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# End-of-life discussions in nonmalignant respiratory disease in the United Kingdom and Canada

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END-OF-LIFE DISCUSSIONS IN NONMALIGNANT RESPIRATORY DISEASE IN THE  
UNITED KINGDOM AND CANADA

by

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A thesis submitted to the Plymouth University in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

School of Nursing and Midwifery  
Faculty of Health, Education and Society

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## End-of-life discussions in nonmalignant respiratory disease

Nonmalignant respiratory diseases (NMRD), such as Chronic Obstructive Pulmonary Disease (COPD), are a leading cause of morbidity worldwide. Research has shown that patients with NMRD in the UK, Canada and the US have less access to palliative care services than patients with other respiratory diseases such as lung cancer. Discussing preferences for end-of-life care in NMRD can be difficult for patients, carers and health professionals, however it is essential to ensure that the patient's wishes are met, particularly when resources are scarce. Despite similar nationalised health care systems in the UK and Canada, a recent report by the Economist Intelligence Unit ranked overall quality of end-of-life care in the UK first out of forty, while Canada was ranked ninth out of forty. Therefore, it was deemed useful to investigate how end-of-life for people with NMRD is discussed between health professionals and patients in the UK and Canada and to develop an instrument allowing health professionals to determine constraints and opportunities for facilitating such discussions in each country as comparing care between countries is helpful to determine the best solutions for individuals and families with complex needs.

This study was guided by the Medical Research Council guidelines for developing and implementing complex interventions, and the research process followed the requirements for the development phase of these guidelines. First, two systematic reviews were carried out to establish the evidence base regarding end-of-life discussions. The first focused on how end-of-life is discussed in NMRD, while the second focused exclusively on end-of-life discussions in a single NMRD (COPD) in the UK and Canada only. The findings of the systematic reviews pointed toward the need for further training of health professionals to

discuss end-of-life with this patient group, as well as the lack indicators that this patient group is ready or willing to discuss end-of-life.

Then, a Delphi study was conducted with specialist respiratory nurses in the UK to determine expert opinion on how health professionals know a patient with NMRD is ready to discuss end-of-life, and to establish the key considerations and topics in such discussions. This study was replicated in Canada with health professionals working with patients with NMRD. Each Delphi study resulted in a country specific tool to assist less experienced health professionals discuss end-of-life with this patient group.

Finally, the findings of these Delphi studies were compared to determine what health professionals in each country could learn from each other, as well as specific considerations in each country, and areas for future research. The findings from the comparison process demonstrated that the emotional intelligence of health professionals, the patient education context and the recognition of cultural issues were all important factors when approaching end-of-life discussions.

Findings from each phase of the intervention development process resulted in a theoretical model of how end-of-life is discussed in the UK and Canada. This model identifies constraints and opportunities for such discussions from a systems level perspective including: end-of-life policies, prognosis in non-malignant respiratory disease, time, clinical indicators, initiation responsibility, the educational role of health professionals, emotional intelligence, cultural competence and readiness versus willingness to discuss end-of-life. Recommendations are made from the findings of this study for research, clinical practice, education and policy. A detailed plan for the next stage of the development of the intervention is included.

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## **Chapter 1. Introduction**

### **1.1 Introduction**

Discussing end-of-life care preferences is essential for people with COPD in order to determine treatment options and maximise quality of life. People with nonmalignant respiratory diseases (NMRD) can experience acute exacerbations of their disease potentially leading to emergency hospitalisation or death (American Thoracic Society and European Respiratory Society, 2004). Therefore, health agencies such as the American Thoracic Society and the European Respiratory Society recommend that healthcare providers assist patients, when their health is stable, to think about palliative care and end-of-life care. End-of-life discussions are discussions about end-of-life care preferences and issues between health professionals and patients (Curtis et al., 2004). By discussing palliative care and end-of-life care when the patient is stable, the patient is prepared for potentially life-threatening exacerbations of their disease while they continue living and enjoying life, rather than being forced into decisions, or having their family make decisions on their behalf when imminent death is pending (Celli et al., 2004).

The significance of end-of-life discussions and access to palliative care services is recognised at the highest level of health service organisation. In 2009, the Department of Health in the United Kingdom (UK) released the End-of-Life Care Strategy, which stated that many health professionals have insufficient training in communicating with patients approaching the end-of-life. The strategy recommended that communication skills programmes be provided as a major workforce development initiative, as they are currently mandatory for oncology, but not for other life-limiting diseases (Department of Health, 2009). In the United States, a New

York State Law was recently passed requiring health professionals to provide palliative care information and end-of-life options to patients diagnosed with a terminal illness, in an effort to ensure that end-of-life discussions take place (New York State Assembly, 2010). However, there is no evidence as to the effectiveness of this new legislation for ensuring that patients and health professionals have end-of-life discussions.

The unpredictable trajectory of NMRD may make timing such discussions more difficult than with other diseases (Murray et al., 2005). In addition, poor health and breathlessness associated with NMRDs will likely add further communication barriers to engaging in such discussions (Booker, 2005). This is a critical issue given that there is a lack of palliative care services available to this population (Partridge et al., 2009), and they have a greater prevalence of anxiety and depression (van Ede et al., 1999).

The World Health Organization defines palliative care as: 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (World Health Organization, 2011, from <http://www.who.int/cancer/palliative/definition/en/>). Recent research findings indicate that patients who were enrolled in palliative care programmes early after diagnosis of a terminal illness experienced significant improvements in their quality of life and mood. The same study also found that patients who received early palliative care survived longer than patients receiving standard care and had less aggressive care at the end-of-life (Temel et al., 2010). A key component of palliative care is end-of-life care; this term is used to describe care provided for the patient and their family in the final stage of life (Curtis, 2008).

Several options are available for palliative and end-of-life care in the terminal stages of the illness, and decisions need to be made, which can present a challenge for health professionals. They must present options, assist with decision-making and ensure that information is communicated across clinical settings (Quill, 2000). Despite the importance of this process and the recommendations by the American Thoracic Society (American Thoracic Society and European Respiratory Society, 2004), evidence shows that healthcare professionals are not adequately addressing advance-care planning and end-of-life care preferences of the patient (Patel et al., 2012). Several studies have found that few patients with advanced COPD have discussed their end-of-life preferences with their physician, received prognostic information or discussed the palliative care services available to them (Heffner et al., 1996, Goodridge et al., 2009, Mulcahy et al., 2005). This literature demonstrates that advance-care planning has not improved greatly with this group of patients since the landmark SUPPORT study investigators found that less than 50 percent of physicians knew their terminally ill patient's wishes for cardiopulmonary resuscitation (The SUPPORT Principal Investigators, 1995). In addition, the authors of a recent integrative review found that further investigation is required to address the complex personal, provider, and system elements in NMRD (Disler et al., 2012). Definitions of the key terms as used throughout this thesis are presented in Table 1.1.

**Table 1.1 Key terms and definitions**

Key Term	Definition
<b>British Lung Foundation Nurses</b>	A group of Specialist Respiratory Nurses who work in the National Health Service (NHS) in the UK, who are funded in part or in whole by the British Lung Foundation.
<b>Chronic Obstructive Pulmonary Disease (COPD)</b>	The most common non-malignant respiratory disease involves chronic diffuse irreversible airflow obstruction and is an umbrella term for chronic bronchitis, emphysema and bronchiectasis.
<b>End-of-life care</b>	Care occurring in the last part of a patient's life, typically in the last few months, depending on the underlying diagnosis and clinical course.
<b>Gold Standards Framework (GSF)</b>	A systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by generalist care providers.
<b>Health professionals</b>	Any person trained to work in any field of physical or mental health, including physicians and social workers.
<b>Palliative care</b>	Care that focuses on improving the quality of life of patients and their families facing the problem associated with life- threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual .

## **1.2 International Comparison**

Comparing care between countries is helpful to determine the best solutions for individuals and their families with complex needs (Higginson, 2005). Western countries such as the UK and Canada have similar approaches to palliative care that include an active approach to assessing, diagnosing and treating the concerns of patients and their families, and multi professional care (Higginson, 2005). This care can be part of palliative care that ‘focuses on the relief of suffering for patients with serious and complex illness and tries to ensure the best possible quality of life for them and their family members’ but may be delivered at the same time as curative or life-prolonging treatments (Meier et al., 2010, kindle location 407). Both countries have public health care systems, entitling citizens and residents to receive government-sponsored health insurance that covers ‘necessary care’ (Ross and Detsky, 2009).

A report by the Economist Intelligence Unit ranked the quality of end-of-life care by country and revealed high variation across developed countries. The UK was ranked first overall, and Canada was ranked ninth along with the United States. The ranking was based on

the Quality of Death Index which scored countries across four categories. The index measures end-of-life care services across 40 developed countries. The overall ranking is based on: the basic healthcare environment (20%), availability of end-of-life care (25%), cost of end-of-life care (15%), quality of end-of-life care (40%). The following table shows the rankings of the UK and Canada in each category (Murray, 2010). The report states that the UK's high ranking can be partially explained by the long history in the field of end-of-life care. The UK is ranked at the top of the categories evaluating quality and availability. Canada is ranked fifth in quality and ninth for availability (Murray, 2010).

**Table 1.2 Ranking of UK and Canada on Quality of Death Index.**

Quality of Death Index Category (percentage contribution to overall ranking)	Ranking (out of 40)	
	United Kingdom	Canada
The basic healthcare environment (20%)	28	20
Availability of end-of-life care (25%)	1	9
Cost of end-of-life care (15%)	18	27
Quality of end-of-life care (40%)	1	5
Overall ranking	1	9

A recent study by Janssen et al. (2011) compared the quality of communication about end-of-life care for patients with COPD in the Netherlands and the US, and the authors propose that understanding international differences may help to improve communication in this area (Janssen et al., 2011). These authors recommended that studies that account for international differences and patient specific factors should be conducted. International research in end-of-life can provide insight into practice and help to further research in this area

as well as promote cross-national learning and collaboration (Raijmakers et al., 2011, Blendon et al., 2003, Centeno, 2014).

Based on similarities between approaches to palliative care, similar health systems and epidemiology (as will be explored in the sections that follow), and the disparities between rankings in the Economist report (Murray, 2010), it was thought that a comparison of end-of-life communication in COPD has potential to provide valuable insight in this area. An international comparison can inform future developments in both countries, and help to determine the best solutions for individuals and their families with complex needs (Higginson, 2005).

### **1.3 End-of-life care in the UK and Canada**

#### **1.3.1 Epidemiology**

The most common NMRD, Chronic Obstructive Pulmonary Disease (COPD) (an umbrella term for chronic bronchitis, emphysema and bronchiectasis(British Thoracic Society)), is a progressive, life limiting disease that is one of the top five causes of mortality worldwide and is a significant health burden (Seemungal et al., 2009). Currently, COPD is the only NMRD with epidemiological data widely available. By 2030, it is estimated that COPD will be the 3<sup>rd</sup> leading cause of mortality worldwide. In the UK it is estimated that between 1 percent and 4 percent of the population have COPD and it accounts for approximately 5 percent of deaths each year, mainly affects individuals who are 45 or older, and is also linked to social deprivation (Department of Health, 2010). Smoking is the most common cause of COPD, and 86 percent of COPD deaths are attributable to this factor (Department of Health, 2010). Despite the high mortality for NMRD, the disease trajectory is unpredictable.

The most common approach used when comparing disease prevalence across countries is self-reported physician diagnosis. However, this method may underestimate the prevalence of COPD by 50 percent or more in individuals over 40 years old. Differentiating between COPD and asthmas in older smokers also provides a challenge for prognostication and there is a possibility that one disease could be misdiagnosed as another (Schirnhofner, 2007). In addition, the mortality rate of COPD may be higher than reported as two common complications of COPD: pneumonia and congestive heart failure may be listed as the cause of death for individuals with COPD (Schirnhofner, 2007).

In Canada, approximately 4.4 percent of the population have been diagnosed with COPD (including a self-report of COPD, chronic bronchitis or emphysema) and COPD accounted for 4 percent of all deaths in 2004. This figure is expected to increase, as the prevalence of COPD rises over the next decade, particularly in the aging female population (Canadian Lung Association, 2008). As in the UK, the cause of COPD in Canada is primarily attributed to smoking; 84 percent of Canadians with COPD had been smokers, while 40 percent were still smoking (Canadian Lung Association, 2008). Interestingly, a higher proportion of women than men aged 74 or under are being diagnosed with COPD, and this trend reverses in people who are 75 or older (Canadian Lung Association, 2008). This higher prevalence among women under 74 will have significant implications for the health care system as there will be an increased need for health care as more older women live alone and an increased need for supportive housing and other community services (Public Health Agency of Canada, 2007).

### **I.3.2 Health Systems**

#### **United Kingdom**

The UK has had a tax-funded National Health Service (NHS) since 1948, which is free at the point of use except for dentistry, optometry and prescriptions (de Silva and Fahey, 2008). The NHS is headed by a cabinet minister, and the planning and delivery system is hierarchical, with the Department of Health providing the policy focus (as set by the current ruling political party), and Foundation Trusts providing their own strategic leadership at the regional level. The budget is allocated to these Foundation Trusts, which then purchase services from health providers based on the standards set by the Department of Health. The Foundation Trusts are regulated by Monitor who is the sector regulator for health services in England. This system is increasingly burdened financially by the aging population and the growing prevalence of chronic disease and as a result there are a number of private providers that provide funded care for patients (de Silva and Fahey, 2008).

The NHS Health and Social Care Model was launched by the government in 2005 to help improve care for people with long term conditions (Department of Health, 2005, de Silva and Fahey, 2008), and was based on the Chronic Care Model developed in the US, as well as other policies in the UK. The model focuses on how to identify individuals with long term conditions so that they can get care, and aims to improve the quality of care, accessibility to care, and contain or reduce the costs of chronic care, and in general to shift from reactive care in hospitals to responsive care in communities (de Silva and Fahey, 2008). People with chronic disease are viewed as a single group, however the NSFs provide evidence-based guidance on specific chronic diseases and develop strategies to support implementation of such guidance.

## Canada

The development of universal health care coverage in Canada started in one province in 1944 and by 1971 all Canadians were guaranteed access to essential medical services regardless of employment, income or health, this coverage was solidified through the Canada Health Act of 1984 that ensures that the provinces follow the principles of public health care (Marchildon, 2012). As in the UK, the federal government sets the standards for the national Medicare system, and the provinces and territories organise and deliver the healthcare services. Within provinces, healthcare is organised by Regional Health Authorities (RHAs), that coordinate and deliver services to defined geographic areas. These RHAs vary in their functions by province (Jiwani and Dubois, 2008). Most hospitals in Canada are private, non-profit making organizations and physicians also practice privately with a fee-for-service payment system. The ten provinces and three territories are responsible for covering prescription pharmaceuticals, providing an variety of public services and for funding or subsidising some long-term care and home care services, however outside of this package, provinces differ in their coverage of medical services (Jiwani and Dubois, 2008).

The Canadian Centre for Disease Prevention and Control (CCDPC) was established under the Public Health Agency of Canada and has developed and implemented a Best Practices Portal for Health Promotion and Chronic Disease Prevention, as well as a disease surveillance website (Jiwani and Dubois, 2008). Also, several national initiatives have focused on the prevention of chronic diseases in the community that primarily focus on lifestyle related factors such as physical activity, healthy eating and smoking (Jiwani and Dubois, 2008). Specifically related to respiratory disease is the National Lung Health Framework (2008) that was supported by Health Canada and the Public Health Agency of Canada. As most provinces and

territories have identified chronic disease as a key priority and developed their own strategies related to chronic disease, the federal government has responded by providing assistance with initiatives such as the Primary Health Care Transition Fund, which helped to establish multidisciplinary teams in primary care (Jiwani and Dubois, 2008).

### **1.3.3 End-of-life care policies**

In the UK, the government developed an NHS end-of-life care programme from 2004-2007 to improve end-of-life care. The programme was designed to encourage the development and adoption of end-of-life care models such as the Gold Standards Framework (2006) to address the needs of local populations. This programme was followed by the NHS End-of-Life Care Strategy (Department of Health, 2008) that was developed to increase access to high quality care for all people approaching the end-of-life, at home, in care homes, in hospitals, hospices and elsewhere. The strategy was also designed to enhance choices for patients, quality, equality and value for money. However, it is important to note that many hospice and palliative care services in the UK are provided and funded by the voluntary sector, for example 76 percent of adult inpatient specialist palliative care units in England in the UK were provided by the voluntary sector (Hospice and Palliative Care Directory 2008).

In Canada, the provinces are responsible for delivering palliative and end-of-life care, and these services are funded by the federal government. In terms of policy, Health Canada, the Public Health Agency of Canada and the Canadian Institute of Health Research all support palliative and end-of-life care. Within Health Canada's strategic policy branch, there is a palliative and end-of-life care unit that addresses issues for Canadian with life limiting conditions. They also ensure that palliative care is considered in relevant policy initiatives throughout the federal government. They work with the provinces on end-of-life related issues and they

provide leadership for all national initiatives related to palliative and end-of-life care (Canadian Lung Association, 2008). In 2012, the Canadian government announced a nation-wide investment to move toward community-integrated palliative care. Currently palliative and end-of-life care is mostly delivered in hospitals and services vary greatly, based on the region. The new initiative has the aim to deliver care in primary and community settings, supported by multi-disciplinary teams (The Quality End-of-life Care Coalition, 2013, Health Canada, 2012). The Public Health Agency of Canada is also involved by providing federal leadership through the Division of Aging and Seniors, and they published a palliative and end-of-life care information sheet and CD for seniors. Finally, the Canadian Institute of Health Research identified palliative and end-of-life care as a strategic research priority in 2002, and they launched an initiative to support the palliative care research community to develop infrastructure, enhance interdisciplinary research collaboration and attract new researchers to the area. However, more work must be done as the National Lung Health Framework (Canadian Lung Association, 2008) states that the need to improve the quality of end-of-life care in Canada is a public health crisis, due to multiple issues such as a high prevalence of symptom distress, caregiver burden, use of inappropriate technologies, poor transition management, significant costs and over dissatisfaction with communication and the quality of care (Canadian Lung Association, 2008). It seems that the new model of community-integrated palliative care may assist in addressing some of these issues. Table 1.3 summarises the comparison of epidemiology, health systems and end-of-life care policies related to COPD in the UK and Canada.

**Table 1.3 Summary of epidemiology, health systems and end-of-life care policies in the UK and Canada.**

	UK	Canada
<b>Epidemiology</b>	<ul style="list-style-type: none"> <li>• 1.4% of the population have COPD</li> <li>• Accounts for 5% of deaths each year</li> <li>• Smoking is the most common cause of COPD</li> </ul>	<ul style="list-style-type: none"> <li>• 4.4% of the population have COPD</li> <li>• Accounts for 4% of deaths each year</li> <li>• Smoking is the most common cause of COPD</li> </ul>
<b>Health systems</b>	<ul style="list-style-type: none"> <li>• NHS is tax-funded and free at the point of use</li> <li>• System is burdened by the aging population and growing prevalence of chronic disease</li> <li>• Health and Social Care Model to identify individuals with long term conditions and provide appropriate and cost-effective care</li> <li>• Shift from hospital to community care</li> </ul>	<ul style="list-style-type: none"> <li>• Universal health care coverage for all Canadians</li> <li>• Chronic disease is a key priority</li> <li>• Chronic disease care through multidisciplinary teams in primary care</li> </ul>
<b>End-of-life care policies</b>	<ul style="list-style-type: none"> <li>• NHS End-of-life Care Strategy launched in 2008 to increase access to care for all in a variety of environments</li> <li>• Many hospice and palliative care services are funded and provided by voluntary sector (e.g. 76% of inpatient palliative care units in England)</li> </ul>	<ul style="list-style-type: none"> <li>• Health Canada has a palliative and end-of-life care unit for life limiting conditions</li> <li>• Palliative and end-of-life care mostly delivered in hospitals</li> <li>• Services vary by region</li> <li>• Aim to deliver community-integrated palliative care to address multiple issues within the current system</li> </ul>

#### **1.4 The research problem**

Regardless of the context or country they are in, it is clear that patients who have progressive illness require skilled assessment in addition to emotional, spiritual and social support for themselves and their families, including the opportunity to discuss their wishes for end-of-life care (Higginson, 2005). The model of communication between patient and professional proposed by Donabedian (1973) is useful to understand end-of-life discussions. The model posits that patients and health professionals may have differing perspectives that can lead to obstacles in communication—with the patient focusing on the impact of care on their

lives, as well as discomfort and pain, while the health professional focuses on the more scientific issues such as illness manifestation, progression and treatment (Donabedian, 1973). This conflicts with the idea that end-of-life conversations are supported by the patient-centered view of medical care (Larson and Tobin, 2000). Roter & Fallowfield (1998) defined patient-centered medicine as an approach that views the illness from the patient's perspective, including the psychosocial consequences, and seeks to empower the patient to make decisions in light of their personal context. The foundation of this concept is professional understanding of patient needs and a focus on quality of life.

In a study about when and how to initiate end-of-life discussions with patients with a terminal illness, care-givers and health professionals agreed that end-of-life discussions should take place when the patient is ready, but also found many patients waited for health professionals to raise the topic (Clayton et al., 2005). The skill of knowing when to broach the end-of-life discussion was described as a balancing act between listening, assessing and weighing the benefits versus the risks of raising the topic. The discussion may be easier to time when the patient and health professional have a long-standing relationship and the health professional is sensitive to their patient's psychological state; however, this may be impossible in the current health care context, where continuity of care can be difficult and health professionals may not be allocated sufficient time to have meaningful conversations with their patients. Therefore, health professionals need to be able to assess when a patient is ready for the discussion, as well as the important components of the discussion.

The emphasis on end-of-life discussion has stemmed from advance directive programmes that aimed to improve the uptake of the practice of advance care planning (Johnstone and Kanitsaki, 2009). Advanced care planning is defined as “a process of communication between a

person and the person's family members, health care providers and important others about the kind of care the person would consider appropriate if the person cannot make their own wishes known in the future" (Shanley & Wall 2004, p.32.). However, this older model of advance care planning has been devised into a new programme in the United States called 'Respecting Patient Choices', which still aims to improve advance care directive use by providing a supportive framework to do so, primarily by training nurses as 'Respecting Patient Choices' Consultants to ultimately systematize the expression of patient end-of-life choices as part of a formal programme (Seal, 2007).

