virtual worlds for health and healthcare in 2009. Journal of Virtual Worlds Research, 2(2).

267. Toth-Cohen S and Gallagher T (2009). Development and evaluation of health and wellness exhibits at the Jefferson Occupational Therapy Education Center in Second Life. Journal of Virtual Worlds Research, 2(2).

268. Townsend EA and Polatajko HJ (Eds.) (2007). Enabling Occupation II: Advancing an Occupational Therapy Vision of Health, Well-being, & Justice through Occupation. Ottawa: CAOT Publications ACE.

269. Trochim WMK (2006). The Research Methods Knowledge Base (third edition). Cincinnati: Atomic Dog Publishing.

270. Trofimuk E, Cotton K and Kashani R (2004) "Ankylosing spondylitis – rehabilitation Appendix" Expert MD (CD ROM).

271. Uhlig T, Fongen C, Steen E, Christie A and Ødegård S (2010). Exploring Tai Chi in rheumatoid arthritis: a quantitative and qualitative study. Biomedical Central Musculoskeletal Disorders, 11(1), 43.

272. University of Eastern Washington (2013). Elluminate Live classroom taught seminar hosted by Dr. Susan Burwash, OT(R) on Pharmacology and Occupational Performance on April 23, 2013.

273. Urriah N (2011). Second Life Statistics. Retrieved from: http://blog.nalates.net/ 2013/01/28/second-life-2012-statistics/ on August 1, 2015.

274. van der Maas LCC, de Vet HCW, Köke A, Bosscher RJ, and Peters ML (2012) Psychometric properties of the pain self-efficacy questionnaire (PSEQ): Validation, prediction, and discrimination quality of the Dutch version. European Journal of Psychological Assessment, 28(1), 68-75.

275. van Haselen R (2000). The economic evaluation of complementary medicine: a staged approach at the Royal London Homeopathic Hospital. The British Homoeopathic Journal, 89, 23-6.

276. Varas-Lorenzo C, Riera-Guardia N, Calingaert B, Castellsague J, Pariente A, Scotti L and Perez-Gutthann S (2011). Stroke risk and NSAIDs: a systematic review of observational studies. Pharmacoepidemiology and Drug Safety, 20(12), 1225-1236.

277. Veehof MM, Taal E, Heijnsdijk-Rouwenhorst LM and Van de Laar MAFJ (2008). Efficacy of wrist working splints in patients with rheumatoid arthritis: a randomized controlled study. Arthritis Care & Research, 59(12), 1698-1704.

278. Verdot V, Saidi A and Fournigault L (2011). Virtual Hybrid Communications. Presented at the 16th International Conference on 3D Web Technology, Paris, France.

279. Vicdan H and Ulusoy E (2010). Symbolic and experiential consumption of body in virtual worlds: from (dis)embodiment to symembodiment. Journal of Virtual Worlds Research, 1(2).

280. Wade S and Hammick M (1999). Action learning circles: Action learning in theory and practice. Teaching in Higher Education, 4(2), 163-178.

281. Wagner, EH, Austin BT and Von Korff M (1996). Organizing care for patients with chronic illness. The Milbank Quarterly, 511-544.

282. Walker, VL (2009). 3D virtual learning in counsellor education: Using Second Life in counsellor skill development. Journal of Virtual Worlds Research, 2(1).

283. Wallach HS and Bar-Zvi M (2007). Virtual-reality-assisted treatment of flight phobia. The Israel Journal of Psychiatry and Related Sciences, 44(1), 29.

284. Wang C, De Pablo P, Chen X, Schmid C and McAlindon T (2008). Acupuncture for pain relief in patients with rheumatoid arthritis: a systematic review. Arthritis Care & Research, 59(9), 1249-1256.

285. Wang Z, Walther JB, Pingree S and Hawkins RP (2008). Health information, credibility, homophily, and influence via the Internet: Web sites versus discussion groups. Health Communication, 23(4), 358-368.

286. Watanabe H, Teramoto W and Umemura H (2007). Effect of predictive sign of acceleration on heart rate variability in passive translation situation: Preliminary evidence using visual and vestibular stimuli in VR environment. Journal of Neuroengineering and Rehabilitation, 4(1), 36.

287. Weiss PL and Katz N (2004). The potential of virtual reality for rehabilitation. Journal of Rehabilitation Research and Development, 41(5), 7-10.

288. Weiss PL, Rand D, Katz N and Kizony R (2004). Video capture virtual reality as a flexible and effective rehabilitation tool. Journal of Neuroengineering and Rehabilitation, 1(1), 12.

289. Wellman B and Gulia M (1999). Net surfers don't ride alone: Virtual communities as communities. Networks in the Global Village. New York: Westview Press, 331-366.

290. Wessel J (2004). The effectiveness of hand exercises for persons with rheumatoid arthritis: a systematic review. Journal of Hand Therapy, 17(2), 174-180.

291. Wiecha J, Heyden R, Sternthal E and Merialdi M. (2010). Learning in a virtual world: experience with using second life for medical education. Journal of Medical Internet Research, 12(1).

292. Wiederhold B and Wiederhold M (2003). A new approach: Using virtual reality psychotherapy in panic disorder with agoraphobia. Psychiatric Times, 20(7). Online edition: www.psychiatrictimes.com. Downloaded on June 29, 2011.

293. Winkler S, Mercier J and Capalini E (2015) Virtual Support and Education Through Second Life–Amputee Coalition National Conference presentation, Tucson, Arizona.

294. Wolfe F, Michaud K and Dewitt EM (2004). Why results of clinical trials and observational studies of antitumor necrosis factor (anti-TNF) therapy differ: methodological and interpretive issues. Annals of the Rheumatic Diseases, 63 (supplementary issue 2), 13-17.

295. Woodburn J, Barker S and Helliwell PS (2002). A randomized controlled trial of foot orthoses in rheumatoid arthritis. The Journal of Rheumatology, 29(7), 1377-1383.

296. Woods J (2008). Avatars and Second Life adultery: A tale of online cheating and real world heartbreak. The Telegraph, 14.

297. Woon CYL, Phoon ES, Lee JYL, Ng SW and Teoh LC (2010). Hazards of steroid injection: Supportive extensor tendon rupture. Indian journal of plastic surgery: official publication of the Association of Plastic Surgeons of India, 43(1), 97.

298. World Health Organization (2014). Chronic Rheumatic Conditions. Retrieved from http://www.who.int/chp/topics/rheumatic/en/ on May 1, 2014.

299. Worldswide, KZero (2014). KZero Universe Chart Q2 2014.

300. Yee N (2006). Motivations for play in online games. CyberPsychology & Behavior, 9(6), 772-775.

301. Yee N, Bailenson JN and Ducheneaut N (2009). The proteus effect: Implications of transformed digital self-representation on online and offline behaviour. Communication Research, 36(2), 285-312.

302. You SH, Jang SH, Kim YH, Kwon YH, Barrow I and Hallett M (2005). Cortical reorganization induced by virtual reality therapy in a child with hemiparetic cerebral palsy. Developmental Medicine & Child Neurology, 47(09), 628-635.

303. Young K (2009). Understanding online gaming addiction and treatment issues for adolescents. The American Journal of Family Therapy, 37(5), 355-372.

304. Young M F, Slota S, Cutter AB, Jalette G, Mullin G, Lai B and Yukhymenko M (2012). Our princess is in another castle: a review of trends in serious gaming for education. Review of Educational Research, 82(1), 61-89.

305. Yorks L (2005). Adult learning and the generation of new knowledge and meaning: Creating liberating spaces for fostering adult learning through practitioner-based collaborative action inquiry. The Teachers College Record, 107(6), 1217-1244.

306. Zdanowski J (2007). Second Life's John Zdanowksi in: Human Capital Careers. Retrieved from: http://ww2.cfo.com/human-capital-careers/2007/10/second-lifes-john-zdanowski/ on April 30, 2015.

307. Zhang W and Doherty M (2006). EULAR recommendations for knee and hip osteoarthritis: a critique of the methodology. British Journal of Sports Medicine, 40(8), 664-669.

308. Zielke MA, Roome T and Krueger AB (2009). A Pedagogical Model for Virtual World Residents: A Case Study of the Virtual Ability Second Life Island. Journal of Virtual Worlds Research, 2(1).

309. Zijlstra TR, Heijnsdijk-Rouwenhorst L and Rasker JJ (2004). Silver ring splints improve dexterity in patients with rheumatoid arthritis. Arthritis Care & Research, 51(6), 947-951.

310. Zmeyov SI (1998). Andragogy. Origins, developments and trends. International Review of Education (electronic version) 44(1) p.105. Retrieved from http://www .springerlink.com/content/u6367k2r10218668/fulltext.pdf on April 4, 2010.

311. Zwarenstein M, Treweek S, Gagnier JJ, Altman DG, Tunis S, Haynes B and Moher D (2008). Improving the reporting of pragmatic trials: an extension of the CONSORT statement. British Medical Journal, 337(7680), 1223-1226.

Appendix 1-Inventory of VW Objects

Station Number / Description	Item name	Description	Screen Shot / Illustration number	Script Contents
Landing Point	Welcome Sign	Sign welcoming users with instructions	Landing Point_001	N/A
Landing Point	Structural Wall (CTL Prefabs - Oxygen OpenSpace - V1)	Structural component	Landing Point_002	N/A
Landing Point	Privacy Fence	Brick wall	Landing Point_002	N/A
Landing Point	Arrows	Arrows on ground guiding user	Landing Point_002	N/A
Welcome	Welcome Mat	Mat welcoming users	Welcome Mat_001	Records avatar entry, IM to email
Welcome	Welcome Sign	Instructions for participants to follow	Welcome Mat_001	N/A
Welcome	Arthritis Fighter	Artificial avatar	Welcome Mat_001	Records avatar entry and stores in memory Gives notecard Holding welcome sign Welcome message in chat Recording chat (not used)
1	Basic Chair	Chair for user to sit on	Station 1_001	Float text instructions
1	Please Sit	Artificial avatar to left of chair	Station 1_001	Record entry (not used) Give inventory (not used) Message (not used) Recording chat (not used)
1	Number 1 sign	Station sign 1	Station 1_002	N/A
1	Projector Screen	Television, Radio, Internet & Slideshow reviewing principles of joint protection	Station 1_002	Pre-programmed, drag and drop PPT file converted to individual JPEG format
1	Structural Wall (CTL Prefab Store - Oxygen Mall - Kiosk Z10 V1- 7p)	Structural Component of **all main display area** stations	Station 1_002	N/A
2	Number 2 Sign	Station sign 2	Station 2_001	N/A

2	Female Artificial Avatar	Female avatar holding right arm out with purse on wrist, text stating “harming wrist”	Station 2_001	Advanced scripting, same as male artificial avatar, also with programmable movements, private channels for listening and broadcasting (not used)
2	X-ray of Healthy Hands	X-ray of healthy hands	Station 2_001	N/A
2	X-ray of Healthy Ankle	X-ray of healthy ankle	Station 2_001	N/A
2	Foot X-ray	X-ray of an inflamed joints, link to card demonstrating normal vs. abnormal joint	Station 2_001	Notecard giver
2	Wrist X-ray	X-ray of a healthy wrist	Station 2_001	N/A
2	Knee X-ray	X-ray of a healthy knee	Station 2_001	Float text
2	Skeleton Left Leg	Skeleton of the left leg	Station 2_001	N/A
2	Skeleton Left Hand	Skeleton of the left hand	Station 2_001	N/A
2	Poster	X-ray of hands afflicted with joint damage, information on joint protection principles	Station 2_001	N/A
3	Number 3 sign	Station sign 3	Station 3_001	N/A
3	Bookshelf	Bookshelf containing 5 boxes	Station 3_001	N/A
3	Joint Harming Box	Box on top of bookshelf with information on safe lifting techniques	Station 3_001	Speak in chat
3	Box on Second shelf	Safe to lift box with information on safe lifting techniques	Station 3_001	Speak in chat
3	Box on Third shelf	Safe to lift box with information on safe lifting techniques	Station 3_001	Speak in chat
3	Box on Fourth shelf	Safe to lift box with information on safe lifting techniques	Station 3_001	Speak in chat
3	Joint Harming Box	Box on floor with information on safe lifting techniques	Station 3_001	Speak in chat
3	Computer desk	Computer desk with information on joint protection principles.	Station 3_001	Speak in chat
3	Office Chair	Office chair with information on proper ergonomics.	Station 3_001	Speak in chat
3	Keyboard	Keyboard with information on proper ergonomics	Station 3_001	Speak in chat
3	Computer Screen	Computer screen with information on proper screen height.	Station 3_001	Speak in chat
3	Poster	Four photos demonstrating proper desk and chair use.	Station 3_001	Float text

3	Poster	Poster on joint protection and work, link to resource "JANcana".	Station 3_001	N/A
4	Number 4 sign	Sign with number 4	Station 4_001	N/A
4	Car	Car providing "RA and driving" notecard	Station 4_001	Float text and notecard giver
4	Poster Image 1	Built up key holder	Station 4_001	N/A
4	Poster Image 2	Car Caddy strap	Station 4_001	N/A
4	Poster Image 3	Handy Bar	Station 4_001	N/A
4	Poster Image 4	Transfer disc	Station 4_001	N/A
4	Poster Image 5	Seat belt holder	Station 4_001	N/A
4	Poster Image 6	Information on car seat set-up	Station 4_001	N/A
4	Poster Image 7	Dycem	Station 4_001	N/A
4	Poster Image 8	Built up steering wheel	Station 4_001	N/A
5	Number 5 Sign	Sign with number 5	Station 5_001	N/A
5	Artificial Avatar "Mr. Sedentary"	Artificial avatar demonstrating poor application of joint protection principles	Station 5_001	N/A
5	Poster	Poster outlining instructions for station	Station 5_001	N/A
5	ProGym Bikemaster GS 2500	Recumbent bike for user to trial	Station 5_001	Cycling animation
5	Poster	Poster prompting user to click on barbells	Station 5_001	N/A
5	Rug	Rug for user to practice Tai Chi on	Station 5_001	N/A
5	Tai Chi 2 solo v.2,1	Pink pose ball, user engages in Tai Chi when clicked	Station 5_001	Tai Chi animations
5	HD - Brownwood Weight Rack - OUT09	Barbell rack, provides notecard on exercise	Station 5_001	Note card giver
5	ProTread Treadmill	Treadmill for user to trial	Station 5_001	Running animation
6	Number 6 sign	Sign with number 6	Station 6_001	N/A
6	Daily Living Aide (1)	Button Hook	Station 6_001	Whisper in chat
6	Daily Living Aide (2)	Built up toothbrush	Station 6_001	Whisper in chat
6	Daily Living Aide (3)	Dressing hook	Station 6_001	Whisper in chat
6	Walker	Standard walker	Station 6_001	Gait animation
6	Crutch Left	Crutch	Station 6_001	Gait animation

6	Cane	Cane	Station 6_001	Gait animation
6	Object	Poster prompting user to teleport to ADL suite	Station 6_001	Teleport animation
7	Number 7 Sign	Sign with number 7	Station 7_001	N/A
7	Washing Machine	Washing machine with notecard on joint protection	Station 7_001	Speak in chat
7	Dishwasher	Dishwasher with notecard on joint protection	Station 7_001	Speak in chat
7	Poster	Jar opener, link to www.abeldata.com	Station 7_001	Speak in chat
7	Poster	Grocery clip	Station 7_001	Speak in chat
7	Poster	Built up cutlery	Station 7_001	Speak in chat
7	Poster	Universal grip turner	Station 7_001	Speak in chat
7	Black Glass Table	Table with notecard on height and energy conservation	Station 7_001	Speak in chat
7	Dycem	Dycem with educational notecard	Station 7_001	Speak in chat
7	Mordechai's Bowl of frosting	Bowl on table	Station 7_001	Speak in chat
7	Oven	Oven with educational notecard	Station 7_001	Notecard giver
7	Refrigerator	Refrigerator with educational notecard	Station 7_001	Notecard giver
7	Screen	Screen with link to video on OT + joint protection. http://www.youtube.com/watch?v=bfELhUPssW0	Station 7_001	Opens video in web browser
8	Number 8 sign	Sign with number 8	Station 8_001	N/A
8	Golf Club 3.5	Golf clubs	Station 8_001	Golfing animation (disabled)
8	Golf Club 2.2	Golf clubs	Station 8_001	Golfing animation (disabled)
8	Golf Ball	Golf balls	Station 8_001	Golfing animation (disabled)
8	Golf Hole # 1	Golf hole	Station 8_001	Golfing animation (disabled)
8	Green Acres Golf Bag (Smaller Strap)	Golf bag	Station 8_001	Golfing animation (disabled)
8	Golf Cart	Golf cart	Station 8_001	Driving animation (set to owner only)
8	Poster	Poster “golf is a good walk spoiled” with educational notecard	Station 8_001	Notecard giver
9	Number 9 Sign	Sign with number 9	Station 9_001	N/A
9	Tool Chest	Tool chest in home workshop	Station 9_001	Float text
9	Extra Saw Blades	Package of saw blades in home workshop	Station 9_001	N/A
9	Table Saw	Table saw in home workshop	Station 9_001	N/A
9	Power Drill	Power drill in home workshop	Station 9_001	N/A
9	Tool Wall	Wall of tools with educational notecard	Station 9_001	Notecard giver

9	Poster	Poster with educational material on home workshop and joint protection	Station 9_001	N/A
10	Number 10 Sign	Sign with number 10, notecard with information on choosing appropriate footwear	Station 10_001	Notecard giver
10	Bookshelf	Bookshelf with variety of joint-harming shoes	Station 10_001	N/A
10	Joint Harming High Heel Shoe	Joint-harming shoe with prompt for user to click Number 10 sign	Station 10_001	Speak in chat
10	Female Bollywood Shoes (Left) x 2	Shoe on shelf	Station 10_001	N/A
10	Club-goer Female Shoe x 2	Shoe on shelf	Station 10_001	N/A
10	Female Dancer Shoe (Right) x 2	Shoe on shelf	Station 10_001	N/A
10	Female Lo-rise Shoes-Black (Right) x 2	Shoe on shelf	Station 10_001	N/A
10	Wedge Shoes (Left) x 2	Shoe on shelf	Station 10_001	N/A
10	Bookshelf	Bookshelf containing a variety of joint-protecting shoes	Station 10_001	N/A
10	Joint Protecting Shoe	Shoe with prompt for user to try on joint-harming shoe	Station 10_001	Speak in chat
10	Male City Shoes Left (Brown) x 2	Shoe on shelf	Station 10_001	N/A
10	Female Average Shoes (Left) x 2	Shoe on shelf	Station 10_001	N/A
10	Boy Next Door Shoe Left x 2	Shoe on shelf	Station 10_001	N/A
10	Musician Female Shoe Right x 2	Shoe on shelf	Station 10_001	N/A
10	Male Shoes Loafers-Grey-Left x 2	Shoe on shelf	Station 10_001	N/A
10	Poster	Information for user on choosing proper footwear	Station 10_001	N/A
11	Number 11 Sign	Sign with number 11	Station 11_001	N/A
11	Poster	Poster with link to www.pattersonmedical.ca	Station 11_001	N/A

11	Poster	Poster with picture of adaptive gardening tool	Station 11_001	N/A
11	Watering Can	Watering can	Station 11_001	Watering animation (fixed)
11	Poster	Poster with picture of adaptive gardening cart	Station 11_001	N/A
11	Poster	Poster with link to www.leevalley.com	Station 11_001	N/A
11	Herb Plot	Herb plot on table	Station 11_001	N/A
11	Coffee Table, Glass & Steel	Table with herb plot on top	Station 11_001	Responds in chat to correct answer
11	Shovel	Shovel on ground next to herb plot	Station 11_001	N/A
11	Basil Herb Pot	Herb plant next to plot	Station 11_001	N/A
11	Thyme Herb Pot	Herb plant next to plot	Station 11_001	N/A
11	Cilantro Herb Pot	Herb plant next to plot	Station 11_001	N/A
11	Tomato Cage	Tomatoes that can be harvested	Station 11_001	N/A
11	Harvest Tomatoes	Green ball prompting user to harvest tomatoes	Station 11_001	Harvesting animation
12	Number 12 sign	Sign with number 12	Station 12_001	N/A
12	Poster	Poster prompting user to click on teleporter	Station 12_001	N/A
12	Poster	Picture of adaptive pencil	Station 12_001	N/A
12	Poster	Photos demonstrating correct/incorrect ways to hold a book	Station 12_001	N/A
12	Poster	In summary poster, prompt for users to visit Group and Social room	Station 12_001	N/A
12	Zip Grid-TP 4	Teleporter to “group and social room”	Station 12_001	Teleportation to Social Area (Easter egg area)
Group and Social House	Skylight	Group and social house structure	House_001	Door open/close animation
Group and Social House	Water-1.07	Pool outside of house entrance	House_002	Fish swimming animation (fixed)
Group and Social House	Welcome Mat	Welcome mat outside of house	House_003	N/A
Group and Social 1	Poster	Poster “welcome to an area for you to socialize in second life”	Group and Social_001	N/A
Group and Social 2	Joint Anatomy Poster	Poster demonstrating normal and arthritic joints	Group and Social_002	N/A

Group and Social 2	Walnut Desk	Desk with laptop on top	Group and Social_002	N/A
Group and Social 2	NoteBook from Squirrel Tech v2.0 Squirrel Mac Edition	Laptop on table	Group and Social_002	Opens web browser (set to owner only)
Group and Social 3	Poster	Poster with list of arthritis friendly products, link to http://www.arthritis.ca/afp?	Group and Social_003	Opens link to specific URL
Group and Social 3	D&S Gothic Night Stand LG	Furniture in section 3 below poster	Group and Social_003	N/A
Group and Social 4	Library Chair	Chair in group and social room	Group and Social_004	N/A
Group and Social 4	4 prims Modern Sofa - Black Leather L	Couch in group and social room	Group and Social_004	N/A
Group and Social 4	Black Leather-Chair with Chrome (x 2)	Chairs in group and social room	Group and Social_004	N/A
Group and Social 4	Garden Chair	Chair in group and social room	Group and Social_004	N/A
Group and Social 4	Screen	Screen “Dancing with Rheumatoid Arthritis”, link to http://www.screencast.com/t/MyYhwrPGaCQ	Group and Social_004	Opens link to specific URL
Group and Social 5	Virtual Ability Poster	Poster with link to “Virtual Ability Island”	Group and Social_005	Provides landmark to Ability Island
Group and Social 6	RA explained to others poster	Poster with link to video http://www.screencast.com/t/xYnpzNP84et	Group and Social_006	Opens link to specific URL
Group and Social 7	Pinboard 1.1	Board for users to leave messages/notes	Group and Social_007	Allows object entry (note)
Group and Social 8	Poster	Poster with instructions for user to click on teleporter	Group and Social_008	N/A
Group and Social 8	Zip Grid-TP 3	Teleporter that brings user back to main area	Group and Social_008	Teleport back to main display area landing point
Group and Social 9	Second floor	Furniture, not scripted, various chairs, one desk and one sofa. Two pictures and a plant	Group and Social_009	N/A
Skybox Structure	Skybox Floor T	Skybox structure for ADL Suite	Skybox_001	Modify level of wall transparency/privacy

ADL Suite 1	Welcome Screen	Poster welcoming user to ADL suite (sky box), instructions to follow	ADL Suite_001	N/A
ADL Suite-toilet	Blue Tile Wall	Structural component of station	ADL Suite_002	N/A
ADL Suite - toilet	Poster	Poster with photo of toilet aide	ADL Suite_002	N/A
ADL Suite - toilet	Poster	Poster with information on adaptive toileting devices equipment	ADL Suite_002	N/A
ADL Suite - toilet	Toilet Seat #3	Toilet with raised toilet seat	ADL Suite_002	N/A
ADL Suite - Toilet	Toilet Seat # 3	Raided toilet seat on floor	ADL Suite_002	N/A
ADL Suite – toilet	Toilet v1	Toilet without raised toilet seat	ADL Suite_002	N/A
ADL Suite-toilet	Toilet Paper White	Toilet paper holder	ADL Suite_002	N/A
ADL Suite-shower	Hand Towel Set on Rack_#02	Towel rack on wall	ADL Suite_003	N/A
ADL Suite - shower	Poster	Poster “suggested solutions to joint protection while bathing”	ADL Suite_003	N/A
ADL Suite - shower	Boy Blue Showerbox	Shower	ADL Suite_003_2	Door open and close Showering animation
ADL Suite - shower	Poster	Poster asking user questions regarding bathing equipment	ADL Suite_004	N/A
ADL Suite-Tub	Blue tile wall	Blue tile wall at station	ADL Suite_004	N/A
ADL Suite – Tub	Boy Blue Carpet	Bath mat	ADL Suite_004	N/A
ADL Suite – Tub	Boy Blue Towel Holder	Towel rack	ADL Suite_004	N/A
ADL Suite – Tub	Poster	Poster providing information to user about bathroom safety equipment	ADL Suite_004	N/A
ADL Suite – Tub	Claw Foot Tub	Bathtub for user to use	ADL Suite_004	Bathing animation
ADL Suite – Tub	Aerobic Step	Aerobic step beneath tub with notecard for user	ADL Suite_004	Note card giver
ADL Suite – Sink	Poster	Poster with information for user on hand washing using joint protection principles	ADL Suite_005	N/A

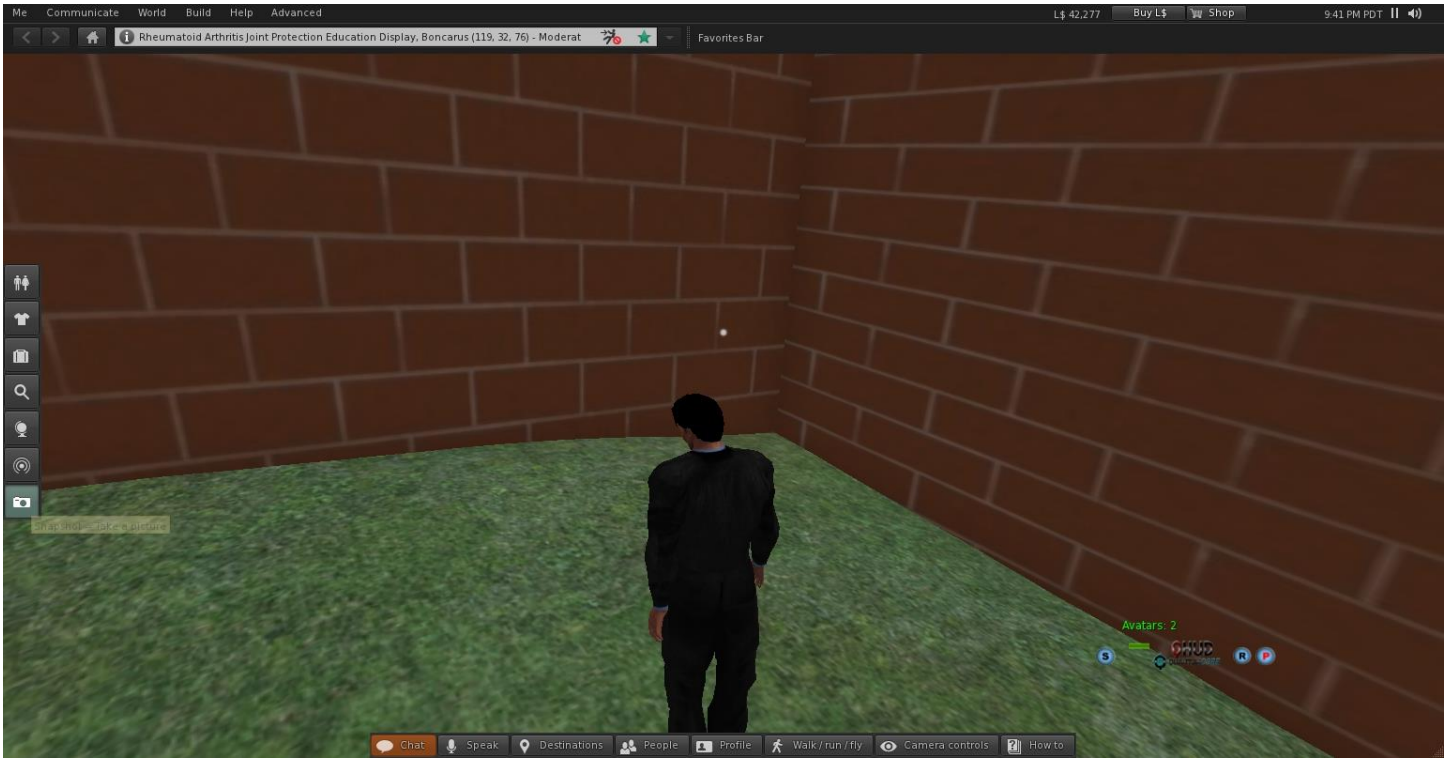
ADL Suite – Sink	Boy Blue Sink	Sink for user to wash hands at	ADL Suite_005	Handwashing animation
ADL Suite - Sink	Boy Blue Shelves	Shelves to right of user	ADL Suite_005	N/A
ADL Suite - Sink	Shampoo Bottle	Shampoo bottle on top of shelf, note card for user	ADL Suite_005	Note card giver
ADL Suite - Sink	Shampoo Bottle (right hand)	Shampoo bottle to right of user	ADL Suite_005	N/A
ADL Suite - Sink	Toothbrushes and Toothpaste Set (Boy Blue)	Toothbrushes and toothpaste to left of user	ADL Suite_005	N/A
ADL Suite-Bed	Chopines Animated Draped Bed - BlueGold	Bed	ADL Suite_006	Bed made, unmade, avatar sleeping/resting animation
ADL Suite-Bed	ADL Information Sign	Information for user on bed set up, link to "Arthritis and Intimacy" guide http://www.arthritis.ca/document.doc?id=39	ADL Suite_006	Open browser to specific URL with downloadable PDF
ADL Suite – Hot Tub	Super Hot Tub 1.1	Hot tub with controls to adjust steam and water level	ADL Suite_007	Hot tub on/off animation
ADL Suite – Hot Tub	Towels	Bath towels	ADL Suite_007	N/A
ADL Suite – Hot Tub	Poster	Information for user on using hot tub	ADL Suite_007	N/A
ADL Suite – Hot Tub	Stepladder	Stepladder allowing user to climb in to hot tub	ADL Suite_007_2	N/A
ADL Suite - Teleport	Floor mat	Information for user to return to main area	ADL Suite_008	N/A
ADL Suite - Teleport	Teleport (Zip Grid-TP 2)	Teleport enabling user to return to main area	ADL Suite_008	Teleports back to station 6 in main display area