Partridge and colleagues (2009) proposed developing formal policies to assist patients with NMRD who are nearing the end-of-life to receive detailed information to help them navigate palliative care services. However, several studies have reported on the difficulties of establishing formal guidelines for end-of-life conversations. This is due to the personal nature of such discussions, the unpredictable disease trajectory, and individual preferences through the identification of facilitators to end-of-life discussions as well as barriers (Anselm et al., 2005, Curtis and Patrick, 1997, Knauft et al., 2005, Murray et al., 2005).

## **1.5 Aims and objectives of the study**

Based on the research problem stated above, the aims of this study were to:

- 1) Determine how health professionals discuss end-of-life with patients with NMRD in the UK and Canada, and
- 2) Develop an instrument allowing health professionals to determine constraints and opportunities within the environment to facilitate successful end-of-life discussions with this patient group in the UK and Canada.

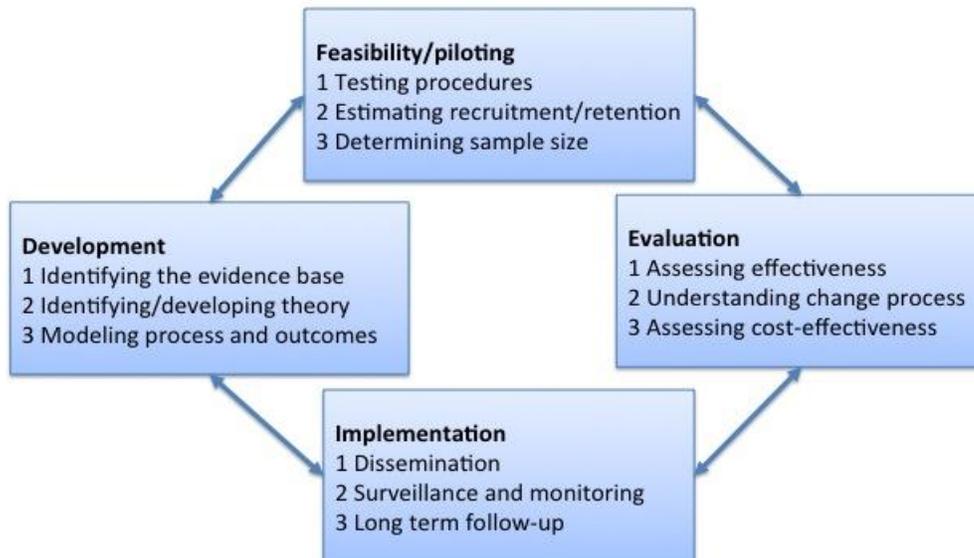
The study aims were addressed through the following objectives:

- a) Establish how health professionals know a patient with NMRD is ready or willing to discuss end-of-life,
- b) Establish the key considerations and key topics in such discussions as defined by health professionals in the field, and
- c) Delineate the differences in end-of-life discussions for patients with NMRD in the UK and Canada.

## **1.6 Study Design**

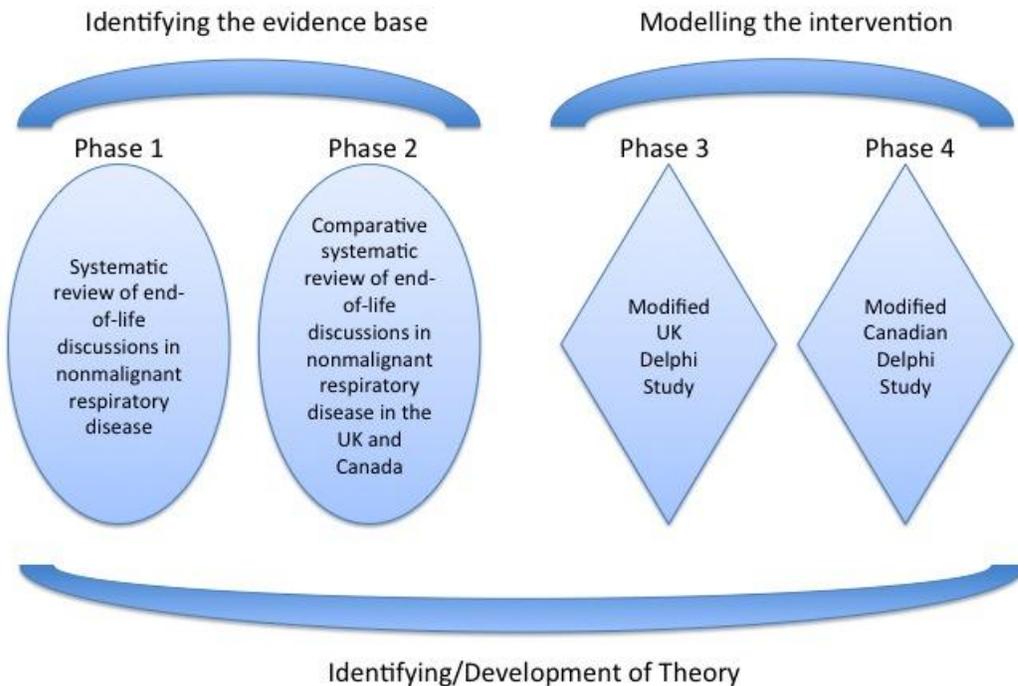
The aims of this study were to explore a phenomenon and then develop an instrument based on these findings. This process was guided by the pragmatic stance, which focuses not on what has gone before, but what will happen in the future as a result of the research (Johnson and Onwuegbuzie, 2004). As is stated throughout the literature, individuals and their families dealing with NMRD have complex and varied needs (Disler et al., 2012). To achieve these aims, the guidance on developing and evaluating complex interventions (Medical Research Council, 2008) set out by the Medical Research Council, provided the blueprint for the design of this study. The guidance proposes four iterative phases as key elements of the development and evaluation process including: development, feasibility/piloting, evaluation and implementation as detailed in Figure 1.1. Due to the time and resource constraints of a doctoral study, only the development process was completed here, with extensive plans for future phases explicated in the recommendations for research section at the end of this thesis (section 9.5).

**Figure 1.1 Key elements of the development and evaluation process for complex interventions reproduced from Medical Research Council (2008).**



The development phase includes three elements: identifying the evidence base, identifying/developing theory and modelling the process and outcomes (Medical Research Council, 2008). This process of development was achieved in this study through four phases as shown in Figure 1.2. First, the existing evidence base was established through two systematic reviews. The first was a general overview of all related literature and the second included literature from the UK and Canada exclusively related to COPD (as the most common NMRD) and a comparison of the findings from each country. The findings of the systematic reviews also contributed to the development of the theoretical model proposed in 8.2.1.

**Figure 1.2 Four phases of the study to develop a complex intervention**



The systematic reviews were followed by two Delphi studies conducted independently in the UK and Canada. These findings of these Delphi studies provided the majority of the evidence that led to the development of the theoretical model, while also resulting in the development of two interventions for use in each country. These Delphi studies were both followed immediately with a questionnaire asking Delphi participants to give their opinion on the clinical applicability of the tools in their own practice. The results of the Delphi studies were also compared to provide further insight into practice in each country for the theory development process. This clinical applicability questionnaire was based on the recommendation in the MRC guidance that the question 'would it be possible to use this?'

should be asked before beginning on the involved process of the evaluation of an intervention (Medical Research Council, 2008, p. 7).

The mixed methods approach was deemed the optimal method to achieve the study aims outlined above, allowing exploration of the research phenomenon and subsequent development of the intervention (Creswell, 2003). Specifically, the mixed methods sequential exploratory design for instrument development guided the use of the Delphi studies for the use of developing an intervention (Creswell, 2003, Collins et al., 2006). The use of this research design will be discussed in Chapter 4.

## **1.7 Reflexivity**

This study originated from an opportunity provided by the British Lung Foundation to explore end-of-life communication in nonmalignant respiratory disease. This opportunity was of interest to me because of my background as a social worker and specifically the work I had done with the elderly in that role. I did case management work for several aged people with nonmalignant respiratory disease, and witnessed how they were managed on an exacerbation by exacerbation basis. Knowing how serious an exacerbation could be, and also the fact that these people were often isolated in their homes and without family support, it struck me how beneficial communication between health professionals and people with this condition approaching the end of life could be. However, this can be an awkward topic and health professionals are often reluctant to broach such discussions (Larson & Tobin, 2000). Therefore, I thought it would be useful to examine how health professionals know a patient is ready or willing to discuss end-of-life, thereby potentially breaking down barriers to such discussions and ultimately improving communication about this topic. I was aware that I brought my own

experiences and attitudes to the topic, and indicate in Chapter 4 how I used a mixed methods design to enhance the rigour of the study.

## **1.8 Structure of the Thesis**

The thesis is structured based on the order that the research was conducted. Chapter 2 includes a comprehensive account of a systematic review of end-of-life discussions in non-malignant respiratory disease, while Chapter 3 is a thorough account of a systematic review of discussing end-of-life in NMRD in the UK and Canada. These systematic reviews are presented first as it was important to establish the evidence base before determining exactly what further research should be conducted. Therefore, Chapter 4 is a detailed discussion of the mixed methods research design for instrument development and the Delphi method that was chosen to carry out the design, and a description of study participants in both the UK and Canada. This is followed by an in depth account of the modified Delphi study conducted in the UK, followed by a description of the clinical applicability process that resulted from the findings of the study and presentation of the tool in Chapter 5. Then, Chapter 6 is a detailed account of the modified Delphi study conducted in Canada, followed by a description of the clinical applicability process that resulted from the findings of the study and presentation of the tool. This is followed by a narrative comparison of the consensus items from both the Canadian and UK Delphi studies. The two Delphi studies are presented separately as it was thought important to discuss the results independently as related to their country specific contexts before comparing them. In addition, relevant literature that was not in the systematic reviews was woven into the discussion sections of Chapters 5 and 6. Then, Chapter 7 is a discussion of the findings of the study as a whole including a review of the research questions posed and a theoretical model of end-of-life discussions in non-malignant respiratory disease, followed by

Chapter 8, which includes a discussion of the original contributions and critical appraisal of this study followed by recommendations for practice, education, policy and research.

## **1.9 Conclusions**

This chapter has provided an overview of end-of-life care and the importance end-of-life discussions in non-malignant respiratory disease as a background to the doctoral study. This was followed by an examination of the value of comparing research from two or more countries in order to determine the best solutions for patients with complex needs and contextual information regarding how care for chronic diseases and end-of-life care is delivered in each country was provided. Then the specific research problem that will be examined throughout this thesis was explicated, and followed by a statement of the aims and objectives of the study. Finally, a brief description of the study was provided followed by an explanation of the structure of the thesis. This chapter will be followed by a systematic review exploring end-of-life discussions in non-malignant respiratory disease.

## **Chapter 2. End-of-life discussions in non-malignant respiratory disease: a systematic review**

### **2.1 Introduction**

In order to identify the evidence base as part of the development of a complex intervention, a systematic review of the literature was conducted looking at end-of-life discussions in NMRD. This chapter contains a comprehensive account of the process and findings of the review. Specifically, the aims of the study are explicated, followed by a detailed description of the design of the systematic review. Then the results of the systematic review are presented in a narrative, with a discussion of the implications of the review.

### **2.2 Aims**

The objectives of this review were to develop an evidence base for end-of-life discussions in NMRD by:

- Examining the key components that should be included in end-of-life care discussions between health professionals and patients with life-limiting progressive NMRD; and
- determining areas of future research that may be helpful for health professionals to understand these specific components without formalising the procedure of end-of-life discussions.

### **2.3 Design**

A protocol outlining inclusion/exclusion criteria and the methods of analysis was developed according to the review method proposed by (Petticrew and Roberts, 2005). This review method allows for either statistical or narrative synthesis of the studies, and includes

question development, literature search, study screening, data collection, data analysis, quality appraisal and synthesis. However, as the guidelines are general, other sources were incorporated into the method when necessary, such as standards for quality appraisal (Kmet et al., 2004) and synthesis (Dixon-Woods et al., 2004). The review was conducted in accordance with the PRISMA guidelines (Liberati et al., 2009).

The components of the review question as defined in the objectives above using the PICO framework (Petticrew and Roberts, 2005) are:

**Population:** Health professionals and/or patients with life-limiting, progressive nonmalignant disease. While the study was undertaken to inform care of patients with NMRD (primarily COPD), papers were included about other nonmalignant diseases with an unpredictable disease trajectory. It was felt that much could be learned as these patients may also have less access to palliative care services than some other patient groups (Partridge et al., 2009). Studies on caregivers were included if the authors reported on the deceased patients' experiences (Hinton, 1996).

**Phenomena of Interest:** End-of-life discussions between patients with a life-limiting progressive nonmalignant disease, or their carers, and health professionals.

**Context:** Any setting where end-of-life discussions occur.

Outcomes were not specified for this study this may have unnecessarily limited the search.

### 2.3.1 Search methods

A sensitive-search strategy was used in an attempt to include all relevant literature. A preliminary broad-based search was conducted in PubMed and CINAHL in order to identify and

obtain the maximum number of keywords from relevant articles. The keywords from each article were entered into an NVivo database, and this list was then analysed for the frequency that each keyword occurred. The most prevalent words were used to develop the search strategy, and to identify thesaurus terms and free-text terms to be used in the search. Methodology specific filters were used for each database. PubMed, CINAHL, BNI, ASSIA, PsycINFO, ScienceDirect and Web of Science were searched between November 2009 and February 2010 for literature published between 1999 and 2010. In addition, the contents of the Journal of Palliative Medicine, the Journal of Pain and Symptom Management, the Western Journal of Nursing Research and the American Journal of Hospice and Palliative Care were hand- searched as these journals yielded the most relevant results in the database search. The reference lists of all articles selected for potential inclusion were also searched. Grey literature was not included as time constraints did not allow a full systematic search of such sources. Search terms or equivalent MeSH headings are listed in Table 2.1.

**Table 2.1 Search terms of equivalent MeSH headings.**

Search Terms	
1. terminal care;	22. disclosure;
2. terminally ill;	23. discussion;
3. chronic disease;	24. family;
4. lung diseases;	25. patient;
5. pulmonary disease, chronic obstructive;	26. patient care conferences;
6. aged;	27. patient-family conferences;
7. palliative care;	28. psychology;
8. hospice care;	29. 20-28/or; <sup>1</sup>
9. hospices;	30. attitude of health personnel;
10. critical illness;	31. patient satisfaction;
11. advancing illness;	32. physician-patient relations;
12. death;	33. nurse-patient relations;
13. end-of-life;	34. professional-patient relations;
14. end of life;	35. 31-34/or; <sup>1</sup>
15. chronic illness;	36. health professional;
16. dying;	37. nurses;
17. prognosis	38. physicians;
18. 1-17/or; <sup>1</sup>	39. hospital;
19. conversation;	40. medical staff;
20. communication;	41. 37-40/or; <sup>1</sup>
21. decision making;	42. 18 and 29 and 35 and 41. <sup>2</sup>

Studies were included if they:

- focused on end-of-life discussions between patients with NMRD, or their caregivers, and health professionals;
- were primary studies conducted using a specified qualitative or quantitative methodology;
- were conducted in any country and were published between 1999 and 2010 in a peer reviewed journal in English;
- involved participants aged 18 or over.
- Studies were excluded if they focused upon:

<sup>1</sup> 18, 29, 35, 41 denote that search term items listed (e.g. 1 to 17) were combined using the boolean term OR between them, meaning that the database searched "terminal care" OR "terminally ill" OR "chronic disease" OR etc. which provided results of any database item containing any of these terms.

<sup>2</sup> 42 indicates that the results of searches conducted in 18, 29, 35 and 41 were combined using the boolean term AND in the database, which provided results of database items containing items from each search group e.g. a database item that included "palliative care", "communication", "patient satisfaction", "nurses".

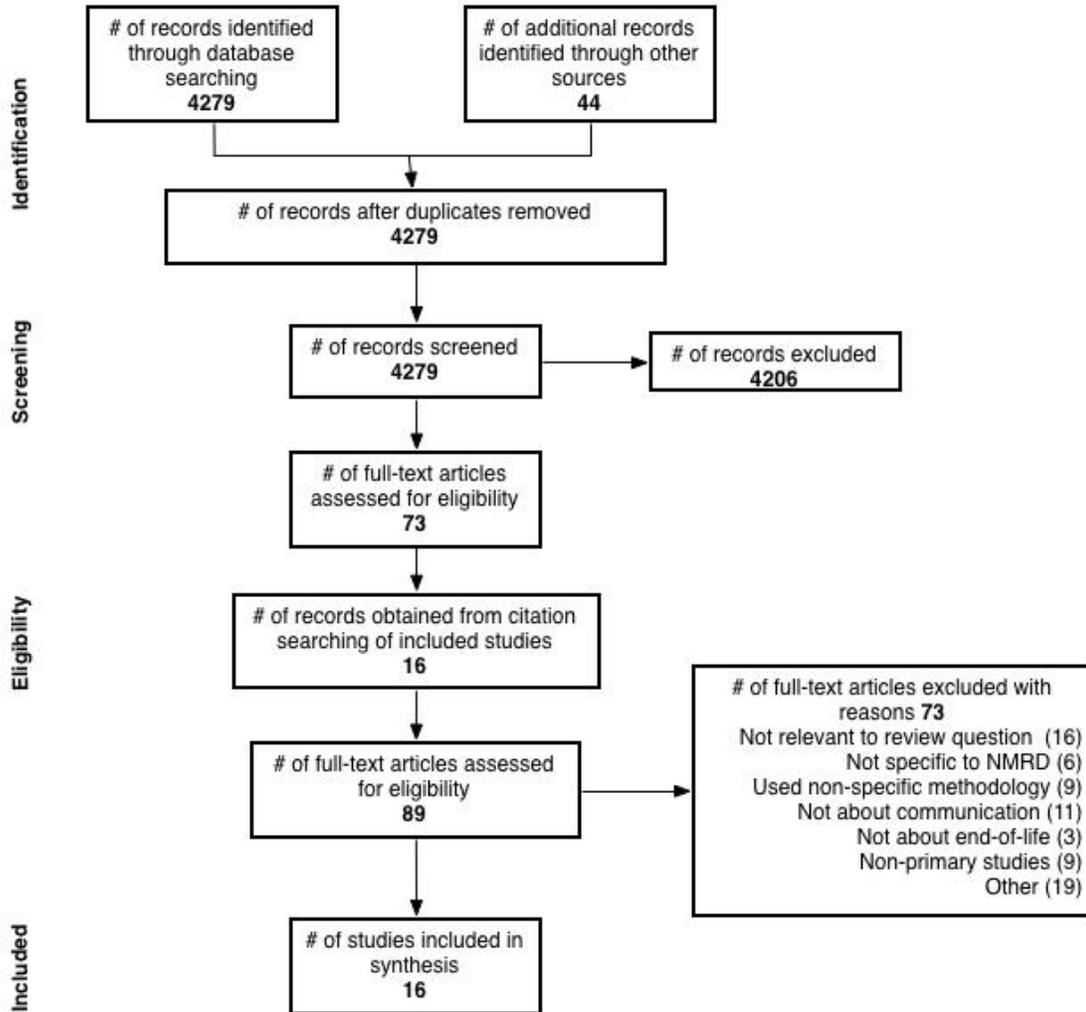
- malignant disease, unless being compared to nonmalignant diseases; or
- the topic of euthanasia as the focus of this study is natural death.

In addition, reviews with duplicate evidence were excluded. A member of the supervisory team reviewed 30 percent of the studies according to the inclusion criteria, and the student and the supervisor met to reach a consensus as to their inclusion/exclusion.

### **2.3.2 Search outcome**

The search and review process conformed strictly to the PRISMA guidelines (Liberati et al., 2009) and is depicted in Figure 2.1.

**Figure 2.1 PRISMA Flow Diagram of search and review process.**



A total of 4279 titles from all databases and 44 titles from hand-searching journals were identified and examined for this review. After 44 duplicates were removed, the first author applied inclusion/exclusion criteria in an un-blinded standardized manner to 4279 titles and abstracts, and narrowed the results down to 73 papers. Citations of papers included at this point were searched, and a further 16 papers were added, making a total of 89 papers that were read in full to be assessed for eligibility. A further 73 titles were excluded during this process, and the final 16 articles selected for inclusion in the review comprised of eight

quantitative studies, and eight qualitative studies. The included studies are described in Table 2.2.

**Table 2.2 Summary table of included studies**

Reference	Aim	Patient group and sample	• Key Findings
Clover et al. (2004) Australia	To explore patients' understanding of their discussions about end-of-life care with nurses in a palliative care setting.	Patient group: COPD, heart disease and other. 11 people (7m, 4f), 57-84 end-of-life, early and late stages after diagnosis, all similar economic and cultural backgrounds - white, middle class.	<ul style="list-style-type: none"> <li>• Patients perceive health professionals as 'all knowing'</li> <li>• Patients wish to avoid confrontations with nurses due to possibility of repercussions for their car</li> <li>• Patients do not necessarily seek to have end-of-life discussions</li> <li>• Nurses miss opportunities to have end-of-life discussions with patients</li> <li>• Patients want health professionals to inform them of what may happen</li> <li>• Patients may want to put off making decisions about their care in order to gather research</li> <li>• There is no participatory model of care</li> <li>• Patients feel cajoled into decisions by health professionals</li> </ul>
Csikai (2006) United States	To understand family caregivers' perceptions of the communication process from initial discussion of the need for end-of-life care and hospice through to the decision to choose hospice and the transition home.	Patient group: COPD, heart disease and other 108 bereaved hospice caregivers (36 months post-patient death) from three hospice agencies.	<ul style="list-style-type: none"> <li>• Patients should be treated as individuals when discussing end-of-life issues (qualitative finding)</li> <li>• In addition to physicians, social workers were often (71.9%) present when hospice was discussed</li> <li>• 35.4% of caregivers often reported that the hospice option was only discussed once with their patient</li> </ul>
Curtis et al. (2004) United States	To examine patient-physician communication amongst a group of patients with oxygen-dependent COPD, in order to identify specific areas of communication about end-of-life care that patients report do not occur, and also to identify specific areas of good and poor quality communication.	Patient group: COPD 115 patients with oxygen-dependent COPD identified from pulmonary clinics in three hospitals and through an oxygen delivery company. Avg 67 end-of-life, mostly male and 84% Caucasian	<ul style="list-style-type: none"> <li>• Talking about prognosis, spirituality, and dying needs to be improved for patients with severe COPD</li> </ul>

**Table 2.2 Summary table of included studies (continued).**

Reference	Aim	Patient group and sample	• Key Findings
Curtis et al. (2008) United States	To examine the interaction between patients' and family members desire to have hope communicated, while also needing to receive specific prognostic information, as well as the desire of health professionals to support hope and provide prognostic information. They aim to provide insight to clinicians.	Patient group: COPD, heart disease and other  Participants were patients with severe chronic obstructive pulmonary disease or advanced cancer, and their families, nurses, and physicians.	<ul style="list-style-type: none"> <li>• Health professionals were able to convey hope to patients and families while also providing truthful information</li> <li>• Patients' hope was decreased when health professionals gave discouraging medical information, presented information disrespectfully or appeared 'cold'</li> <li>• Hope was best communicated when prognostic information was given in a sensitive manner, using statistics 'compassionately' and answering patient questions</li> </ul>
Desharnais et al. (2007) United States	To investigate the effectiveness of patient physician communications regarding health care choices at the end of life.	Patient group: COPD, heart disease and other  22 physicians (M = 47 end-of-life/o, 19 yrs experience) and 71 patients (M = 64 end-of-life). 58% cancer, 42% CHD. Study limited to Caucasians and African Americans	<ul style="list-style-type: none"> <li>• Patient/physician concordance low on whether physician knows a patient's preferences for pain management (14.1%) and place of death (14.1%), and whether the patients spiritual beliefs were affecting the patient's choices of care (29.6%).</li> </ul>
Elkington et al. (2001) United Kingdom	To investigate the role that discussions of prognosis play in general practitioners' management of patients with severe COPD and the factors that influence those decisions	Patient group: COPD  All GP principals in Lambeth, Southward, Lewisham Health Authority	<ul style="list-style-type: none"> <li>• 41% of general practitioners reported often or always discussing prognosis with patients with severe COPD</li> <li>• 82% of general practitioners feel that they have an important role in end-of-life discussions</li> <li>• 72% of general practitioners thought that discussions of prognosis were often necessary or essential in severe COPD</li> <li>• 50% of general practitioners were undecided as to whether patients with COPD wanted to know about their prognosis</li> <li>• The majority of general practitioners that reported not discussing end-of-life with patients stated the following reasons: felt unprepared to discuss, they found it hard to start such discussions, insufficient information in the primary care notes</li> </ul>

**Table 2.2 Summary table of included studies (continued).**

Reference	Aim	Patient group and sample	• Key Findings
Farber et al. (2003) United States	To examine the perceptions of patients, carers and physicians who are already connect with one another in an end-of-life care experience.	Patient group: COPD, heart disease and other  Convenience same of 42 patients, 29 carers facing EOL. Already published findings from interviews with 29 GPs were included	<ul style="list-style-type: none"> <li>• Relationship fluctuations between health professionals and patients, coping with daily living while managing an illness, and the personal experience of facing the end-of-life are key issues in end-of-life care</li> <li>• Patients expect their physicians to be competent and to provide a caring relationship</li> <li>• Coping with daily living while attempting to manage medication are an important issue in end-of-life care</li> </ul>
Fried and O'Leary. (2008) United States	To understand how end-of-life care experiences of older patients and their carers can inform the development of new approaches to advance care planning	Patient group: COPD, heart disease and other  Caregivers of community dwelling people 60 yrs+ to had died of advanced cancer, COPD or HF during follow-up in a longitudinal study	<ul style="list-style-type: none"> <li>• Lack of availability of treatment options can prompt patients and carers to consider end-of-life issues</li> <li>• There are changes in patient preferences at the very end-of-life</li> <li>• There is variability in patient and carer desire for and readiness for information about the patient's illness</li> <li>• There are difficulties with patient-carer communication</li> </ul>
Fried et al. (2003) United States	To investigate the agreement between patients, caregivers and clinicians regarding prognosis communication, and to examine patients' and caregivers' desire for prognostic information.	Patient group: COPD, heart disease and other  214 people, aged 60+ with a limited life expectancy due to cancer, CHF or COPD; and clinicians (n = 96), and their caregivers (informal) (n = 193)	<ul style="list-style-type: none"> <li>• Discrepancies in perceived life expectancy by patients accompanied the discrepancies in perceived communication</li> <li>• Agreement between patients and clinicians was low on whether patients had been informed that their disease was fatal</li> </ul>

**Table 2.2 Summary table of included studies (continued).**

Reference	Aim	Patient group and sample	• Key Findings
Goldstein et al. (2005) United States	To examine the association of patient race and financial status with patient and clinician reports of discussions about prognosis.	Patient group: COPD, heart disease and other  214 people, aged 60+ with a limited life expectancy due to cancer, CHF or COPD; and clinicians (n = 96) (same participants as Fried 2003)	<ul style="list-style-type: none"> <li>• Agreement about prognosis discussions was more likely when patients were younger (&gt;80)</li> <li>• Patients were more likely to agree that end-of-life discussions about prognosis had taken place when patients had a lower financial status or were nonwhite, compared to patients who had a higher financial status or were white</li> </ul>
Grbich et al. (2006) Australia	To retrospectively analyze the end-of-life care that was provided to 20 patients who died in the acute wards of a teaching hospital.	Patient group: COPD, heart disease and other Records of patients who had died within a few days were audited. 10 m, 10 f, had been in hospital avg. 25.7 days - 9 had malignancy, death was expected for 4/12 of non-cancer patients, 6/9 of cancer patients. Staff interviews (40) with two nurses with the highest number of shifts in which each patient in the study nursed.	<ul style="list-style-type: none"> <li>• Found a lack of a holistic palliative care model</li> <li>• There are poor levels of communication among and between staff, patients and families</li> </ul>
Knauft et al. (2005) United States	Authors sought to identify the common barriers and facilitators to communication about end-of-life care	Patient group: COPD  Patients with oxygen dependent COPD and the doctor that was primarily responsible for their lung disease.	<ul style="list-style-type: none"> <li>• 32% of patients with COPD reported having an end-of-life discussion with their physician</li> <li>• The more facilitators for end-of-life discussions reported by a patient with COPD, the more likely they were to report having end-of-life discussions</li> <li>• The greater number of barriers to discussing end-of-life reported by COPD patients, the less likely they were to have discussed this topic</li> <li>• Found two common barriers to having end-of-life discussions for patients with COPD</li> <li>• 'I'd rather concentrate on staying alive'</li> <li>• 'I'm not sure which doctor will be taking care of me'</li> </ul>

**Table 2.2 Summary table of included studies (continued).**

Reference	Aim	Patient group and sample	• Key Findings
Kutner et al. (1999) United States	To describe issues that are important to terminally ill patients receiving palliative care, and to determine whether patient characteristics influence their needs	Patient group: COPD, heart disease and other  Patients with a terminal diagnosis, receiving palliative care, 18+ yrs, English speaking, able to consent.	<ul style="list-style-type: none"> <li>• There is no patient profile that predicts individual end-of-life communication needs</li> <li>• Illness related issues such as individual and social effects may be equally or more important to patients than disease issues</li> </ul>
Lofmark and Nilstun. (2000) Sweden	To test whether common clinical conversations could be used to explore issues of life support limitations for seriously ill patients.	Patient group: COPD, heart disease and other  21 patients consecutively admitted to hospital over a 4-week period. Three patients had DNR orders, others fulfilled criteria of serious illness.	<ul style="list-style-type: none"> <li>• Within a short conversation with a health professional, patients easily accepted and valued direct discussions about forgoing life support</li> <li>• It is important to ask the patient which family members or health professionals that he would like to be present in an end-of-life discussion</li> <li>• Seriously ill patients are not harmed by talking about their prognosis</li> </ul>
Steinhauser et al. (2008) United States	To evaluate the impact of an intervention that promotes discussions of end-of-life preparation and completion on health outcomes in dying persons.	Patient group: COPD, heart disease and other  82 hospice patients (28 f, 35 African American), primary diagnosis of cancer (48), heart disease (5), lung disease (10) and other (19). Aged from 28-96.	<ul style="list-style-type: none"> <li>• Patients in the active end-of-life discussion group showed improvements in functional status, anxiety, depress and preparation for the end-of-life</li> </ul>
Wenrich et al. (2001) United States	To explore which aspects of communication between patients and physicians are important in end-of-life care.	Patient group: COPD, heart disease and other  Purposive sampling of patients with chronic and terminal illnesses (COPD/AIDS or cancer), their family members, health care professionals from hospice or acute care settings, and physicians with expertise in EOL care.	<ul style="list-style-type: none"> <li>• Health professional being willing to discuss end-of-life, listening to patients, encouraging questions, being honest, being sensitive to timing of the discussion, and giving bad news in a sensitive manner are important factors for end-of-life communication</li> <li>• Health professionals need to balance honesty and frank information while not discouraging hope</li> </ul>

\*Please refer to the published paper (Stephen et al 2013) included at the end of this thesis for information about the design of the included studies.

### 2.3.3 Quality appraisal

Studies were evaluated to determine methodological quality; however, studies were not included or excluded from the review based on this evaluation. Qualitative and quantitative papers were evaluated by the standard quality assessment criteria developed by Kmet et al. (2004). This appraisal tool consists of 14 questions for quantitative papers and 10 questions for qualitative papers. To validate the critical appraisal, a member of the supervisory team assessed 30 percent of the studies using the same criteria. Consensus on scoring was reached in several areas, and minor differences in scoring were debated further until consensus was reached. Inter rater reliability was calculated based on the original scores from each reviewer.

Critical appraisal resulted in a score out of one (Kmet et al., 2004). The scores for the eight qualitative studies ranged from 0.65 – 0.9 (mean = 0.79), the eight quantitative studies ranged from 0.68 to 0.95 (mean = 0.83) with an overall mean of 0.81 for the sixteen studies. Detailed results of the quality appraisal process can be found in Table 2.3 and Table 2.4 and represent final consensus rating for papers that were assessed by a second rater. Table 2.5 contains calculations of percent agreement, Cohen's Kappa and number of agreements and disagreements for each item (Kottner et al., 2011).

**Table 2.3 Outcomes of quality appraisal of quantitative studies using Kmet et al. (2004) tool.**

Checklist	Csikai (2006)	Curtis et al. (2004)	DesHarnais et al. (2007)	Elkington et al. (2001)	Fried and Bradley (2002)	Goldstein et al. (2005)	Knauff et al. (2005)	Steinhauser et al. (2006)
Question/objective clearly described?	2	1	2	1	2	2	2	1
Study design evident and appropriate?	2	2	2	2	2	1	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	1	2	2	1	2	2	2	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	2	1	2	2	2
If interventional and random allocation was possible, was it described?	NA	NA	NA	NA	NA	NA	NA	1
If interventional and blinding of investigators was possible, was it reported?	NA	NA	NA	NA	NA	NA	NA	2
If interventional and blinding of subjects was possible, was it reported?	NA	NA	NA	NA	NA	NA	NA	NA
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? means of assessment reported?	2	2	2	2	2	2	2	2
Sample size appropriate?	NA	NA	1	NA	0	1	NA	0
Analytic methods described/justified and appropriate?	1	2	2	2	2	2	2	0
Some estimate of variance is reported for the main results?	2	2	2	2	2	2	1	1
Controlled for confounding?	NA	NA	2	NA	0	NA	NA	2
Results reported in sufficient detail?	2	2	2	2	2	2	2	2
Conclusions supported by the results?	1	2	2	2	2	1	2	2
Summary Score*	0.68	0.94	0.95	0.89	0.77	0.77	0.94	0.73

The summary score for quantitative studies is calculated by determining the total sum of scores, and then subtracting it from the total possible sum (28 – number of NA x 2), and then dividing the total sum by the total possible sum.

**Table 2.4 Outcomes of quality appraisal of qualitative studies using Kmet et al. (2004) tool.**

Checklist	Clover et al. (2004)	Curtis et al. (2008)	Farber et al. (2003)	Fried & O'Leary (2008)	Grbich et al (2006)	Kutner et al. (1999)	Lofmark and Nilstun (2000)	Wenrich et al. (2001)
Question/objective clearly described?	2	2	2	2	2	2	2	2
Design evident and appropriate to answer study question?	2	2	2	2	2	2	2	2
Context for the study is clear?	2	2	2	1	2	2	2	2
Connection to a theoretical framework/wider body of knowledge?	1	2	1	2	2	2	2	1
Sampling strategy described, relevant and justified?	1	2	1	2	2	2	2	1
Data collection methods clearly described and systematic?	2	2	2	2	2	2	2	2
Data analysis clearly described and systematic?	1	2	1	2	1	2	0	2
Use of verification procedure(s) to establish credibility of the study?	0	2	2	2	2	2	0	2
Conclusions supported by the results?	2	2	2	2	2	2	2	2
Reflexivity of the account?	0	0	0	0	0	0	0	0
Summary score <sup>^</sup>	0.7	0.9	0.75	0.85	0.8	0.85	0.65	0.8

<sup>^</sup>The summary score for qualitative studies is calculated by dividing the sum of scores by the total possible sum (20).

**Table 2.5 Inter rater reliability**

	<b>Percent Agreement</b>	<b>Cohen's Kappa</b>	<b>N Agreements</b>	<b>N Disagreements</b>
<b>Csikai (2006)</b>	71	0.53	10	4
<b>Curtis et al. (2004)</b>	93	0.86	13	1
<b>Goldstein et al. (2005)</b>	71	0.48	10	4
<b>Rogers et al. (2000)</b>	90	0.82	9	1
<b>Downar and Hawryluck (2010)</b>	90	0.47	9	1
<b>Grbich et al. (2006)</b>	90	0.79	9	1

Inter rater agreement was assessed for six pairs of observations. Cohen's Kappa ranged from 0.48 (moderate) to 0.86 (excellent) indicating a satisfactory level of inter rater agreement (Landis and Koch, 1977).

#### **2.3.4 Data abstraction**

Data were extracted from the texts into a detailed summary table that contains a description of the study, the population, methods and results, in order to enable comparison across studies according to their relevance to the objective of the review (Garcia et al., 2002, Miles and Huberman, 1994, Petticrew and Roberts, 2005). Any questions arising during this process were discussed with supervisors until a consensus was reached. Due to the size of this table, it could not be reproduced here, instead the contents of the detailed summary table were summarised for the reader in Table 2.2.

#### **2.3.5 Synthesis**

Thematic analysis was used to identify themes and synthesise qualitative and quantitative findings across studies (Dixon-Woods et al., 2004). While there is controversy regarding the synthesis of qualitative and quantitative evidence in systematic reviews (Mays et al., 2005, Dixon-Woods et al., 2001), thematic analysis is commonly used in mixed-methods reviews to identify the key themes in a set of studies, and using tabular summaries adds a greater degree of

synthesis (Mays et al., 2005, Miles and Huberman, 1994). The method of thematic analysis used involved identification of the recurrent themes in the literature, and then summarizing the findings of the studies under the thematic headings (Dixon-Woods et al., 2004). Equal weight was given to qualitative and quantitative data in the synthesis process.

Themes were identified in each of the included papers by coding the results of each paper, grouping these codes into categories, and importing each category into a table. A mind map was then used to group categories into common themes throughout the literature (Dixon-Woods et al., 2004). These themes were discussed between the student and the supervisory team until consensus regarding the synthesis was reached. A diagram displaying the codes, categories and themes is presented in Appendix A.

## **2.4 Findings**

The review process revealed several consistent components throughout the included studies. The findings are organised within three themes: the discussion; the health professional/patient relationship; and patient perceptions. Each theme consists of several key components to end-of-life discussions, which will be discussed in detail. It has been specified where results were reported for physician participants rather than health professionals in general.

### **2.4.1 The end-of-life discussion**

The style and content are key components in end-of-life communication with patients with nonmalignant disease. This includes how and when the discussion is initiated, barriers to discussion, patient concerns about end-of-life, and patient information needs.

Concern over initiating end-of-life discussions was raised in several of the included studies. Patient prognosis is a component of such discussions, as it helps determine when to move away from aggressive life-sustaining treatments (Childers et al., 2007). Patients may want prognostic information soon after diagnosis but may not want to raise the issue themselves (Clover et al., 2004), however, Elkington (2001) found general practitioners (GPs) felt unprepared and found it hard to start end-of-life discussions. This reluctance may be unwarranted; Lofmark & Nilstun (2000) found seriously-ill patients easily accepted and valued frank discussions about forgoing life support even within short clinical encounters.

The willingness of the health professional to discuss end-of-life is an important component of this type of communication (Wenrich et al., 2001). One study found that only 41 percent of GPs reported they often or always discussed prognosis with patients with severe Chronic Obstructive Pulmonary Disease (COPD)(Elkington et al., 2001). Some GPs stated that they did not discuss prognostic information due to insufficient information in the primary-care notes (Elkington et al., 2001). This is problematic as hospice-services information is often not available to patients from other sources than their physicians (Csikai, 2006).

In a study of patients with COPD, the greater the number of barriers reported, the less likely that discussions occurred. Patients cited the barriers most frequently encountered included not knowing what type of care they wanted, and uncertainty regarding which doctor would be caring for them (Knauff et al., 2005). According to the studies in this review, patients' end-of-life concerns include: facing the end-of-life and awareness of impending death (Farber et al., 2003); changes in daily living and managing and coping with a terminal illness (Elkington et al., 2001); and the lack of availability of treatment options (Fried and O'Leary, 2008). The lack of treatment options often led patients to consider end-of-life issues (Fried and O'Leary, 2008).

In several studies, the style of communication was found to be an important factor, and highlights the need to determine individual patient preferences prior to beginning an end-of life discussion (Csikai, 2006). Listening to patients and encouraging questions is important for successful communication (Wenrich et al., 2001), as well as determining who will be present for the discussion; for example, while additional health professionals (such as social workers) are often present for such discussions, this may not always be desired by the patient (Csikai, 2006). A lack of awareness regarding end-of-life options may be attributed to patient denial, therefore sensitivity is an important characteristic of such discussions and preparation for them (Wenrich et al., 2001). However, some patients wanted to receive information soon after diagnosis (Csikai, 2006). A study of bereaved caregivers reported that end-of-life discussions occurred only once (Csikai, 2006).

Elkington et al. (2001) found that 72.5 percent of GPs thought that discussions of prognosis were necessary or essential in severe COPD, and 82 percent felt that GPs had an important role in such discussions. Lofmark and Nilstun (2000) found that patients are generally not harmed by talking about their prognosis, yet authors of one study found that only 32 percent of patients with COPD discussed end-of-life with their physician. The more facilitators for communication that were reported, the more likely they were to report having end-of-life discussions (Knauff et al., 2005). One study found that financial status and race of the patient may play a role in agreement between health professionals and patients about the occurrence of end-of-life discussions. They found that patients were more likely to agree that end-of-life discussions about prognosis had occurred to those with a lower financial status and who were not Caucasian, compared to patients with a higher financial status who were Caucasian (Goldstein et al., 2005). Two possible explanations for this finding were provided:

The first was that the first group may be more likely to hear bad news in general, and therefore may be more likely to accept a terminal diagnosis. The second was that health professionals may put more effort into communicating end-of-life options to these groups as they have a propensity to favour life-sustaining treatments.

Curtis et al. (2004) found that discussion about prognosis needs to be improved for patients with severe COPD. In addition, Curtis et al. (2004) found that there needed to be an improvement in discussions around spiritual issues.

#### **2.4.2 Health professional/patient relationship**

The importance of the health professional-patient relationship has been emphasised in end-of-life communication. Patients expect physicians to be competent, to provide a caring relationship (Farber et al., 2003), and they perceive health professionals as 'all-knowing' (Clover et al., 2004). There may be a power component in this relationship. Patients may wish to avoid confrontation with nurses over decision-making, due to the uncertainty of their situation and of the repercussions they fear may arise from challenging an expert (Clover et al., 2004). In one study of GPs, half were undecided as to whether most patients with COPD wanted prognostic information (Elkington et al., 2001).

The balance between honesty and hope when communicating about end-of-life issues was a common theme in several studies (Curtis et al., 2008, Wenrich et al., 2001). Patients wanted to be informed of what may happen (Clover et al., 2004). Csikai (2006) reported that health professionals should be more forthcoming about the reality of death, but should consider that patients want information that is delivered sensitively, but without too much detailed information. Health professionals are able to convey hope to patients and families while

balancing their duty to provide truthful information by being sensitive, using statistics compassionately, and answering patient questions. Patient hope was decreased when discouraging medical facts were discussed, and information was presented bluntly or the health professional was perceived to be 'cold' (Curtis et al., 2008).

Certain health professionals may be viewed as being more helpful than others. While Clover (2004) reported that nurses miss opportunities to have end-of-life discussions with patients, Csikai (2006) found that nurses and social workers were helpful when discussing the transition to hospice. Social workers were reported to be the most comfortable, most knowledgeable and most available for discussions of end-of-life care (Csikai, 2006). The variations in reported discussions about end-of-life care may be related to the model of care. Clover (2004) did not find evidence of a participatory model of care, with some patients feeling that they had been persuaded by health professionals to make certain decisions. Grbich et al. (2006) also found a lack of a holistic palliative-care model.

### **2.4.3 Patient perceptions**

Patients who participated in a randomised controlled trial with an active end-of-life discussion intervention showed improvements in functional status, anxiety, depression and preparation for end-of-life (Steinhauser et al., 2008). Despite the clear benefit of discussing end-of-life, discrepancies in agreement between whether end-of-life discussions had occurred between health professionals and patients were found in some studies. One study found that when patients inaccurately predicted their life expectancy, they also inaccurately perceived that communication had occurred (Fried and O'Leary, 2008). The same study found that patient and health professional agreement was low on whether prognosis had been discussed, as health

professionals felt that they had provided prognostic information more often than patients felt they did (Fried and O'Leary, 2008).

## **2.5 Discussion**

The studies that were selected for inclusion in this review were of moderate to high quality, and the variety of methodological approaches indicates the wide range of research in this area. Findings were fairly consistent across studies. However, the wide range of methodological and theoretical approaches also means that findings could not be combined using meta-synthesis. Instead thematic analysis, which is well suited to coping with diverse types of evidence was used.

The review adds to current knowledge by revealing several key components of end-of-life communication in NMRD found in the literature. The most prevalent component was the style of the communication. This included the desire for two-way communication, the existence of power issues, and the importance of honest yet hopeful communication. In 1995, authors of a systematic review found a correlation between successful health professional-patient relationships, and improved health outcomes for patients (Stewart, 1995). The importance of the style that health professionals use to communicate with patients has been recognised in several types of patient-health professional interactions. Buller and Buller (1987) found that patients reported less satisfaction when physicians used a controlling style of communication. In another study, when health professionals exhibited patient-centred behaviours, patients were more satisfied with the interaction, felt understood, and felt their concerns were resolved (Henbest and Stewart, 1990, Stewart, 1984). Likewise, in a study for patients with diabetes, Snoek and Skinner (2005) found this patient group reported higher

satisfaction with health care visits when they felt communication was two-way between physicians and patients.