Example script, Teleportation, as seen with sign at station 6 of main display area:

```
vector destination = <110, 8, 393>; // destination in X, Y, Z SIM Coordinates (see the FAQ below if you are not sure what this is)
string optional_message = "Left Click to Teleport";  // If you would like floating text above this teleporter with a message, type it between the quotes on this line.
// --- FAQ ---//
// What are X, Y, and Z coordinates and how do I get them?
//     The coordinates are the location in the sim that you want this teleporter to take you to. There is a very easy way to get them
//     The easiest way >> Go to the position in the SIM you want this teleporter to take you. look at the very top of your screen, you will see just to the right of the menu, a line which reads, the name of the SIM you are in, and the X, Y, and Z location  (3 numbers separated by commas) followed by the SIM rating (PG or Mature), and then SIM name.
//The only part you need here is the three numbers, put those three numbers in as the destination for this teleporter, make sure not to delete the "< "and ">" or the ";" and have commas between the numbers.
//----other script variables (do not change these)----//
vector destination2; //This will be the take off point/return point
vector current_pos; //this will be used to track the teleporter location.
//----this is the portion of the script that does the moving----//
Move_To_Pos()
{ current_pos = llGetPos();//set current pos to the location we are at
   destination2 = llGetPos();//same for destination 2, this is where the teleporter will return to after dropping you off
   while(current_pos != destination)//while we are not at the destination
   { llSetPos(destination);//move to the destination (we can only move in 10m increments, so we simply continue to call this until we are there)
      current_pos = llGetPos();//set current position to where we are so far. }
   llUnSit(llAvatarOnSitTarget());//After we get there, kick off the avatar
   while(current_pos != destination2)//while we are not back to our starting point
   { llSetPos(destination2);//move back to the starting point
      current_pos = llGetPos();//set the corrent position to where we are.}
}
default
{state_entry()//whenever this script is reset or changed and saved.
   {llSetText(optional_message, <1.0, 1.0, 1.0>, 1.0);//set the floating text to the optional message
      llSitTarget(<0.0, 0.0 ,1.0>, ZERO_ROTATION);//set the sit target 1m above the teleporter }
   changed(integer change)//whenever something changes
   {if(change & CHANGED_LINK)//if that change is a change in objects linked to this(triggered by someone sitting on it)
      { if(llAvatarOnSitTarget() != NULL_KEY)//if there is someone sitting on me
         { Move_To_Pos();//call the move to destination script. }
```

Corresponding Screenshots with Listed Inventory:

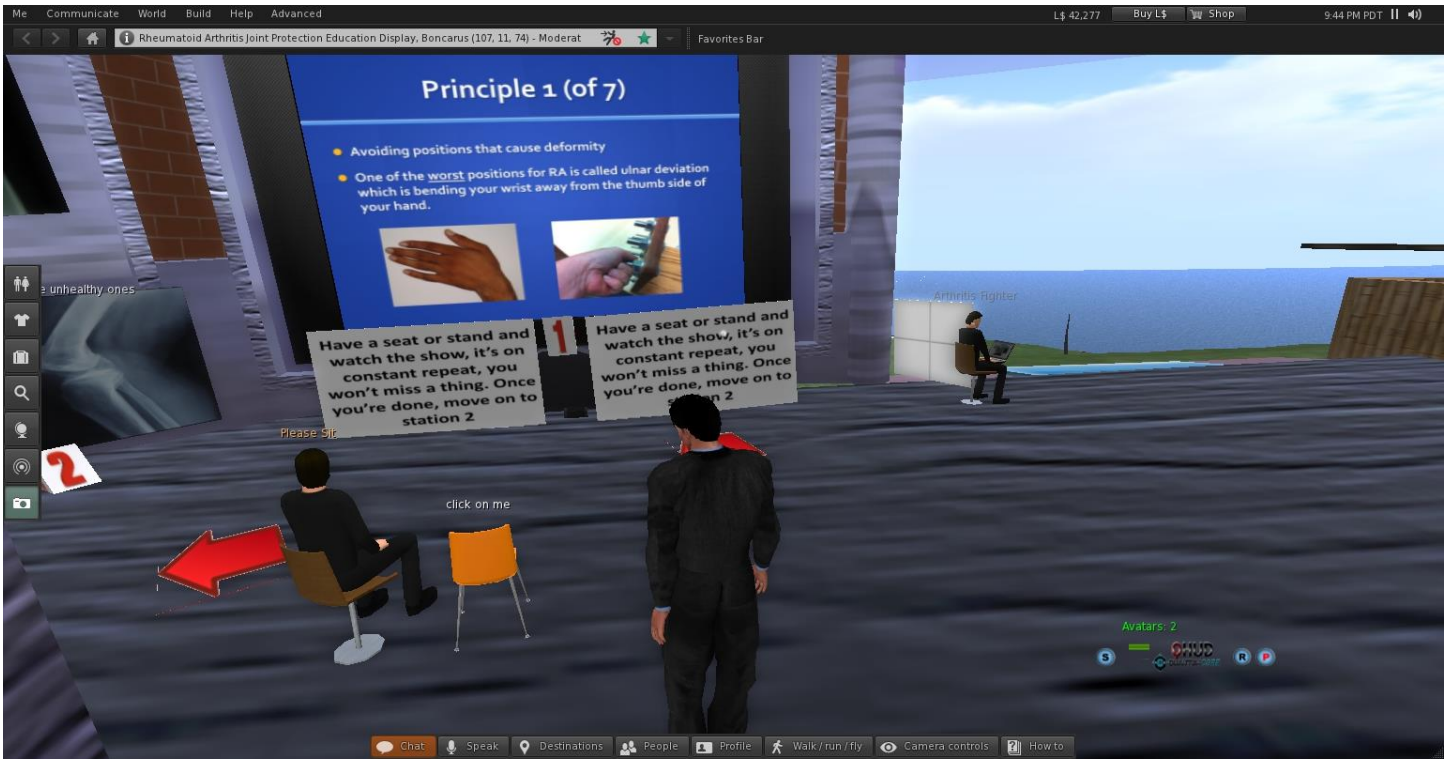
Landing point 1



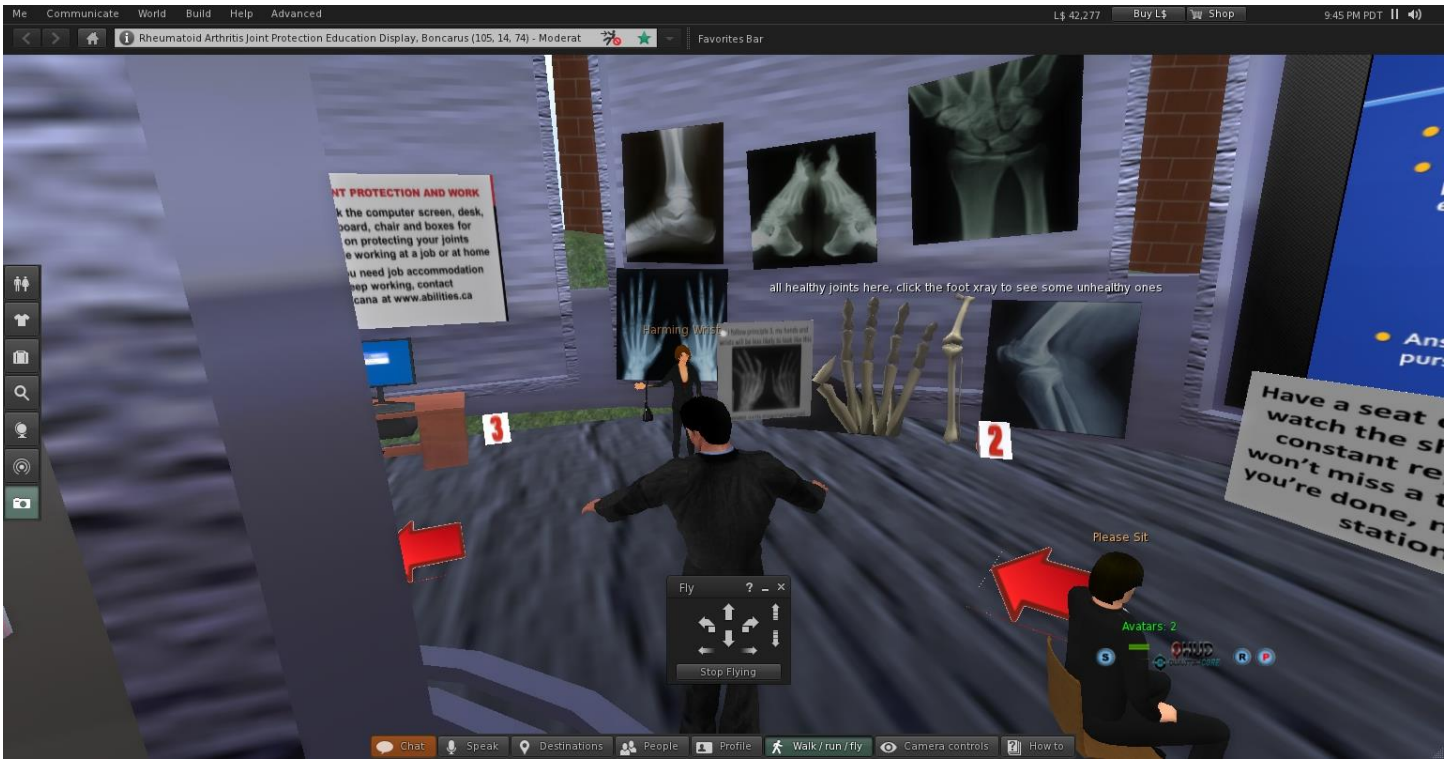
Landing point 2

Welcome area 1

Welcome area 2

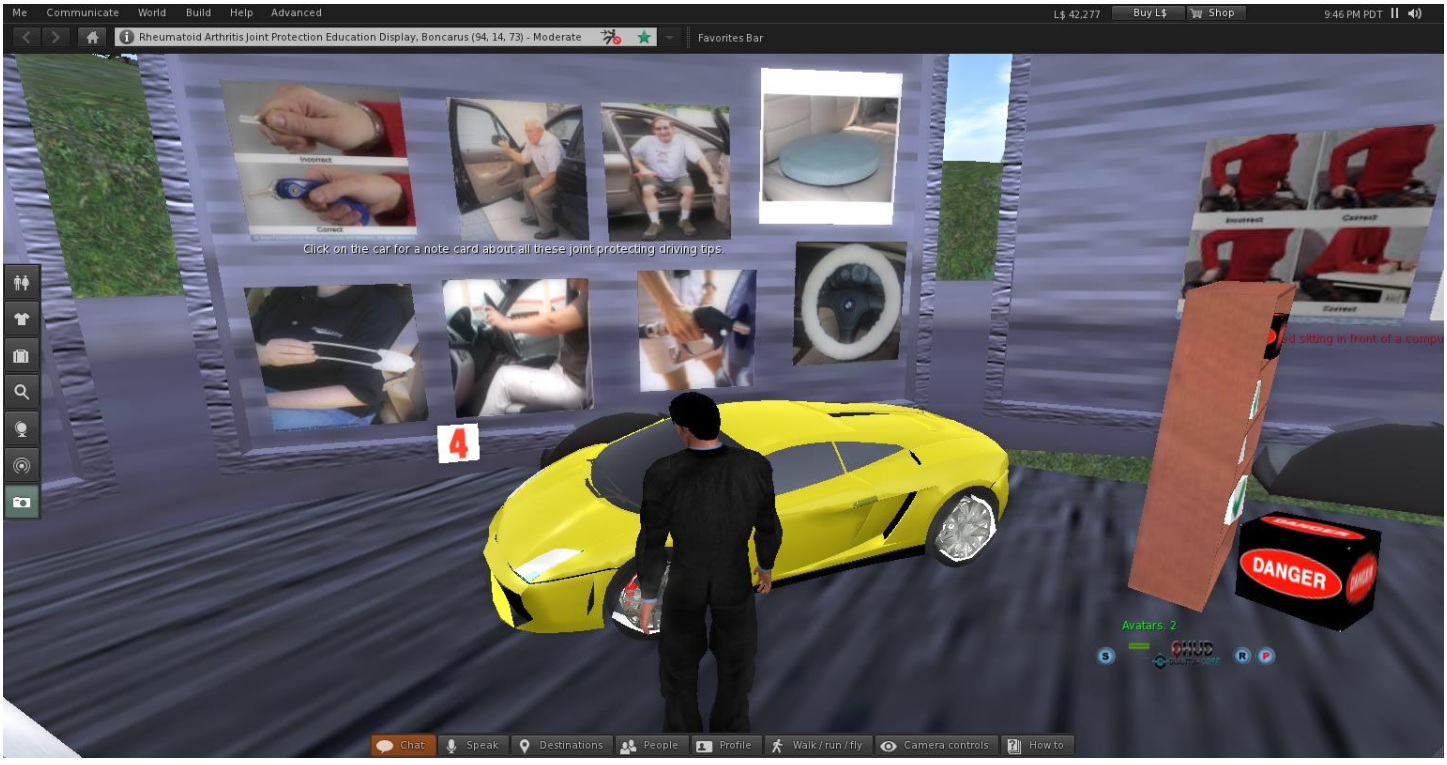


Station 1

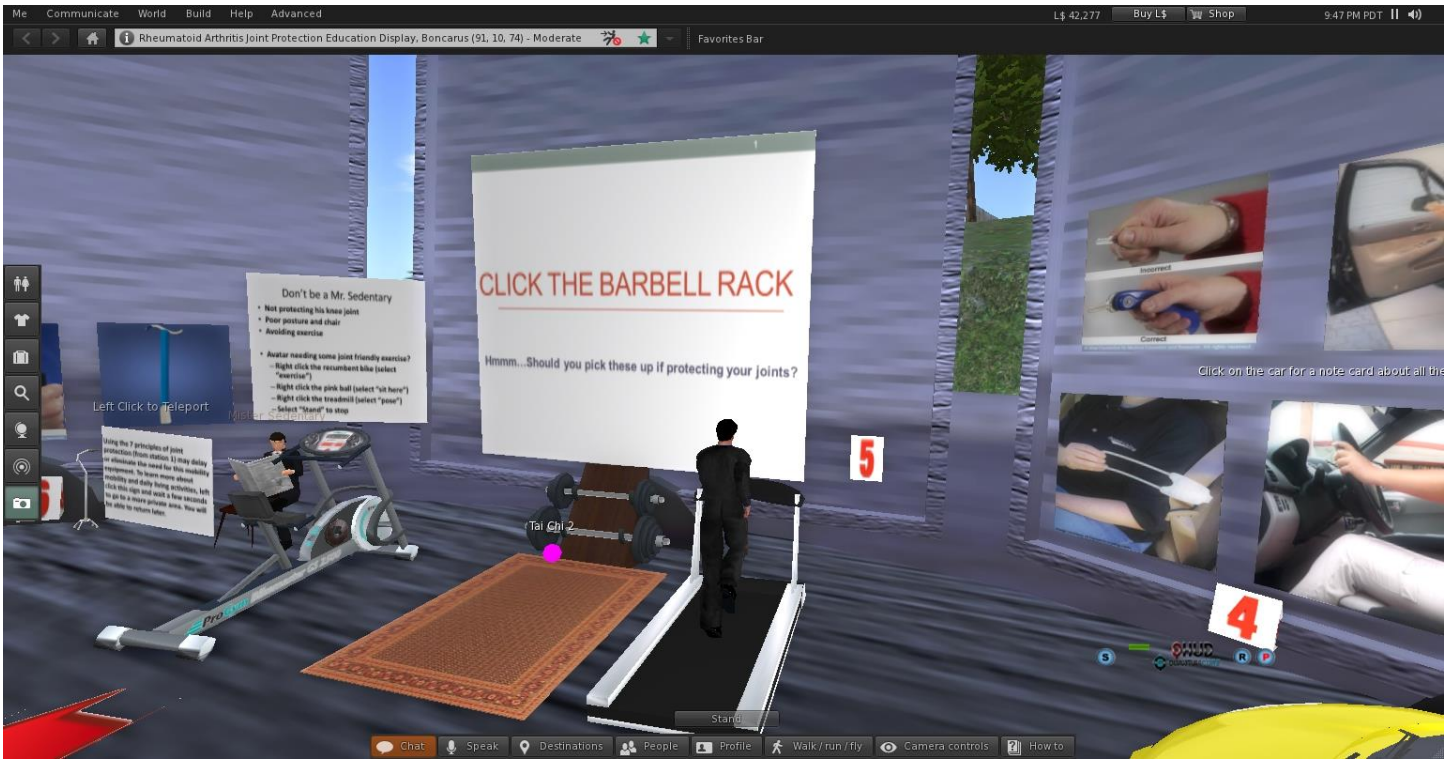


Station 2

Station 3



Station 4



Station 5

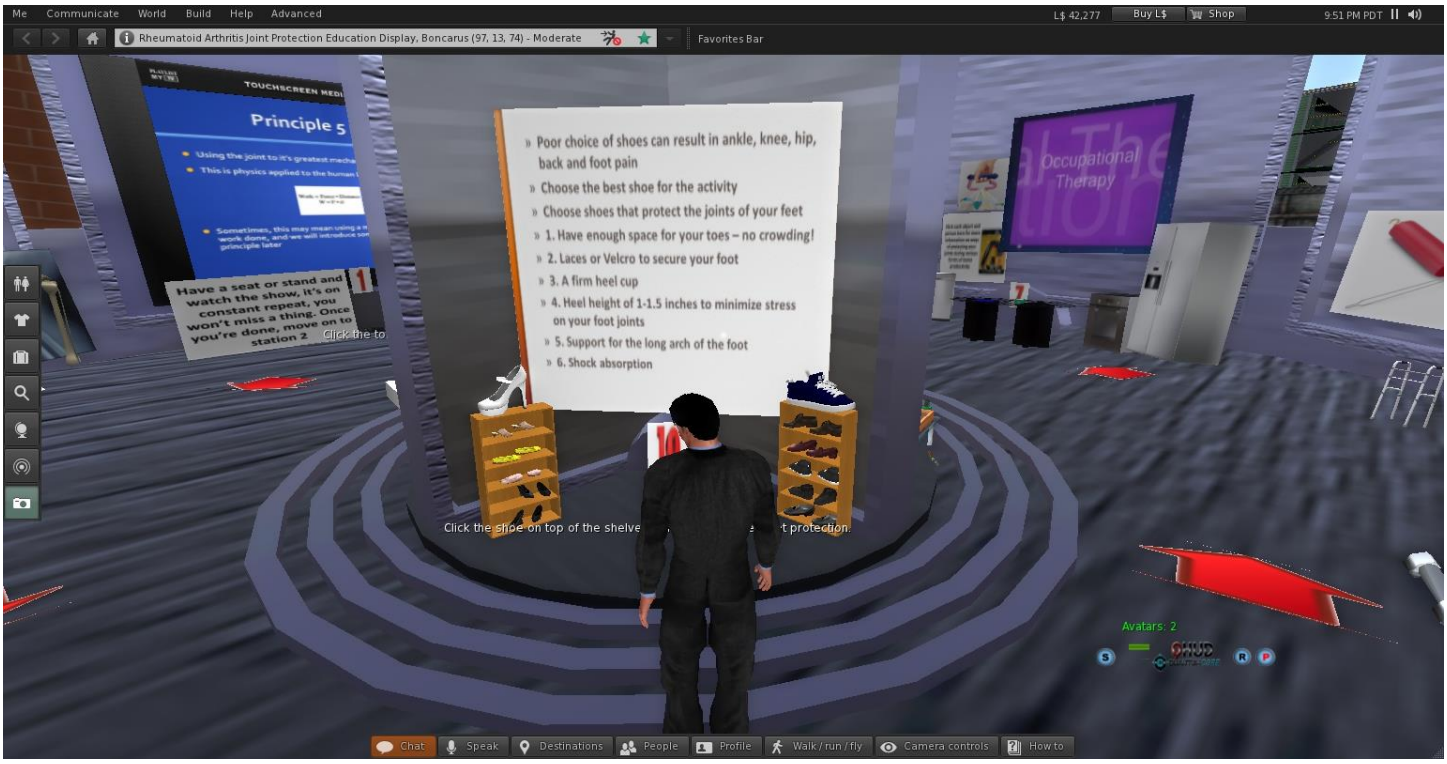
Station 5 (continued)

Station 6

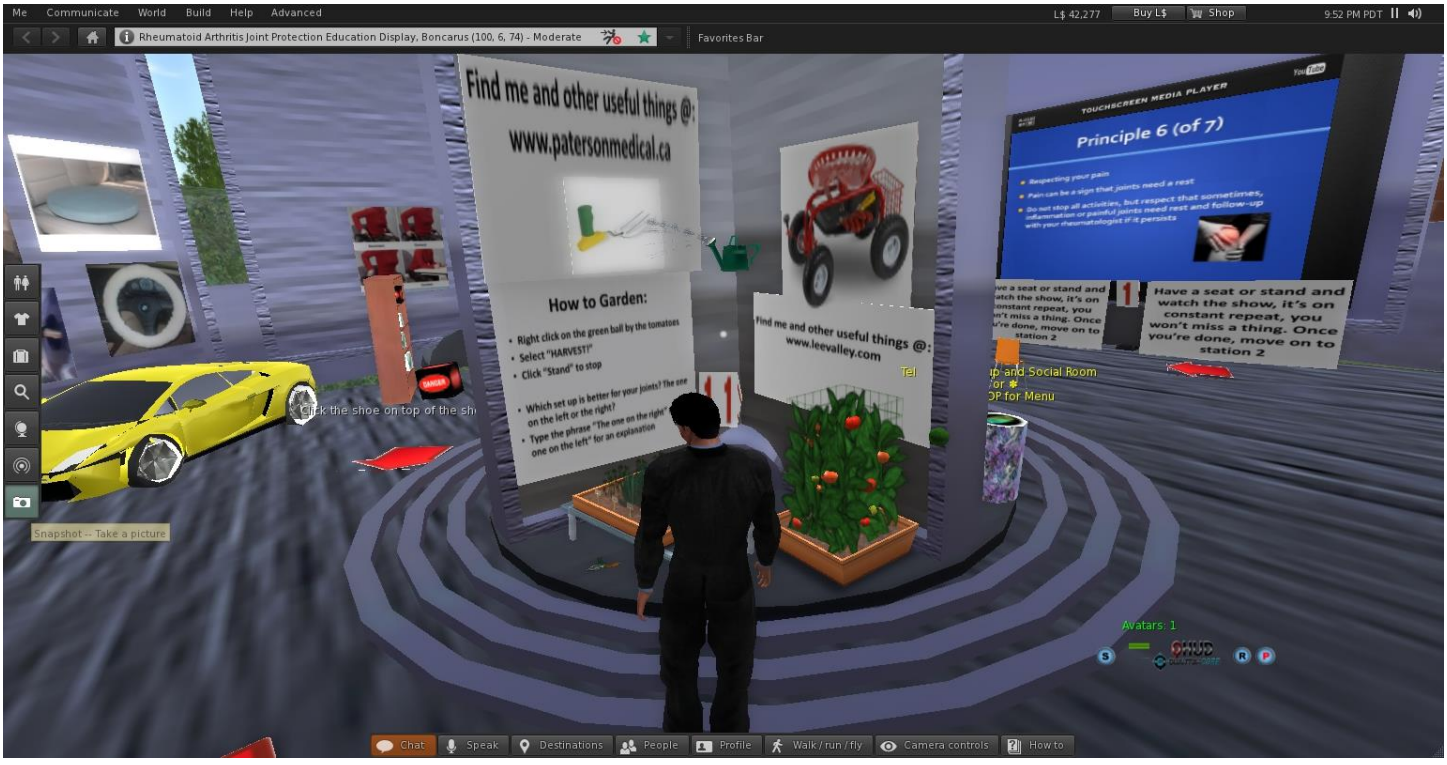
Station 7

Station 8

Station 9



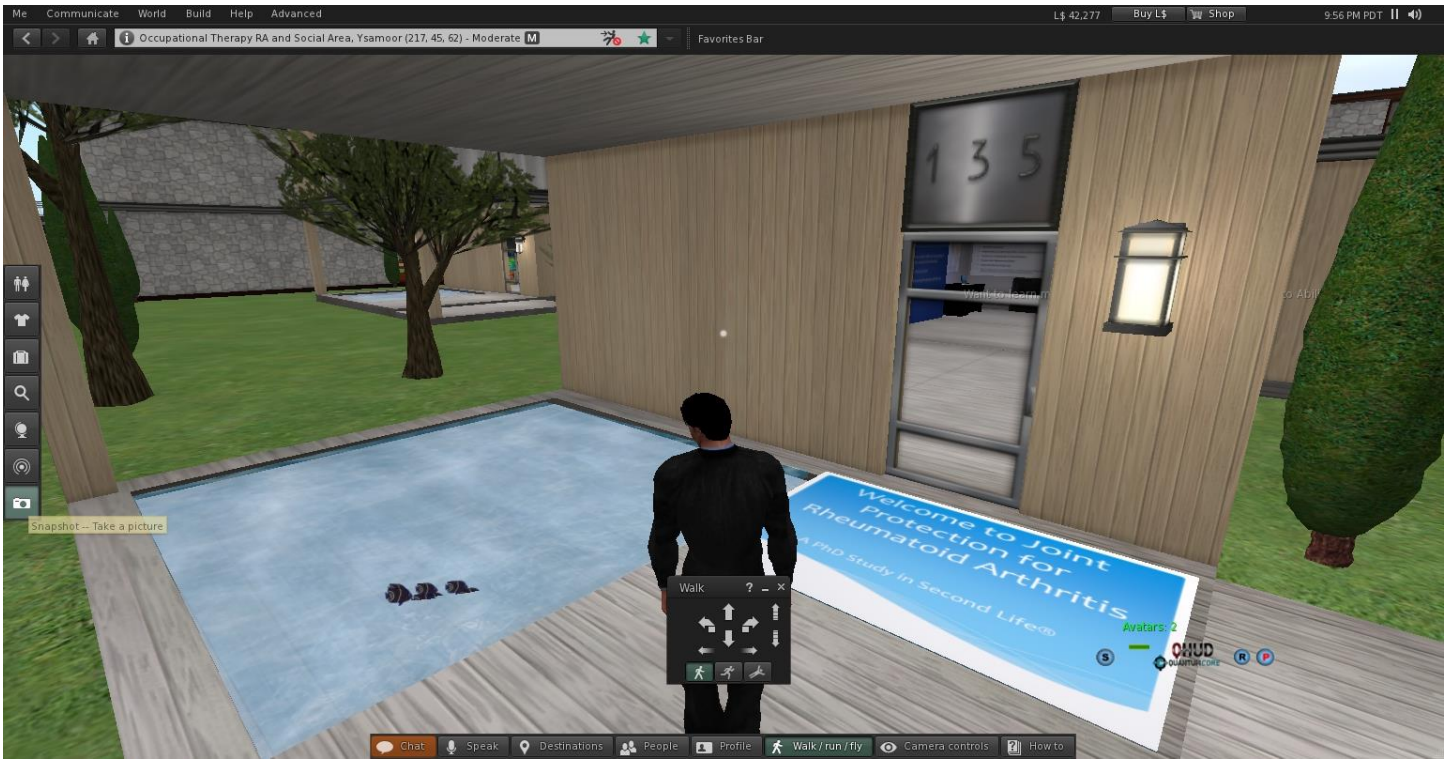
Station 10



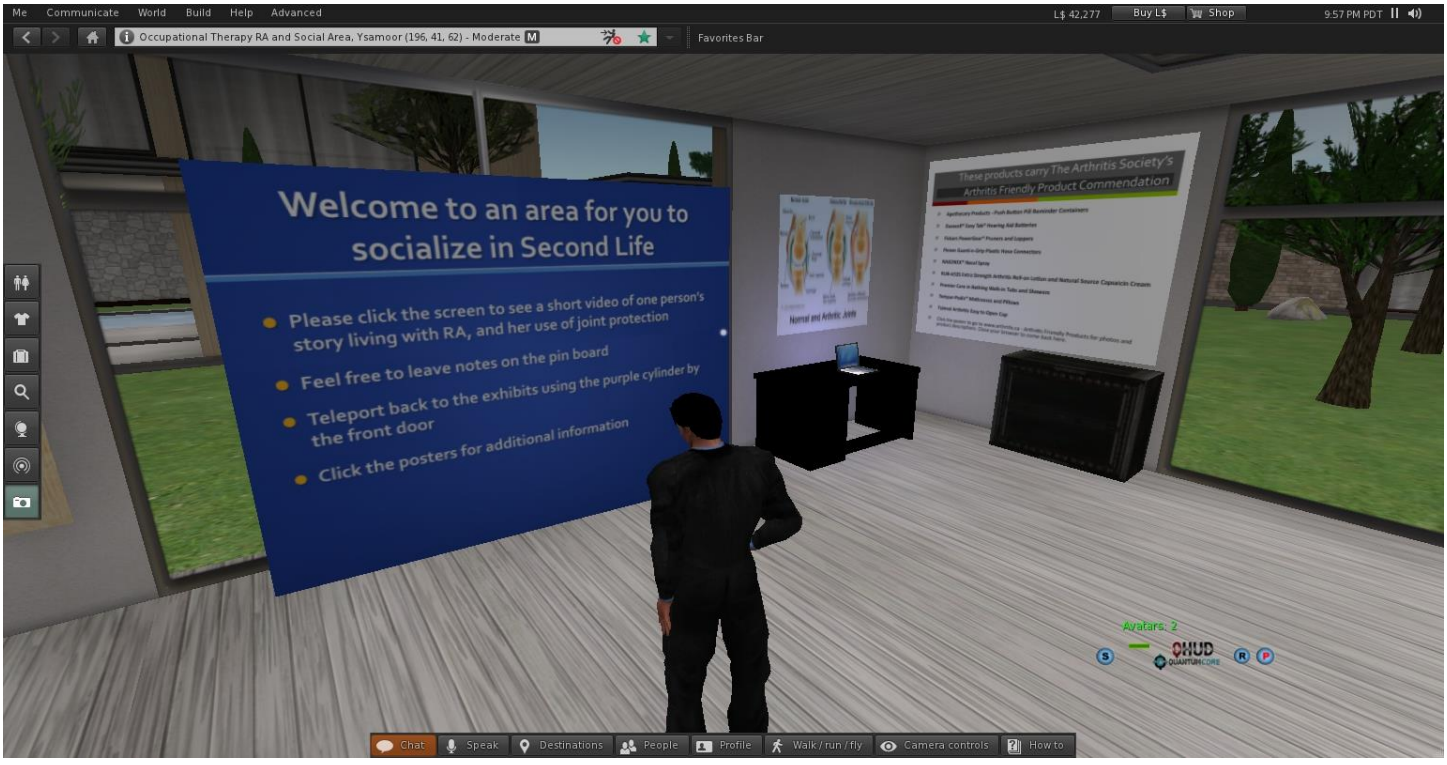
Station 11

Station 12

Group and social area house

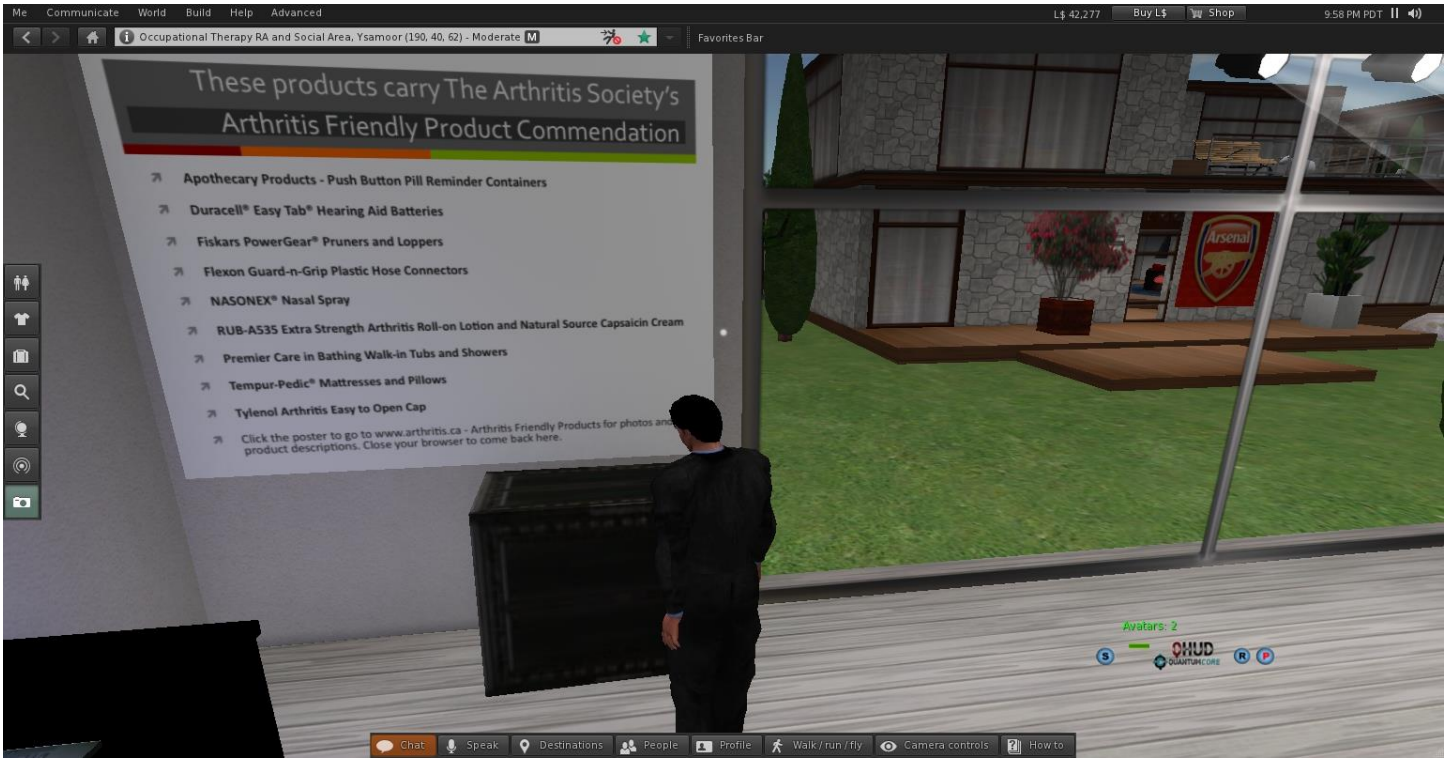


Group and social area house (continued)



Group and social area station 1

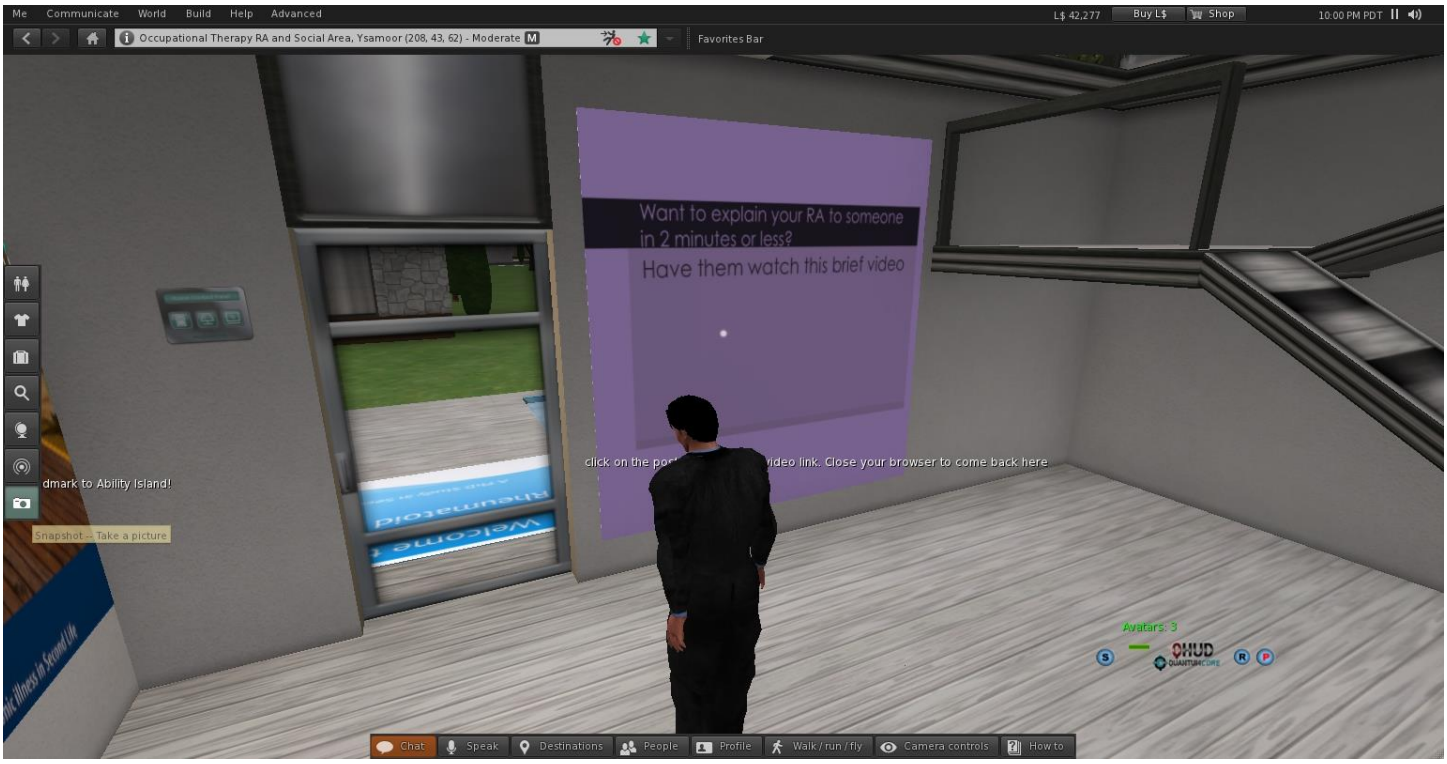
Group and social area 2



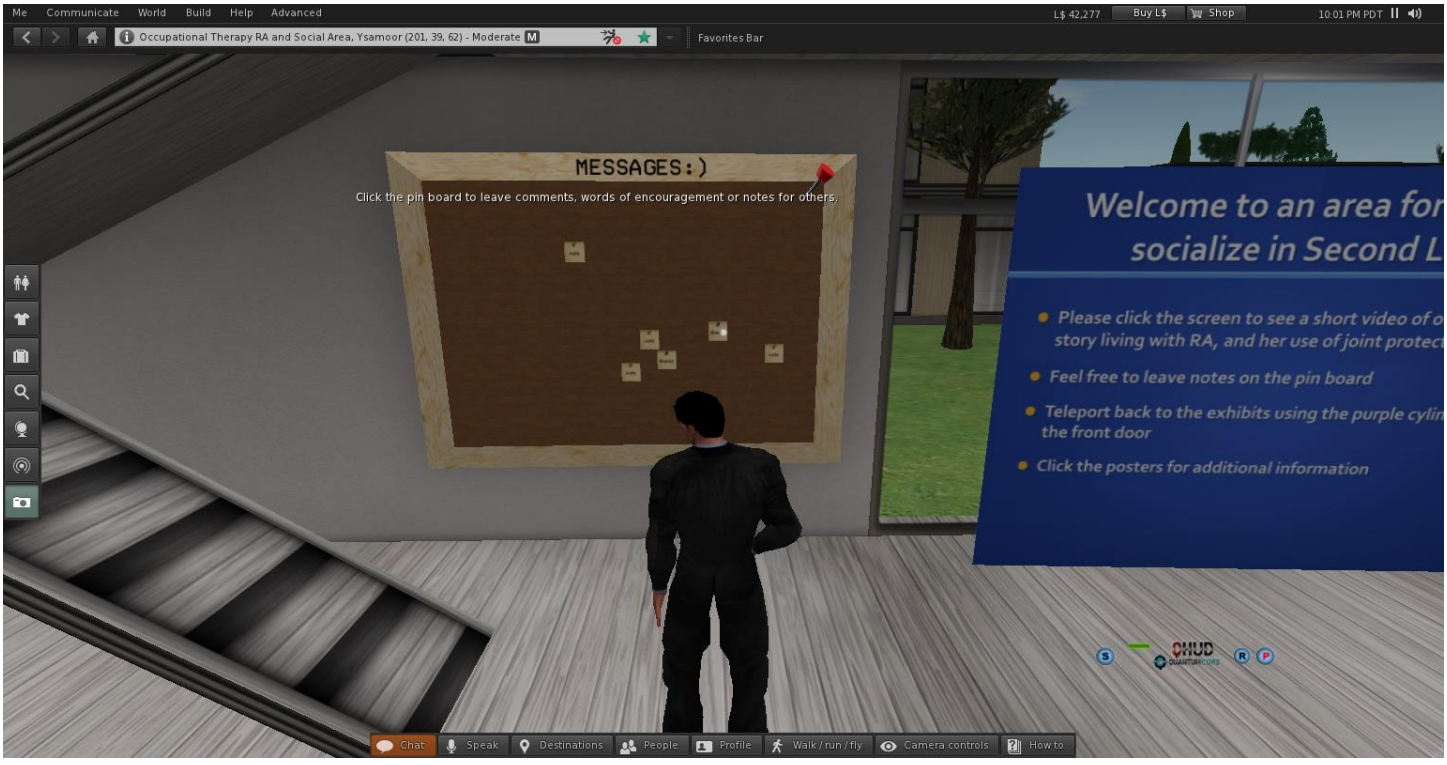
Group and social area 3

Group and social area 4

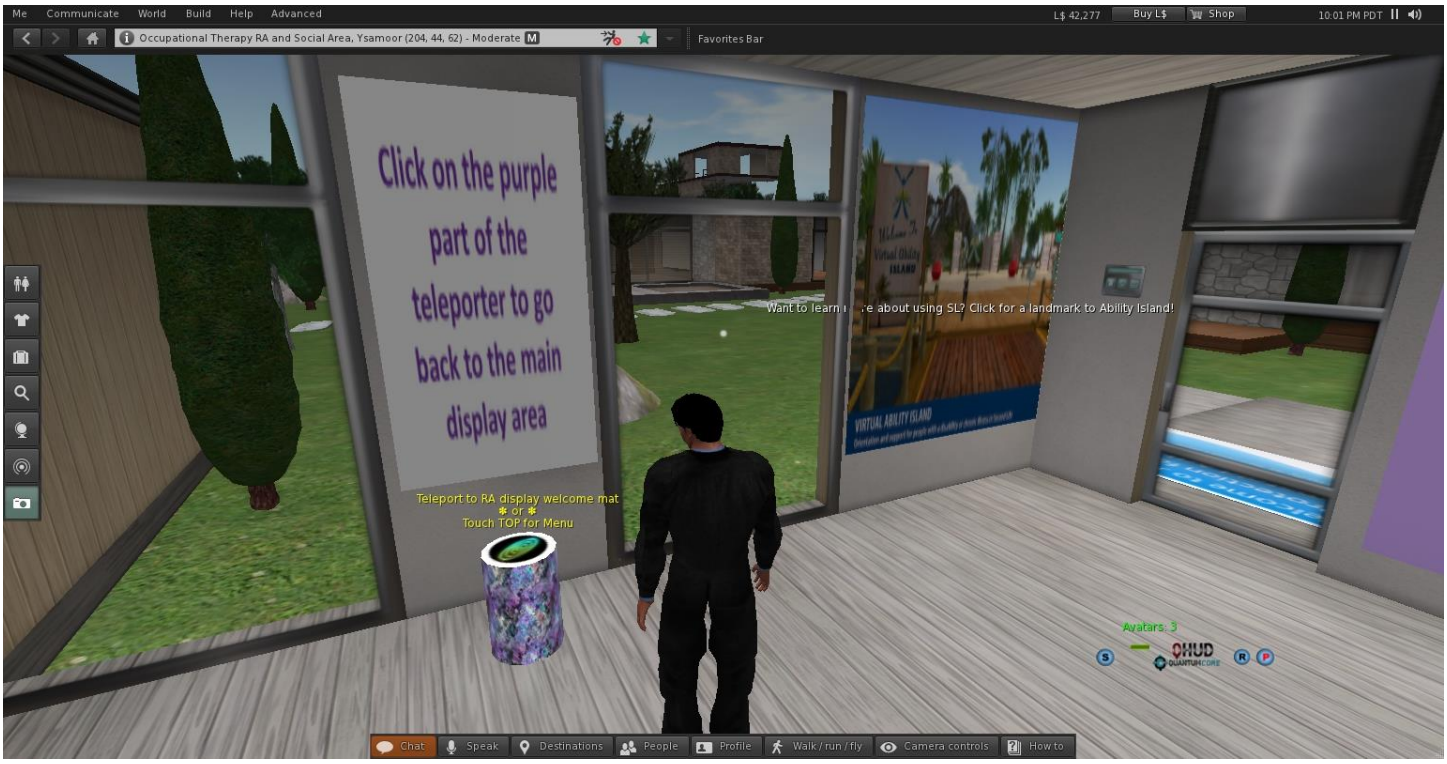
Group and social area 5



Group and social area 6



Group and social area 7



Group and social area 8

Group and social area 9

Skybox welcome area

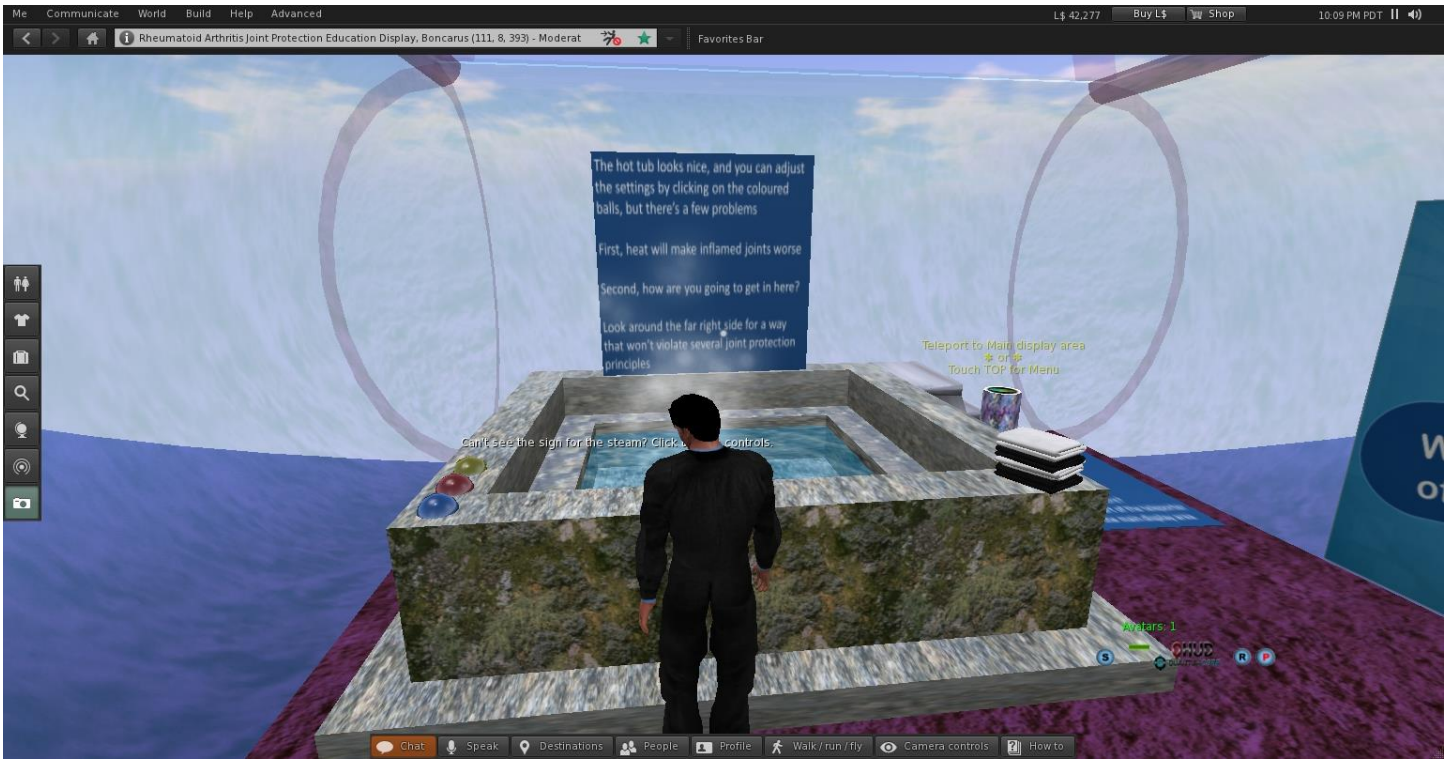
Skybox toilet area

Skybox shower area

Skybox bath area

Skybox sink area

Skybox bed area



Skybox hot tub area

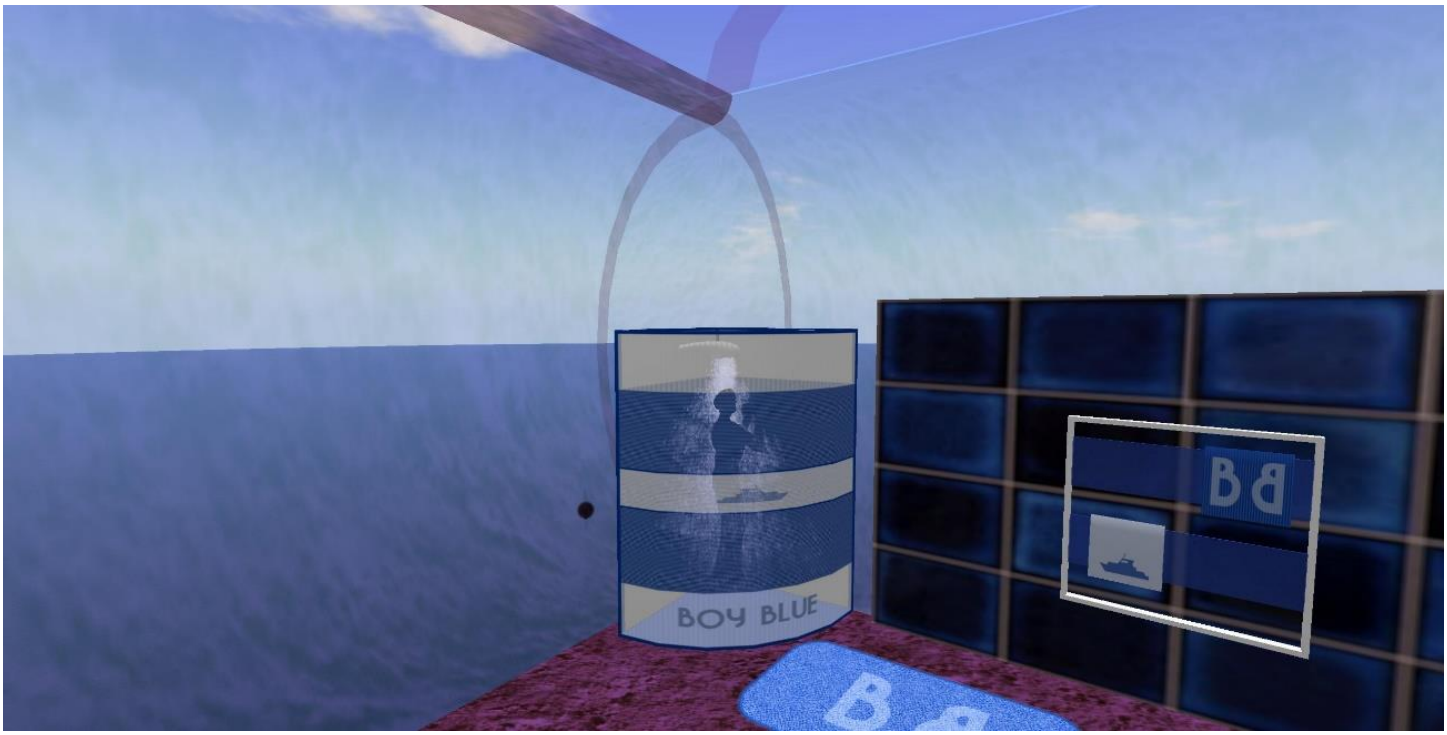
Skybox teleporter area

Appendix 2-Selected Screenshots as VW Content was Developed

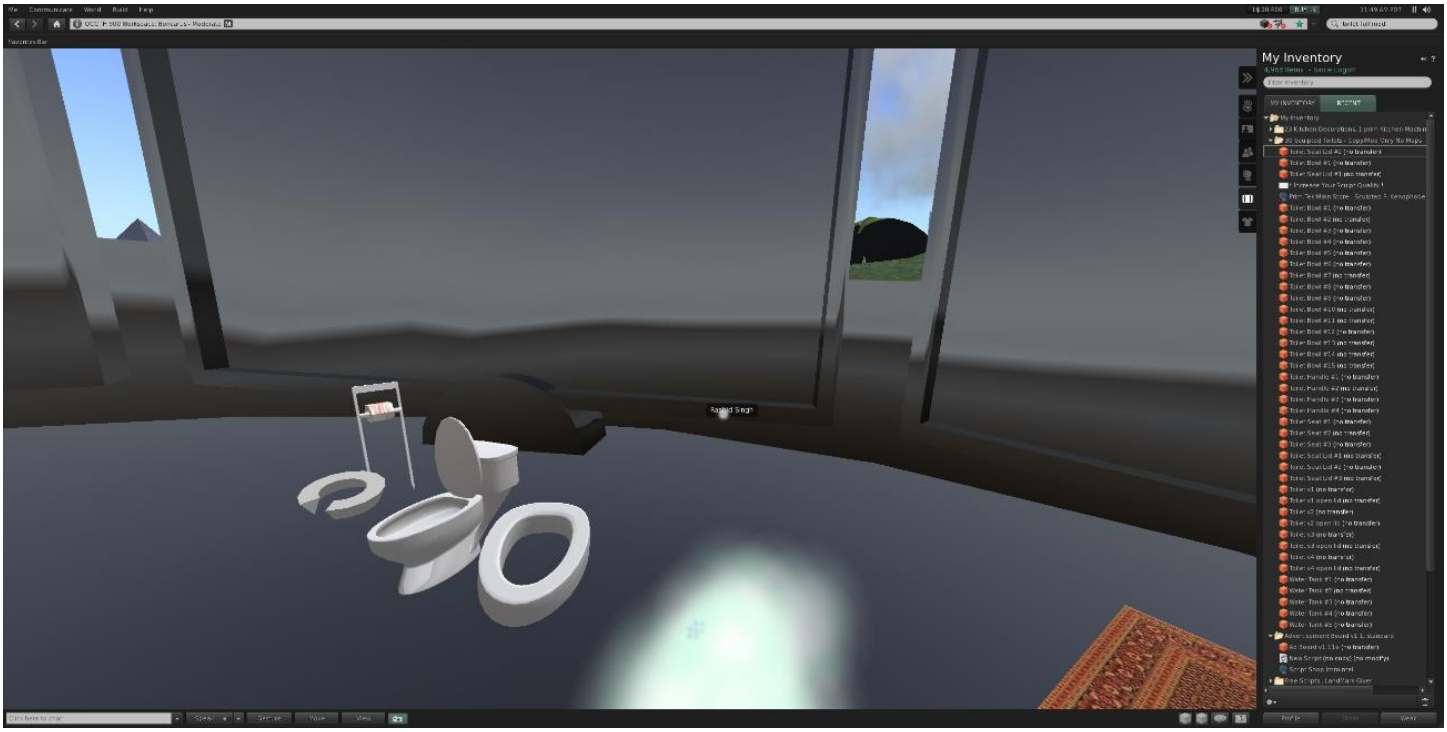
Original colour of display area, noting some objects were purchased and modified, such as the gardening props.