Awareness and recognition of patient and health professional facilitators and barriers to end-of-life communication was also a key component. Other key components were (1) the health professional's recognition of the patient's desire for information about their prognosis and subsequent care options, (2) the initiation of the end-of-life topic by the physician or health professional and (3) an appropriate environment for the discussion, and (4) the provision of prognostic information. This is reflected in the findings by Jones et al. (2004) where information about the future course of their illness was reported as a major issue for patients with COPD, with patients having varied opinions on how much prognostic information they desired. This is a major issue for end-of-life communication as prognostic information is difficult to provide in COPD due to the unpredictable disease trajectory (Murray et al., 2005). These factors must all be considered within the context of providing the information each patient needs.

The findings of this review imply that health professionals should not assume that they know what patients want in terms of end-of-life communication, as preferences vary between patients. Instead, individual needs can be discerned by having preliminary planning discussions about what the patient wants. This preliminary conversation should be initiated by the health professional, and could determine who the patient wants to be present for the discussion, where the discussion will take place, and the appropriate environment for the discussion. The health professional-patient relationship may be key to a successful discussion. Even if they do not have a long-standing relationship, the style of communication, and the health professional's ability to communicate honestly while conveying hope is important. Also, discussions may need

to occur more than once to ensure that both parties are clear on the prognosis and the agreed plans, and to ensure that questions get answered and that changing information needs and care preferences are addressed. This is particularly important when patients may be in and out of the hospital due to exacerbations, as their experiences may change their care preferences or information needs.

The findings in this review are applicable to health professionals, including physicians who work with patients with nonmalignant disease who may need to discuss end-of-life care preferences. However, these findings may not be generalisable as only studies from western cultures were included. Cultural variables were not explored in this review, and were rarely explored within any of the included studies. In addition, the countries that produced the included studies all have a diverse range of health care systems, from nationalised to private. Further research is needed to determine applicability of these findings across countries.

## **2.6 Conclusion**

This review has identified several key components of end-of-life communication in nonmalignant disease and provides an evidence base for the studies that follow. These components are not always evident in the patient experience. While identified in the literature, this means that health professionals need to be more aware of such key aspects, and also to ensure they are providing them when appropriate. What may help to improve the patient experience and the likelihood of end-of-life discussions is the assignment of a key health professional for each patient who is responsible for discussing end-of-life, and for ensuring that wishes are communicated between settings. While it is surprising that psychosocial issues did not arise as a major issue in this review, this area may arise in later phases of the study.

Palliative care resources are scarce for patients with NMRD, and end-of-life communication is critical and must be made a priority by health professionals. This evidence also has implications for other health professional education, to ensure professionals are trained and confident enough to have these discussions. In addition, generalists, without specialized training, are increasingly providing palliative care for patients, and while palliative care rotations are becoming more common in medical training, this area still requires improvement (Meier et al., 2010). This indicates the importance of more widespread implementation of training programmes in disease-specific palliative care communication and delivery. The findings of this review will be discussed further in Chapter 7 in relation to the second systematic review (Chapter 3) and the findings of the Delphi studies (Chapters 5 and 6).

## **Chapter 3. A comparative systematic review of discussing end-of-life in chronic obstructive respiratory disease in the UK and Canada**

### **3.1 Introduction**

This chapter consists of a systematic review of end-of-life discussions in COPD in Canada and the UK, and is the first component of the comparison between end-of-life discussions in these countries, as introduced in Chapter 1, that will continue through this thesis. The findings of Chapter 2 made clear that end-of-life discussions in NMRD are a complex process. The aim of this international comparison is to provide further insight into this process to add to the development of a complex intervention. Literature related exclusively to COPD was reviewed as the most common NMRD to focus the scope of the review and to ensure that this review would provide unique findings to the review in Chapter 2.

First the objectives of the review are presented in 3.2, followed by the review method in 3.3. This is followed by the synthesis of the data in 3.4. The results of the review are presented in are discussed in 3.5, and the chapter is concluded in 3.7.

### **3.2 Objectives**

The objective of this review is to compare the findings of qualitative and quantitative studies about end-of-life discussions in COPD in the UK and Canada to examine how health professionals are discussing end-of-life in these two countries with similar healthcare systems.

Specifically, this review aims to answer the following questions:

- I. How do health professionals know a patient with COPD is ready or willing to discuss the end-of-life?

2. What types of things should be considered when discussing end-of-life with patients with COPD?
3. What topics should be included in end-of-life with patients with COPD?

This review continues the development of the evidence base for the design of the intervention to aid health professionals to discuss end-of-life in NMRD. To achieve these aims, this review includes papers published in a peer-reviewed journal that report on studies using qualitative or quantitative methodology with participants with COPD or health professionals working with such patients from the UK or Canada having end-of-life discussions.

### **3.3 Review Method**

The methods used to conduct this review including the information sources and search strategy (3.3.1), inclusion criteria (3.3.2), study selection (3.3.3), data collection process (3.3.4), and quality appraisal (3.3.5) are described in the sections below. The resulting data synthesis is included in section 3.4.

#### **3.3.1 Information sources and search strategy**

Studies were identified by the author using a two-step search process (Petticrew and Roberts, 2005). First, the MEDLINE database was searched using the terms 'end-of-life' AND 'communication' and 'respiratory'. This search yielded 26 titles, of which five were relevant. The key words from these five papers were used to construct a more detailed search strategy, including MeSH terms. An example of the search strategy from the database is provided in Table 3.1. This strategy was used to search Medline and CINAHL and adapted for EMBASE for literature published in English between 1990 and 2010. MeSH terms found in Table 3.1 were replaced with free-text terms as appropriate to the database. The relevant results from the

database searches were then citation searched for relevance sources, as were any systematic reviews that were found. In addition, the table of contents of the Canadian Respiratory Journal, the Journal of Palliative Medicine, and Palliative Medicine were searched between 1990 and 2010 for relevant studies, as these journals contained the highest numbers of relevant results in the database searches. In order to determine whether all relevant sources had been captured, a limited update search was conducted of MEDLINE, CINAHL and EMBASE in August 2011.

**Table 3.1 Example of search strategy from MEDLINE (EBSCOhost) database.**

Search Terms	
1. (MM "Pulmonary Disease, Chronic Obstructive+");	12. dying;
2. (MH "Lung Diseases");	13. (MH "Prognosis+");
3. (MM "Lung Diseases");	14. (MM "Communication+");
4. 1-3/or; <sup>3</sup>	15. (MH "Decision Making");
5. palliative;	16. (MH "Attitude to Death");
6. (MM "Palliative Care");	17. (MH "Physician-Patient ;Relations")
7. (MH "Quality of Life/PX");	18. discussion;
8. (MH "Disease Progression");	19. 5-13/or;
9. (MH "Death+");	20. 14-18/or;
10. (AB "end of life");	21. 4 and 19 and 20. <sup>4</sup>
11. MH "Advance Directives";	

\*Items 4, 19 and 20 denote that search term items listed (e.g. 1-3) were combined using the boolean term OR between them, meaning that the database searched " Pulmonary Disease, Chronic Obstructive " OR " Lung Diseases " etc. which provided results of any database item containing any of these terms.

\* Item 21 indicates that the results of searches conducted in 4, 19 and 20 were combined using the boolean term AND in the database, which provided results of database items containing items from each search group e.g. a database item that included "lung diseases", "end of life", "decision making".

### 3.3.2 Inclusion and Exclusion Criteria

Papers were included in this review if they met the following criteria:

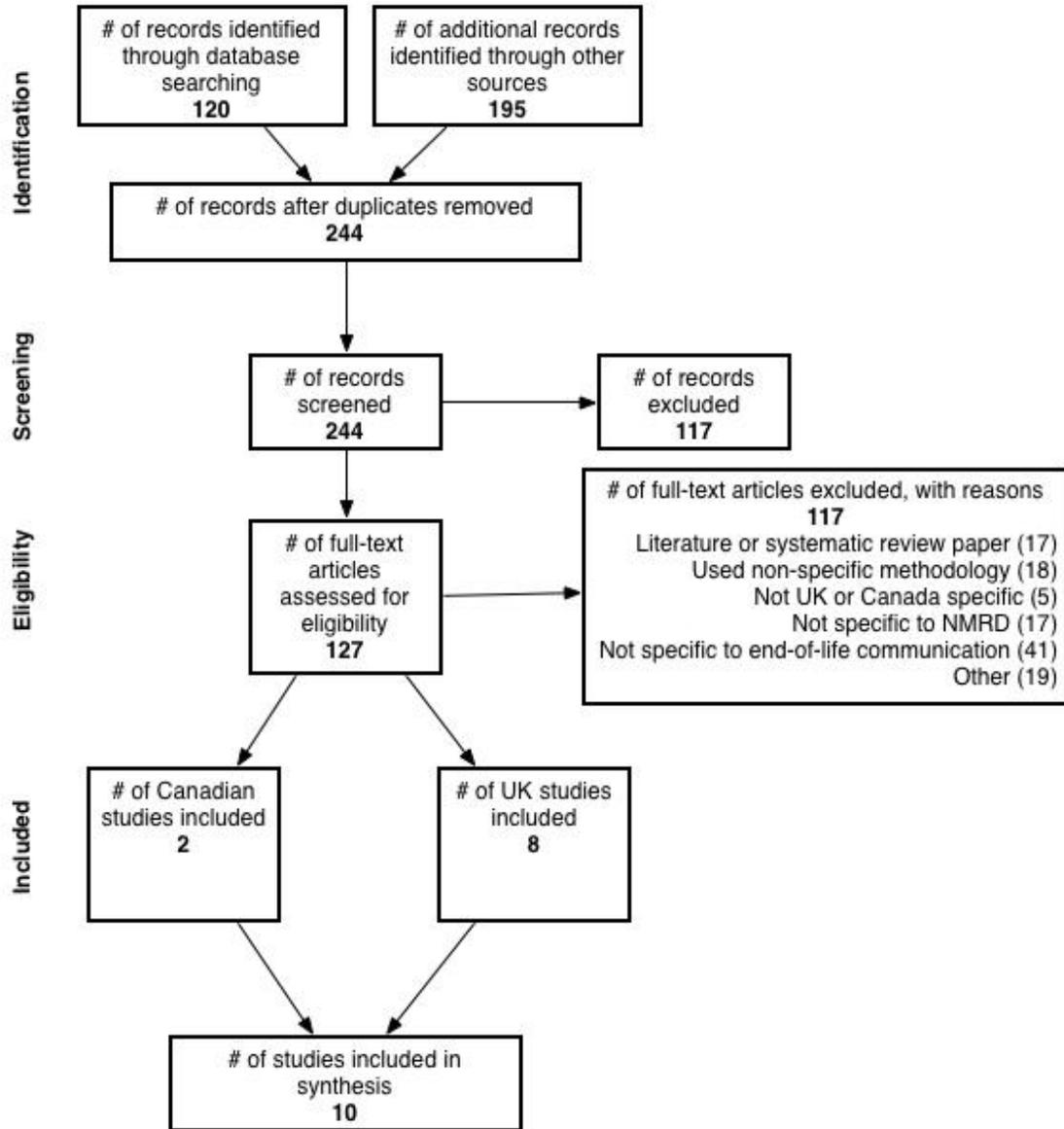
- described specific components of end-of-life communication in COPD between patients and health professionals

- data were collected in either the UK or Canada were original qualitative or quantitative studies published in a peer reviewed journal between 1990 and 2011 in English (discussion papers, literature and systematic reviews and non-journal articles were excluded)
- did not exclusively address discussions about mechanical ventilation as they did not address end-of-life discussions as a whole
- papers in which authors did not report specific components of end-of-life communication in COPD were excluded.

### **3.3.3 Study Selection**

Study selection was conducted by the first author in two stages. First, the titles and abstracts of the search results were screened against the inclusion and exclusion criteria to identify potentially relevant studies. The remaining papers were retrieved in full text and read in full, and again the researcher applied the inclusion and exclusion criteria to identify relevant studies. Any papers where inclusion or exclusion was contentious were discussed with a supervisor until consensus was reached. This process is summarized in the PRISMA flow diagram in Figure 3.1.

Figure 3.1 PRISMA Flow Diagram of search and review process.



### 3.3.4 Data collection process

The data extraction sheet was adapted from the Centre for Reviews and Dissemination's guidance (Centre for Reviews and Dissemination, 2009) on information requirements for data extraction and is presented in Table 3.2. This process was amended slightly from the data abstraction process in the systematic review in Chapter 2 to be more

detailed in order to assist with data synthesis. This included general information about the paper, study characteristics, participant characteristics, intervention (where applicable) details, setting and country information and components of end-of-life discussions in COPD (Table 3.2). The sheet was piloted on three included studies and amended according to the requirements of this review. The data items were extracted by the author and entered into the review database in EPPI Reviewer Software (Thomas et al., 2010). Data extraction was repeated by a member of the supervisory team on a random selection of 30 percent of the articles to verify accuracy and a lack of bias. Disagreements were resolved by discussion until consensus was reached between the student and the supervisor.

**Table 3.2 Data extraction sheet items.**

<b>Category</b>	<b>Extracted Items</b>
<b>Study characteristics</b>	Aim/objectives of the study
	Study design
	Study inclusion and exclusion criteria
	Country of origin
<b>Participant characteristics</b>	Participant type e.g. health professionals, patients, family members
	Age
	Gender
	Disease characteristics
<b>Results/Findings</b>	Components of end-of-life discussions

### **3.3.5 Quality Appraisal**

Qualitative and quantitative papers were evaluated by the standard quality assessment criteria developed by Kmet et al. (2004). This appraisal tool provides a quantitative method for evaluating quantitative and qualitative research using a separate criteria for each method, resulting in quantitative scores (out of 1.0) that can be compared. The evaluation criteria are detailed in Table 3.3 and Table 3.4 along with the scoring for the appraisals of both the quantitative and qualitative studies. To validate the quality appraisal process, 30 percent of the

studies were assessed by a member of the supervisory team using the same criteria. Studies were evaluated to determine methodological quality, however studies were not included or excluded from the review based on this evaluation. This strategy is recommended by Mays et al. (2005) when qualitative studies are included in the synthesis because studies that are appraised as weak may be included successfully in a synthesis, and the worth of certain studies is often revealed during the synthesis process.

**Table 3.3 Outcomes of the quality appraisal of qualitative studies using Kmet et al. (2004) tool.**

Checklist	Crawford (2010)	Goodridge et al. (2009)	Gott et al. (2009)	Gysels and Higginson (2010)	Spence et al. (2009)	Pinnock et al. (2011)
Question/objective clearly described?	2	2	2	2	2	2
Design evident and appropriate to answer study question?	2	2	2	2	2	2
Context for the study is clear?	2	2	2	2	2	2
Connection to a theoretical framework/wider body of knowledge?	2	2	2	1	2	2
Sampling strategy described, relevant and justified?	2	1	2	1	2	2
Data collection methods clearly described and systematic?	2	1	1	1	2	2
Data analysis clearly described, complete and systematic?	1	1	2	1	1	2
Use of verification procedure(s) to establish credibility of the study?	0	0	2	0	2	2
Conclusions supported by the results?	2	2	2	2	2	2
Reflexivity of the account?	0	0	0	0	0	0
Summary Score	0.75	0.65	0.85	0.6	0.85	0.9

*The summary score for qualitative studies is calculated by dividing the sum of scores by the total possible sum (20). Items are scored for the degree that they meet the criteria for each question detailed by the authors of the quality appraisal guidance: (2 = yes, 1 = partial, 0 = no).*

**Table 3.4 Outcomes of the quality appraisal of quantitative studies using Kmet et al. (2004) tool.**

Checklist	Buxton et al. (2010)	Elkington et al. (2001)	Gore et al. (2000)	Rocker et al. (2008)
Question/objective clearly described?	2	2	2	2
Study design evident and appropriate?	2	2	2	2
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	2	2
Subject (and comparison group, if applicable) characteristics sufficiently described?	2	2	2	2
If interventional and random allocation was possible, was it described?	0	1	NA	0
If interventional and blinding of investigators was possible, was it reported?	0	1	NA	0
If interventional and blinding of subjects was possible, was it reported?	0	1	NA	0
Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? means of assessment reported?	1	1	2	1
Sample size appropriate?	0	1	2	2
Analytic methods described/justified and appropriate?	2	2	2	2
Some estimate of variance is reported for the main results?	0	1	2	1
Controlled for confounding?	0	1	1	0
Results reported in sufficient detail?	2	2	2	2
Conclusions supported by the results?	2	2	2	2
Summary Score	0.54	0.94	0.75	0.64

*The summary score for quantitative studies is calculated by determining the total sum of scores, and then subtracting it from the total possible sum (28 – number of NA x 2), and then dividing the total sum by the total possible sum. Items are scored for the degree that they meet the criteria for each question detailed by the authors of the quality appraisal guidance: (2 = yes, 1 = partial, 0 = no).*

**Table 3.5 Summary of included studies**

Reference	Country	Research Question	Study Design	Participants	Quality assessment score
<b>Buxton et al. (2010)</b>	United Kingdom	Do current and future planned end-of-life provision for COPD patients in the UK meet the current palliative care guidance?	Web-based audit survey	239 respiratory units in England, Scotland, Wales, Northern Ireland and offshore islands (98%) of eligible trusts responded	0.54
<b>Crawford (2010)</b>	United Kingdom	What are health professionals' experiences of discussing end-of-life with patients with COPD?	Qualitative phenomenological interviews	3 respiratory nurses, 2 lung cancer nurse specialists, 2 respiratory physicians	0.75
<b>Elkington et al. (2001)</b>	United Kingdom	What role do discussions of prognosis play in GPs management of patients with severe COPD and what are the factors influencing those discussions?	Structured questionnaire	214 GP principals in London, (55%) response rate.	0.93
<b>Goodridge et al. (2009)</b>	Canada	What is the applicability, development and monitoring of indicators measuring the quality of end-of-life care for individuals with severe COPD?	Delphi survey	Patients with COPD and their family members Interdisciplinary, nationally represented group of professionals with an interest in end-of-life care for patients with COPD	0.65
<b>Gore et al. (2000)</b>	United Kingdom	How are the care needs of patients with COPD met in comparison to those with lung cancer?	Semi-structured interviews Quantitative quality of life measures Medical record audits	50 patients with severe COPD 50 patients with inoperable non-small cell lung cancer (NSCLC)	0.75
<b>Gott et al. (2009)</b>	United Kingdom	What are barriers to advance care planning discussions in COPD?	Focus groups	39 health care professionals caring for patients with COPD	0.85
<b>Gysels and Higginson (2010)</b>	United Kingdom	How does the experience of breathlessness in COPD influence patients' attitudes towards the end-of-life and their quality of life?	Qualitative interviews and participant observation of outpatient consultations	18 patients with COPD	0.6

**Table 3.5 Summary of included studies (continued)**

<b>Pinnock et al. (2011)</b>	United Kingdom	What is the experience of patients with severe COPD and their caregivers?	Serial qualitative interviews	21 patients with severe COPD, 13 informal caregivers, 18 professional caregivers	0.9
<b>Rocker et al. (2008)</b>	Canada	What are the ratings of importance and satisfaction with various elements of end-of-life care for Canadians with advanced COPD?	Quantitative survey	118 patients with severe COPD	0.64
<b>Spence et al. (2009)</b>	United Kingdom	Do professionals feel that patients with advanced COPD have palliative care needs, and what are the barriers for health and social care professionals to delivering palliative care to these patients?	Focus groups	23 health and social care professionals caring for patients with COPD	0.85

### **3.4 Data Synthesis**

The data synthesis process has been adapted from the comparative review process detailed in Slort et al. (2011). Two tables were generated from the data extraction sheet (Table 3.2). The first (Table 3.5) includes the characteristics of each included study: country, research question, study design, participants and the score resulting from the quality appraisal process; while the second (Table 3.7) includes the relevant data from each study. Specifically, Table 3.7 contains data from each study that is organized by review question and theme. Whether the data is found in a Canadian study, a UK study or both is also indicated in the table.

### **3.5 Results**

This section contains a description of the studies included in the review, a summary of the methodological quality of included studies as presented in Table 3.3 and Table 3.4 and a comparison between Canadian and UK studies and finally a synthesis of the findings.

#### **3.5.1 Description of included studies**

Using the search strategy detailed above in Table 3.1, the author located 315 citations. After 71 duplicates were removed, 244 citations were screened for inclusion by reading the titles and abstracts. This process resulted in 117 citations being excluded, leaving 127 to be retrieved in full-text and assessed for inclusion. A further 117 citations did not meet the inclusion criteria, leaving 10 studies (2 Canadian, and 8 UK) included in the review. This process is detailed in Figure 3.1.

#### **3.5.2 Methodological quality of included studies**

As detailed in Table 3.3 and Table 3.4 the quality of the included studies ranged from medium to high according to the Kmet criteria (Kmet et al., 2004). The scores for the

qualitative studies ranged from 0.6 – 0.9 (mean = 0.77), and for the quantitative studies ranged from 0.54 – 0.94 (mean = 0.73), with an overall mean of 0.75 for all included studies. To determine inter rater reliability, Cohen’s Kappa calculation was used. Table 3.6 contains calculations of percent agreement, Cohen’s Kappa and number of agreements and disagreements for each item (Kottner et al., 2011). Inter rater agreement was assessed for three pairs of observations. Cohen’s Kappa ranged from .44 (moderate) to 1.0 (excellent) including a satisfactory level of inter rater agreement (Landis and Koch, 1977).

**Table 3.6 Inter rater reliability**

	<b>Percent Agreement</b>	<b>Cohen's Kappa</b>	<b>N Agreements</b>	<b>N Disagreements</b>
<b>Rocker et al. (2008)</b>	64	0.44	9	5
<b>Buxton et al. (2010)</b>	64	0.46	9	5
<b>Goodridge et al. (2009)</b>	100	1	10	0

### **3.5.3 UK/Canada comparison**

Eight studies from the UK, and two studies from Canada met the inclusion criteria. It was anticipated that studies would be evenly distributed between the countries, but a lack of Canadian studies in the area precluded this. Table 3.7 provides a comparison of findings from both countries, but due to the lack of Canadian studies, most findings were from the UK. There were very few unique Canadian findings, however some UK findings were also found in Canada. One unique finding from Canada was that end-of-life discussions should be culturally safe for patients.

Components of end-of-life discussions are summarised in Table 3.7. Findings are categorized by whether they reported by a UK or Canadian study, or both and also by the research question that they address: How do you know a patient is ready or willing to discuss

end-of-life?; What considerations should be made during end-of-life discussions?; and what topics should be included in end-of-life discussions.