Initial development involved programming many objects available for purchase, including a notecard giver, a YouTube® player and artificial avatars.

Initial kitchen area, display area 7, needing both programming and resizing of screen and several other objects that needed to be added, scripted and tested, pending the successful completion of the washing machine as a prototype for other station learning objects. Note: teleporter at station 6 pictured here was replaced with the sign as it appears in the finalised form.

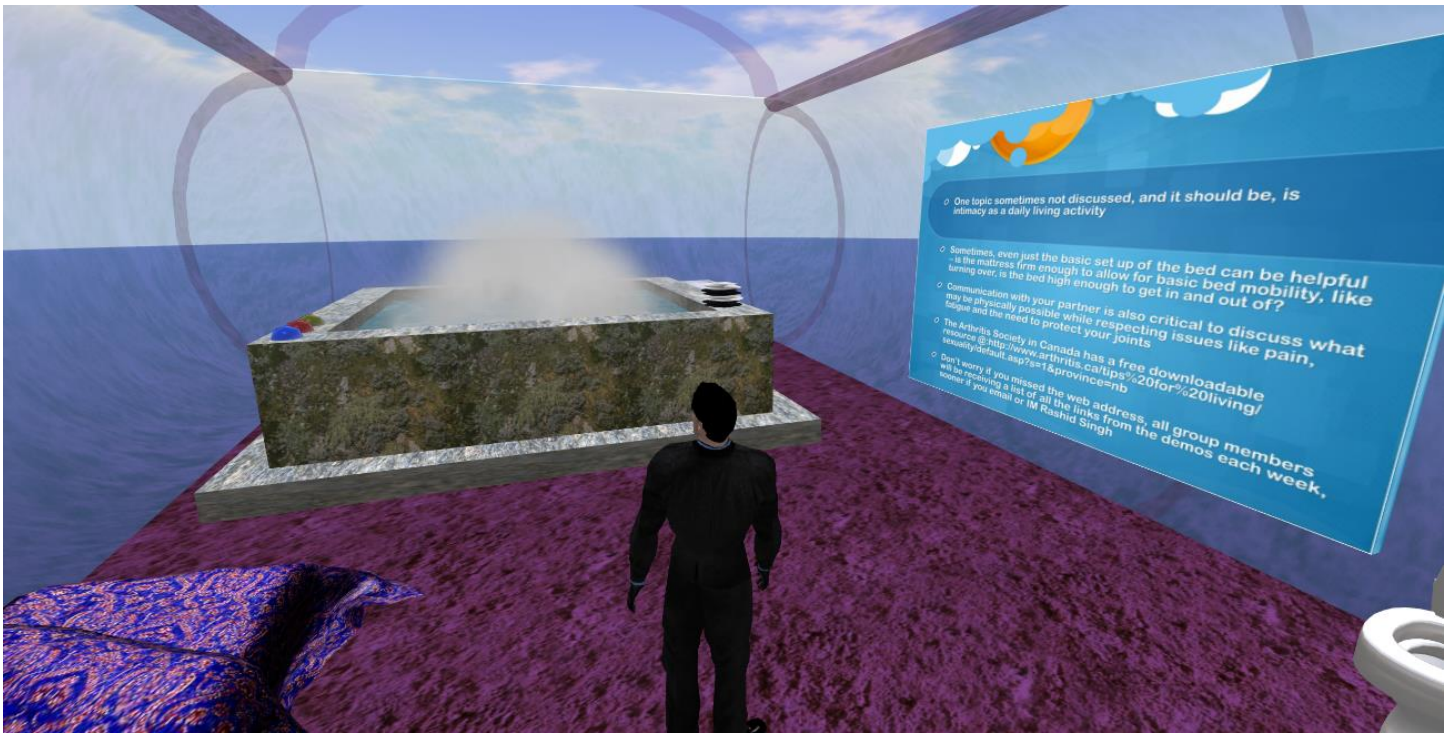


Shower door and showering animation working, including sound of running water. No information has been added yet to walls and the walls remain very transparent throughout the skybox, requiring re-programming from default settings.



Very early building of the basic ADLs content. Noting this was originally to be in the main display area, then moved based on participant feedback. There were no raised toilet seat in SL, so this involved learning how to use sculpted prims and much trial and error to build this single object. Samples of earliest attempts are pictured here.

Early development of “Easter egg” area, including determining where seating would allow for best viewing, setting landing point and programming video screen player.



Later development of skybox, noting that the walling off of the toilet area occurred later, the screen required moving and changing of the message to line up better with the display discussed, walls are still too transparent and most of the signage is still missing.

Appendix 3-Approved Invitation Letters and Posters

Phase 1 Letter-Qualitative Interviews of Occupational Therapists

UNIVERSITY OF ALBERTA

2-64 Corbett Hall
Edmonton, Alberta, Canada T6G 2G4

www.ot.ualberta.ca

Tel: 780 492 2499
Fax: 780 492 4628

Dear :

You are receiving this letter as an invitation to participate in a study involving the development of a joint protection program that can be delivered via distance using an open access virtual world (VW) program. Your participation, as an Occupational Therapist with expertise in rheumatology, would be valuable for providing input into the development of a joint protection program aimed at providing education to clients living with RA. The overall purpose of the research is to determine if such a program is effective. This pilot study aims to ensure feasibility and to develop the methodology for testing the VW program in a subsequent trial. Participation in this study is voluntary.

This research is being conducted by Rashid Kashani, Occupational Therapist and Assistant Professor, at the University of Alberta. The study is for partial completion of a PhD in Health Studies at the University of Plymouth in the United Kingdom. The supervisory team for this study is comprised of Professor Ray Jones, Dr. Anne Roberts and Dr. Maged NK Boulos at the University of Plymouth. It is not anticipated that these specific research findings will be commercialized. Results may be published in academic journals or presented at conferences, but nothing that is published will specifically identify any participant.

The time commitment anticipated is 2-3 hours to take part in 2-3 audio taped qualitative interviews and for you to trial a VW program, at your leisure, over a period of 30 days. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required. All interviews will be transcribed and personally identifying information, if any, will be removed and kept confidential. The principal investigator has a signed Oath of Confidentiality Statement regarding personally identifying information, if any, obtained through this study. While some results may be displayed, providing sample statements, they will not contain information personally identifying you. All data we get from this study (including the audio-taped data) will be maintained in a secure office for a minimum period of five years as per University of Alberta policy and then securely destroyed.

Research conducted in this study complies with University of Alberta Standards for the Protection of Human Research Participants. This policy is available for inspection at the following link to the policy manual: http://www.uofaweb.ualberta.ca/gfcpolicymanual/policymanualsection66.cfm. To participate, a signed Informed Consent form, explaining all benefits and risks, must be completed prior to participation. This form will explain potential risks and benefits, right to privacy, how information is kept secure and your right to withdraw from the study at any time up to study completion without risk or penalty to you. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

If you are interested in participating in this research, or have further questions, please contact me. If you are not interested in participating, you are under no obligation to respond and will not be contacted again.

Thank you.

Rashid Kashani, Principal Investigator (Use of VW for Clients with RA)
Occupational Therapist and Asst. Professor
Dept. of Occupational Therapy, Faculty of Rehabilitation Medicine
CH 2-64, University of Alberta, Edmonton, Alberta T6G 2G4
Kashani@ualberta.ca
Phone – (780) 492 6104 Fax – (780) 492 4628
Skype - rkashani

Poster of Phase Two Using Participants Living with RA and Having Attended or Taught in a Prior ASMP

Do you have Rheumatoid Arthritis (RA)?

Have you ever taken classes about managing your RA?

Would you like to try out a computer-based program?

We are looking for people living with RA to provide input and try out an arthritis resource delivered over the Internet. If you have RA, have taken any arthritis self-management program and would like more information about being a volunteer, please contact:

Rashid Kashani, Asst. Professor and Occupational Therapist

E-mail: kashani@ualberta.ca
Phone: (780) 492 6104
Fax: (780) 492 4628
Mail: 2-64, OT Dept., Corbett Hall, University of Alberta, Edmonton, AB. T6G 2G4

Phase 2 Letter-Qualitative Interviews of Participants Living with RA and Having Attended or Taught in a Prior ASMP

UNIVERSITY OF ALBERTA

Department of Occupational Therapy
Faculty of Rehabilitation Medicine

2-64 Corbett Hall
Edmonton, Alberta, Canada T6G 2G4

www.ot.ualberta.ca

Tel: 780 492 2499
Fax: 780 492 4628

Dear :

You are receiving this letter as an invitation to participate in a study involving the development of a joint protection program that can be delivered via distance using an open access virtual world (VW) program. Your participation, as a person living with rheumatoid arthritis (RA) and having taken or taught a self-management program yourself would be valuable for providing input into the development of a joint protection program aimed at providing education to clients living with RA. The overall purpose of the research is to determine if such a program is effective. This pilot study aims to ensure feasibility and to develop the methodology for testing the VW program in a subsequent trial. Participation in this study is voluntary.

This research is being conducted by Rashid Kashani, Occupational Therapist and Assistant Professor, at the University of Alberta. The study is for partial completion of a PhD in Health Studies at the University of Plymouth in the United Kingdom. The supervisory team for this study is comprised of Professor Ray Jones, Dr. Anne Roberts and Dr. Maged NK Boulos at the University of Plymouth. It is not anticipated that these specific research findings will be commercialized. Results may be published in academic journals or presented at conferences, but nothing that is published will specifically identify any participant.

The time commitment anticipated is 2-3 hours to take part in 2-3 audio taped qualitative interviews and for you to trial a VW program, at your leisure, over a period of 30 days. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required. All interviews will be transcribed and personally identifying information, if any, will be removed and kept confidential. The principal investigator has a signed Oath of Confidentiality Statement regarding personally identifying information, if any, obtained through this study. While some results may be displayed, providing sample statements, they will not contain information personally identifying you. All data we get from this study (including the audio-taped data) will be maintained in a secure office for a minimum period of five years as per University of Alberta policy and then securely destroyed.

Research conducted in this study complies with University of Alberta Standards for the Protection of Human Research Participants. This policy is available for inspection at the following link to the policy manual: http://www.uofaweb.ualberta.ca/gfcpolicymanual/policymanualsection66.cfm. To participate, a signed Informed Consent form, explaining all benefits and risks, must be completed prior to participation. This form will explain potential risks and benefits, right to privacy, how information is kept secure and your right to withdraw from the study at any time up to study completion without risk or penalty to you. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

If you are interested in participating in this research, or have further questions, please contact me. If you are not interested in participating, you are under no obligation to respond and will not be contacted again.

Thank you.

Rashid Kashani, Principal Investigator (Use of VW for Clients with RA)
Occupational Therapist and Asst. Professor
Dept. of Occupational Therapy, Faculty of Rehabilitation Medicine
CH 2-64, University of Alberta, Edmonton, Alberta T6G 2G4
Kashani@ualberta.ca
Phone – (780) 492 6104 Fax – (780) 492 4628
Skype - rkashani

Phase 3 Poster for RCT

Do you have Rheumatoid Arthritis (RA)?
Would you like to access a free program on joint protection?
We are looking for people living with RA to try out and provide input on this resource that is:
Available over the internet
Accessible 24/7
Designed by Occupational Therapists and people living with RA
If you have RA, have not yet taken a program or classes to manage your RA, are 18 or older and have access to a computer, please contact:
Rashid Kashani, Occupational Therapist and PhD student
Email: rkashani@shaw.ca
Phone: (780) 619 4269
Mail: PO Box 52196, Edmonton, AB T6G 2G4

This study is for partial completion of a PhD at the University of Plymouth, Devon, UK and has been approved by an Ethics Research Review Panel (Alberta).

Kashani, R. VWs, Clients with RA and Joint Protection: A Pilot RCT

Phase 3 Invitation Letter to Pilot RCT

UNIVERSITY OF ALBERTA

2-64 Corbett Hall Edmonton, Alberta, Canada T6G 2G4

Tel: 780 492 2499 Fax: 780 492 4628 (www.ot.ualberta.ca)

Hello

You are receiving this letter as an invitation to participate in a study involving the development of a joint protection program that can be delivered via distance using an open access virtual world (VW) program. Your participation, as a person living with rheumatoid arthritis (RA) and having taken or taught a self-management program yourself would be valuable for providing input into the development of a joint protection program aimed at providing education to clients living with RA. The overall purpose of the research is to determine if such a program is effective. This pilot study aims to ensure feasibility and to develop the methodology for testing the VW program in a subsequent trial. Participation in this study is voluntary.

This research is being conducted by Rashid Kashani, Occupational Therapist and Assistant Professor, at the University of Alberta. The study is for partial completion of a PhD in Health Studies at the University of Plymouth in the United Kingdom. The supervisory team for this study is comprised of Professor Ray Jones, Dr. Anne Roberts and Dr. Maged NK Boulos at the University of Plymouth. It is not anticipated that these specific research findings will be commercialized. Results may be published in academic journals or presented at conferences, but nothing that is published will specifically identify any participant.

The time commitment anticipated is 1–2 hours for you to trial a VW program, at your leisure, over a period of 30 days. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required to use the program and you will also answer a short survey. Personally identifying information, if any, will be removed and kept confidential. The principal investigator has a signed Oath of Confidentiality Statement regarding personally identifying information, if any, obtained through this study. While some results may be displayed, providing sample statements, they will not contain information personally identifying you. All data we get from this study (including the audio-taped data) will be maintained in a secure office for a minimum period of five years as per University of Alberta policy and then securely destroyed.

Research conducted in this study complies with University of Alberta Standards for the Protection of Human Research Participants. This policy is available for inspection at the following link to the policy manual: http://www.uofaweb.ualberta.ca/gfcpolicymanual/policymanualsection66.cfm. To participate, a signed Informed Consent form, explaining all benefits and risks, must be completed prior to participation. This form will explain potential risks and benefits, right to privacy, how information is kept secure and your right to withdraw from the study at any time up to study completion without risk or penalty to you. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

If you are interested in participating in this research, or have further questions, please contact me. If you are not interested in participating, you are under no obligation to respond and will not be contacted again.

Thank you.

Rashid Kashani, Principal Investigator (Use of VW for Clients with RA)
Occupational Therapist and PhD Student
PO Box 52196 Edmonton AB T6G 2T5
rkashani@shaw.ca
Phone – (780) 619 4269 Fax – (780) 436 4268
Skype - rkashani

Appendix 4-Ethical Approvals for Each Study Phase and Administrative Approval for Pilot RCT Recruitment (Phase 3)

Phase 1:

Approval Form (as accessed from HERO workspace)

ID:	Pro00013515
Title:	Virtual Worlds, OT and RA
Study Investigator:	Rashid Kashani
Description:	This is to inform you that the above study has been approved.

Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

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Phase 2:

Approval Form

Principal Investigator:	Rashid Kashani
Study ID:	Pro00013549
Study Title:	The Use of Virtual Worlds Technology for Educating Clients with Rheumatoid Arthritis - The "Client as Expert" Perspective

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application, including revisions received today, has been reviewed and approved on behalf of the committee.
A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.
Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services administrative approval, and operational approval for areas impacted by the research, should be directed to the Alberta Health Services Regional Research Administration office, #1800 College Plaza, phone (780) 407-6041.

Sincerely,
Beverley O'Brien, DNSc.
Chair, Health Research Ethics Board - Health Panel
Note: This correspondence includes an electronic signature (validation and approval via an online system).

Phase 3:

-Original Message-----
From: hero@ualberta.ca [mailto:hero@ualberta.ca]
Sent: Thu 26/05/2011 1:27 PM
To: Kashani, Rashid
Participant: HERO: Your Ethics Application is Approved

University of Alberta <http://www.ualberta.ca/img/200x50.gif>

_____

Ethics Application has been Approved

ID: Pro00020496
<https://hero.ualberta.ca/HERO/Rooms/DisplayPages/LayoutInitial?Container=com.webridge.entity.Entity[OID[659C987A359347498E049A2D0361D417]]>
Title: Teaching Clients How to Manage Rheumatoid Arthritis Using Joint Protection Techniques: A Pilot Randomized Control Trial of a Virtual World Program
Study Investigator: Rashid Kashani
<https://hero.ualberta.ca/HERO/Personalization/MyProfile?Person=com.webridge.account.Person%5BOID%5BE8D6E681489ECC409B8468034ECCD497%5D%5D>
Description: This is to inform you that the above study has been approved.

Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

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<http://www.edmonton.ca/>

Administrative Approval Phase 3:

To:
Rashid Kashani BA, BSc, BScOT, MScOT (C)(R)
Professional Practice Leader, Occupational Therapy
University of Alberta Hospital/Stollery Children's Hospital/Mazankowski Alberta Heart Institute/Kaye Clinic
Aberhart #1, Room 8311
11402 University Avenue
Edmonton, Alberta T6G 2J3
Phone: 780 407 1333
Email: rashid.kashani@albertahealthservices.ca

I am in Tuesdays, Wednesdays & Thursdays

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From: operationalapprovals@encaps.com [mailto:operationalapprovals@encaps.com]
Sent: Thursday, January 23, 2014 7:54 AM
To: Rashid Kashani
Participant: Operational Approval (#20788) - Approved

Hello,

Your request has been approved and a copy has been sent to NACTRC on your behalf (see the attached pdf.)

Grantor Type	Grantor	Decision	Response Given On	Comments	Phone Number
ASSESSOR	Andrew Switzer	Approved	Jan-22-2014 16:25	As stated in outline no AHS resources required to conduct study.	780-407-1924
ASSESSOR	Karen Yukes	Pending			780-407-7100
APPROVER	Elizabeth Seib	Approved	Jan-23-2014 07:53		780-407-2748

Site / Area: Kaye Edmonton Clinic / Rheumatology
PI Name: Rashid Kashani
Protocol Title: Teaching Clients How to Manage Rheumatoid Arthritis Using Joint Protection Techniques: A Pilot Randomized Control Trial of a Virtual World Program

If you need assistance, please contact operationalapprovals@nactrc.ca

Thank you.

This message and any attached documents are only for the use of the intended recipient(s), are confidential and may contain privileged information. Any unauthorized review, use, retransmission, or other disclosure is strictly prohibited. If you have received this message in error, please notify the sender immediately, and then delete the original message. Thank you.

Appendix 5-Information Letters and Consent Forms for Phases 1-3 of study

Phase 1

UNIVERSITY OF ALBERTA

2-64 Corbett Hall | www.ot.ualberta.ca | Tel: 780 492 2499

Edmonton, Alberta, Canada T6G 2G4 | Fax: 780 492 4628

CONSENT FORM

Title of Research Study: **The Use of Virtual Worlds Technology for Educating Clients with Rheumatoid Arthritis the Occupational Therapy Perspective**

Principal Investigator(s): Rashid Kashani
Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos

You are being invited to take part in this study because you are an occupational therapist who has treated clients living with rheumatoid arthritis (RA). I would like to interview you and find what your expectations of a joint protection program or classes you may have offered to clients living with RA and what those experiences have been. I will be creating a virtual world (VW) based joint protection program based on information you provide in your interview. I would also like you to trial the virtual world based program based on your input and provide feedback on it.

What will you have to do?: If you agree to take part, I will ask you to come to my office 2 times, and possibly a third time, over a period of 2 months. I will ask you to provide me with information regarding your opinions and expectations of a joint protection program aimed at clients with RA. A VW program will be developed based on the input you provide and you will have opportunity to trial the program over a period of 30 days. If you do not have computer access, I can arrange it for you. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required.

Following the 30-day trial, you will be asked for feedback about your experiences using the program. If revisions are required, a third interview may be necessary. Each interview is anticipated to take up to one hour. Interviews will be audio taped and then transcribed.

Benefits: There may be no direct benefit to you for participating in this study. We hope that the information that we get from the study may assist in the development of new media to deliver education / treatment to clients that might not otherwise receive it and increase access to programs for future clients. You may be interested in seeing how a VW can work for your clients.

Risks: We do not anticipate that this study will pose any risks to you. You will have to use a computer, possibly more than you are used to. Typing is minimal for the intended program, but as with any computer use, there may be a low risk of repetitive strain. There are some time constraints for the trial period, so a 30-day trial period has been selected to fit into your schedule and minimize potential stress.

Voluntary Participation: Participating in this study is voluntary and you can quit at any time up until completion of all study interviews. All you have to do is send me an e mail and I will not contact you again.

Confidentiality: All information will be kept confidential. The principal investigator has a signed Oath of Confidentiality Statement regarding personally identifying information, if any, obtained through this study. All data will be maintained in a secure office for a period of five years as determined by policy at the University of Alberta and then securely destroyed. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

Do you have more questions? If you want to find out more, you can talk to me via phone (780) 492 6104 or email (Kashani@ualberta.ca) at any time.

Part 1 (to be completed by the Principal Investigator):

Title of Project: The Use of Virtual Worlds Technology for Educating Clients with Rheumatoid Arthritis – The Occupational Therapy Perspective

Principal Investigator(s): Rashid Kashani Phone Number(s): 780 492 6104 / 780 619 4269

Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos Phone Number: 011 44 1752 587640

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand benefits & risks involved in taking part in this study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant

_____

(Printed Name) _____ Date:_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Phase 2

UNIVERSITY OF ALBERTA

2-64 Corbett Hall | www.ot.ualberta.ca | Tel: 780 492 2499

Edmonton, Alberta, Canada T6G 2G4 | Fax: 780 492 4628

CONSENT FORM

Title of Research Study: **The Use of Virtual Worlds Technology for Educating Clients with Rheumatoid Arthritis: The "Client as Expert" Perspective**

Principal Investigator(s): Rashid Kashani
Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos

You are being invited to take part in this study because you are living with rheumatoid arthritis (RA) and have previously completed or taught a self-management course in arthritis. I would like to interview you and find what your expectations of a joint protection program, or classes you may have received, and what those experiences have been. I will be creating a virtual world (VW) based joint protection program based on information you provide in your interview. I would also like you to trial the virtual world based program based on your input and provide feedback on it.

What will you have to do?: If you agree to take part, I will ask you to come to my office 2 times, over a period of 2 months. I will ask you to provide me with information regarding your opinions and expectations of a joint protection program aimed at clients living with RA. A VW program will be developed based on the input you provide and you will have opportunity to trial the program over a period of 30 days. If you do not have computer access, I can arrange it for you. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required.

Following the 30-day trial, you will be asked for feedback about your experiences using the program. If revisions are required, a third interview may be necessary. Each interview is anticipated to take up to one hour. Interviews will be audio taped and then transcribed.

Benefits: There may be some direct benefit to you for participating in this study. You may get new information regarding joint protection techniques. We hope that the information that we get from the study may assist in the development of new media to deliver education / treatment to other clients that might not otherwise receive it and increase access to programs for future clients. You may be interested in seeing how a VW can work for your ongoing RA management.

Risks: We do not anticipate that this study will pose any risks to you. You will have to use a computer, possibly more than you are used to. Typing is minimal for the intended program, but as with any computer use, there may be a low risk of repetitive strain. There are some time constraints for the trial period, so a 30-day trial period has been selected to fit into your schedule and minimize potential stress.

Voluntary Participation: Participating in this study is voluntary and you can quit at any time up until completion of all study interviews. All you have to do is send me an e mail and I will not contact you again.

Confidentiality: All information will be kept confidential. The principal investigator has a signed Oath of Confidentiality Statement regarding personally identifying information, if any, obtained through this study. All data will be maintained in a secure office for a period of five years as determined by policy at the University of Alberta and then securely destroyed. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

Do you have more questions? If you want to find out more, you can talk to me via phone (780) 492 6104 or email (Kashani@ualberta.ca) at any time.

Part 1 (to be completed by the Principal Investigator):

Title of Project: **The Use of Virtual Worlds Technology for Educating Clients with Rheumatoid Arthritis: The "Client as Expert" Perspective**

Principal Investigator(s): Rashid Kashani Phone Number(s): 780 492 6104 / 780 619 4269

Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos Phone Number: 011 44 1752 587640

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand benefits & risks involved in taking part in this study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant

_____

(Printed Name) _____ Date:_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Phase 3

UNIVERSITY OF ALBERTA

2-64 Corbett Hall | www.ot.ualberta.ca | Tel: 780 492 2499

Edmonton, Alberta, Canada T6G 2G4 | Fax: 780 492 4628

CONSENT FORM

Title of Research Study: **Teaching Clients How to Manage Rheumatoid Arthritis Using Joint Protection Techniques: A Pilot Randomized Control Trial of a Virtual World Program**

Principal Investigator(s): Rashid Kashani
Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos

You are being invited to take part in this study because you are living with rheumatoid arthritis (RA) and have not yet taken a self-management course in arthritis. I would like to invite you to trial a virtual world (VW) based program geared towards joint protection and self-management of RA.

What will you have to do?: If you agree to take part, I will invite you to trial the VW program over a period of 30 days. The time you spend using this program is entirely up to you, as you will have 24-hour access. A minimum of one hour is anticipated as being required. You will be able to move around various interactive displays and exhibits and get information about joint protection.

At some point in the 30-day trial, you will be asked to complete short surveys about your arthritis and you will be able to give feedback about your experiences using the program. The surveys are short, taking less than 20 minutes to complete and you will have a choice if preferring to complete this survey by email or regular mail service. Any information about who you are, such as email address or name will be removed and kept secure prior to being used in the study.

Benefits: There may be some direct benefit to you for participating in this study. You may get new information regarding joint protection techniques. We hope that the information that we get from the study may assist in the development of new media to deliver education / treatment to other clients that might not otherwise receive it and increase access to programs for future clients. You may be interested in seeing how a VW can work for your ongoing RA management.

Risks: We do not anticipate that this study will pose any risks to you. You will have to use a computer, possibly more than you are used to. Typing is minimal for the intended program, but as with any computer use, there may be a low risk of repetitive strain. There are some time constraints for the trial period, so a 30-day trial period has been selected to fit into your schedule and minimize potential stress.

Voluntary Participation: Participating in this study is voluntary and you can quit at any time up until completion of all study interviews. All you have to do is send me an e mail and I will not contact you again.

Confidentiality: All information obtained through this study will be kept confidential. All data will be maintained in a secure office for a period of five years as determined by policy at the University of Alberta and then securely destroyed. You may also contact the University of Alberta Health Research Ethics Board at (780) 492 0302 should there be any questions regarding your rights as a research participant.

Do you have more questions? If you want to find out more, you can talk to me via phone (780) 492 6104 or email (Kashani@ualberta.ca) at any time.

Part 1 (to be completed by the Principal Investigator):

Title of Project: Teaching Clients How to Manage Rheumatoid Arthritis Using Joint Protection Techniques: A Pilot Randomized Control Trial of a Virtual World Program

Principal Investigator(s): Rashid Kashani Phone Number(s): 780 492 6104 / 780 619 4269

Co-Investigator(s): Ray Jones, Anne Roberts, Maged KN Boulos Phone Number: 011 44 1752 587640

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand benefits & risks involved in taking part in this study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable information?	☐	☐

Who explained this study to you? _____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant

_____

(Printed Name) _____ Date:_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix 6-Semi-structured Interview Questions for Phase 1 and 2 of Study

Phase 1 Interviews with therapists to inform VW development:

Interview Script-Interview 1:

The purpose of this interview is to gain an understanding of your experiences in teaching joint protection techniques to clients living with Rheumatoid Arthritis (RA) and your expectations of a virtual world (VW) based program themed around RA and joint protection. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. Tell me about your history of working with clients living with RA.

   Potential probes-How long? Types of interventions used? Do you teach joint protection? How much time is specifically spent on joint protection?

2. What do you consider essential content in a RA self-management program specific to joint protection?

   Potential probes-Do you cover: bADLs? iADLs? Work? Leisure? Any specific activities?

3. Is there any other content you would like to add that you presently do not cover in a RA self-management program specific to joint protection? If so, what is it?

   Potential probes-Why is the material not presently covered? Are there plans to cover that content? What barriers exist in adding content to programs?

4. In your opinion, are there clients who may benefit from a RA self-management program who do not attend? If so, what do you think are barriers to attending such a program?

5. When you teach a joint protection class or give a client information on joint protection, are there some participants that you might feel uncomfortable discussing either in a group setting or individually?

   Potential probes-Do you cover topics such as sexual health, peri-care or toileting? Do clients seem hesitant in discussing these topics in groups or individually?

6. Are there any tools you presently use to determine the effectiveness of your joint protection teaching or self-management program as a whole? How do you determine the effectiveness of your interventions?

   Potential probes-Do you use informal measures like client feedback? Can you identify a tool or tools that might be of use that you presently do not use?

7. If an online means of delivering self-management content was available, what would your expectations be of that web-based content?

8. Do you have concerns regarding this being used as an alternative to traditional in-person methods being presently used in most self-management programs?

Potential probes-Any concerns regarding safety? Ability to interact with a professional? Is the client missing anything else you typically provide in a self-management program? Any barriers/limitations regarding access?

9. Is there anything else I should know about your experiences or opinions regarding teaching joint protection to clients living with RA?

10. Is there anything else I should know about your experiences or opinions regarding the use of a VW based program to teach joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, a VW program will be developed and you will be invited to trial it for up to 30 days. You will be invited to a follow up interview to provide feedback. If significant revisions are required of the program, you may be invited to a third interview to provide further feedback.

Interview Script 2 Following Trial of VW:

You have had an opportunity to trial a VW program intended to teach joint protection techniques to clients with RA. This program was based on themes derived from analysing input from OTs, including yourself, with experience in delivering this information as part of a self-management program in RA. Today you will be asked for feedback on this program. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. What your experiences were in trialling the virtual world program?

Potential probes-Were there negative experiences? Were there positive experiences? Did anything surprise you? Did anything disappoint you? How much time did you spend using the program?

2. Did the VW program cover the main content of what you typically cover in a RA self-management program?

Potential probes-Was there something missing? Was there anything above the usual content?

3. If you had this program as an option for clients to use, with what type of clients would you use it?

Potential probes-Would clients who cannot attend a traditional program benefit? What are some of the reasons that these clients cannot or do not attend?

4. If this program was an option for clients to use, are there any clients you would not recommend this program for?

Potential probes-Is access to the Internet an issue? Is computing skills an issue? Do you see a certain segment of newly diagnosed clients not being able to use this program?

5. Given the information provided, can you identify any outcome measures or standardized tools that may capture potential effects of using this program?

Potential probes-Are the outcome measures or tools you presently use applicable? What sort of outcome measures might be of interest?

6. Is there anything else I should know about your experiences or opinions regarding using this program as a means of teaching joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, a third interview may be required if significant revisions to the VW program are required.

Interview Script 3 (Was not required as only two minor revisions were needed):

You have had an opportunity to trial a VW program intended to teach joint protection techniques to clients with RA. This program was based on themes derived from analysing input from OTs, including yourself, with experience in delivering this information as part of a self-management program in RA. Based on your feedback on the shortcomings of the program content, revisions have been made, and you have been given an invitation to review the recommended revisions. Today you will be asked for feedback on this revised program. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. Did the revisions made address your concerns regarding the shortcomings of the virtual world program?

Potential probes-How were these addressed? What is still missing from the program?

2. Given your experiences in trial of the VW program, were there any new or different experiences since the initial trial period?

Potential probes-Were there negative experiences? Were there positive experiences? Did anything surprise you? Did anything disappoint you? How much time did you spend using the program?

3. If you had this revised program as an option for clients to use, with what type of clients would you use it?

Potential probes-Would clients who cannot attend a traditional program benefit? What are some of the reasons that these clients cannot or do not attend?

4. If this revised program was an option for clients to use, are there any clients you would not recommend this program for?

Potential probes-Is access to the Internet an issue? Is computing skills an issue? Do you see a certain segment of newly diagnosed clients not being able to use this program?

5. Given the information provided, can you identify any outcome measures or standardized tools that may capture potential effects of using this program?

Potential probes-Are the outcome measures or tools you presently use applicable? What sort of outcome measures might be of interest?

6. Is there anything else I should know about your experiences or opinions regarding using this revised program as a means of teaching joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, you may request a copy of the results. The results of this phase of the study will be used to the inform the subsequent phases of the study

Phase 2 Interviews with Participants Living with RA and Previous ASMP Experience

Interview Script-Interview 1:

The purpose of this interview is to gain an understanding of your experiences in learning about joint protection techniques and managing Rheumatoid Arthritis (RA) and your expectations of a virtual world (VW) based program themed around RA and joint protection. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. Tell me about your history of living with RA.

Potential probes-How long? Types of interventions used? Do you teach joint protection? Do you use joint protection?

2. What do you consider essential content in a RA self-management program specific to joint protection?

Potential probes- bADLs? iADLs? Work? Leisure? Any specific activities?

3. Is there any other content you would like to add that you presently do not cover in a RA self-management program specific to joint protection? If so, what is it?

Potential probes-Why is the material not presently covered? Are there plans to cover that content? What barriers exist in adding content to programs?

4. In your opinion, are there clients who may benefit from a RA self-management program who do not attend? If so, what do you think are barriers to attending such a program?

5. Are there some participants that you might feel uncomfortable discussing either in a group setting or individually?

Potential probes-Do you cover topics such as sexual health, peri-care or toileting? Do clients seem hesitant in discussing these topics in groups or individually?

6. How do you/teachers of joint protection classes determine the effectiveness of the class?

Potential probes-Do you use informal measures like client feedback? Can you identify a tool or tools that might be of use that you presently do not use?

7. If an online means of delivering self-management content was available, what would your expectations be of that web-based content?

8. Do you have concerns regarding this being used as an alternative to traditional in-person methods being presently used in most self-management programs?

Potential probes-Any concerns regarding safety? Ability to interact with a professional? Is the client missing anything else you typically provide in a self-management program? Any barriers/limitations regarding access?

9. Is there anything else I should know about your experiences or opinions regarding teaching joint protection and living with RA?

10. Is there anything else I should know about your experiences or opinions regarding the use of a VW based program to teach joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, a VW program will be developed and you will be invited to trial it for up to 30 days. You will be invited to a follow up interview to provide feedback. If significant revisions are required of the program, you may be invited to a third interview to provide further feedback.

Interview Script 2 Following Trial of VW:

You have had an opportunity to trial a VW program intended to teach joint protection techniques to clients with RA. This program was based on themes derived from analysing input from OTs, and expert clients, including yourself, with experience in delivering this information as part of a self-management program in RA. Today you will be asked for feedback on this program. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. What your experiences were in trialling the virtual world program?

   Potential probes-Were there negative experiences? Were there positive experiences? Did anything surprise you? Did anything disappoint you? How much time did you spend using the program?

2. Did the VW program cover the main content of what you typically cover or expect to see in a RA self-management program?

   Potential probes-Was there something missing? Was there anything above the usual content?

3. If you had this program as an option for clients to use, with what type of clients would you use it?

Potential probes-Would clients who cannot attend a traditional program benefit? What are some of the reasons that these clients cannot or do not attend?

4. If this program was an option for clients to use, are there any clients you would not recommend this program for?

Potential probes-Is access to the Internet an issue? Is computing skills an issue? Do you see a certain segment of newly diagnosed clients not being able to use this program?

5. Given the information provided, can you identify any outcome measures or standardized tools that may capture potential effects of using this program?

Potential probes-Are the outcome measures or tools you presently use applicable? What sort of outcome measures might be of interest? (Participants will be shown or sent tools and select what they feel best capture what the program may address).

6. Is there anything else I should know about your experiences or opinions regarding using this program as a means of teaching joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, a third interview may be required if significant revisions to the VW program are required.

Interview Script 3 (Was not required as only two minor revisions were needed):

You have had an opportunity to trial a VW program intended to teach joint protection techniques to clients with RA. This program was based on themes derived from analysing input from OTs, and expert clients, including yourself, with experience in delivering this information as part of a self-management program in RA. Based on your feedback on the shortcomings of the program content, revisions have been made, and you have been given an invitation to review the recommended revisions. Today you will be asked for feedback on this revised program. As per the Informed Consent form, you may choose to not respond to any or all of the questions. This interview is being audio recorded.

1. Did the revisions made address your concerns regarding the shortcomings of the virtual world program?

Potential probes-How were these addressed? What is still missing from the program?

2. Given your experiences in trial of the VW program, were there any new or different experiences since the initial trial period?

Potential probes-Were there negative experiences? Were there positive experiences? Did anything surprise you? Did anything disappoint you? How much time did you spend using the program?

3. If you had this revised program as an option for clients to use, with what type of clients would you use it?

Potential probes-Would clients who cannot attend a traditional program benefit? What are some of the reasons that these clients cannot or do not attend?

4. If this revised program was an option for clients to use, are there any clients you would not recommend this program for?

Potential probes-Is access to the Internet an issue? Is computing skills an issue? Do you see a certain segment of newly diagnosed clients not being able to use this program?

5. Given the information provided, can you identify any outcome measures or standardized tools that may capture potential effects of using this program?

Potential probes-Are the outcome measures or tools you presently use applicable? What sort of outcome measures might be of interest?

6. Is there anything else I should know about your experiences or opinions regarding using this revised program as a means of teaching joint protection to clients living with RA?

Thank you. Upon completion of transcribing and analysing the data obtained through these interviews, you may request a copy of the results. The results of this phase of the study will be used to the inform the subsequent phases of the study

Appendix 7-Sample Interview Broken into Nodes for Coding

Coding Summary by Node
Phase II second interview participant 7

it was clearly laid out following the numbers

Well the self-management program I took maybe covered maybe a little broader umm participant

compared to the course I took there were things in this one that weren't covered in my, in the course that I took

things like the gardening
exercises
some of the bathing information was probably additional to what I had heard before.
the intimacy content was not covered in the course that I took

I think there was quite a few things that were new

it might be good for people who are newly diagnosed

I liked that you could spend more time or less time at areas

You could save things for later or go back to get things if you wanted
print something off or keep it

I liked that you could choose to go when it suited you

you could do it in smaller increments
trying to pace out your day, you can actually do it in pieces when it suits you

you could do it at a time when you are feeling better

when I took my course, I was having a lot of fatigue problems and found it difficult to go for four straight days to sit in a classroom

I found this would be better for people, you know, that are in a flare

newly diagnosed, because, they could do it when it suited them

I did come across difficulties getting the YouTube videos to work.

parts of the stations that wasn't working on my computer, so I had to try it on a different computer to be able to view them

it would have to be people that were motivated

when I took my course, I was having a lot of fatigue problems and found it difficult to go for four straight days to sit in a classroom

people who don't have a computer

who aren't ….. Familiar with using technology
some people that are gonna be better in a group setting
so it might be too individual

some people need that motivation of going a group as opposed to doing it by themselves

Just the challenges of…of getting the YouTube… videos to play.

I mean you'd certainly depend on what kind of computer systems people are using

whether it would work or not and whether
..umm, I guess knowing that for testing would be helpful.

just how to get things moving and what you would want to save
.. those notes to keep for later or.. what to do when you right click on things

There are some instructions at the site, but just to get it going would have been helpful

Once it got going it was fine

would have been helpful actually, sort of a bit of an orientation

some guidance as to how to get it started

assume that right now the only people that go there are the people you invited

if you're opening it to a broader group. It gonna…. can other people show up there and who might they be

any sort of confidentiality issues there might be as people were leaving notes for each other in that social area

how to get it to get the avatar to move and interact and that kind of thing

it just took a little practice to get going

I had to download it

I had to find the password

get in and figure out how to use it

then to actually go through everything and watch the videos

By themselves to go on and figure it out

get on and actually use it

Certainly they would need to have a computer

access to the computer program

have enough savvy to know how to download it

how to use it

I would say people that are, you know, more familiar, comfortable with using online resources

just how to get things moving and what you would want to save.. those notes to keep for later or.. what to do when you right click on things

took me about two hours, from start to finish

it took maybe one and half to two hours

when I took my course, I was having a lot of fatigue problems and found it difficult to go for four straight days to sit in a classroom

newly diagnosed, because, they could do it when it suited them

I'm not familiar with specific tools that would catch… or measure that

I would think there would be some outcome measures related to people's functional status

how they rate their knowledge

whether they're using some of the information or suggestions that they've learned

I think there would be some sort of measures related to that that you could look at, but I wouldn't know of specific tools.

well initially, It was a little challenging just to figure out what I was supposed to do

how to get it to get the avatar to move

Appendix 8-Sample of Recruitment Strategies Used

Recruitment Strategy	Medium	Estimated reach
@rickyjohnson	Twitter	16 690
Personal "status update"	Facebook	
Email to family physician	Email	1
@arthritis update	Twitter	16 115
@arthritisSympt	Twitter	13 484
@ArthritisAshley	Twitter	5448
@beautycult	Twitter	4722
@RA_Guy	Twitter	4702
@RA_information	Twitter	3336
@NRAS_UK	Twitter	2208
@arthritisfriend	Twitter	1485
@drsanjaygupta	Twitter	1745826
@rawarrior	Twitter	6840
@EverydayHealth	Twitter	227102
@LisaEmrich	Twitter	3623
@socialmediashan	Twitter	3021
@ArthritisDigest	Twitter	1812
@Aletaha et al.,heum	Twitter	5188
@kstew_arthritis	Twitter	1199
@Dadwithra	Twitter	824
@momsvictories	Twitter	855 Suspended again
RA Guy Blog	PM on blog: http://www.rheumatoidarthritisguy.com	
Show Us Your Handshttp://www.showusyourhands.org	Email to info@showusyourhands.org	
All Flared up http://allflaredup.wordpress.com/	PM on blog: http://allflaredup.wordpress.com/	
Inflamed: living with rheumatoid arthritis http://inflamed.wordpress.com	Email to: lunda7@yahoo.com	
http://rheumablog.wordpress.com/	Email to: bluewren56@gmail.com	
http://carlascorner.wordpress.com	PM on blog	
http://rheumfuloftips.wordpress.com/	Email to: info@auntiestress.ca	
http://figmentoffitness.wordpress.com/	Pm on blog	
http://www.fromthispointforward.com/	Pm on blog	
http://mommywithra.blogspot.ca/	Pm on blog	
http://pollyannapenguin.wordpress.com/	Pm on blog	
http://livingwithra.wordpress.com/	Pm on blog	

http://warmsocks.wordpress.com/	Email to warmsocks.blogquestions@gmail.com	
http://thelifeandadventuresofcatepoo.blogspot.ca/	Email to cateepoo88@gmail.com	
http://www.livingrheum.com/	Pm on blog	
http://pensandneedlesblog.blogspot.ca/	Email to: pensandneedlesblog@gmail.com	
Email to local hospital OT and PT	Email x 2 (November, January)	50+
"Hashtags" used on twitter by RAfighter		
#RA		
#Rheumatoid Arthritis		
#OT		
#innovative		
#research		
#study		
#proud2bOT		
#jointprotection		
#livingwithRA		
#tipoftheday		
#rheumatoid		
#tech		
#health		
#rehab		
#secondlife		
#hashtag		
#innovation		
#PhD		
#friendly		
#livingwell		
#lecreuset		
#adaptive		
#technology		
#shoes		
#thanksgiving		
#stress		
#pain		
#virtual		
#arthritis		
#healthpromotion		
#rheum		
#happy		
#new		
#year		

"RAfighter" twitter account stats (as of January 9, 2014): 107 tweets, 503 following, 55 followers with noted issues of multiple accounts suspended of those contacted and limited engagement by followers.

Appendix 9- AIMS 2-SF with Scoring Instructions

AIMS-2 SF
ARTHRITIS IMPACT MEASUREMENT
SCALES 2 Short Form

INSTRUCTIONS : Please answer the following questions about your health.
Most questions ask about your health during the past 4 weeks.
There are no right or wrong answers to the questions and most can be answered with a simple check (✓).
Please answer every question.

DURING THE PAST 4 WEEKS ...	All days	Most days	Some days	Fews days	No days
1. How often were you physically able to drive a car or use public transportation?	❑	❑	❑	❑	❑
2. How often were you in a bed or chair for most or all of the days ?	❑	❑	❑	❑	❑
3. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports ?	❑	❑	❑	❑	❑
4. Did you have trouble either walking several blocks or climbing a few flights of stairs ?	❑	❑	❑	❑	❑
5. Were you unable to walk unless assisted by another person of by a cane, crutches, or walker ?	❑	❑	❑	❑	❑
6. Could you easily write with a pen or pencil ?	❑	❑	❑	❑	❑
7. Could you easily button a shirt or blouse ?	❑	❑	❑	❑	❑
8. Could you easily turn a key in a lock ?	❑	❑	❑	❑	❑
9. Could you easily comb or brush your hair ?	❑	❑	❑	❑	❑
10. Could you easily reach shelves that were above your head ?	❑	❑	❑	❑	❑
11. Did you need help to get dressed ?	❑	❑	❑	❑	❑
12. Did you need help to get in or out of bed ?	❑	❑	❑	❑	❑

AIMS2 SF 1.3 - Quality of Life Group in Rheumatology, France 1995. Arthritis & Rheumatism 1997; 40: 1267-74
Adaptation from AIMS2 - R. Meenan - Boston, Ms

DURING THE PAST 4 WEEKS	All days	Most days	Some days	Few days	No days
13. How often did you have severe pain from you arthritis ?	❑	❑	❑	❑	❑
14. How often did your morning stiffness last more than one hour from the time you woke up ?	❑	❑	❑	❑	❑
15. How often did your pain make it difficult for you to sleep ?	❑	❑	❑	❑	❑
	Always	**Very often**	**Some times**	**Almost never**	**Never**
16. How often have you felt tense of high strung ?	❑	❑	❑	❑	❑
17. How often have you been bothered by nervousness or your nerves ?	❑	❑	❑	❑	❑
18. How often have you been in low or very low spirits ?	❑	❑	❑	❑	❑
19. How often have you enjoyed the things you do ?	❑	❑	❑	❑	❑
20. How often did you feel a burden to others ?	❑	❑	❑	❑	❑
	All days	**Most days**	**Some days**	**Few days**	**No days**
21. How often did you get together with friends or relatives ?	❑	❑	❑	❑	❑
22. How often were your on the telephone with close friends or relatives ?	❑	❑	❑	❑	❑
23. How often did you go to a meeting of a church, club, team or other group ?	❑	❑	❑	❑	❑
24. Did you feel that your family or friends were sensitive to your personal needs ?	❑	❑	❑	❑	❑
If you are unemployed, disabled or retired, END of questionnaire.	**All days**	**Most days**	**Some days**	**Few days**	**No days**
25. How often were you unable to do any paid work, house work or school work ?	❑	❑	❑	❑	❑
26. On the days that you did work, how often did you have to work a shorter day ?	❑	❑	❑	❑	❑

AIMS2 SF 1.3 - Quality of Life Group in Rheumatology, France 1995. Arthritis & Rheumatism 1997; 40: 1267-74
Adaptation from AIMS2 - R. Meenan - Boston, Ms

Appendix 10-PSEQ

Pain Self-Efficacy Questionnaire scoring: Each item is rated by selecting a number on a 7-point scale: 0 = not at all confident 6 = completely confident A total score is calculated by summing the scores for each of the 10 items, yielding a maximum total score of 60. Higher scores reflect stronger self-efficacy beliefs.

PAIN SELF EFFICACY QUESTIONNAIRE (PSEQ)

M.K.Nicholas (1989)

NAME: _____ DATE: _____

Please rate how **confident** you are that you can do the following things at present, **despite the pain**. To indicate your answer circle **one** of the numbers on the scale under each item, where 0 = not at all confident and 6 = completely confident.

For example:

0	1	2	3	4	5	6
Not at all Confident						**Completely confident**

Remember, this questionnaire is **not** asking whether of not you have been doing these things, but rather **how confident you are that you can do them at present, despite the pain.**

---

1. I can enjoy things, despite the pain.

0	1	2	3	4	5	6
Not at all Confident						**Completely confident**

2. I can do most of the household chores (e.g. tidying-up, washing dishes, etc.), despite the pain.

0	1	2	3	4	5	6
Not at all Confident						**Completely confident**

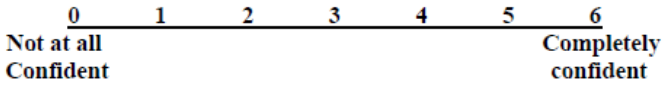
3. I can socialise with my friends or family members as often as I used to do, despite the pain.

0	1	2	3	4	5	6
Not at all Confident						**Completely confident**

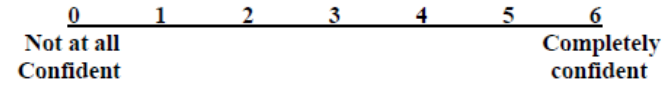
4. I can cope with my pain in most situations.

0	1	2	3	4	5	6
Not at all Confident						**Completely confident**

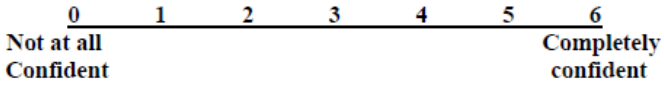
5. **I can do some form of work, despite the pain. ("work" includes housework, paid and unpaid work).**



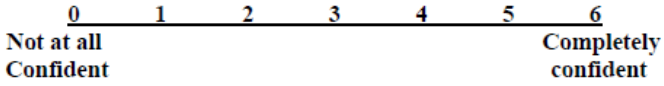
6. **I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite pain.**



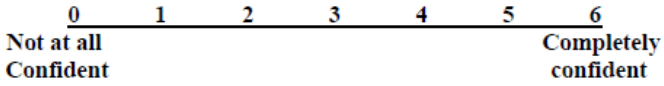
7. **I can cope with my pain without medication.**



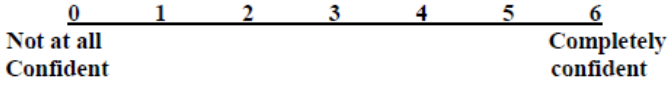
8. **I can still accomplish most of my goals in life, despite the pain.**



9. **I can live a normal lifestyle, despite the pain.**



10. **I can gradually become more active, despite the pain.**



Source: Nicholas M.K. Self-efficacy and chronic pain. Paper presented at the annual conference of the British Psychological Society. St. Andrews, 1989.

Appendix 11-Complete Sample Survey

COMPLETE

- **Collector:** New Email Invitation (Email)
- **Started:** Wednesday, November 27, 2013 4:04:09 PM
- **Last Modified:** Wednesday, November 27, 2013 4:15:31 PM
- **Time Spent:** 00:11:22
- **Email:** xxxxxxxxxxxxxxxxxxxxxxxxx (redacted by investigator)
- **IP Address:** 108.173.233.41

PAGE 5: Survey questions

Q4: In what country do you currently reside?

- Canada

Q5: In what year were you born? (Enter 4-digit birth year; for example, 1976)

1955

Q6: What is the highest level of school you have completed or the highest degree you have received?

- Bachelor degree

Q7: Are you male or female?

- Female

Q8: How many years ago did you first have symptoms of RA?

15

Q9: How many years ago did you actually get diagnosed with RA?(this may be the same answer as the previous question)

4

Q10: Do you take any medications for RA?

- Yes

PAGE 6

Q11: What medications do you presently take for RA?

dilaudid

Q12: Have you previously taken classes about managing your RA, such as via the Arthritis Society?

- Yes

Q13: There are many types of RA, do you know if you have a particular type of RA, such as seronegative, palindromic, psoriatic, etc?

- No

PAGE 7: AIMS-2 SF Arthritis Impact Measurement Scales 2 Short Form

Q14: DURING THE PAST 4 WEEKS...

- **How often were you physically able to drive a car or use public transportation?** Some days
- **How often were you in a bed or chair for most of all of the days?** Most days
- **Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?** All days
- **Did you have trouble either walking several blocks or climbing a few flights of stairs?** All days
- **Were you unable to walk unless assisted by another person or by a can, crutches, or walker?** Most days
- **Could you easily write with a pen or pencil?** Most days
- **Could you easily button a shirt or blouse?** Most days
- **Could you easily turn a key in a lock?** Most days
- **Could you easily comb or brush your hair?** Most days
- **Could you easily reach shelves that were above your head?** Some days
- **Did you need help to get dressed?** No days
- **Did you need help to get in or out of bed?** No days
- **How often did you have severe pain from your arthritis?** Some days
- **How often did your morning stiffness last more than one hour from the time you woke up?** Some days
- **How often did your pain make it difficult for you to sleep?** Most days
- **How often have you felt tense or high strung?** Few days

- **How often have you been bothered by nervousness or your nerves?** Few days
- **How often have you been in low or very low spirits?** Most days
- **How often have you enjoyed the things you do?** Few days
- **How often did you feel like a burden to others?** Some days
- **How often did you get together with friends or relatives?** Few days
- **How ofter where you on the telephone with close friends or relatives?** Some days
- **How often did you go to a meeting of a church, club, team or other group?** Few days

Q15: Do you perform any paid work, housework volunteer or do school work as a student?

- Yes

PAGE 8

Q16: DURING THE PAST 4 WEEKS...

- **How often were you unable to do any paid work, housework or school work?** Some days
- **On the days that you did work, how often did you have to work a shorter day?** All days

PAGE 9: Pain Self-Efficacy Questionnaire (PSEQ)

Q17: This questionnaire is not asking whether or not you have been doing these things, but rather how confident you are that you can do them at present, despite the pain.0 = not at all confident, 6 = completely confident

- **I can enjoy things, despite the pain.**5
- **I can do most of the household chores (e.g. tidying up, washing dishes, etc.) despite the pain.**5
- **I can socialize with my friends or family members as often as I used to, despite the pain.**4
- **I can cope with most situations.**4
- **I can do some form of work despite the pain ("work includes housework, paid and unpaid work).**5
- **I can still do many of the things I enjoy doing, such as hobbies or leisure activity, despite the pain.**5
- **I can cope with my pain without medication.**1
- **I can still accomplish most of my goals in life, despite the pain.**5
- **I can live a normal lifestyle, despite the pain.**3
- **I can gradually become more active, despite the pain.**4

PAGE 10: Computer use

Q18: Rate your level of computer literacy:

- Average

Q19: Have you used a virtual world (VW), such as Second Life, before this study?

- No

PAGE 11

Q20: Did you access the joint protection program in Second Life?

- Yes

PAGE 12: VW questions

Q21: Did you have any problems accessing or using the program?

- Yes
- **If yes, please specify what issues you may have had.** A lot of problems still learning how to move around

Q22: How many times did you go into the virtual world program?
3

Q23: About how much time in total do you think you spent in the virtual environment?
1.5 hours

Q24: Did using the virtual program cost you anything? (This includes anything you may have had to purchase to use the program, time away from work, additional travel time, etc.)

- No

PAGE 13: Some questions about your joint protection knowledge

Q25: What wrist position would you most frequently avoid if following principles of joint protection?

- Ulnar deviation

Q26: Which of the following is not a principle of joint protection?

- Avoid or limit exercise where able

Q27: Which of the following activities can you do and still follow joint protection principles?

- All of the above

Q28: Appropriate joint protection includes things like:

- Being selective with choice of footwear, setting up your computer chair properly and modifying the heights some activities are done at, such as gardening.

Q29: Which of the following are examples of daily living activities that have been modified to follow principles of joint protection?