**Table 3.7 Considerations, triggers and topics for end-of-life discussions in the UK and Canada.**

<b>1. How do you know a patient is ready or willing to discuss end-of-life? (Triggers for discussion)</b>	
<b>UK</b>	<b>Canada</b>
Use of Gold Standards Framework (GSF) to address EOL care and preferred place of care (Buxton et al.)	Discussion triggered when HCP would not be surprised if the patient died in the next year (Goodridge et al., 2009)
Advance care planning has been carried out in the last 12 months of life (Buxton et al.)	
Using the advanced decisions and preferred priorities of care to start discussion and document decisions (Buxton et al.)	<b>Both</b>
Health professional looks for cues from patient (Crawford, 2010)	Patient asks health professional about end-of-life (Goodridge et al., 2009, Crawford, 2010)
Health professional reads the patient for when to initiate the discussion (Crawford, 2010)	Patient experiences a serious impairment of functional status (Goodridge et al., 2009, Gott et al., 2009, Spence et al., 2009)
Trigger to discuss end-of-life is missed by health professional (Crawford, 2010)	
Non-imminent death is not discussed with patients (Pinnock et al., 2011)	
<b>2. Considerations for end-of-life discussions</b>	
<b>a. Prognosis</b>	
<b>UK</b>	<b>Canada</b>
Patient's family guides information provided to patient about prognosis (Elkington et al., 2001)	--
Time constraints prevent prognostic discussions (Elkington et al., 2001, Crawford, 2010)	
Difficult to determine end-of-life phase in severe COPD (Elkington et al., 2001, Gott et al., 2009, Spence et al., 2009)	<b>Both</b>
Discussions of prognosis remove hope for patients (Elkington et al., 2001, Crawford, 2010)	Patients with severe COPD want prognostic information (Elkington et al., 2001, Rocker et al., 2008)
Patients should ask for prognostic information (Elkington et al., 2001)	Patients may not get prognostic information despite wanting or asking for it (Gysels and Higginson, 2010, Elkington et al., 2001, Pinnock et al., 2011, Gore et al., 2000, Rocker et al., 2008)
Prognostic discussions are difficult to start with patients (Elkington et al., 2001)	
Patients value discussions about prognosis (Elkington et al., 2001)	
Health professionals soften information about prognosis for patients (Crawford, 2010)	
Health professionals find it difficult to formally diagnose COPD (Pinnock et al., 2011)	

**Table 3.7 Considerations, triggers and topics for end-of-life discussions in the UK and Canada (continued)**

**b. Responsibility to initiate end-of-life discussion**

<b>UK</b>	<b>Canada</b>
Lack of agreement between health professionals about whose responsibility it is to initiate the discussion and where (Gott et al., 2009, Spence et al., 2009)	--
It is easier for health professionals to discuss end-of-life when the patient initiates the discussion (Crawford, 2010)	<b>Both</b>
Patients do not realise that they have end-of-life choices to make unless health professionals raise the subject (Gott et al., 2009)	Physicians have an essential involvement in end-of-life decision making (Goodridge et al., 2009, Spence et al., 2009) End-of-life discussions should be initiated by the health professional (Goodridge et al., 2009, Gore et al., 2000)

**c. Understanding COPD as a life limiting illness**

<b>UK</b>	<b>Canada</b>
Lack of understanding of COPD as a life limiting illness (Gott et al., 2009, Gore et al., 2000)	--
Inadequate information provision about the likely course of COPD at diagnosis (Gore et al., 2000, Gott et al., 2009, Spence et al., 2009, Pinnock et al., 2011)	<b>Both</b>
Patients view death as a natural process instead of an anticipated consequence of their disease (Pinnock et al., 2011)	--

**d. Roles in end-of-life discussions**

<b>UK</b>	<b>Canada</b>
GPs have important role in discussing prognosis (Elkington et al., 2001, Spence et al., 2009)	Important role of families in end-of-life discussions (Goodridge et al., 2009)
	<b>Both</b>
	--

**e. Language of care**

<b>UK</b>	<b>Canada</b>
Medical language used during end-of-life is not understood by patients (Crawford, 2010, Gore et al., 2000)	Discussions should be culturally safe for all patients (Goodridge et al., 2009)
Health professionals avoid using the words 'death and dying' words (Crawford, 2010)	<b>Both</b>
	--

**f. Continuity of care and ability to share information between health professionals**

<b>UK</b>	<b>Canada</b>
Health professionals work with COPD patients at different points in the illness, making it difficult to define roles and maintain relationships (Crawford, 2010)	--

**Table 3.7 Considerations, triggers and topics for end-of-life discussions in the UK and Canada (continued)**

Information about end-of-life discussions are documented and shared between settings (Buxton et al., Elkington et al., 2001)	<b>Both</b>
	--
<b>g. When to discuss end-of-life with patients</b>	
<b>UK</b>	<b>Canada</b>
Choosing the 'right time' to discuss is important (Spence et al., 2009, Crawford, 2010, Pinnock et al., 2011)	--
Time constraints make it difficult for health professionals to discuss sensitive issues (Gott et al., 2009, Spence et al., 2009, Crawford, 2010)	<b>Both</b>
<b>g. When to discuss end-of-life with patients (continued)</b>	
End-of-life discussions should occur while patients are outpatients or in rehabilitation programmes and are well enough to make decisions (Buxton et al., Gott et al., 2009)	End-of-life should be discussed as early as possible after diagnosis (Goodridge et al., 2009, Spence et al., 2009)
Hospitals are noisy and lack privacy for end-of-life discussions (Gott et al., 2009)	
GP consultation appointments are not an appropriate time to discuss as the patient is typically unwell (Gott et al., 2009)	
Discussions should occur when deterioration worsens (Crawford, 2010)	
Difficult to discuss when patients are breathless, tired and distressed (Spence et al., 2009)	
The point of referral to palliative care services is unclear (Gott et al., 2009, Spence et al., 2009, Pinnock et al., 2011)	
Pattern of consultation prevents initiating discussions about the future (Pinnock et al., 2011)	
Uncertain disease trajectory makes timing the discussion difficult (Crawford, 2010)	
Gradual change of focus from active treatment to patient comfort (Spence et al., 2009)	
<b>h. Perceived negative effects of discussing end-of-life care</b>	
<b>UK</b>	<b>Canada</b>
Health professionals avoid discussing palliative care to avoid distressing patients (Spence et al., 2009, Crawford, 2010)	--
End-of-life discussions may deter patients from trying to manage their disease (Gott et al., 2009)	<b>Both</b>
Discussing palliative and end-of-life care with patients may result in patients feeling health professionals are giving up (Spence et al., 2009)	--
There are a lack of palliative care services for COPD patients, making it difficult to discuss care wishes (Crawford, 2010)	

**Table 3.7 Considerations, triggers and topics for end-of-life discussions in the UK and Canada (continued)**

**i. Feelings about discussing end-of-life**

<b>UK</b>	<b>Canada</b>
Health professionals anxiety in engaging in the discussion (Crawford, 2010)	--
Health professionals manage their emotions in order to regularly discuss end-of-life with patients (Crawford, 2010)	<b>Both</b>
Patients create their own boundaries about discussing end-of-life (Crawford, 2010)	--

**j. Medical profession and end-of-life discussions**

<b>UK</b>	<b>Canada</b>
Health professionals are trained to focus on a cure at all costs over palliative care (Gott et al., 2009, Spence et al., 2009, Crawford, 2010)	--
Health professionals state that they have not received training in breaking bad news or end-of-life discussions (Gott et al., 2009)	<b>Both</b>
Health professionals do not understand the benefits of palliative and end-of-life care and are therefore reluctant to use such resources (Spence et al., 2009)	--

**3. Topics for end-of-life discussions**

<b>UK</b>	<b>Canada</b>
--	Surrogate decision makers (Goodridge et al., 2009)
	Resuscitation (Goodridge et al., 2009)
	Emergency treatment (including intubation (Goodridge et al., 2009)
	Ongoing mechanical ventilation (Goodridge et al., 2009)
	<b>Both</b>
	--

### 3.5.4 Synthesis of results

The greatest number of findings from included studies were in the category labelled considerations for end-of-life discussions, sub-categorised into considerations relating to prognosis, and considerations relating to when to discuss end-of-life. The question with the least number of findings was topics for end-of-life discussions. Only one Canadian study reported topics that should be included in end-of-life discussions (Goodridge et al., 2009).

Section one of Table 3.5 looks at how health professionals know that a patient is ready or willing to discuss end-of-life. Studies from both the UK and Canada reported two indicators; (i) the patient asks the health professional about end-of-life (Goodridge et al., 2009, Crawford, 2010), and (ii) the patient has had a decline in functional status (Goodridge et al., 2009, Gott et al., 2009, Spence et al., 2009). Findings from the UK specifically reported the use of standardized tools such as the Gold Standards Framework (2006) and the preferred priorities of care documents to tell them when a patient was clinically ready to discuss (Buxton et al., 2010). Other findings reported that the health professional looks for indicators from the patient directly, implying that the health professional and patient may have a prior relationship whereby cues could be interpreted (Crawford, 2010). Two studies also reported that triggers to discuss end-of-life were missed by health professionals, and that unless death was imminent, it would not be discussed with patients (Pinnock et al., 2011). One Canadian study added to these results that discussions were triggered by using the 'surprise question' – when the health professional would not be surprised if the patient died in the next year (Goodridge et al., 2009).

Section two of Table 3.7 reports considerations for end-of-life discussions. These findings are subdivided further into sub-categories. The areas with the most items were when to discuss end-of-life with patients and prognosis. Timing came up as a contentious issue in several studies

(Spence et al., 2009, Crawford, 2010, Pinnock et al., 2011, Gott et al., 2009, Buxton et al., 2010, Goodridge et al., 2009). Some stated that there was a 'right time' to discuss (Buxton et al., 2010, Gott et al., 2009), and others indicated that time constraints in the current system made finding this time to discuss very difficult (Pinnock et al., 2011). In addition, there were conflicting findings about discussing soon after diagnosis, or when the patient's condition started to deteriorate (Goodridge et al., 2009, Spence et al., 2009, Crawford, 2010). Findings were also contradictory about discussing when patients are well and attending outpatient programmes, when they were in the hospital, or during GP consultations (Buxton et al., 2010, Gott et al., 2009).

The issue of prognosis in relation to discussing end-of-life was another contentious topic. Prognosis was acknowledged as being difficult to determine in COPD (Elkington et al., 2001, Crawford, 2010). Timing was raised as an issue that prevented discussing prognosis with patients, that health professionals felt that discussions of prognosis would remove hope for patients, and that prognostic discussions were difficult to start with patients (Crawford, 2010, Elkington et al., 2001). On the other hand, some studies found that patients value and want to discuss prognosis, but may not get such information despite asking their health professionals to discuss it with them (Elkington et al., 2001, Rocker et al., 2008).

Another area of disagreement in the included papers was about whose responsibility it is to discuss end-of-life with patients. Authors of several papers found that physicians should be involved and the discussion should be initiated by health professionals (Gott et al., 2009, Goodridge et al., 2009, Spence et al., 2009, Gore et al., 2000), while researchers in another study found that it was easier for health professionals when patients initiated the topic (Crawford, 2010).

It was also found that there was a lack of understanding by patients of the nature of COPD as a life limiting disease (Gott et al., 2009, Gore et al., 2000). This is likely related to the inadequate provision of information to patients as mentioned previously related to prognostic information (Gore et al., 2000, Gott et al., 2009, Spence et al., 2009, Pinnock et al., 2011). As a result of this misunderstanding patients with COPD may not view death as a consequence of their disease (Pinnock et al., 2011).

Such misunderstanding may also be related to the language used in care, which was found to be too medical for patients, and in some cases health professionals avoided using words such as death and dying (Crawford, 2010, Gore et al., 2000).

A positive area in UK findings was that information sharing between health professionals when end-of-life discussions do occur was sufficient (Crawford, 2010, Buxton et al., 2010, Elkington et al., 2001). However, a lack of continuity of care was found to make discussions difficult, and related back to the issue of responsibility for such discussions (Crawford, 2010). Perhaps not surprisingly, health professionals viewed end-of-life as having negative effects on patients in terms of creating distress, feeling that they were being 'given up on' and deterring patients from managing their disease (Spence et al., 2009, Crawford, 2010, Gott et al., 2009). Authors of one study also found that the lack of end-of-life services for COPD patients meant that discussing patients' wishes for care may be fruitless as wishes may not be met (Crawford, 2010).

These findings are put in context by the final area in considerations for end-of-life discussions, that the medical profession concentrated on cure at all costs, and therefore health professionals may not have adequate training in discussing death, breaking bad news and

palliative care (Gott et al., 2009, Spence et al., 2009, Crawford, 2010). The final category of topics for end-of-life discussions only had findings from one Canadian study (Goodridge et al., 2009), which suggested four key topics for end-of-life discussions, which are listed in Table 3.7.

### **3.6 Discussion**

The aim of this review was to synthesise evidence from research conducted in the UK and Canada about how health professionals discuss end-of-life with patients with COPD. Ten studies were included, seven of which were based on qualitative research methods and three on quantitative methods. In these studies, several components of end-of-life discussions with patients with COPD were identified and grouped according to the research question that they addressed, and then further into themes.

This work can be distinguished from other work in the area as it provides an multi-national perspective on this difficult issue, and finds that issues are similar in both countries, but that also that more research is needed to ascertain the views of health professionals in Canada should be conducted before direct comparisons can be made. In addition, the specificity of the inclusion criteria of only studies looking at COPD assists in making specific recommendations for this patient group.

The finding that there is a lack of Canadian literature in this area was unexpected. Interestingly, the research questions from the Canadian studies and the UK studies seemed to differ significantly. Authors of the two Canadian studies aimed to measure the quality of end-of-life care and related end-of-life discussions, while most UK studies specifically focused on experiences and attitudes regarding discussing end-of-life from different perspectives. It is

important to note that the authors of two UK studies also looked to measure whether end-of-life needs were being met.

The results revealed that while health professionals have an understanding of when a patient may be ready to discuss end-of-life, they have a negative view of the perceived effect of these discussions on their patients, potentially explaining why it is often reported that such discussions do not occur. This perceived negative effect by health professionals which is not supported by the review findings that patient perceptions, may be in part related to anxiety on the part of the health professional over having such discussions. This issue has been addressed in the literature. Fallowfield and Jenkins (2004) found that it is difficult for health professionals to get the balance of being honest and encouraging/hopeful when giving bad news to patients. In addition, Curtis proposed a diagram for health professionals to understand the interaction between desire for hope and realistic prognostic information (Curtis et al., 2008). In fact, recently Nolan (2011) found that the quality of the 'presence' of a support professional (in this case, chaplains) helped patients maintain a 'hopeful manner'. Therefore simply being with the patient can be hope fostering and the same was found by Reinke et al. (2010) found similarly that nurses support patients' hope by developing a relationship, providing prognostic information and following the lead of the patient.

Providing prognostic information was a contentious issue in the wider literature. Those conducting a recent US study found that there are several high quality prognostic indices for older adults, but concluded that neither a clinician or a prognostic tool can predict with certainty how long a person will live (Yourman et al., 2012). The UK end-of-life strategy recommends that there are 'effective mechanisms to identify those who are approaching the end-of-life' and states that people approaching the end-of-life are offered a care plan

(Department of Health, 2009). The Canadian literature is more specific as it provides prognostic indicators and states that these patients will benefit from timely discussion about end-of-life issues, highlighting the value of palliative services (O'Donnell et al., 2008).

The findings clearly demonstrated that there is a lack of agreement about who is responsible for initiating end-of-life discussions. This ambiguity may be specific to COPD, as the UK Cancer Palliative Care guidelines state that key information should be delivered by the most senior health professional available, and that all health professionals should be able to respond appropriately to patient concerns (National Institute for Clinical Excellence (NICE), 2004). The Canadian guidelines for COPD state that physicians have a responsibility to help patients and caregivers with COPD to plan for the end-of-life and to access support (O'Donnell et al., 2008). In addition, Abarshi (2011) found that GPs discussed end-of-life issues more with patients with cancer than with other conditions.

The UK end-of-life strategy states that discussions about end-of-life should be undertaken by health professionals who are appropriately trained in communication skills, assessment, care planning, and symptom management as related to end-of-life care (Department of Health, 2009). However, the end-of-life strategy also notes that providing such training for health professionals should be a priority in education, perhaps explaining why health professionals may currently be lacking the necessary skills.

Interestingly, the recommendation of being sensitive to the patients' cultural needs was unique to the Canadian literature. This may reflect the Canadian government's commitment to cultural diversity and its expression in health policy (Department of Canadian Heritage, 2009).

Future research in the UK could investigate the experiences of discussing end-of-life in COPD in various cultural groups.

### **3.7 Conclusions**

This review provides an international comparison of the literature from the UK and Canada related specifically to end-of-life discussions in COPD to contribute to the evidence base for the development of the intervention. The findings highlight a lack of Canadian literature in this area, thereby indicating the need for further research.

The review also highlights a discrepancy in the evidence base regarding initiation responsibility. In Chapter 2 it is reported that it is the responsibility of the health professional to raise the end-of-life topic, while the findings of this review demonstrate that the patient indicates readiness to discuss by raising the topic themselves, or the health professional uses a decline of functional status to indicate that a discussion should take place. In addition, there is a lack of literature regarding topics for end-of-life discussions specific to COPD in both countries, indicating a need to explore this area further in the Delphi studies that will follow. The contribution of the evidence base established here will be discussed in relation to the studies that will be reported in Chapters 5 and 6, in Chapter 7.

## **Chapter 4. Research Design and Methods**

### **4.1 Introduction**

The findings of the systematic reviews presented in Chapters 2 and 3 demonstrate significant gaps in the literature related to end-of-life discussions in NMRD. Specifically, there is a lack of literature addressing the psychosocial needs of patients, as well as disagreement relating to the responsibility to initiate end-of-life discussions. First, training health professionals to discuss end-of-life with this patient group may be key to moving the care of patients with severe NMRD forward. Second, indicators that this group of patients are ready or willing to discuss end-of-life have not been established, nor have topics for end-of-life discussion specific to COPD.

This chapter presents an overview of the mixed methods research design and methods used to address the aims of the study:

- 1) To determine how health professionals in the UK and Canada discuss end-of-life; and
- 2) To develop an instrument allowing health professionals to determine constraints and opportunities to facilitate successful end-of-life discussions specific to NMRD in Canada and the UK;

through the objectives, which were to:

- a) Establish how health professionals know a patient with NMRD is ready or willing to discuss end-of-life;
- b) Establish the key considerations and key topics in such discussions as defined by health professionals in the field; and

- c) Delineate the differences in end-of-life discussions for patients with NMRD in the UK and Canada.

As described in section 1.6 of Chapter 1, to achieve these aims the guidance on developing and evaluating complex interventions set out by the Medical Research Council (MRC) (2008) provided the blueprint for the design of the study. The guidance consists of four independent phases, of which the first was completed through this doctoral study. This process is outlined in Figure 1.1 and Figure 1.2 of Chapter 1. What follows in this chapter is a discussion of how the specific research design and methods used to develop theory model the process under investigation.

Building on the evidence base established in the two systematic reviews, reported in Chapters 2 and 3 as per the MRC guidance, a sequential exploratory mixed methods design was employed to investigate this issue in the UK and Canada and develop a tool specific to each country to aid health professionals in discussing this issue with patients. Then, the results of these investigations were compared to provide further insight into this area and identify areas for improvement in both countries.

In section 4.2 the research design is set in the context of the overall assumptions guiding the project. In section 4.3 the methods used to carry out the research design is examined and critiqued in relation to other possible methods. This is followed in section 4.4 by a detailed description of the procedures and in 4.5 by a discussion of the process of establishing the clinical applicability of the tools. The method of international comparison will be described in section 4.6. A discussion of how rigour was established throughout the study follows in section 4.7. In section 4.8, the specifics of the study participants will be explicated, including the sample

design and the limitations of this design. This is followed by a description of the recruitment procedures in section 4.9, and by a discussion of ethical issues in the study in section 4.10. Finally, the chapter is concluded in section 4.11.

## **4.2 Research Design**

In this section the overall assumptions guiding this project will be discussed in section 4.2.1. This will be followed by an in-depth discussion of mixed methods research and the specific research design used for this study.

### **4.2.1 Worldviews and Pragmatism**

In research, the worldview refers to the beliefs or assumptions that guide the investigation (Guba and Lincoln, 2005). Worldviews consist of common elements, but the approach to these elements is different. The elements are referred to as ontology, which represents the views on the nature of reality, epistemology, which represents how knowledge is gained, axiology, which is the role of values in research, methodology, which is the research process and rhetoric, which is the language used in research (Creswell and Plano Clark, 2007b).

While there are several worldviews worthy of consideration for health researchers, such as postpositivism (Popper), constructivism (Lincoln and Guba, 1985) and advocacy and participatory view (Heron and Reason, 1997), these views are traditionally associated with either purely quantitative or purely qualitative methodology. Pragmatism is the most fitting paradigm for mixed methods research (Creswell and Plano Clark, 2007b) and is based on using 'what works', employing varied methods and values both objective and subjective knowledge (Creswell and Plano Clark, 2007b).

In research, the pragmatist seeks to clarify the significance of findings, and is focused on the consequences of the project (Cherryholmes, 1992). Cherryholmes (1992) explicates Dewey's writing on pragmatism where he states that the pragmatic view does not emphasise what has gone before (such as past literature on the topic of choice), but instead on what will happen in the future as a result of the research (Dewey, 1980). This view means that instead of research being designed to 'report and register past experiences' (Dewey, 1980, p.32), it can be a basis for ordering what will happen in the future (Cherryholmes, 1992).

Overall a practical and applied view of research should guide decisions made about methodology (Tashakkori and Teddlie, 2003). The pragmatic approach in research is useful as it connects the epistemological concerns about the knowledge that is produced with the technical concerns of the methods used to generate such knowledge (Morgan, 2007). As elucidated above, pragmatism focuses on the outcomes of the research being undertaken, is centred on the research problem, rather than the methods used to solve it (Tashakkori and Teddlie, 2003).

#### **4.2.2 Mixed methods design**

In this section the definition and development of mixed methods research are examined. The specific research design is then presented, followed by the key decisions made relating to this research design. Finally, limitations of the research design are discussed.