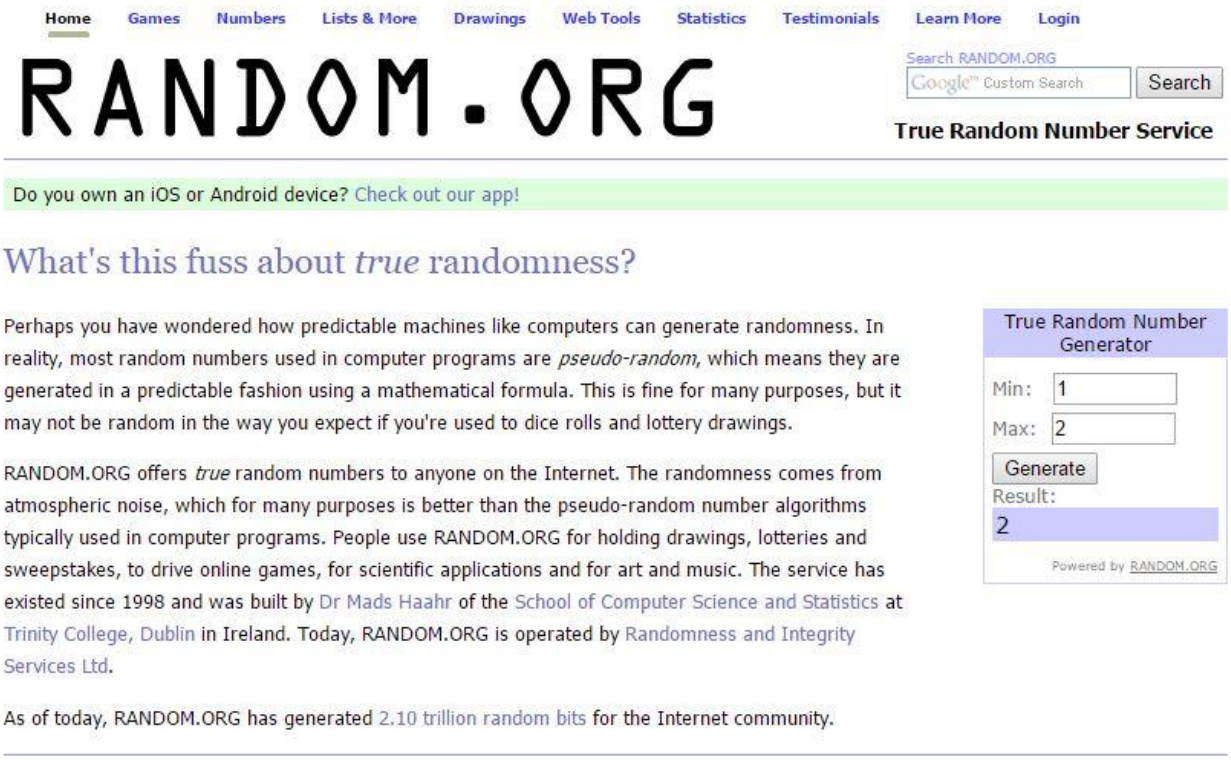
- All of the above.

Q30: Is there anything else you would like to let us know?

- Yes

- **If yes, please include additional comments here.** I am grateful to be in the study... hope to learn more about the "virtual world".

Appendix 12-Random Generation of Assignment to Condition



Appendix 13-SPSS 21.0 Outputs

```
DESCRIPTIVES VARIABLES=age yrsRA yrsdx
  /STATISTICS=MEAN STDDEV MIN MAX.
```

Descriptives

Notes

Output Created		08-APR-2015 01:34:58
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	All non-missing data are used.
Syntax		DESCRIPTIVES VARIABLES=age yrsRA yrsdx /STATISTICS=MEAN STDDEV MIN MAX.
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
age	50	24.0	73.0	47.500	11.4629
yrsRA	49	1.0	39.0	11.796	9.7168
yrsdx	49	.3	39.0	9.231	8.9966
Valid N (listwise)	49				

```
FREQUENCIES VARIABLES=country school knowtype meds COMPEX VWUSE
  /ORDER=ANALYSIS.
```

Frequencies

Notes

Output Created		08-APR-2015 03:28:35
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics are based on all cases with valid data.
Syntax		FREQUENCIES VARIABLES=country school knowtype meds COMPEX VWUSE /ORDER=ANALYSIS.
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Statistics

		country	school	knowtype	meds	COMPEX	VWUSE
N	Valid	50	50	50	50	50	50
	Missing	0	0	0	0	0	0

Frequency Table

country

		Frequency	%	Valid %	Cumulative %
Valid	1.0	23	46.0	46.0	46.0
	2.0	27	54.0	54.0	100.0
	Total	50	100.0	100.0	

school

		Frequency	%	Valid %	Cumulative %
Valid	1.0	9	18.0	18.0	18.0
	2.0	41	82.0	82.0	100.0
	Total	50	100.0	100.0	

knowtype

		Frequency	%	Valid %	Cumulative %
Valid	1.0	3	6.0	6.0	6.0
	2.0	47	94.0	94.0	100.0
	Total	50	100.0	100.0	

meds

		Frequency	%	Valid %	Cumulative %
Valid	1.0	41	82.0	82.0	82.0
	2.0	9	18.0	18.0	100.0
	Total	50	100.0	100.0	

COMPEX

		Frequency	%	Valid %	Cumulative %
Valid	1.0	4	8.0	8.0	8.0
	2.0	46	92.0	92.0	100.0
	Total	50	100.0	100.0	

VWUSE

		Frequency	%	Valid %	Cumulative %
Valid	1.0	6	12.0	12.0	12.0
	2.0	44	88.0	88.0	100.0
	Total	50	100.0	100.0	

```
  FILE='C:\Users\Rashid\Documents\most up to date data set.sav'.
DATASET NAME DataSet1 WINDOW=FRONT.
CROSSTABS
  /TABLES=group BY country school knowtype COMPEX VWUSE
  /FORMAT=AVALUE TABLES
  /STATISTICS=CHISQ
  /CELLS=COUNT
  /COUNT ROUND CELL.
```

Crosstabs

Notes

Output Created		06-MAY-2016 22:46:31
Comments		
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	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics for each table are based on all the cases with valid data in the specified range(s) for all variables in each table.
Syntax		CROSSTABS /TABLES=group BY country school knowtype COMPEX VWUSE /FORMAT=AVALUE TABLES /STATISTICS=CHISQ /CELLS=COUNT /COUNT ROUND CELL.
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01
	Dimensions Requested	2
	Cells Available	131029

[DataSet1] C:\Users\Rashid\Documents\most up to date data set.sav

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
group * country	50	100.0%	0	0.0%	50	100.0%
group * school	50	100.0%	0	0.0%	50	100.0%
group * knowtype	50	100.0%	0	0.0%	50	100.0%
group * COMPEX	50	100.0%	0	0.0%	50	100.0%
group * VWUSE	50	100.0%	0	0.0%	50	100.0%

group * country

Crosstab

Count

		country		Total
		1.0	2.0	
group	1.00	13	12	25
	3.00	10	15	25
Total		23	27	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.725[a]	1	.395		
Continuity Correction[b]	.322	1	.570		
Likelihood Ratio	.726	1	.394		
Fisher's Exact Test				.571	.285
Linear-by-Linear Association	.710	1	.399		
N of Valid Cases	50				

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 11.50.

b. Computed only for a 2x2 table

group * school

Crosstab

Count

		school		Total
		1.0	2.0	
group	1.00	4	21	25
	3.00	4	21	25
Total		8	42	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.000[a]	1	1.000		
Continuity Correction[b]	.000	1	1.000		
Likelihood Ratio	.000	1	1.000		
Fisher's Exact Test				1.000	.649
Linear-by-Linear Association	.000	1	1.000		
N of Valid Cases	50				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 4.00.

b. Computed only for a 2x2 table

group * knowtype

Crosstab

Count

		knowtype		Total
		1.0	2.0	
group	1.00	1	24	25
	3.00	2	23	25
Total		3	47	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.355[a]	1	.552		
Continuity Correction[b]	.000	1	1.000		
Likelihood Ratio	.361	1	.548		
Fisher's Exact Test				1.000	.500
Linear-by-Linear Association	.348	1	.556		
N of Valid Cases	50				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 1.50.

b. Computed only for a 2x2 table

group * COMPEX

Crosstab

Count

		COMPEX		Total
		1.0	2.0	
group	1.00	1	24	25
	3.00	3	22	25
Total		4	46	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	1.087[a]	1	.297		
Continuity Correction[b]	.272	1	.602		
Likelihood Ratio	1.133	1	.287		
Fisher's Exact Test				.609	.305
Linear-by-Linear Association	1.065	1	.302		
N of Valid Cases	50				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 2.00.

b. Computed only for a 2x2 table

group * VWUSE

Crosstab

Count

		VWUSE		Total
		1.0	2.0	
group	1.00	2	23	25
	3.00	4	21	25
Total		6	44	50

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.758[a]	1	.384		
Continuity Correction[b]	.189	1	.663		
Likelihood Ratio	.771	1	.380		
Fisher's Exact Test				.667	.334
Linear-by-Linear Association	.742	1	.389		
N of Valid Cases	50				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 3.00.

b. Computed only for a 2x2 table

```
CORRELATIONS
  /VARIABLES=JPSCORE yrsRA /PRINT=TWOTAIL NOSIG
  /MISSING=PAIRWISE.
```

Correlations

Notes

Output Created		22-JUN-2015 23:19:52
Comments		
Input	Data	C:\Users\Rashid\Documents\most up to date data set.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	39847
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics for each pair of variables are based on all the cases with valid data for that pair.
Syntax		CORRELATIONS /VARIABLES=JPSCORE yrsRA /PRINT=TWOTAIL NOSIG /MISSING=PAIRWISE.
Resources	Processor Time	00:00:05.53
	Elapsed Time	00:00:03.60

```
[DataSet1] C:\Users\Rashid\Documents\most up to date data set.sav
```

Correlations

				JPSCORE	yrsRA
JPSCORE	Pearson Correlation			1	.368**
	Sig. (2-tailed)				.009
	N			49	49
	Bootstrap[c]	Bias		0	-.003
		Std. Error		0	.075
		95% Confidence Interval	Lower	1	.214
			Upper	1	.509
yrsRA	Pearson Correlation			.368**	1
	Sig. (2-tailed)			.009	
	N			49	49
	Bootstrap[c]	Bias		-.003	0
		Std. Error		.075	0
		95% Confidence Interval	Lower	.214	1
			Upper	.509	1

**. Correlation is significant at the 0.01 level (2-tailed).

c. Unless otherwise noted, bootstrap results are based on 1000 stratified bootstrap samples

```
ONEWAY SECOMP JPSCORE AIMSCOM BY GROUP
  /MISSING ANALYSIS.
```

Oneway

Notes

Output Created		08-APR-2015 20:01:41
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User-defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on cases with no missing data for any variable in the analysis.
Syntax		ONEWAY SECOMP JPSCORE AIMSCOM BY GROUP /MISSING ANALYSIS.
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
SECOMP	Between Groups	40.500	1	40.500	.248	.621
	Within Groups	7841.920	48	163.373		
	Total	7882.420	49			
JPSCORE	Between Groups	10368.000	1	10368.000	20.819	.000
	Within Groups	23904.000	48	498.000		
	Total	34272.000	49			
AIMSCOM	Between Groups	36.980	1	36.980	.507	.480
	Within Groups	3499.520	48	72.907		
	Total	3536.500	49			

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JPSCORE
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:56:20
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JPSCORE /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.00

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JPSCORE	1.00	25	52.800	27.6164	5.5233
	2.00	25	24.000	15.2753	3.0551

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JPSCORE	Equal variances assumed	17.193	.000	4.563	48	.000	28.8000	6.3119	16.1091	41.4909
	Equal variances not assumed			4.563	37.428	.000	28.8000	6.3119	16.0158	41.5842

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSCOM
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:06:33
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSCOM /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSCOM	1.00	25	26.560	8.4562	1.6912
	2.00	25	24.840	8.6201	1.7240

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMS COM	Equal variances assumed	.022	.882	.712	48	.480	1.7200	2.4151	-3.1358	6.5758
	Equal variances not assumed			.712	47.982	.480	1.7200	2.4151	-3.1359	6.5759

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SECOMP
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:41:23
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SECOMP /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.06

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SECOMP	1.00	25	35.440	12.9617	2.5923
	2.00	25	33.640	12.5992	2.5198

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SECOMP	Equal variances assumed	.492	.486	.498	48	.621	1.8000	3.6152	-5.4689	9.0689
	Equal variances not assumed			.498	47.961	.621	1.8000	3.6152	-5.4691	9.0691

```
GET
  FILE='C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav'.
DATASET NAME DataSet1 WINDOW=FRONT.
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JP1
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 14:43:51
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JP1 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.03
	Elapsed Time	00:00:00.03

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JP1	1.00	25	3.200	7.4833	1.4967
	2.00	25	3.200	7.4833	1.4967

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JP1	Equal variances assumed	.000	1.000	.000	48	1.000	.0000	2.1166	-4.2557	4.2557
	Equal variances not assumed			.000	48.000	1.000	.0000	2.1166	-4.2557	4.2557

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSAF
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:03:41
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSAF /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSAF	1.00	25	4.84	2.357	.471
	2.00	25	4.40	1.803	.361

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSAF	Equal variances assumed	3.870	.055	.741	48	.462	.440	.594	-.753	1.633
	Equal variances not assumed			.741	44.918	.462	.440	.594	-.755	1.635

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JP2
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 14:45:09
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JP2 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JP2	1.00	25	11.200	10.1325	2.0265
	2.00	25	4.800	8.7178	1.7436

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JP2	Equal variances assumed	7.438	.009	2.394	48	.021	6.4000	2.6733	1.0249	11.7751
	Equal variances not assumed			2.394	46.954	.021	6.4000	2.6733	1.0218	11.7782

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSCOM
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:06:33
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSCOM /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSCOM	1.00	25	26.560	8.4562	1.6912
	2.00	25	24.840	8.6201	1.7240

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSCOM	Equal variances assumed	.022	.882	.712	48	.480	1.7200	2.4151	-3.1358	6.5758
	Equal variances not assumed			.712	47.982	.480	1.7200	2.4151	-3.1359	6.5759

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JP3
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 14:46:45
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JP3 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JP3	1.00	25	12.000	10.0000	2.0000
	2.00	25	6.400	9.5219	1.9044

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JP3	Equal variances assumed	1.274	.265	2.028	48	.048	5.6000	2.7616	.0473	11.1527
	Equal variances not assumed			2.028	47.885	.048	5.6000	2.7616	.0470	11.1530

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JP4
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 14:48:26
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JP4 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01

[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JP4	1.00	25	12.000	10.0000	2.0000
	2.00	25	1.600	5.5377	1.1075

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JP4	Equal variances assumed	43.199	.000	4.549	48	.000	10.4000	2.2862	5.8033	14.9967
	Equal variances not assumed			4.549	37.455	.000	10.4000	2.2862	5.7696	15.0304

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=JP5
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 14:49:37
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=JP5 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
JP5	1.00	25	14.400	9.1652	1.8330
	2.00	25	8.000	10.0000	2.0000

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
JP5	Equal variances assumed	2.911	.094	2.359	48	.022	6.4000	2.7129	.9453	11.8547
	Equal variances not assumed			2.359	47.640	.022	6.4000	2.7129	.9442	11.8558

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSPHY
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:01:43
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Han	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSPHY /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSPHY	1.00	25	3.480	2.1432	.4286
	2.00	25	3.880	1.9000	.3800

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSPHY	Equal variances assumed	.038	.846	-.698	48	.488	-.4000	.5728	-1.5518	.7518
	Equal variances not assumed			-.698	47.320	.488	-.4000	.5728	-1.5522	.7522

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSSYM
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:02:42
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSSYM /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSSYM	1.00	25	5.96	2.715	.543
	2.00	25	5.32	2.174	.435

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSSYM	Equal variances assumed	.863	.358	.920	48	.362	.640	.696	-.759	2.039
	Equal variances not assumed			.920	45.808	.362	.640	.696	-.761	2.041

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSAF
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:03:41
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSAF /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.01

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSAF	1.00	25	4.84	2.357	.471
	2.00	25	4.40	1.803	.361

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSAF	Equal variances assumed	3.870	.055	.741	48	.462	.440	.594	-.753	1.633
	Equal variances not assumed			.741	44.918	.462	.440	.594	-.755	1.635

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSSOC
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:04:45
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSSOC /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSSOC	1.00	25	5.16	1.405	.281
	2.00	25	4.52	1.782	.356

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMS SOC	Equal variances assumed	.491	.487	1.410	48	.165	.640	.454	-.273	1.553
	Equal variances not assumed			1.410	45.515	.165	.640	.454	-.274	1.554

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=AIMSWK
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 01:05:36
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=AIMSWK /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
AIMSWK	1.00	25	7.12	3.734	.747
	2.00	25	6.72	3.879	.776

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
AIMSWK	Equal variances assumed	.265	.609	.371	48	.712	.400	1.077	-1.765	2.565
	Equal variances not assumed			.371	47.931	.712	.400	1.077	-1.765	2.565

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF1
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:47:04
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF1 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF1	1.00	25	4.320	1.3454	.2691
	2.00	25	3.720	1.4866	.2973

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF1	Equal variances assumed	.044	.834	1.496	48	.141	.6000	.4010	-.2063	1.4063
	Equal variances not assumed			1.496	47.529	.141	.6000	.4010	-.2065	1.4065

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF2
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:48:06
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF2 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.03
	Elapsed Time	00:00:00.03

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF2	1.00	25	3.800	1.6583	.3317
	2.00	25	3.600	1.4720	.2944

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF2	Equal variances assumed	.204	.654	.451	48	.654	.2000	.4435	-.6917	1.0917
	Equal variances not assumed			.451	47.334	.654	.2000	.4435	-.6920	1.0920

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF3
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:49:34
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF3 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF3	1.00	25	3.480	1.8285	.3657
	2.00	25	3.760	1.6145	.3229

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF3	Equal variances assumed	.487	.489	-.574	48	.569	-.2800	.4879	-1.2609	.7009
	Equal variances not assumed			-.574	47.275	.569	-.2800	.4879	-1.2613	.7013

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF4
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:50:28
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF4 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF4	1.00	25	4.320	1.3454	.2691
	2.00	25	3.880	1.2689	.2538

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF4	Equal variances assumed	.309	.581	1.190	48	.240	.4400	.3699	-.3037	1.1837
	Equal variances not assumed			1.190	47.836	.240	.4400	.3699	-.3037	1.1837

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF5
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:51:15
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF5 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.00

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF5	1.00	25	4.000	1.7321	.3464
	2.00	25	3.480	1.8055	.3611

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF5	Equal variances assumed	.053	.819	1.039	48	.304	.5200	.5004	-.4861	1.5261
	Equal variances not assumed			1.039	47.917	.304	.5200	.5004	-.4862	1.5262

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF6
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:52:00
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF6 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF6	1.00	25	3.600	1.6583	.3317
	2.00	25	3.360	1.5513	.3103

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF6	Equal variances assumed	.411	.525	.528	48	.600	.2400	.4542	-.6732	1.1532
	Equal variances not assumed			.528	47.788	.600	.2400	.4542	-.6733	1.1533

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF7
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:52:39
Comments		
Input	Active Dataset	DataSet2
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	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF7 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.02
	Elapsed Time	00:00:00.02

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF7	1.00	25	1.880	1.8779	.3756
	2.00	25	2.440	1.9382	.3876

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF7	Equal variances assumed	.398	.531	-1.038	48	.305	-.5600	.5398	-1.6452	.5252
	Equal variances not assumed			-1.038	47.952	.305	-.5600	.5398	-1.6453	.5253

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF8
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:53:17
Comments		
Input	Active Dataset	DataSet2
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF8 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.00

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF8	1.00	25	3.320	1.8646	.3729
	2.00	25	3.120	1.5631	.3126

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF8	Equal variances assumed	1.967	.167	.411	48	.683	.2000	.4866	-.7784	1.1784
	Equal variances not assumed			.411	46.581	.683	.2000	.4866	-.7792	1.1792

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEFF9
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:53:55
Comments		
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	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEFF9 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.00

```
[DataSet2]
```

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEFF9	1.00	25	3.320	1.6513	.3303
	2.00	25	3.320	1.4640	.2928

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEFF9	Equal variances assumed	.385	.538	.000	48	1.000	.0000	.4414	-.8874	.8874
	Equal variances not assumed			.000	47.321	1.000	.0000	.4414	-.8877	.8877

```
T-TEST GROUPS=GROUP(1 2)
  /MISSING=ANALYSIS
  /VARIABLES=SELFEF10
  /CRITERIA=CI(.95).
```

T-Test

Notes

Output Created		08-APR-2015 00:54:52
Comments		
Input	Active Dataset	DataSet2
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	Split File	<none>
	N of Rows in Working Data File	50
Missing Value Handling	Definition of Missing	User defined missing values are treated as missing.
	Cases Used	Statistics for each analysis are based on the cases with no missing or out-of-range data for any variable in the analysis.
Syntax		T-TEST GROUPS=GROUP(1 2) /MISSING=ANALYSIS /VARIABLES=SELFEF10 /CRITERIA=CI(.95).
Resources	Processor Time	00:00:00.00
	Elapsed Time	00:00:00.00

[DataSet2]

Group Statistics

	GROUP	N	Mean	Std. Deviation	Std. Error Mean
SELFEF10	1.00	25	3.480	1.7108	.3422
	2.00	25	3.400	1.4142	.2828

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SELFEF10	Equal variances assumed	1.491	.228	.180	48	.858	.0800	.4439	-.8126	.9726
	Equal variances not assumed			.180	46.360	.858	.0800	.4439	-.8134	.9734

```
*Nonparametric Tests: Independent Samples.
NPTESTS
  /INDEPENDENT TEST (SECOMP JPSCORE AIMSCOM) GROUP (GROUP)
KRUSKAL_WALLIS(COMPARE=PAIRWISE) MEDIAN(TESTVALUE=SAMPLE
COMPARE=PAIRWISE)
  /MISSING SCOPE=ANALYSIS USERMISSING=EXCLUDE
  /CRITERIA ALPHA=0.05  CILEVEL=95.
```

Nonparametric Tests

Notes

Output Created		08-APR-2015 19:29:45
Comments		
Input	Data	C:\Users\Rashid\Desktop\updated test participant data for APRIL.sav
	Active Dataset	DataSet1
	Filter	<none>
	Weight	<none>
	Split File	<none>
	N of Rows in Working Data File	50
Syntax		NPTESTS /INDEPENDENT TEST (SECOMP JPSCORE AIMSCOM) GROUP (GROUP) KRUSKAL_WALLIS(COMPARE=PAIRWISE) MEDIAN(TESTVALUE=SAMPLE COMPARE=PAIRWISE) /MISSING SCOPE=ANALYSIS USERMISSING=EXCLUDE /CRITERIA ALPHA=0.05 CILEVEL=95.
Resources	Processor Time	00:00:00.37
	Elapsed Time	00:00:00.37

```
[DataSet1] C:\Users\Rashid\Desktop\updated test participant data for
APRIL.sav
```

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The medians of SECOMP are the same across categories of GROUP.	Independent-Samples Median Test	1.000	Retain the null hypothesis.
2	The distribution of SECOMP is the same across categories of GROUP.	Independent-Samples Kruskal-Wallis Test	.915	Retain the null hypothesis.
3	The medians of JPSCORE are the same across categories of GROUP.	Independent-Samples Median Test	.000	Reject the null hypothesis.
4	The distribution of JPSCORE is the same across categories of GROUP.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.
5	The medians of AIMSCOM are the same across categories of GROUP.	Independent-Samples Median Test	1.000	Retain the null hypothesis.
6	The distribution of AIMSCOM is the same across categories of GROUP.	Independent-Samples Kruskal-Wallis Test	.560	Retain the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Appendix 14-Publications (2) in Peer-Reviewed Journals Related to Present Study:

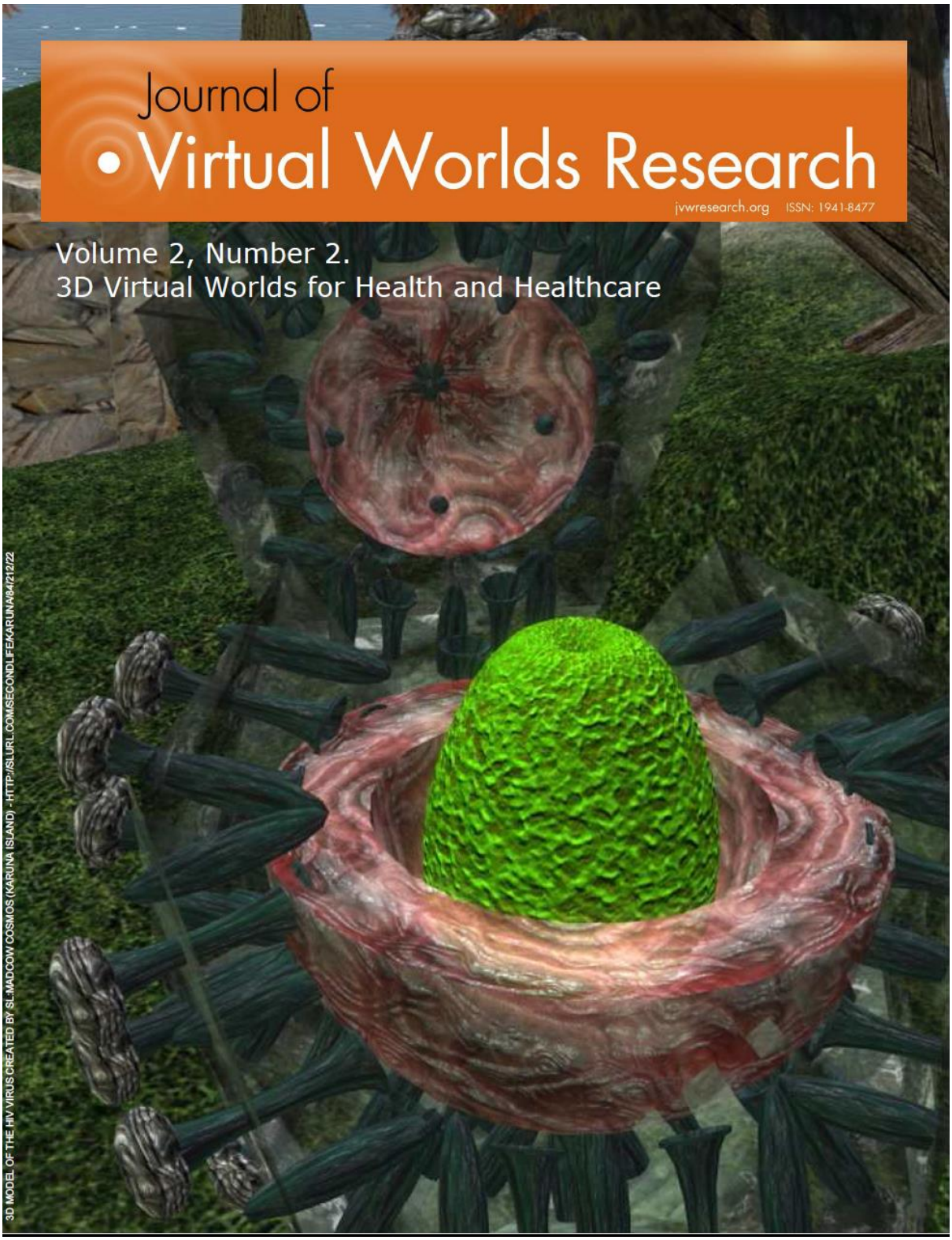
Article 1: Kashani, R, Jones, R, Roberts, AEK, Boulos, MNK (2009). Virtual worlds, collective responses and responsibilities in health, Journal of Virtual Worlds Research, 2(2), 4 - 7

Three citations to date:

(2015) Cited in British Journal of Occupational Therapy, 78(5). A pilot project of the learning experience of undergraduate occupational therapy students in a three-dimensional virtual environment in the UK, by Angela D Hook, Sarah J Bodell and Lee Griffiths.

(2014) Cited in Journal of Virtual Worlds Research, 7(1), Overview: Virtual Reality in Medicine, by Pensieri C and Pennacchini M.

(2011) Cited in Health Technology and Informatics, 164. Robots, multi-user virtual environments and healthcare: synergies for future directions, by Moon A, Grajales FJ III and Van der Loos HF.


Journal of
Virtual Worlds Research
jvwresearch.org ISSN: 1941-8477
Volume 2, Number 2.
3D Virtual Worlds for Health and Healthcare
3D MODEL OF THE HIV VIRUS CREATED BY SL.MADCOW COSMOS (KARUNA ISLAND) - HTTP://SLURL.COM/SECONDLIFE/KARUNA/84/212/22

Volume 2, Number 2
3D Virtual Worlds for Health and Healthcare
August 2009

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Virtual Worlds, Collective Responses and Responsibilities in Health

By Rashid M Kashani, University of Alberta, Canada
Anne Roberts, Ray Jones and Maged K. Boulos, University of Plymouth, UK

Abstract

Virtual worlds are an exciting area offering opportunities in clinical teaching and interventions. Clinicians and academics alike may approach these emerging opportunities with enthusiasm or scepticism. Attitudes towards applying virtual worlds in clinical practice may arise from a number of sources, facilitating a more or less positive view towards this media. Virtual worlds have the potential to provide a considerable amount of control to end users' (in this case, the client's) hands. The argument put forth is that we should collectively acknowledge changes in information technology and the power that this gives the health care user, but we also have a collective responsibility to ensure virtual worlds are adapted, tested, and studied with sufficient rigour to benefit health care consumers and population needs. Occupational therapists specifically may be in a unique position to adopt the use of virtual worlds in clinical practice.

Keywords: virtual worlds; health; occupational therapy; client; clinician.

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Virtual Worlds, Collective Responses and Responsibilities in Health

By Rashid M Kashani, University of Alberta, Canada
Anne Roberts, Ray Jones and Maged K. Boulos, University of Plymouth,UK

Following a recent demonstration of virtual worlds using Second Life (SL) to a visiting academic and a handful of observers, one student occupational therapist (OT) created an avatar on SL the same day. Later that evening, I received an instant message on my Blackberry for Professor Boa, my SL avatar. "Hi, this is Anna [her avatar name]. There are weird people bothering me. How do I get out of here?"

While lending some immediate support and answering another question from her the next day, I reflected on how her experiences were not unlike others first venturing into this medium. My student continued to use SL despite her initially unpleasant experiences. For others though, such experiences may result in abandoning virtual worlds out of frustration. The new user experience, which is often characterized by a combination of learning the social norms and technical aspects of interacting with a virtual community, may be a sufficient barrier preventing clinicians from seeing the potential value of using virtual worlds in education, research, and interventions. In fact, several factors require acknowledgment before clinicians widely adopt virtual worlds in practice. The aim of this paper is to stimulate discussion around potential barriers to adopting virtual world applications for use in health care, and ways to eliminate or reduce barriers.

Fear of the Unknown

Immersing oneself into a completely new and different environment can feel threatening. One is learning to navigate and interact in a novel, immersive, and sometimes misunderstood medium. Some media coverage has included a decidedly biased slant and lack of understanding of the purpose of virtual worlds, referring to them repeatedly as games (Garntner, 2009). There have been documented issues with virtual crimes too (Holyoke, 2007). Some SL avatars wait at orientation areas for new arrivals, such as the "weird people" mentioned by my student, and embarrass them with their lack of familiarity with virtual worlds. Such experiences may be enough to make some health professionals reluctant to adopt this media.

Clinician Barriers

While most health professionals are required by their regulatory body to maintain a portfolio of clinical competencies, many formal continuing competence opportunities offered to clinicians, such as to OTs, may be focused on the maintenance of existing skill sets, or restricted to an approved course list (American Occupational Therapy Association, 2008). Depending on the specific profession and legislated continuing competency program, learning to use a virtual world may not count towards a clinician's continuing competency hours.

An additional obstacle to adopting the use of virtual worlds in clinical practice may be a perception that one must be fluent in computer programming and graphics applications to interact within a virtual world. As a result of these perceptions, clinicians may not see virtual worlds as a priority for practice development, state that they do not have time to explore them, and derive most of their information on virtual worlds from the popular press, as there are few research papers to date on clinical applications in virtual worlds. For example, occupational therapy literature has very few studies dedicated to virtual technologies. At the time of writing, an OTDBASE search reveals fewer than twenty studies using virtual reality, and none specific to virtual worlds.

Paternalism

The transfer of more control, not less, into a client's hands is a goal towards which many health professions, particularly OTs, strive. SL, however, has been characterized as potentially addictive (Cremorne, 2007) or having deleterious side-effects (Gorini, Gaggioli, Vigna and Riva, 2008), even by supporters of this media (although without providing empirical data). Clinicians may be inclined to protect those deemed at risk for manipulation in a virtual world, or even to discourage clients from using them, especially since the popular press has skewed public perception of them as potentially causing harm.

Responsibility of virtual world designers and administrators

If virtual worlds are to be used widely in health application, there needs to be more than just acknowledgement that there are real technical issues in using them. Developers need to address issues pertaining not only to bandwidth, but also acknowledge cognitive and physical skills required to access present forms of virtual worlds. Other responsibilities are the assurance of safety and inclusivity beyond the basic terms of service. Depending on the user population and demographics, some may still find the user interface of virtual worlds, such as SL, too physically or cognitively taxing for meaningful interactions. What must also be acknowledged by virtual world administrators is that those who elect to discount the issues of the new user experience, or provide a decidedly skewed view in the media, do virtual worlds a disservice as a legitimate tool of clinical practice.

Virtual world designers and administrators need to respond to the technical issues, but also have to become adept at addressing public opinion, possibly both through position statements and through collaborating on research. Without addressing the issues of public opinion, inclusivity, and protection of what may perceived as the more vulnerable users, adoption may be slowed by these barriers. Virtual world designers and administrators need to consider purposively recruiting health professionals and health consumers as a means to collaboratively construct virtual worlds free of these barriers.

Including clinicians who are early adopters of virtual worlds in the planning and implementation of orientations, development of more inclusive user interfaces and a concerted effort to support widespread research might ameliorate some of the direct challenges previously outlined. There needs to be a specific action plan by developers to demonstrate increasing ease of use, a reduction in technological barriers, and development of partnerships between developers and the clinical community. Approaching disciplines that incorporate the influence of cultural, social and physical environments, such as occupational therapy, would be prudent.

What then, might be the clinician responsibility?

Virtual worlds offer a level of three dimensional interactivity and flexibility not available in other forms of online interaction. Clinicians, researchers, and educators need to be introduced to both the potential beneficence as well as adverse effects of virtual worlds to health and well being. Given the available literature in some disciplines, many areas remain unstudied. Therefore, rigorous studies are needed to focus on specific populations to determine if this is an effective intervention. While this may sound like a new, daunting practice challenge, it behoves clinicians to realize that this sound scientific reasoning is missing from many clinical practices, not just in the area of virtual worlds (Booth, n.d.).

Perhaps what are needed in addition to the tailoring of specialized programs are more in-depth orientations and more formal mentor support in using virtual worlds with specific populations. The development of this support may ameliorate some of the new user issues of the present day, and our own concerns of exposing those we consider at risk to this media. Academics may try to introduce this as both a tool and a meaningful occupation of future clients. Clinicians and researchers could be encouraged to develop programs and orientations specific to individualized client populations.

Geographic areas in some virtual worlds do focus on inclusion of those with varying cognitive and physical ability. SL has an area dedicated to this concept of inclusion, an area called Virtual Ability. Though an orientation area, such as Virtual Ability, for people with varying abilities is a valuable resource, perhaps what are needed are customized orientations for specific population needs. Further exploration is also required to see if these are effective in meeting client needs. While several different disciplines are capable of researching and using this media in teaching and clinical use, OTs have specialized activity analysis skills, and are in a unique position to develop programs addressing specific diagnostic population needs within an immersive virtual world environment. Virtual worlds offer medical information, and much more, in terms of socialization, creativity, occupation, and even spirituality.

How we best determine tailoring and testing of individualized programs and engaging input into their development and testing remain significant questions. Input from expert clinicians and consumers of health services may serve as a partnership in the development of the next-generation social web and may be a natural progression from the collaborative nature of many social web developments in wide use presently.

Bibliography

American Occupational Therapy Association (2008). *Continuing Education WebFind: American Occupational Therapy Association's Searchable Database of Approved CE Providers*. Retrieved February 12, 2009 from http://www.aota.org/News/Announcements/CEWebFind.aspx

Booth, A. (n.d.). *What Proportion of Health Care Is Evidence Based? Resource Guide*. Retrieved January 19, 2009 from http://www.shef.ac.uk/scharr/ir/percent.html

Cremorne, L. (2007). Addiction – SL as the Double-Edged Sword. *The Metaverse Journal*. Retrieved January 22, 2009 from http://www.metaversejournal.com/2007/01/10/addiction-sl-as-the-double-edged-sword/

Gartner, H. (2009). Strangers in Paradise. *The Fifth Estate, CBC News*. Retrieved January 30, 2009 from http://www.cbc.ca/fifth/2008-2009/strangers_in_paradise/

Gorini, A., Gaggioli, A., Vigna, C. and Riva, G. (2008). A Second Life for eHealth: Prospects for the Use of 3-D Virtual Worlds in Clinical Psychology. *Journal of Medical Internet Research*, 10(3):e21. Retrieved January 30, 2009 from http://www.jmir.org/2008/3/e21/

Holyoke J. (2007). SL Crime Wave!-L$3 Million Bank Heist!!!: Were Weekend Griefing Attacks a Cover for Bank Jobs? *The Alphaville Herald*. Retrieved January 29, 2009 from http://www.secondlifeherald.com/slh/2007/11/was-the-griefin.html

OTDBASE (2008). Retrieved February 20, 2009 from http://www.otdbase.org/search/index.jsp

Virtual Ability (n.d.). Virtual Ability Inc. http://slurl.com/secondlife/Virtual%20Ability/71/124/26 and http://virtualability.org/

Article 2: Kashani R, Burwash S and Hamilton A (2010). To be or not to be on Facebook, that is the question, Occupational Therapy Now, 12(6), 19-22.

Eight citations to date:

(2015) Cited in Open Journal of Occupational Therapy: "The Future in Their Hands: The Perceptions of Practice Educators on the Strengths and Challenges of "Generation Y" Occupational Therapy Students." C Hills, K Boshoff, S Gilbert-Hunt, S Ryan and DR Smith.

(2015) Cited in British Journal of Midwifery. "Is Facebook an appropriate platform for professional discourse?" A Power.

(2014) Cited in Willard and Spackman's Occupational Therapy (Hardcover) by Barbara A. Boyt Schell PhD OTR FAOTA, Marjorie Scaffa Ph.D OTR FAOTA, 12th edition, page 462.

(2014) Cited in Scientific Research Journal of India. "Ethical challenges for occupational therapists in India to use social media". K Sau, D Sridhar, S. Kumar.

(2013) Cited in International Journal of Therapy and Rehabilitation. "Public and private blogging during placements: perspectives of occupational therapy students". C Wiid, C McCormack, A Warren, S Buckley, M Cahill.

(2013) Cited in BMJ open. 'Have you seen what is on Facebook?' The use of social networking software by healthcare professions students. J White, P Kirwan, K Lai, J Walton, S Ross.

(2013) Cited in Indian Journal of Occupational Therapy. "Netiquette: a modern day essential for occupational therapists".Sau K.

(2013) Cited in Australian Occupational Therapy Journal. "Managing ‘Generation Y’ occupational therapists: Optimising their potential." C Hills, S Ryan, H Warren-Forward, DR. Smith.

To be or not to be on Facebook: That is the question

Rashid Kashani, Susan Burwash and Anita Hamilton

Health care professionals have a mandate to continually improve professional knowledge and skills, much of which is dependent on networking skills. In the last decade, our capacity to network with colleagues has been enhanced by expansion and improved usability of online technology. As the knowledge era arrived, so did interactive online tools including databases, discussion forums, informative blogs, wikis and online communities, allowing us to acquire, share and generate knowledge from our home or work space.

Concerns that some occupational therapists have about using online tools for collaboration and networking are centred on confidentiality, professionalism and self-protection (Baerlocher & Detsky, 2008). A simple way to overcome these concerns is to create closed and protected online communities. However, this can be costly, overwhelming, time consuming and therefore prohibitive for most individuals or agencies. As a result, using mainstream online technologies for professional networking has emerged as a viable option.

Facebook is an online community with over 400 million unique users (Facebook, 2010) and is the premier site in the English-speaking world. This article will explore current uses of Facebook by occupational therapy practitioners, academics and students, suggest a set of guidelines for using this particular online community to ensure we uphold our professional code of ethics while enhancing professional development and networking, and present two case scenarios illustrating ethical considerations.

About Facebook

Facebook is a social networking site that allows members to create an individual profile, a 'group' around a special interest or a 'page' to disseminate information about a person, group or product. Presently there are over 1000 groups or pages related to occupational therapy in Facebook. Group pages range from 1 or 2 members or 'fans' to almost 6100 fans of the American Occupational Therapy Association's page. The majority of groups and

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Table 1: Selected Facebook groups and pages.

Name of Group/Page	Description of Site	Number of members / fans
Facebook Occupational Therapy Association (FOTA)	Largest OT group on Facebook. An initiative by AOTA to increase consumer awareness of OT	14 201 members
Collaborating & Sharing Ideas With Other Occupational Therapists	"You can brainstorm here! Talk to other therapists and see what they think or if they can help you out!"	6132 members
British Association and College of Occupational Therapists	"We are here to help and guide our members throughout their studies and careers."	2215 fans
OT • Occupational therapy	Purports association with WFOT. However ,unclear if this is true	3150 members
American Occupational Therapy Association	Official fan page for AOTA	6099 fans
American Occupational Therapy Association	Official group page for AOTA	2751 members
OT 4 OT	Group for OTs who are early adopters of online technology	420 members
YogOT	Group for OTs and OTAs interested in clinical applications of yoga	86 members
MiSTERS OF OCCUPATIONAL THERAPY	A group for male OTs. But has a lot of female participants as well. Started by a B.C. occupational therapist	181 members
MHOTCoP	A group originally set up for mental health OTs in Alberta, Canada	11 members
ADVANCE for Occupational Therapy Practitioners	"Committed to helping therapists enhance their impact on the health-care industry."	2268 members
Occupational Therapists 4 Micro-credit	Occupational therapists interested in micro-credit	10 members

Table 2: Facebook pros, cons and cautions

Positive aspects of Facebook:	Potential negatives aspects of Facebook:	Cautions:
-sense of knowing what others are doing	-somewhat addictive	-applications can access your information
-ability to start a special interest group or fan page	-social "not-working" (being on social-networking websites, and not working (Urban Dictionary, 2009)	-consider who made the application and for what purpose
-getting information about OT out where people are really spending time	-time waster	-applications can produce SPAM
-instant messaging in chat, not stored for long, or at all	-potential identity theft	-netiquette of making friends and ignoring requests
-can be more private than email	-too much information about people with whom you are friends	-privacy issues
-way of getting grassroots connections	-vulnerable client users may be prone to manipulation	
	-exclusion of Facebook nonusers	
	-not always being used as intended	
	-every time there is an update privacy settings require resetting	

pages have been developed by student groups, national associations, health care recruiters and special interest groups. Few occupational therapy academic programs have created official pages or groups; however, many occupational therapy students set up pages as a way to share information with their classmates. Table 1 lists some selected occupational therapy-related groups or pages while Table 2 outlines the pros, cons, and cautions of using Facebook.

Does what happens on Facebook stay on Facebook?

All information that you upload to Facebook is potentially available to any Internet user. Therefore maintaining privacy settings and keeping up to date with changes to Facebook policies is extremely important. Facebook users have ways to increase the likelihood that what happens on Facebook stays on Facebook, and is only shared with individuals whom they chose. However, diligence is required by users as default settings for Facebook accounts mean that information is potentially shared with anyone on the Internet. In addition to the concern surrounding what remains private and what is shared, it is important to realize that, at the time of writing of this article (February, 2010), Facebook accounts closed at the request of users are not permanently deleted but are archived and stay on Facebook's server. So to answer the question "Does what happen on Facebook stay on Facebook?" the answer is "yes", all information stays on Facebook as an archive rather than being deleted, and "no" it does not necessarily stay just within Facebook, it can be copied and shared with others if account privacy settings are not set at a high level. Information about how to set up a Facebook account is outlined in Table 3 and information about how to check privacy settings are outlined in Table 4.

Ethics

There are a variety of ethical questions emerging as a result of use of social networks. Concerns include protection of one's own information as well as privacy issues that arise when a supervisor, preceptor or instructor sifts through online information of someone with whom they are not directly connected. There are added ethical dilemmas as occupational therapists. For example, who

Table 3: Setting up a Facebook page.

1.Go to https://www.facebook.com/ (Note: the 's' indicates connecting to a secure site)	3.Go to "Privacy" settings
2.Fill in the information on the main page	4.Set all components to "Friends only"

Table 4: Protecting yourself.

-Keep postings and personal information shared at the level where you will not have to repair your identity
-Identity presentation. Is this honest and accurate?
-Multiple personalities. Consider setting up an account for professional use and another for social networking, especially if you have existing separate work and personal e-mail accounts
-Dealing with friend requests will depend on the context. If the answer cannot be found in ethics guidelines, develop some self-monitoring rules. For example, accept all friend requests from students previously preceptored on fieldwork, or none at all
-Be aware that you may not automatically have a right to use information found online given recent rulings of the Office of the Privacy Commissioner of Canada

should be added as a friend? Should use of this media be limited to family and friends? What about adding colleagues and students?

These decisions have the potential to blur professional and personal boundaries and separation of the real and virtual representation of oneself. Studies involving medical students and their Facebook profiles reveals fewer than 38 percent had set their privacy to protect personal information, including home address, sexual orientation and political perspectives (Thompson et al., 2008). This same study reports up to 70 percent of profiles reviewed contained material that could be deemed negatively, including portrayals of excessive alcohol consumption, overt sexuality and patient privacy violations. A subsequent letter to the editor of this same journal recommends a national conversation be facilitated to produce general guidelines for physicians to draw upon in using social networking sites (Gorrindo & Groves, 2008).

Privacy of online information has also garnered considerable Canadian attention. Facebook has had to address a complaint made by the Office of the Privacy Commissioner of Canada, alleging the social networking service had committed up to 22 privacy breaches. The complaint includes several issues with how information is used, stored and shared with third parties, even after information has been deleted by a user (Office of the Privacy Commissioner of Canada, 2009). One proposal made by Facebook to the Privacy Commissioner of Canada is that they will develop a future option to delete versus deactivate accounts. This is not yet an option for Facebook users, but is a potential future development; meaning that third parties can still obtain information, even from deactivated accounts. Similar concerns exist in the United States regarding unintended Facebook use and have resulted in some universities blocking the site (Read & Brock, 2006). In another report, lawyers advised against administrators using the site to monitor student behaviour for fear of litigation (Van Der Werf & Martin, 2007).

Other ethical quandaries can be addressed by reviewing and applying national guidelines developed by the Canadian Association of Occupational Therapists (CAOT, 2007) and further reinforced by provincial codes of ethics, such as those developed by provincial organizations across Canada. Examples of provincial guidelines readily available for public viewing include those of the Alberta College of Occupational Therapists (ACOT, 2005), College of Occupational Therapists of Ontario (COTO, 2002) and the Ordre des ergotherapeutes du Quebec (OEQ, 2009). Specific guidelines from CAOT (2007) encouraging caution for the following uses of Facebook include:

- using professional communication with clients, colleagues, partners and stakeholders,
- ensuring confidentiality and privacy of others personal information,
- recognizing and managing issues related to conflict of interest, and
- abiding by legislative requirements and codes of ethics established by provincial occupational therapy regulatory organizations, as applicable, and other organizations to which the member has obligations.

In addition to guidelines serving to limit behaviour, other CAOT (2007) guidelines potentially encourage therapists to use Facebook:

- contributing to interdisciplinary collaboration and development of partnerships to advance the occupational performance of populations,
- promoting the profession to the public, other professional organizations and government at regional, provincial and federal levels, and
- contributing to development and/or dissemination of professional knowledge.

The sample of provincial ethics guidelines also serves to delineate behaviour while using this medium, including safeguarding client information from unwarranted disclosure and avoiding any activity or relationship which would exploit or cause harm to another person or to the profession.

For example, ACOT (2005) ethics guidelines state that inherent in the client-therapist relationship is differential power that can be exploited. As occupational therapists we should, therefore, not engage in any forms of relationship with clients that could potentially cause harm or exploit the relationship. Such forms of relationship could include using Facebook for financial, personal, sexual, material or business purposes with clients. Even virtually, engaging in such activities would be exploiting the therapeutic relationship. See Table 5 for case scenario examples.

Conversely, the provincial sample of ethics guidelines as outlined could also be interpreted as incentives for using this media as a means of improving the knowledge base of the profession. As occupational therapists, we need to be cognizant of how we contribute to the body of knowledge of occupational therapy. These provincial guidelines state that through a variety of media, we can share our experiences and influence development of our body of knowledge. In-servicing, newsletter submissions, panel discussion participation, student supervision, and clinical research are examples of activities listed in these guidelines (ACOT, 2005). As a profession, it is timely to consider updating our practice guidelines to also

Table 5: Case scenarios: Potential ethical dilemmas.