##### **Definition of mixed methods research**

Mixed methods research is the combination of both qualitative and quantitative approaches to address a particular research problem (Tashakkori and Teddlie, 2003, Green et al., 1989, Creswell, 2003, Morse, 1991). A fundamental principle of mixed methods research is that data are collected using multiple strategies, methods and approaches, resulting in a

combination of methods with complementary strengths and weaknesses that are not repeated (Johnson and Turner, 2003). The need for mixed methods research was established in medical clinical practice research (Stange and Zyzanski, 1989). However, it is more than a "mechanically superior" (p. 73) way to answer research questions (Morgan, 2007), rather, mixed methods studies should result in better outcomes than studies based on only one method to answer the research question (Johnson and Onwuegbuzie, 2004).

The mixed method approach was pioneered by Jick in 1979, who advocated combining both qualitative and quantitative methods rather than simply collecting both types of data without deliberately planning integration of the two in the research design. He stated that by using this approach researchers could have more confidence in their findings, as the use of mixed methods led to better understanding of the research questions while allowing for testing of competing theories (Jick, 1979). Morse (1991) further developed the thinking about mixed methods by developing two types of mixed methods research design - triangulation and sequential design, and also emphasised that either qualitative or quantitative methods needed to provide the theoretical background study. Therefore, she expanded on the idea that mixed methods research was not just to obtain complementary findings using two approaches, but could lead to the development of new knowledge and theory.

### **Mixed methods design for development of a research instrument**

The use of mixed methods must be appropriate for the given research project (Jick, 1979). The guidelines for reporting and conducting mixed research (Leech & Onwuegbuzie (2010) state that this rationale must be reported. In this study, the rationale for instrument fidelity as articulated by Collins, Onwuegbuzie & Sutton (2006) is that the researcher wants to maximise the value or suitability of an instrument that is being created through the study.

Using mixed methods, the researcher can assess the fidelity of the instrument being developed throughout the study and make modifications as needed. The researcher can subsequently assess whether the information from the instrument is valid, and put the information in context (Collins et al., 2006).

Collins et al. (2006) provide a conceptual framework to assess fidelity of the instrument. They state that content related validity, specifically face validity and sampling validity can be employed. Face validity can be established during the tool validation process by determining the extent that the items are relevant, important and interesting to the respondent, while sampling validity addresses the extent to which the set of items sample the total content of the area under investigation (Collins et al., 2006).

The guidelines put forward by Leech and Onwuegbuzie (2010) state that the specific purpose for combining qualitative and quantitative approaches must be stated, while Collins et al. (2006) provide a framework of 65 purposes from which to choose. The eight potential purposes specific to instrument fidelity studies (Collins et al., 2006) are to:

- assess adequacy of observational protocols in varied settings
- validate individual scores on outcomes measures
- identify the adequacy of measures used
- explain within- and between-participant variations in outcomes on instruments
- assist with conceptual and instrument development
- determine the optimal conditions for administering instrument for specific population
- develop items for an instrument

- provide some basis for identifying possible sources of error in the underlying measures

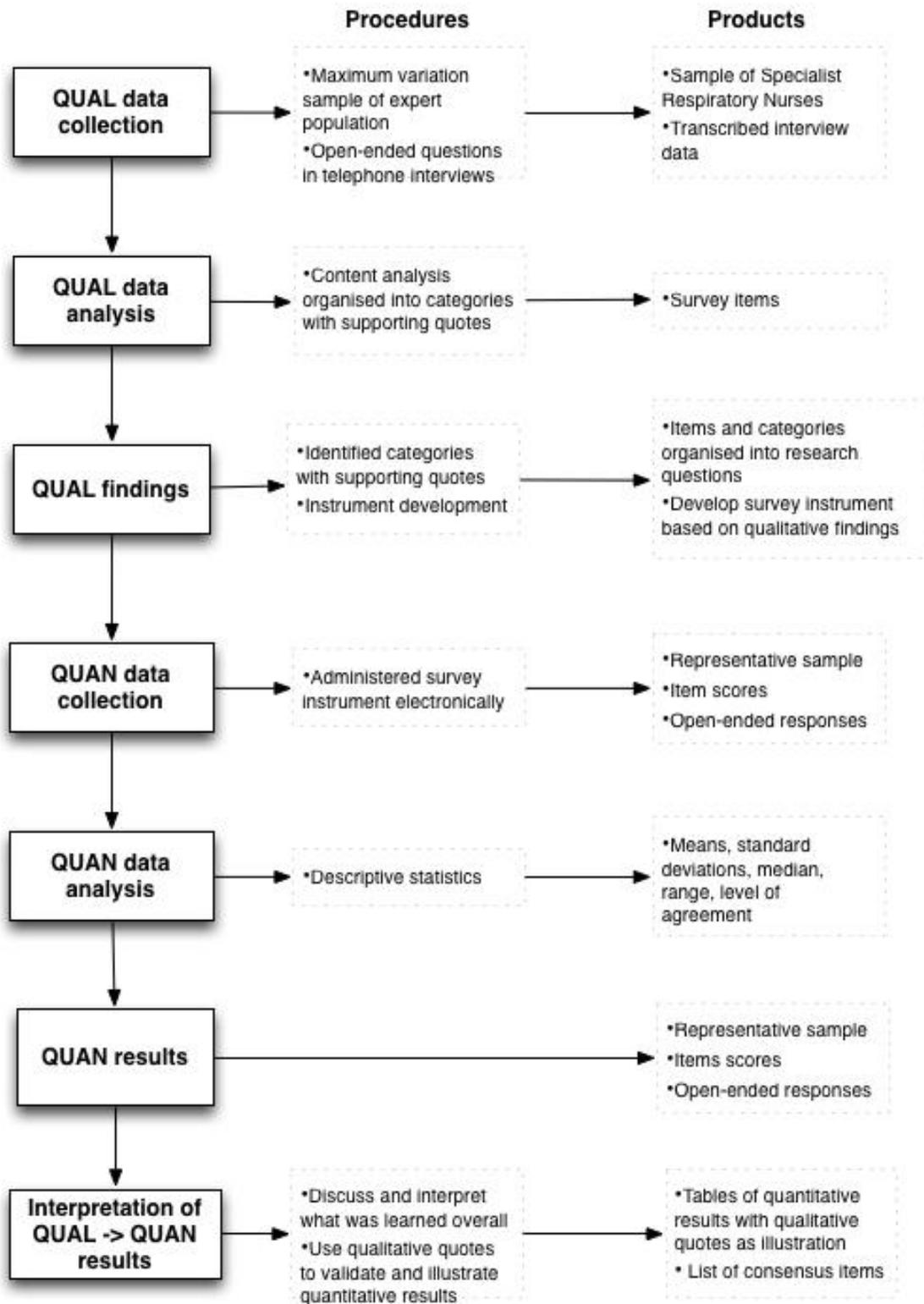
Based on the pragmatic view of research, the desired consequences of the research study guided the choice of an exploratory mixed methods design for instrument development. As elucidated in section 1.5, the purposes of the current study were to develop theory and model process and outcomes to contribute to the instrument being developed. These purposes are compatible with Creswell's reasons for conducting a sequential exploratory study, which is often to develop and test an instrument, explore a phenomenon, and to expand on qualitative findings (Creswell, 2003). This study is a multiphase, mixed methods study including systematic review, modified Delphi studies and a comparison of the international Delphi panel results.

A mixed methods design was deemed appropriate for an international comparison. Qualitative research allowed for an exploration of the issue at hand, and quantitative methods were used to develop further understanding. The combination of these approaches resulted in an international comparison of end-of-life discussions in NMRD.

Collins, Onwuegbuzie & Sutton (2006) also state that establishing instrument fidelity is an acceptable rationale for using mixed methods. Therefore, in this study the mixed methods sequential exploratory design for instrument development was used, consisting of two distinct phases: qualitative followed by quantitative (Creswell, 2003). In this type of design, the researcher first collects and analyses qualitative data. This is based on the idea that qualitative exploration of the phenomena of interest is required before quantitative research can be done. It is useful when the researcher needs to design and test an instrument when one is not currently available. The qualitative findings from the first phase guide the development of the quantitative survey instrument. In the second phase of data collection, the researcher

implements and validates the instrument (Creswell, 2003). Figure 4.1 details the process of the sequential exploratory design as employed in this study.

Figure 4.1 Sequential Exploratory Design.



## **Decisions made in mixed methods research**

The key issues when choosing a mixed methods research design are timing, weighting and mixing (Creswell and Plano Clark, 2007a). Each issue as it pertains to the specific mixed methods research design in this study will be addressed in detail below.

### **Timing**

The concept of timing (Creswell and Plano Clark, 2007a) has also been expressed as time orientation (Leech and Onwuegbuzie, 2010), sequence of collecting qualitative and quantitative data (Morgan, 1998) or implementation (Creswell, 2003, Green et al., 1989), and refers to the selection of either concurrent or sequential data collection. The selection of timing is pragmatically based on the objectives of the researcher and is important to articulate so that readers know how the data from each type are related. Using concurrent data collection, the researcher would want to determine whether findings from qualitative and quantitative data collection were in agreement. In sequential data collection, the researcher must make the additional decision of which type of data to collect first. It is appropriate to collect quantitative data first, when the objective is to test variables with a large sample and then to explore issues in depth with a qualitative phase. When qualitative data are collected first, this is usually to allow for an exploration of the research problem, and then follow this exploration with quantitative data (Creswell and Plano Clark, 2007a).

As described in the previous section, in the exploratory design for instrument development the results of the first method (qualitative) were used to help develop the second method (quantitative) in order to create and test an instrument where one was not currently available (Creswell and Plano Clark, 2007a). This design is based on the proposition that exploration is needed as instruments are not available and variables are unknown (Creswell and

Plano Clark, 2007a). Qualitative data collection is completed first to identify items to develop the quantitative instrument.

### **Weighting**

The concept of weighting articulated by Creswell (2007a) has also been called emphasis of approach (Leech and Onwuegbuzie, 2010), variation of priority or weight given to each form of data (Morgan, 1998), priority (Creswell, 2003) and status (Green et al., 1989), and refers to whether more weight is given to the qualitative or quantitative data when interpreting the results, or whether equal priority is given to each type (Creswell, 2003). The decision of weighting may be based on: the practical constraints of data collection; the need to understand one type of data before collecting the next type, the preference of the audience for one type over the other, and the comfort level of the researcher (Creswell, 2003). In the exploratory design for instrument development, the quantitative data is usually emphasised as it relates to the final form of the instrument (Creswell and Plano Clark, 2007a).

### **Mixing**

The concept of mixing (Creswell and Plano Clark, 2007a) has also been referred to as level of mixing (Leech and Onwuegbuzie, 2010) and integration (Creswell, 2003), and is the stage or stages of research when qualitative and quantitative data are integrated (Creswell, 2003). This decision is again based on the purpose of the research, and in this case on the purpose of instrument development. In the exploratory design for instrument development, qualitative findings guide the development of items and scales for the quantitative survey instrument. It is this development of items that connects the initial qualitative phase to the following quantitative phase (Creswell and Plano Clark, 2007a).

### **Limitations of the sequential exploratory design**

Overall, the limitations of mixed methods research are that it is more time consuming, complex and resource intensive than mono-method research (Creswell, 2003). Researchers require a working knowledge of both quantitative and qualitative methods and how to combine them (Schneider and Whitehead, 2013). As with any type of research design, the mixed methods sequential exploratory design has limitations (Creswell and Plano Clark, 2007a). Each will be described and addressed below.

The two-phase sequential approach requires a considerable amount of time to execute, as each phase is dependent on the completion of the previous phase. Therefore, sufficient time must to be allocated to each phase allowing for data collection and full analysis. In the current study this was addressed by creating a detailed project plan, and allocating sufficient time for each phase. The dependency of one phase on the next can be problematic to specify quantitative phase procedures in advance for the purpose of ethical approval, however in this case, the calculation of descriptive statistics was likely be the only method of analysis of the quantitative data, and therefore this was stated in ethics applications.

In this type of design, Creswell (2003) recommends that different individuals participate in qualitative and quantitative phases. However, as is traditional in the specific method used (described in section 4.3.1), the same participants were used throughout the study. A smaller group of participants, making up a maximum variation sample were used in the qualitative phase and more participants were recruited in the quantitative phase to allow results to be more generalizable to the population.

Another issue that can arise in a sequential exploratory design is how to decide which data from the qualitative phase to use in the instrument, and how to use the data to design the instrument. Again, the use of a specific method to establish consensus among experts addresses this issue. Content analysis of the qualitative data captured each relevant item and each item was included in the quantitative instrument for consideration by participants. As is described above, most of the limitations of a sequential exploratory design for instrument develop are addressed by using a specific method. This method will be described in detail in section 4.3.1.

### **4.3 Methods**

In this section the methods used in the sequential exploratory design for instrument development are presented. First, consensus methods and the types available are explored, followed by an explication of the Delphi and how it was applied in this study. Next, the process of endorsement of the instrument is discussed. This is followed by a description of how the results of the UK and Canadian Delphi studies were compared. Finally, the issue of establishing rigour is examined.

#### **4.3.1 Delphi Method**

##### **Consensus methods in research**

The purpose of formal consensus methods is to synthesise judgements of a group of people, and to determine levels of agreement on controversial subjects (Fink et al., 1984, Murphy et al., 1998). When published information is inadequate, consensus methods allow a way to harness the knowledge and experience of experts while also allowing decisions to be made (Jones and Hunter, 1995). Before discussing the methods of obtaining consensus formally,

it is important to examine the concept of consensus in research. There are two types of agreement possible within formal consensus methods: the extent to which the participant agrees with the issue at hand, determined by their rating on a categorical scale; and the extent to which participants agree with each other on a given issue, determined by calculating averages and dispersion statistics for each item (Jones and Hunter, 1995). Methods of deciding consensus vary and can involve voting to determine percentage agreement, or using rating scales to reach a predetermined mean rating, or where a majority of participants must rate a topic at a certain level for inclusion (Nair et al., 2011). Therefore, consensus does not necessarily indicate full agreement between participants on a given issue (Nair et al., 2011). Usually, a predetermined level of agreement is determined to establish when consensus has been reached.

Why should group decision-making be formalised? Murphy et al. (1998) refer to social psychological research from the mid 1900s that demonstrated the role of social facilitation. This research showed that performance of tasks can be improved or inhibited in front of a group, dependent on how well mastered this task was. In addition, conformity research shows that people in groups will sometimes conform to the judgements of others, potentially because group members feel pressured to say what others say, and also because people use others to interpret the nature of reality, when that reality is ambiguous. Therefore, the presence and actions of others is not neutral in its effects, and these processes may hinder group decision-making (Murphy et al., 1998).

Consensus methods aim to overcome the difficulties of reaching decisions in groups, while allowing the inclusion of a wide range of knowledge, experience and interaction between

members (Jones and Hunter, 1995, Murphy et al., 1998, Nair et al., 2011). In addition, they have several other useful features put forth by several authors on the subject:

- several people are less likely to arrive at a wrong decision than an individual (Murphy et al., 1998);
- a decision made by a select group of people is likely to lend authority to the decision produced (Murphy et al., 1998);
- decisions are improved as they have been argued between members (Murphy et al., 1998);
- formal consensus methods are scientifically credible (Murphy et al., 1998);
- they offer a method of dealing with conflicting evidence (Jones and Hunter, 1995);
- they allow for a more significant role for qualitative assessment of evidence (Jones and Hunter, 1995);
- derive quantitative estimates can be derived through qualitative approaches (Jones and Hunter, 1995).

Despite several advantages, there are some issues that must be attended to when utilizing these methods such as the choice of participants, avoiding one or more people dominating the group, the cost of bringing people together, and finally the tendency to assume that group decisions are unanimous and not attend to the degree of dissent within the group (Murphy et al., 1998). Each method has an approach to addressing these issues. The three most common formal consensus methods are: the Delphi, the nominal group technique, the consensus development conference, and the RAND-UCLA Appropriateness method.

## Consensus Methods

This section will examine the features of the four most common methods of establishing consensus in order to determine the most appropriate method for this study.

Guidelines published by Fink et al. (1984) set out a criteria to evaluate consensus methods. These guidelines are helpful in evaluating the four consensus methods that will be discussed in the following paragraphs and are:

- Consensus study should focus on a clearly defined problem
- Decisions should be made by relying on the judgements of experts as well as the available empirical data
- Consensus participants should be representative of their profession, have the ability to implement findings, or be recognised as experts in their field
- The consensus process should be facilitated by an objective and skilled leader
- The level and type of consensus should be defined in advance
- Findings of consensus studies should be presented as clear and specific guides for action
- Large consensus studies should have backing from relevant organisations or government agencies
- The dissemination and subsequent use of the findings of the consensus study should be monitored.

Following the short description of each method, the advantages and disadvantages of each method are presented in Figure 4.2.

## **Nominal Group Technique**

The nominal group technique was developed in the United States in the 1960s to investigate issues related to social services, government, education and industry (Delbecq and Van de Ven, 1971). It is a type of structured meeting with the aim of providing a method to acquire qualitative information from an expert group (Delbecq and Van de Ven, 1971, Fink et al., 1984, Jones and Hunter, 1995). It is usually conducted with a group of 9-12 participants and consists of two rounds where group members rate, discuss and then re-rate a series of items or questions. In the nominal group technique participants join together and individually list their responses to the topic. Then, after a set period of time, each person takes turns presenting the most important item on their list, until all lists are exhausted. All ideas are recorded on a chart for the entire group to see. A highly structured group discussion of each idea follows, where each idea is separately evaluated and clarified. Next, individuals privately rank or rate the worth of each idea. Items with a high ranking according to a predefined cut off are kept, while low ranking items are discarded. This concludes with a prioritised list of ideas or solutions (Nair et al., 2011).

## **The Delphi Method**

Development of the Delphi (subsequently referred to as the Delphi) began in the 1950s at RAND corporation by Dalkey and Hemler (1963). The goal of the Delphi is to turn individual opinion into group consensus (Hasson et al., 2000). There are four key features to the method: iteration, controlled feedback, anonymity of participants and statistical aggregation of group response (Rowe and Wright, 1999). In the first round, expert panellists give their opinion individually and anonymously on a given issue, usually via mail or internet. The results are tabulated and reported to the entire group anonymously. Then group members have the

ability to reconsider their response in light of the group opinion and they rate each item. Individual responses are then tabulated again, and once again given back to the entire group. Usually the Delphi is conducted over 3-4 rounds until consensus is reached (Fink et al., 1984).

### **Consensus Development Conference**

The consensus development conference (CDC) is a process developed by the US National Institute of Health in the 1970s. It brings together physicians, researchers, consumers and others to evaluate the appropriateness of using an existing technology such as a drug, a procedure or a device in health care. The method is unstructured, but is based on judicial decision-making methods, scientific conferences, and the town hall meeting structure (Lomas, 1991). A group of selected individuals meet in person to reach consensus. Participants take part in a chaired open meeting where evidence is presented by interest groups or experts who are not part of the decision making group. Then the decision-making group meet privately in a second chaired meeting to consider the evidence and to reach a consensus. When consensus cannot be achieved, group members are encouraged to provide minority views (Murphy et al., 1998).

### **RAND-UCLA Appropriateness Method**

This method was developed to evaluate the use of medical procedures in the US, and combines scientific evidence with expert opinion (Nair et al., 2011). The method involves two interdependent groups - a core panel and an expert panel. The core panel conducts a literature review. The core panel then provides a synthesised review from the literature to the expert panel, and lists clinical scenarios also devised from the literature. There are then two rounds of rating the appropriateness of the intervention. In the first round, the expert panel is sent clinical scenarios by mail, and participants rate the interventions on Likert scales. In the second

round, the expert panel meet in person and are led by a moderator. The expert panel are given the results of the ratings of each scenario, and panel members can discuss their individual views on the appropriateness of the intervention in each scenario. After the discussion, each panellist is able to reconsider their original rating and re-rate the clinical scenario. The results are then summarised using descriptive statistics, and these ratings are used to determine whether an intervention is appropriate or inappropriate (Nair et al., 2011).