Case 1: An occupational therapist working in a school setting completes an assessment on a child with the child's mother in attendance. The occupational therapist and the client's mother discuss the assessment findings and collaborate on a planned course of action. Later that evening, the client's mother searches online for information about the occupational therapist, and finds the occupational therapist's Facebook page. There are no privacy settings and all of the occupational therapist's information, pictures, videos and wall posts are visible to anyone. The client's mother is highly offended by some of the content she reviews, significantly affecting her impression of the therapist and causing her to question if this is someone she wants involved with her daughter.

Issues:

1. Privacy setting of the Facebook account. Privacy controls on Facebook have been established to limit public viewing. In this case, they should have been used to limit the visibility of the content of a personal page to only those that have been identified as 'friends'.

2. Visible and posted content. Given that third parties, social connections and potentially the public can access posted information, precautions should be in place to prevent private content from being posted.

3. Accessed information. The parent in this case was using a social networking site to research someone's professional standing. This needs to be kept in mind when posting private information on the Internet.

Case 2: An occupational therapist using Facebook discovers Canadian Musician, Matthew Good, is on Facebook. He is open about living with a diagnosis of bipolar disorder. He is also an advocate for mental health and has a number of links on his fan pages to blogs relevant to occupational justice, mental health and innovations in electronic media. The occupational therapist becomes a fan of the artist on Facebook, posts the link to the artist's blog page and a number of other current links to resources, community-based initiatives and government studies

Potential issues:

1. The client/therapist relationship divide may become blurred in this situation. The occupational therapist would be ill-advised to enter into a treating relationship with the artist if a social relationship, even virtual, develops.

2. The disclosure of information may not be intended for a therapeutic relationship. However, the artist has made his information part of a public basis of advocacy and discussion. This public accessibility of the information encourages discussion and dissemination of information. In addition, occupational therapists are ethically responsible to participate in improving their knowledge base in topical areas.

include ethical use of electronic media, such as Facebook, and keep in step with global trends.

So, should you be on Facebook?

Adopting online technologies to network and build online communities of practice has both risks and benefits for professional practice. Online social networks such as Facebook offer a fast and easily accessible online space to form communities of practice while also enabling us to work towards enhancing public awareness of occupational therapy. When using online social networks we need to be cognizant of upholding professional ethics and preserving boundaries between our professional and personal lives. Effectively managing our relationships, real or virtual, and managing what information is available online both contribute to ensuring our visible online image is professional. We have outlined steps each individual can take to ensure that they can experience the benefits of online social networking while managing the risks to maintain the boundaries between private and professional life.

References

Alberta College of Occupational Therapist (2005). *ACOT Code of Ethics*. http://www.acot.ca/pages/Professional_standards_and_Practice_Guidelines).

Baerlocher, M.O. & Detsky, A.S. (2008). Online medical blogging: Don't do it! *Canadian Medical Association Journal*, 179-292.

Canadian Association of Occupational Therapists (2007) *Code of Ethics*. http://www.caot.ca/default.asp?pageid=35.

College of Occupational Therapists of Ontario (2002) *Code of Ethics*. http://www.coto.org/resource/ethical.asp.

Facebook. http://www.facebook.com/press/info.php?statistics.

Gorrindo, T. & Groves, J.E. (2008). Intersection of online social networking with medical professionalism: Can medicine police the Facebook boom. *Journal of General Internal Medicine*, 23(12), 2155.

Office of the Privacy Commissioner of Canada (2009). http://www.priv.gc.ca/media/nr-c/2009/nrc_090827_e.cfm.

Ordre des ergotherapeutes du Quebec. *Code of Ethics of Occupational Therapists, English version* (2009). http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=3&file=/C_26/C26R78_A.HTM.

Read, B. (2006). Information technology. *Chronicle of Higher Education*. 52(20), 38-41.

Thompson, L. A., Dawson, K., Ferdig, R., Black, E.W., Boyer, J., Coutts, J., & Paradise Black, N. (2008). The intersection of online social networking with medical professionalism. *Journal of General Internal Medicine*. 23(7), 954-957.

Urban Dictionary. http://www.urbandictionary.com.au/.

Van Der Werf, M (2007). Beware of using social-networking sites to monitor students, lawyers say. *Chronicle of Higher Education*. 53(6), 26-28.

Appendix 15 – Conference Presentations Related to Present Study

University of Plymouth

Occupational Therapists' Expectations of a Virtual World Program for Client Education

Rashid Kashani, University of Plymouth, Dr. Ray Jones, Professor, University of Plymouth, Dr. Anne Roberts, Associate Professor, University of Plymouth and Dr. Maged NK Boulos, Associate Professor, University of Plymouth

Abstract	Introduction	Methods	Results	Discussion
During preliminary research for a pilot randomized control trial (RCT), Occupational Therapists (OTs) provided expert input via qualitative interviews.	This study will culminate in a pilot RCT for a current PhD study at the University of Plymouth. This stage is the development of VW content.	Once ethics approval was obtained, 5 of 6 expert OTs identified agreed to participate.	Information on expected content was substantial , consistent & informative regarding JP & RA.	Interviews provided the basis for multiple stations on a VW platform aimed at teaching JP for RA management (depicted below), primarily around key principles of JP and specific activities
The objective was to determine the content OTs expect of a Virtual World (VW) program designed to teach clients living with rheumatoid arthritis (RA) about joint protection (JP)	What is described here are the preliminary stages of this study: qualitative interviewing & thematic analysis of clinician interviews about this technology.	Transcription of interviews was followed by coding with nVivo software & thematic analysis at saturation; member checks were also used.	Thematic analysis indicates OTs working in rheumatology may experience role strain, not use outcome measures and require further education about online safety.	As this may be a clinically & cost effective means of delivering educational material, what first must occur is the development of appropriate content with expert input. Input from both clinician & client experts, will provide the foundation for a future pilot RCT.

Conclusion

The intent of this part of the study was to get expert input in developing the content of a VW program for JP and RA. Some results indicate there may be a need to further educate OTs about the new social web and they may need an introductory module in learning to use a VW program for client teaching. Guidelines and recommendations for more commonly used forms of the new social web are being developed to better educate occupational therapists given publicized issues with online privacy and safety [1].

References
[1]R. Kashani, S. Burwash, and A. Hamilton, To be or not to be on Facebook: That is the question, Occupational Therapy Now 12(6) (2010), 19-22.

Poster Presentation from Cybertherapy 16, International Conference in Gatineau, Quebec, in June, 2011. Published as an abstract in Journal of CyberTherapy and Rehabilitation, June 22, 2011 authors: Kashani R Jones R, Roberts AEK and Boulos MNK.

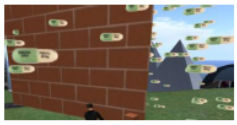
OWNING OCCUPATION WITH PLYMOUTH UNIVERSITY

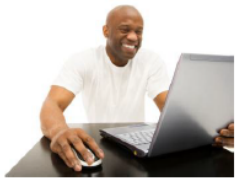
Wanted: Occupational Therapists to Apply Their Skill to Virtual Occupations, Please Apply in-World

Authors: RM Kashani, R Jones, AEK Roberts, MKN Boulos, Plymouth University

Internet based Virtual world (VW) programs have expanded rapidly in number and membership over the past decade. Registered populations of online communities of Second Life® and Blue Mars® are presently greater than North America and Europe combined (KZero, 2010). Estimates suggest 2 billion people will be using VWs by 2013. Individuals may access VWs for entertainment, socialization, paid employment or curiosity. Occupations occurring in VWs mirror real world ones, having meaning, providing opportunities for achievement, social connectedness, fun, just right challenges and may combat occupational deprivation.

As Occupational Therapists (OTs) are in a position to facilitate engagement in occupations, they are in a strong position to participate in development and use of VWs and virtual occupations. OTs have opportunities to contribute to the science of virtual occupations including facilitation of client participation in virtual occupations and as a therapeutic modality. Examples from the authors' current research and work with OT students describe virtual occupations linking to practice. Examples include students participating in virtual building, students depicting a client story via allegory, clients discovering new means of addressing occupational deprivation and as a potential means of providing self-management education for clients living with rheumatoid arthritis.

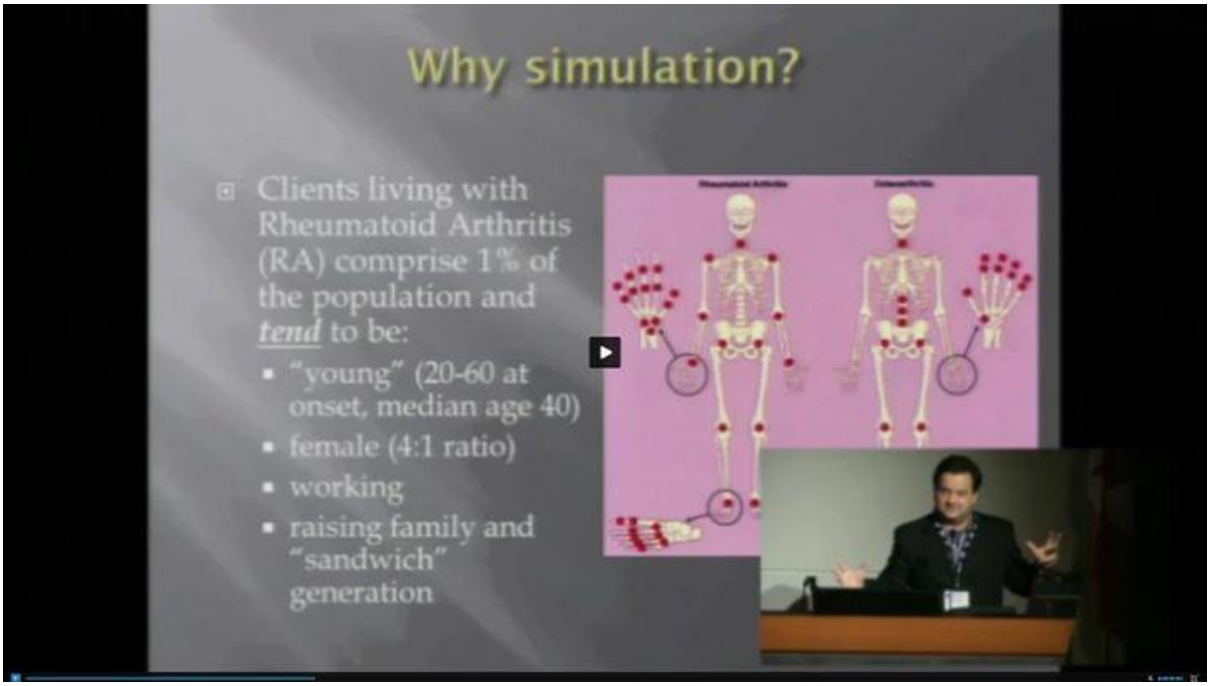




Students building for assistive technology project – for partial credit in a module on assistive technology OT students were required to produce a model of the final product. After seeing research another instructor was engaged in, some elected to use this media instead of basic diagrams or other mainstream means, such as PowerPoint	Students presenting a client's narrative – for partial credit in mental health course OT students used a VW to tell a client story as allegory. The client became engaged in the VW as a meaningful occupation after seeing the final presentation and the various activities his avatar could engage in, including building, exploring and socializing	Researching education and self-management of rheumatoid arthritis – as part of a current PhD study in progress a VW educational area themed around joint protection and rheumatoid arthritis is being developed based on input from clients and OTs. Qualitative interviews are being used to develop the program content. A pilot RCT is underway for the final phase of this study which will determine the feasibility of a full RCT, and potentially, clinical efficacy
Occupational engagement for student using a new media / teaching tool with a high level of flexibility	Unexpected benefit to client, reduced occupational deprivation	Flexible and testable opportunities to explore person/environment/occupation fit

Kzero (2010) Virtual Worlds 2011+. Downloaded from: www.kzero.co.uk/order-reports.php
Image: Mercury New Media (2010). Downloaded from: www.mercurynewmedia.com/What/Content-Management

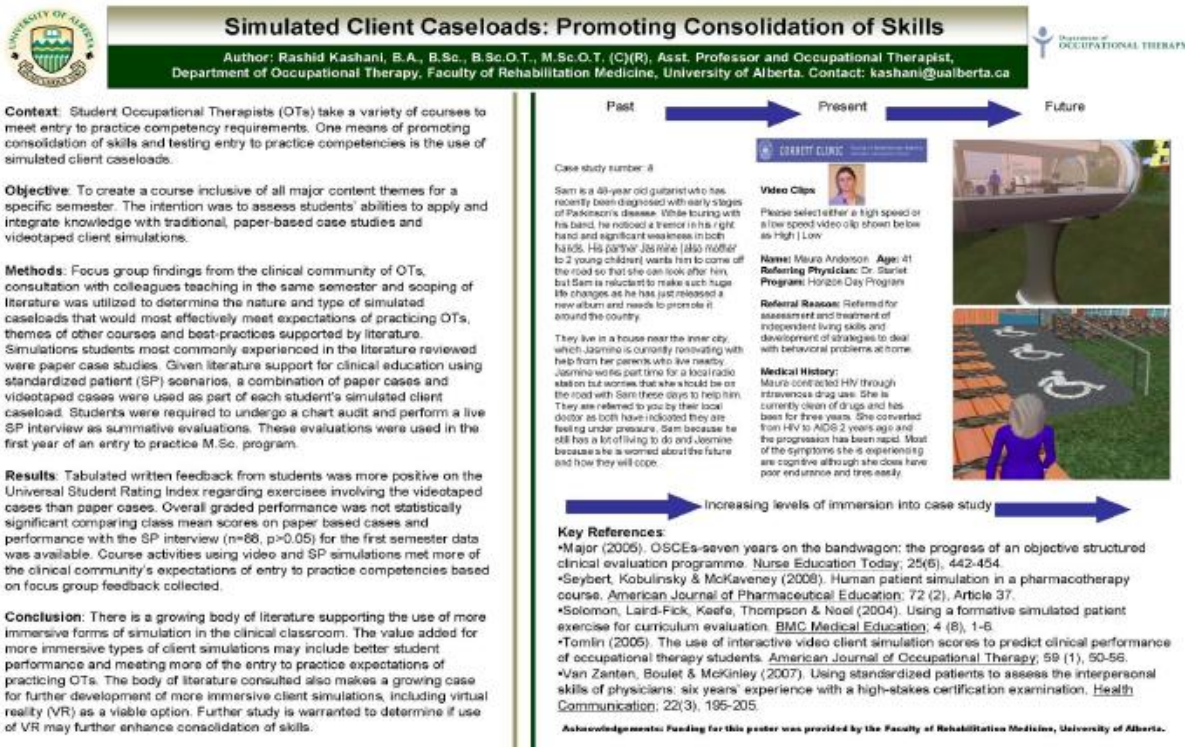
Poster Presentation from Owning Occupation, Occupational Science Conference in Plymouth. Devon, September, 2011. Authors Kashani R, Jones R, Roberts AEK and Boulos MNK.



Podium presentation from Northern Alberta Institute of Technology (NAIT) SIMFEST Conference, May 2012.

Technology-Enhanced Simulation stream (Podium 1) presentation. Video recording of presentations for Podium 1 stream is at: http://www.nait.ca/83074.htm, presentation starts at 20:20. Authors: Kashani R, Jones R, Roberts AEK and Boulos MNK.

Appendix 16 – Presentations Indirectly Related to Study



Simulated Client Caseloads: Promoting Consolidation of Skills

Author: Rashid Kashani, B.A., B.Sc., B.Sc.O.T., M.Sc.O.T. (C)(R), Asst. Professor and Occupational Therapist,
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Context: Student Occupational Therapists (OTs) take a variety of courses to meet entry to practice competency requirements. One means of promoting consolidation of skills and testing entry to practice competencies is the use of simulated client caseloads.

Objective: To create a course inclusive of all major content themes for a specific semester. The intention was to assess students' abilities to apply and integrate knowledge with traditional, paper-based case studies and videotaped client simulations.

Methods: Focus group findings from the clinical community of OTs, consultation with colleagues teaching in the same semester and scoping of literature was utilized to determine the nature and type of simulated caseloads that would most effectively meet expectations of practicing OTs, themes of other courses and best-practices supported by literature. Simulations students most commonly experienced in the literature reviewed were paper case studies. Given literature support for clinical education using standardized patient (SP) scenarios, a combination of paper cases and videotaped cases were used as part of each student's simulated client caseload. Students were required to undergo a chart audit and perform a live SP interview as summative evaluations. These evaluations were used in the first year of an entry to practice M.Sc. program.

Results: Tabulated written feedback from students was more positive on the Universal Student Rating Index regarding exercises involving the videotaped cases than paper cases. Overall graded performance was not statistically significant comparing class mean scores on paper based cases and performance with the SP interview ($n=88$, $p>0.05$) for the first semester data was available. Course activities using video and SP simulations met more of the clinical community's expectations of entry to practice competencies based on focus group feedback collected.

Conclusion: There is a growing body of literature supporting the use of more immersive forms of simulation in the clinical classroom. The value added for more immersive types of client simulations may include better student performance and meeting more of the entry to practice expectations of practicing OTs. The body of literature consulted also makes a growing case for further development of more immersive client simulations, including virtual reality (VR) as a viable option. Further study is warranted to determine if use of VR may further enhance consolidation of skills.

Past → Present → Future

Case study number: 8

Sam is a 48-year old guitarist who has recently been diagnosed with early stages of Parkinson's disease. While touring with his band, he noticed a tremor in his right hand and significant weakness in both hands. His partner Jasmine (also mother to 2 young children) wants him to come off the road so that she can look after him, but Sam is reluctant to make such huge life changes as he has just released a new album and needs to promote it around the country.

They live in a house near the inner city, which Jasmine is currently renovating with help from her parents who live nearby. Jasmine works part time for a local radio station but worries that she should be on the road with Sam these days to help him. They are referred to you by their local doctor as both have indicated they are feeling under pressure. Sam because he still has a lot of living to do and Jasmine because she is worried about the future and how they will cope.

Video Clips

Please select either a high speed or a low speed video clip shown below as High | Low

Name: Maura Anderson **Age:** 41
Referring Physician: Dr. Starlet
Program: Horizon Day Program

Referral Reason: Referred for assessment and treatment of independent living skills and development of strategies to deal with behavioral problems at home.

Medical History:
Maura contracted HIV through intravenous drug use. She is currently clean of drugs and has been for three years. She converted from HIV to AIDS 2 years ago and the progression has been rapid. Most of the symptoms she is experiencing are cognitive although she does have poor endurance and tires easily.

Increasing levels of immersion into case study

Key References:

•Major (2005). OSCEs-seven years on the bandwagon: the progress of an objective structured clinical evaluation programme. Nurse Education Today; 25(6), 442-454.
•Seybert, Kobulinsky & McKaveney (2008). Human patient simulation in a pharmacotherapy course. American Journal of Pharmaceutical Education; 72 (2), Article 37.
•Solomon, Laird-Fick, Keefe, Thompson & Noel (2004). Using a formative simulated patient exercise for curriculum evaluation. BMC Medical Education; 4 (8), 1-6.
•Tomlin (2005). The use of interactive video client simulation scores to predict clinical performance of occupational therapy students. American Journal of Occupational Therapy; 59 (1), 50-56.
•Van Zanten, Boulet & McKinley (2007). Using standardized patients to assess the interpersonal skills of physicians: six years' experience with a high-stakes certification examination. Health Communication; 22(3), 195-205.

Acknowledgements: Funding for this poster was provided by the Faculty of Rehabilitation Medicine, University of Alberta.

ISSOTL October, 2007 Poster Presentation, Conference of the International Society for the Scholarship of Teaching and Learning (ISSOTL) Edmonton, pertaining to the future use of VWs for simulated client caseloads with occupational therapy students. Author: Rashid Kashani

http://wfotcongress2010.pbworks.com/f/WFOT+workshop+May+7+2010.pdf

Virtually presented about using VWs at the World Federation of Occupational Therapy (WFOT) Conference on using technology in occupational therapy practice, Santiago Chile, May, 2010. Authors: Hamilton A, Penman M, Jacobs K, Hook A, Bodell S, Burwash S, Kashani R, Hayward C, Wade W and Guetschow J.

This was an international collaboration between Canada, The United Kingdom, The United States, Australia and New Zealand.

It's not Possible to be a Sage on the Cyberstage

PROCEEDINGS

Vivien Hollis, Anita Hamilton, Susan Burwash, Rashid Kashani, Shaniff Esmail, University of Alberta, Canada

Global Learn, May 17, 2010 in Penang, Malaysia ISBN 978-1-880094-79-2 Publisher: Association for the Advancement of Computing in Education (AACE)

Conference Info Proceedings Book

Abstract & Citation

Abstract

Abstract: Few university entry-to-practice professional health programmes utilize the broad range of computer technology to enhance student learning. One Canadian Occupational Therapy Programme is an exception and is unique in its breadth and depth of usage. In this paper we present as learning tools, WebCT Vista, YouTube™, Skype™, digital video recordings, iClicker®, Second Life®, ePortfolios, wikis, blogs and Facebook and discuss the way in which these computer technologies supports entry-to-practice preparedness for practice. We provide examples of creative use by students and academics. Computer technology is used in innovative approaches to learning, preventing teacher-centred 'sage of the stage' grandstanding but, rather, requiring students to focus on constructing their learning through the personal involvement that is required when computer technology is exploited for this purpose. The benefits of computer technology, in educational terms, are increased collaboration with peers and health care colleagues and increased active engagement in the learning process.

Citation

Hollis, V., Hamilton, A., Burwash, S., Kashani, R. & Esmail, S. (2010). It's not Possible to be a Sage on the Cyberstage. In Z. Abas, I. Jung & J. Luca (Eds.), *Proceedings of Global Learn 2010* (pp. 1332-1341). Association for the Advancement of Computing in Education (AACE).

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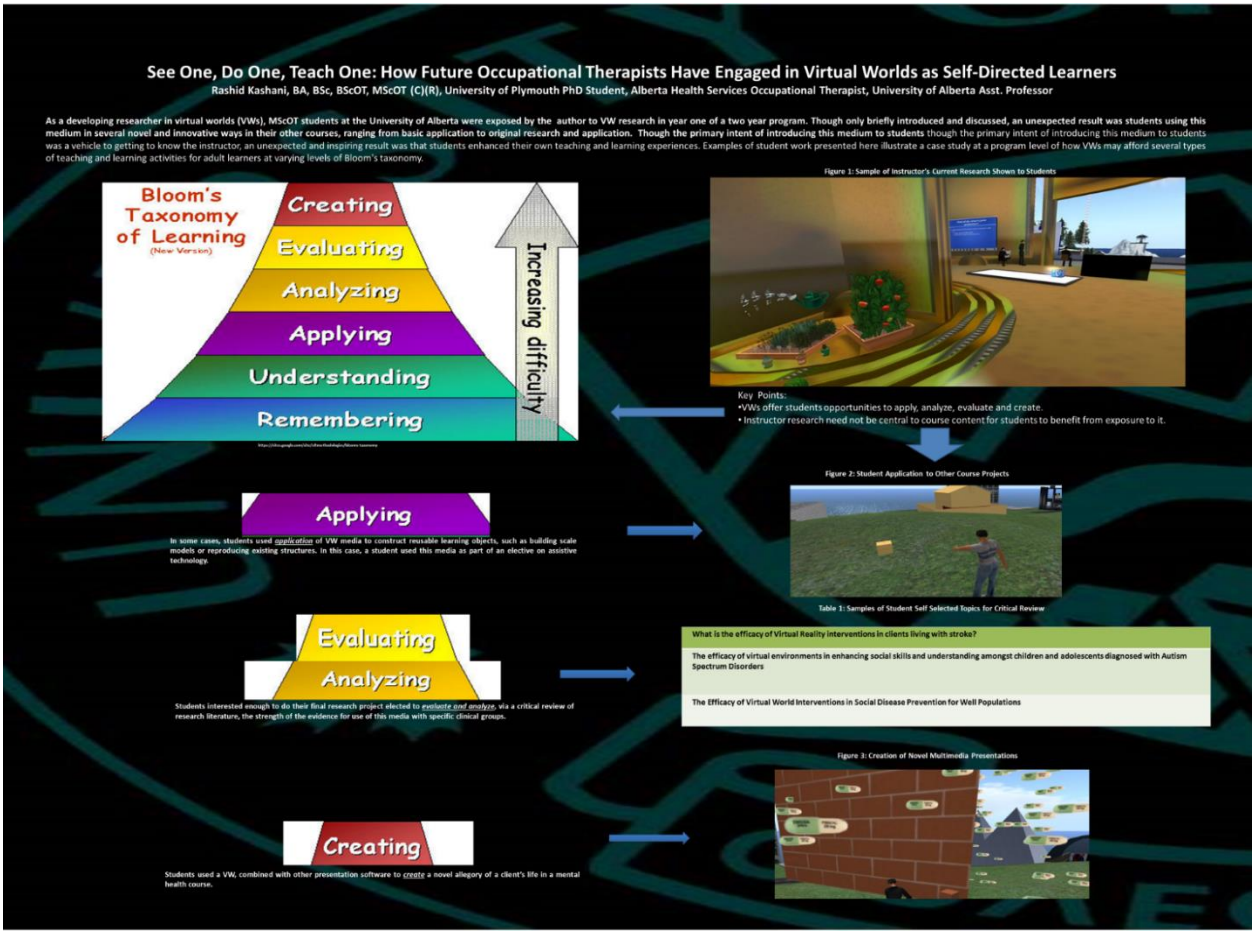
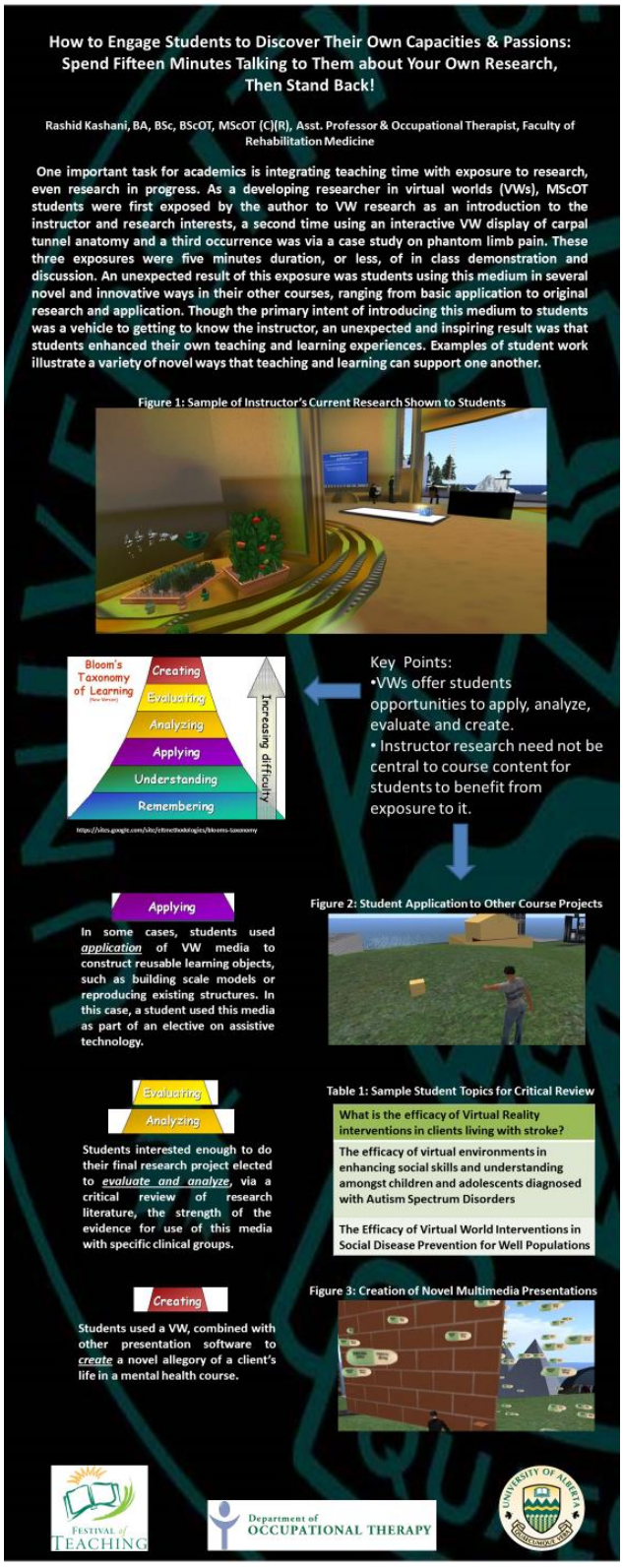
Provided narrated screen captures and videotaped simulations of present techniques used on electronic feedback and teaching aides used in classes, including e-portfolio, video capture of performance on Observed Skill Clinical Evaluations (OSCEs) and VWs in teaching activities. Presented as a paper at Global Learn 2010, Penang.

Published as conference proceedings: It's not possible to be a sage on the cyberstage, Association for the Advancement of Computing in Education, Proceedings of the Global Learn Conference, 2010. Authors: Hollis V, Hamilton A, Burwash S, Kashani R and Esmail S.



Virtual Worlds Best Practice in Education (VWBPE) March, 2011 – This was an interactive poster that linked to a narrated discussion of the poster, which focused on how VWs were being used in the author's classes in order to engage self-directed learning. This was presented in SL using an artificial avatar presenter that opened a web URL with the narrated poster presentation and contact information. Author: Kashani R



Celebration of Teaching and Learning Banner, presented at University of Alberta. Requested to present VWBPE presentation live at Celebration of Teaching and Learning, April, 2011. Author: Kashani R

The following is the most up to date course outline the principal investigator guest presents/has presented a seminar in for, time permitting, in 2011, 2012, 2013 and 2015. The course is graduate level, coordinated by Dr. Kim Solez in the Faculty of Medicine and Dentistry, University of Alberta, and themed on the future of medicine and technology, discussing both the benefits and pitfalls of advances in this area, and ethical issues as we move towards a theoretical point of singularity with the possible advent of artificial intelligence (AI). For example, one topic discussed in my seminar is the dark side of VWs. Most recent presentation was October 8, 2015, as outlined below:

Technology and the Future of Medicine LABMP 590 Schedule Fall 2015 CCIS L1-140 2-3:20 pm

September 1 Introduction/The Future of Medicine Kim Solez (EW)

3 The Technological Singularity Explained and Promoted Kim Solez (EW) 2 pm

Engineering Tomorrow Entrepreneurship in Medicine/

Innovation Shawna Pandya (KS) 6 pm in e Hub space 9007 Hub Mall.

8 Free Will and the Future of Medicine Kiera Prasad (KS/EW) 2 pm

Engineering Tomorrow Entrepreneurship Workshop

Shawna Pandya (KS) 6 pm in e Hub space 9007 Hub Mall.

10 Introduction to Regenerative Medicine Kim Solez (EW) 2 pm

Promise and Perils of AI Part I

Richard Sutton (KS) 6 pm in e Hub space 9007 Hub Mall.

15 Promise and Perils of AI Part II Osmar Zaiane (KS)

17 Promise and Perils of AI Part III Osmar Zaiane (KS)

22 Promise and Perils of AI Part IV Osmar Zaiane (KS)

24 There's Still Plenty of Room at the Bottom Ross Lockwood (KS)

29 Medical Ethics in a World of Robots (What will we allow when everything is possible? Kiera Prasad (KS/EW)

October 1 Promise and Perils of Nanotechnology Ross Lockwood (KS) **International Longevity Day Celebration**

6 Real Life on Fake Mars Ross Lockwood (EW)

8 Second Life/Virtual Worlds and Medicine Rashid Kashani (KS)

13 Spirituality and the Singularity Kiera Prasad (KS/EW)

15 Mid-Term Exam

20 Techniques & the Future: Optogenetics Meets CRISPR Consolato Sergi (EW)

22 Promise and Perils of AI Part V Patrick Pilarski (KS)

27 Bioengineered Kidney & Future of Regenerative Medicine I Jason Wertheim (by Skype) (KS) **(Flipped classroom)**

29 Bioengineered Kidney&Future of Regenerative Medicine II Harald Ott (by Skype) (KS) **(Flipped classroom)**

November 3 Will Humanity's Successors Be Our Descendants? David Pearce (from UK via Skype) (EW) **(Flipped classroom)**

5 Technology and the Body Jonathan White **(Flipped classroom) Deadline for choosing topic and mentor.**

17 Quantum Biology Part I Jack Tuszynski

19 Quantum Biology Part II Jack Tuszynski

24 Promise and Perils of Biotech Robert Rennie (Anthrax infection used as focus for discussion)

26 LGBTQ Inclusion and the Singularity Jan Buterman (KS) **Paper due**

December 1 & December 2 Student presentations (KS/EW)

Glossary

Artificial Avatar – An avatar that is not controlled by a human operator. A product that mimics some avatar movements at rest, serving as a security and monitoring device with a number of features that can be customised by the owner to allow or deny access, take attendance, listen to an record chat on a parcel of land, interact with users in chat like a Turing machine and give inventory as programd, such as notecards or other objects.

Avatar – A representation of the user in a VW. These are typically selected by the user and have some varying degree of customization available.

Building – A process of linking shapes, usually simple prims (polygons), together and modifying them in size, shape and colour to comprise an object that visually appears as a representation of a real world object.

Cave – A specialized VR environment where the entire room forms the environment around the user, often involving not only all four walls, but the floor and ceiling as well.

Griefing – A form of VW harassment, typically involving interfering with the ability of other avatars to interact with the VW, such as introduction of noise, random objects, offensive images and may also culminate in virtual assault of other avatars via weapons, particles or interfering via taking over the VW program viewer of other users.

Haptic – A device that uses movement inputs from the user to perform actions, usually in a VR environment. Examples include a wearable helmet that tracks head movements and changes the orientation of the environment or gloves that track finger movements and appear as a pair of virtual hands to the user.

Multi User Virtual Environment (MUVE) – an online environment that allows several users to interact, typically in real time.

Prim – A primitive. A single object / polygon that impacts the performance of a region. Multiple prims are linked to comprise objects in a VW. There is a limit on the number of prims that may be placed in a region as these impact server and platform performance.

Region – A specific area of a VE with X, Y and Z coordinates. In SL, these are typically given names in SL. These are a definitive size, frequently subdivided into smaller parcels of land, and will support a maximum number of avatars and prims before region performance is impacted, or possibly crashes.

Scripting – A programming language that gives objects built in VWs to have certain behaviours. These behaviours vary widely and can include giving a note card, moving, animating an avatar or the object behaving as it would in real life, such as a door opening when pushed or touched.

Second Life® (SL) – One of many existing VWs. At this time, SL is one of the more widely studied and used VWs. Owned and operated by a third party, Linden Labs, this VW has its own economy and currency. Users are referred to as residents and are given the option of a free or premium account where virtual land can be purchased and a stipend of the VW currency is provided.

Trolling – A form of virtual harassment, typically done by making inflammatory remarks in the new social web. This is commonly seen in chat rooms and social networking sites. In a VW, this can not only be in the chat function, but also via voice message, in person live call, placing or wearing signage and interfering with others' ability to interact with the VW environment. Some users claim, for example, that simply following an avatar around constantly and impeding their ability to freely use the VW, they are not, in fact, griefing others, but acting as trolls. The primary difference between griefing and trolling behaviour is the level of attack or offense, trolling being the more subtle of the two, attempting to invoke a retaliation over time by the harassed party.

Virtual Reality (VR) – a means of creating an environment, either via a computer, or using haptic devices. The environment does not have the same permanence as a VW as the environment shuts off when the user leaves the environment or the simulation is turned off. There is also no interaction with other users.

Virtual Technology (VT) – a general term, referring to any type technology where there is a representation of physical objects or other people, or both, and encompasses all forms of virtual worlds and virtual reality.

Virtual World (VW) – an online multi-user virtual environment (MUVE), typically delivered over the Internet where user objects have some level of permanence and other users can interact with objects in the world and other users, typically in real time. The world continues to exist, including objects left by the user, even after leaving the VW. Ability to create content in-world, such as objects with specific behaviours is often, but not necessarily a feature. The usual interface is the user's computer screen.

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November 2015