**Figure 4.2 Advantages, disadvantages and criticisms of consensus methods.**

Method	Advantages	Disadvantages and Criticisms
Nominal group technique (NGT) (Delbecq & Van de Ven 1971)	<ul style="list-style-type: none"> <li>• Procedures are highly reliable (Fink et al 1984)</li> <li>• Participants meet in person, there is person contact between experts (Nair et al 2011)</li> <li>• All participants can voice opinions (Nair et al 2011)</li> <li>• Group voting can occur if desired (Nair et al 2011)</li> </ul>	<ul style="list-style-type: none"> <li>• An experienced moderator is required to avoid an individual dominating the group (Nair et al 2011)</li> <li>• Time to discuss all issues is limited, and only a small number of issues can be discussed and agreed on (Nair et al 2011)</li> <li>• Economic and time costs due to in-person group meeting (Nair et al 2011)</li> <li>• Produces less frequent and stable consensus than other consensus methods (Nair et al 2011)</li> </ul>
Delphi Method (Dalkey & Helmer 1963)	<ul style="list-style-type: none"> <li>• Participants are able to express views anonymously that lead to a group opinion (Fink et al 1984)</li> <li>• Process is easy to understand (Fink et al 1984)</li> <li>• Participants can exchange information in an iterative process, while also being a low cost process (Fink et al 1984)</li> <li>• Consensus can be gained without eliminating minority views at an early stage (Mead 2001)</li> <li>• The process of gaining consensus is transparent to members and outlined in detail. Therefore the potential that two groups come to a different opinion is not due to the method, but rather based on a true difference in opinion. (Mead 2001)</li> <li>• The data can be statistically manipulated (Mead 2001)</li> <li>• Questioning can be open-ended (Bowles 1999)</li> <li>• Attitudes can be measured (Bowles 1999)</li> <li>• Feedback is controlled but also anonymous (Bowles 1999)</li> <li>• Qualitative and quantitative analysis is possible within the same study (Bowles 1999).</li> <li>• Ability to collect number of opinions without geographical boundaries (Whitehead &amp; Schneider 2013, Jones &amp; Hunter 1995, Nair et al 2011)</li> <li>• Participants are free to express opinions without being unduly influenced by other participants (Whitehead &amp; Schneider 2013, Nair et al 2011)</li> <li>• Individuals can participate on their own schedule and with minimal expense, particularly if conducted electronically (Whitehead &amp; Schneider 2013, Jones &amp; Hunter 1995, Marsden et al 2003, Nair et</li> </ul>	<ul style="list-style-type: none"> <li>• Participant selection process may be a source of bias (Keeney 2001, Nair et al 2011, Jones &amp; Hunter 1995)</li> <li>• Due to the time commitment required from participants, there is a risk of attrition (Beech 2001, Whitehead &amp; Schneider 2013)</li> <li>• The researcher must intervene to reorder and reduce data between rounds, if done incorrectly statements may move away from their original meaning (Green 1999)</li> <li>• Study findings may lack external validity, and therefore must be triangulated with other data (Kennedy 2004, Jones &amp; Hunter 1995)</li> <li>• Delphi method does not allow potentially positive aspects of the interaction of group members (such as resolving disagreements) (Fink et al 1984)</li> </ul>

<p>Delphi Method (continued)</p>	<p>al 2011)</p> <ul style="list-style-type: none"> <li>• The study can be conducted over a short period of time (Whitehead &amp; Schneider 2013)</li> <li>• The method is flexible and can be modified based on the needs of the researcher (Whitehead &amp; Schneider 2013, Nair et al 2011, Fink et al 1984)</li> <li>• Small groups of participants can be used, number of participants can range from 4 to 3000 (Whitehead &amp; Schneider 2013, Cambell &amp; Cantrell 2001, Nair et al 2011)</li> <li>• It is less likely that the moderator may bias the group, unlike face-to-face meeting methods (Nair et al 2011)</li> <li>• The method allows for qualitative and quantitative analysis within the same study (Bowles 1999)</li> </ul>	
<p>Consensus Development Conference (CDC) (Fink et al 1984)</p>	<ul style="list-style-type: none"> <li>• Results are often widely circulated in lay and medical media (Nair et al 2011)</li> <li>• Panellists are a mix of practicing physicians, researchers and consumers (Nair et al 2011)</li> </ul>	<ul style="list-style-type: none"> <li>• Interaction between group members is not structured (Nair et al 2011)</li> <li>• No formal feedback system (Nair et al 2011)</li> <li>• Has not been used for making new criteria sets (Nair et al 2011)</li> <li>• Requires resources beyond the disposal of most researchers (Jones &amp; Hunter 1995)</li> </ul>
<p>RAND-UCLA Appropriateness Method (RAM)</p>	<ul style="list-style-type: none"> <li>• Published literature is incorporated into the method (Nair et al 2011)</li> <li>• Includes both confidential individual ratings and group discussion (Nair et al 2011)</li> <li>• Panel is often interdisciplinary which encourages consensus from a wide group (Nair et al 2011)</li> <li>• Method is easily reproducible (Nair et al 2011)</li> </ul>	<ul style="list-style-type: none"> <li>• Significant amount of time required from conducting the systematic review to multiple rounds of consensus (Nair et al 2011)</li> <li>• In person meeting is costly, may lead to time delay and opinionated individuals may dominate the group (Nair et al 2011)</li> <li>• Core panel must construct the clinical scenarios and analyse and interpret the results (Nair et al 2011)</li> <li>• Items are rated on a nine-point Likert scale which can be unwieldy (Nair et al 2011)</li> <li>• Expert panellists are required to vote on several (sometimes 1000+) case scenarios (Nair et al 2011)</li> </ul>

There are several methodological issues that need to be considered when using consensus methods (Jones and Hunter, 1995). The first is the selection of experts for the panel and the potential for bias. This can be resolved by using a different mix of participants in further panels. In addition, the question can be asked as to whether health professionals who are willing to participate in expert panels are representative of their colleagues. One study found no significant differences in participants and non-participant physicians. Another issue is whether the composition of the panel can affect the results (McKee et al., 1991). However, particular individuals are unlikely to have an impact on the group decision if there are enough participants (Murphy et al., 1998). Instead, it is recommended to recruit a representative sample, which will result in credibility and acceptance of the findings. The final issue is of measuring the accuracy of the answer that is obtained. It cannot be assumed that the answer found by consensus panels is 'correct' and it should be matched to observable events or scientific literature (Pill, 1971). These issues will be addressed in further sections.

### **Using the Delphi Method**

The Delphi has been found to be an effective way of gaining and measuring consensus in healthcare (Endacott et al., 1999, Keeney et al., 2001, Keeney et al., 2006, Skulmoski et al., 2007). It has been established as being an accurate way of establishing consensus among experts in a particular field. It is effective in the health care field where there will usually be an available group of experts in a specific area, and is appropriate when a large survey is not (de Meyrick, 2003). There is no clear evidence in favour of meeting based methods over the Delphi (Pill, 1971). While some critics state that the nominal group technique is superior, their specific differences are due to practical rather than theoretical difficulties with the technique. They agreed that the Delphi is the superior method of gaining consensus when experts are not

able to meet physically (Rowe and Wright, 1999). Mead and Moseley (2001) stated that the benefits of the Delphi overcome the limitations of other consensus methods such as the nominal group technique or consensus conferences (see 4.3.1).

The use of the Delphi in nursing can be linked back to a study by (Lindeman) in 1975 when it was used to determine nursing research priorities. Since the evidence based movement in healthcare and subsequent focus on the integration of the best available clinical evidence, the Delphi is highly relevant as it makes use of expert opinion where evidence is lacking. Mead (2001) states 'the Delphi starts where the evidence leaves off' (p. 10), while Crisp (1997) succinctly describes the philosophy of the Delphi "the underlying assumption of the Delphi is that  $n + 1$  heads are better than one, and the sum of potentially useful information from a group is at least as great as, but usually greater than that of any one individual" (p. 117). In addition, while the development of theory is not usually the objective of most Delphi research, it can be used to produce theoretically relevant research (Okoli and Pawlowski, 2004). In line with the pragmatic view of research, this means that Delphi studies can rapidly contribute to theory and practice, as health professionals will immediately have lists available to them of factors that have gained consensus in the study, and have been developed by experts in the field. In addition, the Delphi technique may promote change, as participants may be inspired to implement the changes that have been decided on in the study (Bowles, 1999).

### **Limitations of the Delphi Method**

Like any research method, there are limitations to the Delphi that must be addressed by the researcher. The limitations can be divided into five categories: participant selection, response rates and attrition, problems with data collection, problems with data analysis and the

accuracy of the findings. Issues related to each of the five categories and how they were addressed for this study will be examined below.

### **Participant selection**

The use of experts in the Delphi can be a source of bias as the formation of the panel can affect the results (Keeney et al., 2001, Nair et al., 2011, Jones and Hunter, 1995).

DeMeyrick (2003) suggested the idea that some participants who are too expert may be biased in coming up with, or considering new ideas. The issue of variable definitions of who is expert in the given field may also be an issue (Beech, 2001). Finally, often Delphi participants are not described in detail, and therefore the reader may be unsure who has developed consensus on the issue (Schneider and Whitehead, 2013).

### **Response rates and attrition of participants**

As a time commitment is required from participants of Delphi studies (de Meyrick, 2003), studies based on the Delphi may suffer from poor response rates (Beech, 2001), and variable attrition rates (Schneider and Whitehead, 2013, Beech, 2001), which may contribute to sample bias (Bowles 1999).

### **Data analysis**

The definition of consensus in Delphi is often inconsistent (Schneider and Whitehead, 2013, Beech, 2001). In fact, Crisp (1997) states that the definition of consensus is one of the most controversial aspects of the Delphi. Often researchers oversimplify the research problem to make answering easier for participants (de Meyrick, 2003). In addition, the iterative process does require some intervention by the researcher, who must reorder and reduce the data

somewhat. When done incorrectly, the statements can move away from the verbatim responses that they were originally based on (Green et al., 1999).

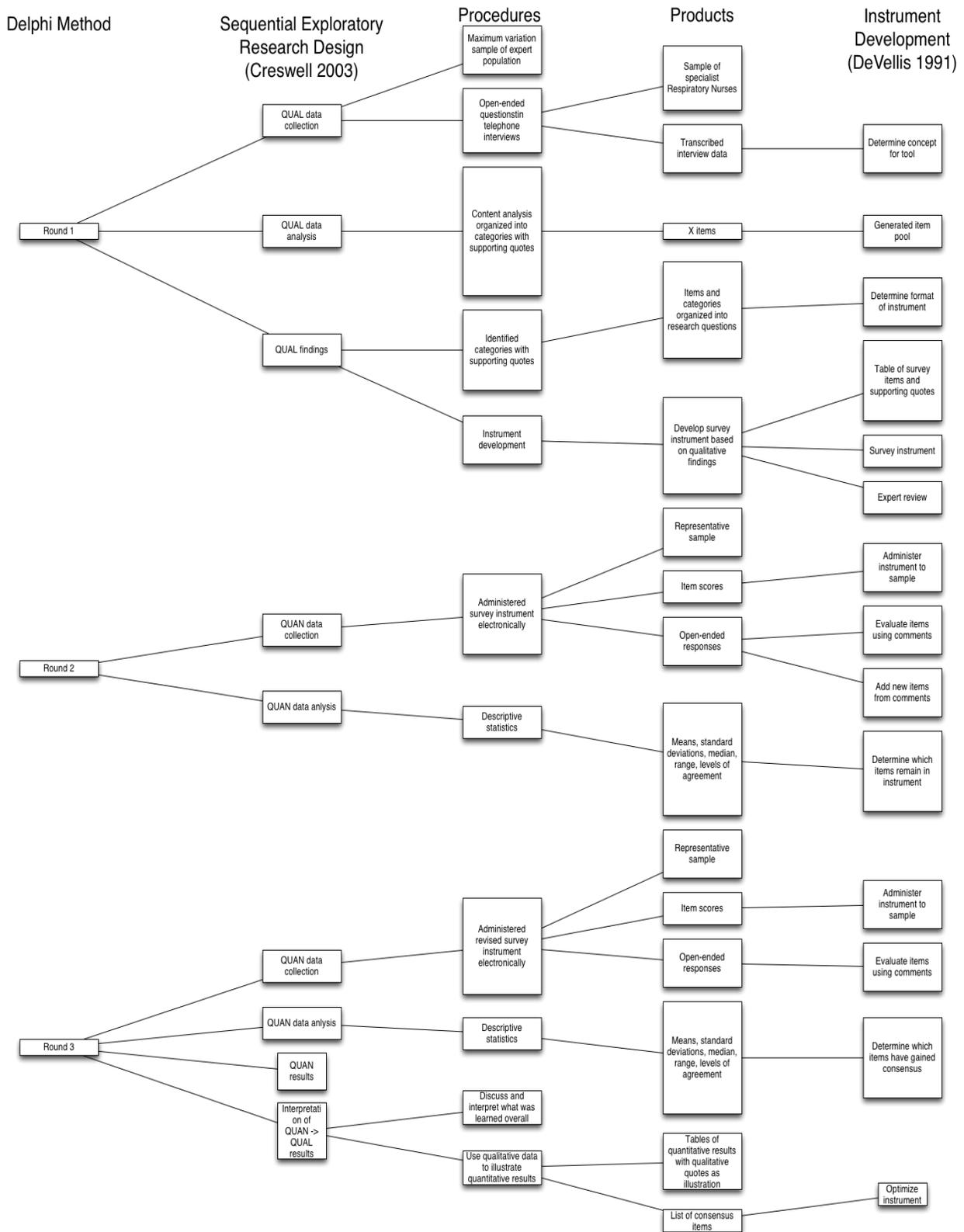
### **Accuracy of findings**

The findings of Delphi studies represent expert opinion, but are not indisputable fact (Schneider and Whitehead, 2013, Jones and Hunter, 1995). Methodological rigor will be ensured through the production of an audit trail of all theoretical, methodological and analytical decisions made throughout the research project. This will be achieved through the use of a journal to chronicle such decisions and thought processes. While Delphi studies have the potential to provide very valuable information, few researchers take steps after completion of the Delphi to support or refine their findings. This may be a threat to applicability or external validity of the results, therefore efforts must be made to match the results to observable events (Kennedy, 2004, Jones and Hunter, 1995). The way that these issues were approached in this study will be addressed in the sections that follow.

#### **4.4 Description of Delphi procedures in the UK and Canada**

In the following sections, the procedures for the Delphi studies conducted in the UK and Canada are described. The procedures for both studies were as similar as possible, however areas where there was some divergence are highlighted. The process of data collection and data analysis are explicated for each round of the Delphi studies. Due to the iterative nature of the Delphi, these procedures are best explained together by round rather than separately as may be traditional when reporting research methods. Figure 4.3 demonstrates how each stage of the Delphi aligns with the sequential exploratory design for instrument development.

**Figure 4.3 Parallel processes in the sequential exploratory design for instrument development**



#### **4.4.1 Round I**

Due to the gaps in the literature established in the systematic reviews, exploratory interviews rather than existing literature was deemed appropriate for the first round of the Delphi (Rowe and Wright, 1999, Kennedy, 2004). Exploratory interviews can provide in-depth understanding of a particular area, while also generating a framework for further research or improving the quality of survey design (Atkinson et al., 2000). Using interviews in the first round of the Delphi rather than a questionnaire can increase the return rates of questionnaires in the second round, thereby providing an additional advantage to using interviews in the first round (McKenna, 1994). Therefore, round I of the Delphi consisted of semi-structured telephone interviews with nine participants. Interviews took place during October and November, 2010. Each interview lasted between 20 to 40 minutes. Before starting the Delphi, each participant completed a demographic questionnaire and a consent form.

Developing questions for the initial round of data collection in the Delphi can be problematic as the researcher must not be too specific, thereby leading participants to certain answers, but structure is needed so that participants are clear on the information desired (Green et al., 1999). It is important to allow unstructured responses in the first round so that Delphi panel members can raise issues that they think are important, rather than responding only to what the researcher asks about. Therefore, the interview schedule (figure 4.2) was designed to give participants sufficient opportunity to share their thoughts on the topic (Rowe and Wright, 1999).

The questions for the interview arose from the author's interpretation of the literature including the systematic reviews in chapters 2 and 3. Participants were asked three primary questions: how they knew patients with NMRD were ready or willing to discuss end-of-life,

what are the key considerations in end-of-life discussions in NMRD and what are the key topics in end-of-life discussions in non-malignant respiratory disease? Each question was supported by a number of prompts available to the researcher. In addition, the interviewer asked if there was anything important that had not been covered at the end of each interview. The interview guide used in both Canadian and UK Delphi is displayed in Table 4.1.

**Table 4.1 Round I Delphi interview guide**

Interview guide questions
<ul style="list-style-type: none"><li>• Tell me about what your role entails in relation to end-of-life care? Discussions?</li><li>• Cast your mind back to your experiences discussing or not discussing end-of-life care with patients - how did the discussion come about and what happened, or why did you not bring up end-of-life care?</li><li>• Why didn't the discussion take place?</li><li>• What made it easier to have the discussion?</li><li>• How did you know the patient was ready to discuss?</li><li>• What were the clinical indicators/psychosocial indicators?</li><li>• How did your professional knowledge and experience contribute to the situation?</li><li>• What do you view as barriers to having end-of-life discussions with patients?</li><li>• What do you view as facilitators to having end-of-life discussions with patients?</li><li>• Based on everything you have told me today, what do you think are the key elements to end of life discussions</li></ul>

The interviews for the UK Delphi were conducted on the telephone, using a call recorder attachment for the digital voice recorder. Calls were recorded into sound files, which were then transcribed verbatim. The interviews for the Canadian Delphi were conducted using Skype to call telephone lines in Canada. Call recorder software was used to record these calls into sound files, which again were transcribed verbatim. Transcripts were entered into an NVivo database (2008) to be analysed. Using NVivo facilitates the exploration of many codes, groups and ability to sort the data. It also speeds up the manual process of analysing first round responses and enables data errors to be spotted quickly (Mead, 2001).

First, a content analysis was conducted on the interview data to extract all relevant content and organize the data by interview question (Endacott et al., 1999, Powell, 2003). Interviews were read first, and then during a second reading, content relevant to any of the interview questions was highlighted and coded in vivo. When conducting analysis of Delphi data it is important to use participants' own wording to enhance construct validity, while also minimize the potential for researcher bias (Endacott et al., 1999, Green et al., 1999, Hasson et al., 2000). While Mead (2001) cautions against categorizing the results to avoid producing an effect where respondents pay more attention to the categories than the individual statements, the researcher felt given the number of items that codes may help to organize the thinking of participants, and grouping items where possible may reduce fatigue from looking at a long list of items.

Items were organized by research question, and then by group into an online questionnaire for participants. The items and their groupings were reviewed by the researcher's supervisors to ensure that data were fairly presented before being sent to participants (Hasson et al., 2000).

#### **4.4.2 Round 2**

There were two aims of Round 2: 1) to present Round 1 items to all participants and allow them to rate each item, and 2) to give participants joining in Round 2 an opportunity to propose additional items. The questionnaire was designed to be completed online for the convenience of the study participants and due to the wide geographic spread of participants (Chang et al., 2010, Skulmoski et al., 2007). Surveys were designed using survey monkey <https://www.surveymonkey.com/> and participants were sent a link to each round of the Delphi via email. Participation was tracked using a spreadsheet in Google docs

([www.docs.google.com](http://www.docs.google.com)). Prior to data collection, the researcher informally investigated whether potential participants for the UK study were internet literate and were comfortable with online interaction. While not all health professionals are regular email users, the nurse manager confirmed that these participants were comfortable using online methods of communication.

Using online data collection can complement findings collected offline, and online research allows for a more representative sample, leading to potentially greater generalizability of results. In addition, using online methods to collect data will help to save money and will speed up the process in sequential mixed methods design (Hesse-Biber and Griffin, 2012). In addition to an online questionnaire, an identical paper questionnaire was also available for participants preferring this approach.

Participants were asked to indicate their agreement with each item on a 5-point Likert type scale, ranging from strongly agree to strongly disagree. They were provided with space to enter additional comments on each item and were encouraged at the end of each section to add any items that were not included in the list, for consideration in the next round.

The online questionnaire was tested by four people (two experienced supervisors, one respiratory consultant nurse, and one nurse manager) before being sent to participants in round 2 to ensure rigour (Hasson et al., 2000) and ease of use. Questionnaire testers were asked to evaluate whether the tool was clear, whether items needed further clarification, and to report the length of time they spent completing the questionnaire.

This process led to some re-wording in the biographical questionnaire, clarification of wording on several items in the questionnaire and some re-ordering of items. After this was

amended and approved by the director of studies, electronic access to the questionnaire was provided to participants. The paper version of the Round 2 questionnaire was also sent to the same four people for review to ensure consistency with the online questionnaire.

The questionnaires were as similar as possible, however, the online questionnaire required a response to each item, and participants would get an error message if they tried to proceed having skipped an item. This meant that no data were missing from the online group surveys, however the paper questionnaire yielded some missing data. Respondents did not report any technical difficulties with the online questionnaires.

Quantitative analysis of the Round 2 Delphi data included the following descriptive data analysis (Keeney et al., 2006, Holey et al., 2007):

- Percentage response rates for each item
- Percentages for each level of agreement (i.e. strongly disagree to strongly agree) for each statement to compensate for varying response rates between rounds and items
- Median and range
- Mean and standard deviation.

All of the items with a mean score of three or higher were included in the next round (Mead and Moseley, 2001). There are no specific rules regarding the cut off point for moving items to the next round, therefore, this decision was made because in most items there was relatively high agreement between panel members on most items, thereby indicating that items with a lower mean than three and a low level of agreement were unlikely to reach consensus.

Participants also used the additional comments areas to clarify items, amend the items and suggest new items for the Round 3 questionnaire (Okoli and Pawlowski, 2004).

#### **4.4.3 Round 3**

The goal of the third round was to enable participants to consider their opinions in light of the group response in Round 2 (Chang et al., 2010, Rowe and Wright, 1999). Therefore, the questionnaire was designed to include both the comments and the mean response from Round 2. Comments were not labelled so their author remained anonymous. There was also an opportunity to rank each item again, and provide comments. Mean scores from the previous round were provided, and were accompanied by their value label (e.g. agree or undecided) to provide meaning for participants as they had assigned a word in the previous round, not a value (Chang et al., 2010). As in the previous round, a testing process occurred for the round 3 questionnaire, where some concerns regarding formatting of the questions for the ease of understanding and responding were addressed.

This questionnaire was in similar format to that used in the previous round. Items that had been changed due to participant response in the previous round were labelled for participants. As with the previous round, participants were asked to rate each item on a 5-item Likert-type scale from 'strongly agree' to 'strongly disagree' and were provided with space to add additional comments on each item. Unlike the previous round, they were not asked to add additional items at the end of each section, as this was thought to be the final round of the Delphi, due to the high degree of agreement in the previous round. The scores for each item were entered into a SPSS database to calculate descriptive statistics as in the previous round.

Consensus for each individual item was determined based on:

- Items having an agreement (agree or strongly agree) level of 70 percent or more (Powell, 2003);
- Items having a median rating of 4 or above (Chang et al., 2010);
- Range level of items, 2 or less was considered to indicate strong agreement, but items with a higher range were still considered to have consensus if the percentage of agreement and the median were high enough (Holey et al., 2007).

While suggested by Holeý (2007) that Kappa values be used to determine agreement between rounds, Kappa values were not used to determine consensus for individual items due to the inherent problems with this statistic. After doing kappa calculations (both weighted and unweighted) on each item in the Delphi and consulting with a statistician, a fatal flaw in using this statistic was revealed. With a low n (number of participants), which is inherent to the Delphi, perfect agreement within may result in a kappa of 0 when it should actually be 1. The formula does not work when the sum of the expected values and the sum of the observed values are identical. Therefore, the kappa statistic was not used to calculate agreement on individual items in the Delphi.

#### **4.4.4 Tool Development**

Items that had gained consensus opinion in Round 3 of the Delphi were formatted into a tool to aid health professionals when having end-of-life discussions with patients who have NMRD. While the author had an approximate idea about the type of tool needed to address the needs of health professionals in this area, the final format of the tool was informed by the round one interviews and the existing literature. Figure 4.3 shows how the tool items were developed through each stage of the Delphi process and how the procedures of tool

development posited by DeVellis (1991) mirror the process of the sequential exploratory research design. The tool was divided into three sections: how do you know a patient is ready to discuss, key considerations in a discussion and key topics to discuss. Each section lists the items that reached a stable consensus in the Delphi study using the criteria set out by Holey (2007) in the Delphi study. The tools developed in each Delphi are presented in Chapters 5 and 6 in Figure 5.6 and Figure 6.6.

#### **4.5 Establishing clinical applicability of the tool**

The following sections explicate the tool endorsement procedure that was employed for the tools developed from the results of the Delphi studies conducted in Canada and the UK in order to establish clinical applicability of the tool.

While the Delphi is intended for exploratory research and can provide valuable information, it is important that this information be corroborated for validity of the results (Kennedy, 2004). Often, the process of following up on Delphi findings is forgotten due to the limited description of the panel, the imprecise measures of consensus or high attrition (Bowles, 1999). However, it is important to follow up with participants regarding the final consensus to determine applicability and credibility of the findings (Powell, 2003). In this study, it was also important to establish face validity of the instrument that was created, in order to be able to prepare for further development as described in section 8.4.1. Therefore, the final round of data collection was intended to establish the face validity of the tool, while also providing participants with an opportunity to view the results of the Delphi study and determine their applicability and credibility.

Participants were sent a questionnaire and asked to view a draft copy of the tool online. The questionnaire was conducted online with survey monkey, and the draft tool was created as a Google doc ([docs.google.com](https://docs.google.com)) to enable access to those with permission. Participants were asked to answer a short questionnaire about the tool, whether they agreed that it represented the views that they have provided in the Delphi study (Mead, 2001), and to determine whether the tool would be useful in clinical practice.

The questionnaire consisted of the following questions:

- Does this tool accurately reflect end-of-life discussions in NMRD
- How useful would the tool be in clinical practice?
- As an experienced practitioner, would you use this tool in your clinical practice?
- Do you think this tool would be useful to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease?
- Would you recommend this tool to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease?
- How might you use this tool in your clinical practice? (open ended)
- Is there anything that could be added or changed about this tool to make it more useful for clinical practice? (open ended).

The results of this process are reported in Chapters 5 and 6.

## 4.6 Comparison of Delphi Studies

As outlined in the introduction chapter, one aim of this study is to delineate the differences in end-of-life discussions for patients with NMRD in order to provide insight into the process. International comparisons in health care, and specifically end-of-life care, are not uncommon in the literature (Higginson, 2005, Janssen et al., 2011, Kirk et al., 2004).

There is great variation in the reasons for conducting international studies. Some examples include to compare outcomes between countries, to test interventions with different populations, to recruit more patients, or to develop international consensus about the management of a condition. Some international studies do not distinguish between findings from different countries, while others focus entirely on the comparison of these differences (Endacott et al., 2009).

There is a substantial body of literature indicating that comparison of practice across countries is an appropriate methodological approach. Janssen et al (2011) compared quality of patient-clinician communication about end-of-life care, and facilitators and barriers to communication in the USA and the Netherlands. To do this they compared survey data from outpatients with COPD in each country. Specifically they compared data from the Quality of Communication questionnaire and Barriers and Facilitators questionnaire. Overall they found that the quality of communication in end-of-life care needed to be improved in both countries, and that future research should examine international differences, as well as patient specific facilitators and barriers to such communication. Klinger et al. (2013) conducted an analysis of literature, policy documents and interviews with key informants to determine why many patients do not die at their preferred location in four countries: Canada, England, Germany, and the United States. They conducted a case study in each country and then used the cross-

country health policy analysis to make comparisons. Barriers to caring for the terminally ill were legislative, regulatory, financial issues, and public perception of end-of-life care. Facilitators were standards of practice and guidelines, an aging population, stable funding for hospice and palliative care and advance care planning. The authors concluded that the system level issues need to be addressed so that policy can be implemented as intended. In an effort to promote cross-national learning and collaboration, Blendon et al. (2003) carried out a survey in Australia, Canada, New Zealand, the UK and the United States looking at the experiences of sicker adults. The authors screened an initially random sample of adults to find non-institutionalized sicker adults, then 750 or more qualifying individuals in each country participated in a telephone structured survey. General findings were dissatisfaction in each country with the health care system, medical and medication errors, inadequate care coordination and poor patient-physician communication. Kirk et al. (2004) conducted a qualitative study with patients receiving palliative care for cancer and their families in Australia and Canada, exploring information sharing during their illness. They found the way that the communication process affects how patients and their families perceive information. They also found six requirements for sensitive information sharing: "playing it straight, staying the course, giving time, showing you care, making it clear and pacing information" (p.3). Junger et al. (2012) conducted an online Delphi study to understand palliative care delivery across Europe, with members of the European Association for Palliative Care. The expert consensus allowed clarification of issues needing attention such as definitions for end-of-life care, and the recognition of cultural aspects of care need to be recognized.

Comparing findings between countries is not without challenge. One issue mentioned by Bosch and Titus (2009) is the difficulty in comparing international datasets, when differences

in terminology and constructs need to be interpreted and may lead to bias. In addition, Endacott et al (2009) pointed out that factors specific to each country such as health care resources, epidemiology and culture should be highlighted during data comparisons.

Specifically, comparing the results of two Delphi studies is not common in the literature. To the author's knowledge, a comparison has only been carried out by Duffield (in 1993), and Kennedy (in 2000). Comparing Delphi studies can add validity to their findings (Duffield, 1993), and can result in interesting discussion regarding the similarities and differences between countries.

#### **4.6.1 Method of international comparison**

The process of examining differences in how health professionals know that patients with NMRD are ready or willing to discuss end-of-life was two-fold. First, a narrative comparison of the epidemiology of non-malignant respiratory disease, health systems in Canada and the UK and end-of-life care policies in each country was undertaken in the introduction chapter to provide context. Then, a comparison of the findings of the two Delphi studies conducted in Canada and the UK was carried out. As mentioned previously, there are few models for the comparison of Delphi studies as only two appear to exist in the literature. One is a PhD thesis by Kennedy (1999) and was not available at the time of writing. Some details of the study were available in (Kennedy, 2000), however the full details of the comparison were not provided. Briefly, Kennedy (1999) compared the results of a Delphi study with midwives to determine whether the consensus items were supported by the recipients of care.

Duffield (1993) provides an excellent model of how to compare Delphi studies. She tabulated the means from the final round for each item, and then discussed similarities and

differences. Then, items that were excluded by only one panel (12 items out of 168) were tabulated and discussed. This process led to the validation of the 93 percent of the items.

However, the present study differed from previous comparisons of Delphi studies as rather than presenting a list of competencies to participants to be evaluated, qualitative interviews were used to collect data in the first round. Therefore, there were likely to be many more differences between groups. In addition, the researcher needed to match items between panels that conveyed the same concept, but were described using different language due to the use of in vivo coding. Due to likely major differences between panels, the comparison will be narrative rather than statistical. It was not thought to be valuable to compare the means of the consensus items, as they would all have similar means due to reaching the predetermined level of consensus as discussed in 4.3.1. Therefore, the process of comparison of Delphi studies was as follows. Consensus items from each Delphi were matched like for like and listed in a table and divided by category as in the Delphi studies. The wording from each panel for each item was included to provide maximum transparency. Items that were not matched with a like item from the other panel were tabulated. Items that were excluded by one or both panels throughout the Delphi process were listed in a table.

As the reason for the comparison was to provide insight into the practices in each country, the interesting similarities and differences between the panels' findings will be considered during the development of the theoretical model in Chapter 7.

#### **4.7 Establishing rigour**

In mixed methods research, rigour is established by determining the trustworthiness of qualitative and quantitative data interpretations (Johnson and Onwuegbuzie, 2004, Creswell and

Plano Clark, 2007a). In a sequential exploratory design, the development and testing of a new instrument leads to more meaningful results for the entire study (Creswell and Plano Clark, 2007a). In the following two sections, the process of determining trustworthiness of qualitative data, and determining the validity and reliability of the quantitative data will be discussed. While the Delphi is believed to be inherently valid (Kennedy, 2004), the rigour of both qualitative and quantitative methods will be discussed. Finally, the rigour of the comparison of UK/Canadian data will be discussed.

#### **4.7.1 Establishing trustworthiness and dependability in qualitative research**

In qualitative research, it is important to assess trustworthiness - whether the data collected accurately represents the participants' experiences (Lincoln and Guba, 1985). Two methods of establishing trustworthiness in qualitative research are inherent in the Delphi - member checking and triangulation. Member checking, where the findings are shown to participants to check whether they are an accurate representation of their experiences (Creswell, 1998), is achieved as qualitative data collected in the first round is developed into an instrument that is then viewed by the same participants. In addition, triangulation of data from several participants through the development of consensus demonstrates trustworthiness of the data that has been collected (Creswell, 1998).

The maximum variation sampling strategy used to recruit participants for the qualitative phase of the Delphi also helped to establish the trustworthiness of the study by resulting in a sample that was both geographically diverse and varied in experience. The sampling strategy is described in section 4.8.1.

In addition, the use of the Delphi, meant that participants were able to share their experiences and expertise in an anonymous environment, where they were able to express their opinions without the influence of other group members who could be potentially dominating, as described in section 4.8.1.

#### **4.7.2 Establishing validity and reliability**

Validation is built into the mixed methods sequential exploratory design for instrument development as qualitative responses are given back to participants in quantitative form to reconsider, thereby enhancing the accuracy of the data (Creswell, 2003). Meanwhile, the Delphi is inherently valid as the contents of the study are dictated by the expert panellists. The use of participants who have knowledge and an interest in the topic will help to ensure the content validity of the Delphi, and the use of successive rounds of the questionnaire helps to establish face validity (Goodman, 1987, Beech, 2001, Sharkey and Sharples, 2001). Decisions to include items in the final consensus opinion are strengthened by reasoned argument in which assumptions are challenged, thus helping to enhance validity of the method (Hasson et al., 2000).

An early study was conducted on the Delphi at RAND to compare the Delphi process to another group making decisions without feedback in between. The authors found that it was the reconsideration of the questions between rounds in both groups fostered convergence over time. In addition, a sharper consensus was obtained by the Delphi group, and that their process was more efficient, however the accuracy of the judgement was no different with the control group (Brown, 1968).

There is no evidence of reliability of the Delphi, as it is impossible to determine whether two groups of experts would develop the exact same results. However, the reliability of the

instrument produced by using the Delphi may be determined using Cronbach's Alpha for internal consistency if the sample size is large enough (Nunnally and Bernstein, 1994, p. 228).

This process was undertaken and the results are presented in chapters 5 and 6.

Holey et al. (2007) recommend the use of the mean and standard deviation statistics for each item, combined with the range and median descriptive statistics to demonstrate whether convergence has occurred. As was discussed in section 4.4.3. It is mentioned here as it is believed that the use of these simple statistics can demonstrate maximum stability and reduce subjectivity.

The process of comparing the UK and Canadian Delphi panel results may help to establish validity in this study. As mentioned previously, authors of two known studies have compared results of two Delphi panels. In the first, Duffield (1993) used a validation study to compare the findings of two Delphi panels. There was 93 percent agreement between the panels, suggesting the validity of the first panel's findings. Authors of the second comparison study looked at codes from a narrative phase and the Delphi phase of the study and found congruence between the two (Kennedy, 2000). These findings suggest not only that congruence may be found between the UK and Canadian panels in the present research, but also that the Delphi produces valid results.

#### **4.8 Study Participants**

The following section outlines how study participants were selected to take part in both the Canadian and UK Delphi studies. First, the sample design is described, then the concept of expert, which is central to the Delphi, is discussed, next the recruitment procedures are outlined and finally the number of participants is examined.

#### **4.8.1 Sample design**

In order to best address the research question, decisions were made about which individuals could provide the best information. In qualitative research individuals are purposefully selected based on their ability to provide the best information, whereas, in quantitative research, where generalisability of results is paramount, individuals are chosen in order to best represent the population being studied. As the first stage of this mixed methods study was qualitative, the qualitative approach to sampling was taken here. Two types of purposive sampling have been employed in this study: maximum variation and criterion. The issues related to this approach are discussed in the sections that follow.

Maximum variation sampling is ideal in a qualitative study as it enables the researcher to gain the views of a range of participants and identify cases that can provide meaningful information, thereby gaining rich data from a small number of cases (Patton, 1990, Patton, 2005, Corbin and Strauss, 1990). As discussed previously, using a panel of experts ensures high content, face-to-face and concurrent validity (Sharkey and Sharples, 2001, Beech, 2001).

The concept of expert is central to the Delphi, as selecting experts in the field of inquiry rather than a random sample of individuals will result in significantly better and considerably different responses than those of non-experts (Goodman, 1987). The expert in a Delphi study can be defined in various ways, such as knowledge defined by professional qualification or registration as a certain group or by a predefined number of years of experience (Baker et al., 2006). Therefore, the expert groups often consist of informed individuals who are specialists in their field or people with knowledge on a particular subject (Keeney et al., 2001). Keeney (2001) stated that the commitment of participants to participating in the Delphi study is directly

related to their interest in the research question. Those who are willing to discuss the issue are likely to be affected by the results of the study.

As discussed previously, one of the key features of Delphi is iteration, and participants must be questioned several times about the same topic. Therefore, it is important that participants are able to maintain involvement throughout the study. Attrition is a known problem with Delphi studies, and it may contribute to sample bias (Polit and Hungler, 1999, Bowles, 1999). As the purpose of the quantitative stage is to validate the qualitative data, it is inherent in the Delphi that participants are involved in all phases of the data collection. As with any multi-phase study, some participant drop out is to be expected (Beech, 2001).

Keeney (2001) stated that decisions about the size of the sample as well as heterogeneity in Delphi studies should be made, based on the purpose of the project, the research design and the time frame. The primary assumption of the Delphi is that the sum of information that comes from a group is as great or but usually greater than the sum of potentially useful information from one individual (Crisp et al., 1997). It is stated in the literature that there is little empirical evidence that the number of participants in a Delphi study affects the reliability or validity of the process (Murphy et al., 1998, Rowe and Wright, 1999); representativeness of the group is more important than size (Powell, 2003). However, other authors do state limits on participant numbers. Baker (2006) stated that Delphi studies should have no more than 20 participants, and as the sample size is not based on a statistical calculation, and previous studies using the Delphi in healthcare used as few as 12-15 respondents (Downar & Hawryluck, 2010; Fiander & Burns, 1998).

Members of different disciplines are rarely included on one Delphi panel, and therefore the range of professionals included in the Canadian Delphi, and the comparison between the Canadian and UK studies is unique (Baker et al., 2006).

### **Round 1 sampling method**

The first round of the Delphi was conducted using telephone interviews. For this round only a maximum variation sampling strategy was used to select participants who had already been recruited to participate in the first round. A lack of representativeness in qualitative research can threaten validity, and therefore the maximum variation sampling strategy is important for the integrity of the study (Morse, 1991). It was anticipated that approximately 8-15 people would participate in the first round, until data saturation had been reached. This strategy was used to ensure that issues from the spectrum of experience that respiratory health professionals have were captured in the study. This sample of participants also participated in subsequent rounds of data collection. Of eleven participants who consented to the Delphi before round 1 began, nine were selected to be interviewed for the first round. Selection was based on their geographic location and work setting to achieve a maximum variation sample (Patton, 2005).

### **Round 2-4 sampling method**

The purposive sampling method, specifically criterion sampling, has influenced the choice of experts. British Lung Foundation nurses were chosen to participate (see inclusion criteria below) based on their experience with the research problem being explored as well as their geographic location (Creswell and Plano Clark, 2007a, Keeney et al., 2006).

## **Inclusion and exclusion criteria**

In the past, Delphi panels have been criticised as the health care 'experts' are not close enough to the realities of clinical practice to provide useful feedback (Baker et al., 2006). The members of both Delphi panels were all currently in clinical practice with the patient group that we wished to study. Meier (2010) stated that nurses are well suited to participate in end-of-life care research as they see the patient 'even when other health professionals have disappeared'. The inclusion and exclusion criteria for members of both the UK and Canadian Delphi studies are below.

### **Inclusion and exclusion criteria in the UK Delphi**

Individuals were included if they were Specialist Respiratory Nurses working in the NHS, whose posts were funded in part or in whole by the British Lung Foundation (BLF). A badged nurse is an existing respiratory nurse specialist and the main benefit badging offers to nurses and their Primary Care Trust (PCT) is the opportunity to work in partnership with a voluntary organisation. The contracts signed with PCTs for badged nurses are generally for 3 years with an option to extend, and commit the BLF to the provision of study days, uniforms and the other benefits. In order to achieve BLF status for their role, these nurses had to demonstrate a level of expertise in respiratory nursing, hence this was considered a useful proxy for expertise in this Delphi study. Specialist respiratory nurses who were not employed by the BLF were not eligible to participate in the study.

### **Inclusion and exclusion criteria in the Canadian Delphi**

Individuals were included if they were members of the professional arm of the Canadian Lung Association - the Canadian Respiratory Health Professionals (CRHP). The CRHP group

aims to engage health care professionals and provide national leadership to achieve the promotion of lung health, prevention of lung disease and the management of lung disease (2013).

Members of the CRHP must be members in good standing of a recognised clinically based discipline (e.g. nurses, physiotherapists, respiratory therapists, pharmacists, dieticians, occupational therapists, social workers) and have a primary role in education, patient care, research or management in respiratory care. They must be a Canadian citizen or a landed immigrant and have an interest in the prevention, management, treatment, research or surveillance of respiratory disease. Registration with this group was considered to be a proxy for expertise discussing end-of-life and was therefore sufficient for inclusion in the Delphi panel. Unlike the UK, where specialist respiratory nurses do the majority of work with respiratory patients, in Canada, respiratory care is provided by a wide range of professionals working together, often in multi-disciplinary teams (Canadian Lung Association, 2008). Respiratory health professionals who were not members of CRHP were not eligible to participate.

#### **4.8.2 Limitations of the sampling strategy**

While it is important to involve service users in research, including them in a Delphi study alongside professionals can be difficult as they may not feel credible within this group (Baker et al., 2006). As one of the aims of the study was to establish how health professionals know a patient with NMRD is ready or willing to discuss end-of-life, the opinions of service users were not featured in this study. A separate study to look at ready or willingness to discuss end-of-life from the perspective of patients and carers could be designed to follow this study.

## **4.9 Recruitment procedures**

In this section the process of recruiting participants for both the UK and Canadian Delphi studies is presented, together with some limitations of the recruitment process.

### **4.9.1 Recruitment of participants in the UK**

In order to gain access to participants, the BLF granted access to their population of nurses to approach for recruitment into the study. Approximately 40-50 people were provided with information about the study. Recruitment took place via the BLF staff email communication system and the staff website. Personal information was not collected at this time. It was estimated that approximately 40 people would volunteer to participate. However, it was considered that if a lower number consented to take part, it would not affect the results of the study.

Potential participants were informed by reading the study information sheet that they might be asked to be interviewed for the first round of data collection before the online survey component began, and that if they wished to participate they could still decline to be interviewed. To prevent attrition in Delphi studies, it is important for the researcher to clearly outline what is involved in each stage of the Delphi (Mead, 2001). The initial recruitment phase took place from September to November 2010, and a total of 11 nurses indicated interest in participating. Recruitment was conducted by sending study information to the nurse manager, who sent it out to all of the BLF Nurses via email. The researcher also attended the BLF nurse study day to recruit participants in person and an additional eight participants joined. In total, 19 participants completed the consent process; nine agreed to be interviewed and eleven agreed to complete the online questionnaires.

#### **4.9.2 Recruitment of Participants in Canada**

Potential participants received information about the study from the monthly e-newsletter sent out to members of the Canadian Respiratory Health Professionals group. The newsletter included a link for interested parties to provide contact information to the researcher. Once contact information was received from a potential participant, an email including an attached information sheet and link to the online consent form was sent. The initial period of recruitment took place from August to October 2011, and 19 people requested further information about the study. In total, 14 participants consented, and 11 were selected to be interviewed based on their geographic location, professional designation and work setting to achieve a maximum variation sample (Patton, 2005).

#### **4.9.3 Limitations of the recruitment procedure**

As participants were recruited through their professional associations and not directly by the researcher, non-participants were not followed up, as the researcher did not have access to their contact information. Participants that initially expressed interest by filling out the interest form for the study were contacted several times regarding participation. The researcher stopped attempting to contact them after three emails.

#### **4.10 Ethical Issues**

This section includes a discussion of ethical principles in research and information about ethical approval of both Delphi studies. This is followed by descriptions of the relevant ethical principles of confidentiality and anonymity, informed consent and the risks, burdens and benefits of participating in research and how they were addressed in this study.

#### **4.10.1 Ethical principles in research**

The conduct in this study was guided by the guidelines for ethical conduct in research set out by the National Health Service Health Research Authority. Ethical approval of both UK and Canadian Delphi studies was received from the Plymouth University Faculty of Health Ethics Committee and the UK Delphi study was approved by the National Research Ethics Service South West 4 Research Ethics Committee (REC reference: 10/H0102/11) in 2010 (letters of approval are presented in Appendix B). In Canada, the chair of the research committee of the CRHP agreed that the approval of the Plymouth University Faculty of Health Ethics Committee was sufficient to conduct the Canadian Delphi study. Therefore, further ethical approval was not sought from a Canadian institution.

The ethical issues that were relevant to the conduct of this study were confidentiality and anonymity, informed consent, and the risks, burdens and benefits to participants. These issues will be addressed below.

#### **Confidentiality/anonymity**

The Caldicott Principles were followed to ensure the maximum level of confidentiality (Department of Health, 1997). True anonymity is ensured when no one can link a response to a respondent. Due to the iterative process inherent in the Delphi technique, true anonymity could not be achieved. While an individual's responses were not identifiable to other participants, they were known to the researcher (Keeney et al., 2006). This has been termed 'quasi-anonymity' (McKenna, 1994).

Personal (job, experience, and qualification information) information was only used to determine whether the person met the inclusion criteria and could participate in the study.

Access to this identifiable information was restricted to the researcher and her supervisory team. The respondent names were disassociated from their responses during the coding and recording process. As an additional precaution, data transmitted from participants via survey monkey was done over a secure website and encrypted using SSL, 128 bit encryption technology, thereby minimising the risk of submitting personal information over the internet. Direct quotations from respondents from Delphi Round I were published in this thesis, however any identifiable information has been removed. Data from the online survey were printed and will be kept in paper form along with printed copies of the electronic consent forms for seven years in a locked cabinet in the director of studies' office, in adherence with the Plymouth University data protection policy.

### **Informed consent**

Potential participants were provided with a written information sheet (prepared according to guidelines outlined by the National Research Ethics Service (UK)) prior to consenting to the study. As the recruitment process was executed electronically, this information sheet was provided as an attachment to an email. Participants were also invited to visit the study website, where they were invited to contact the researcher to discuss participation.

When participants stated that they would like to participate, they were directed to the survey website, where consent was taken electronically, following the guidelines for taking informed consent from adult participants. All potential participants were provided with an electronic information sheet and were given a minimum of 24 hours to consider participation prior to electronic consent being sought. In addition, paper copies the information sheet and the consent forms were made available upon request.

When respondents agreed to participate, they were informed of exactly what they would be asked to do, using written information that accompanied each online questionnaire. Hasson, Keeney and McKenna (2000) recommend that participants have an understanding of the aims of the study as well as the process, in order to build a research relationship which may be helpful in maintaining participation throughout the Delphi. Therefore, this information accompanied each round of the online questionnaire.

### **Risks, burdens and benefits**

Each participant received a series of three surveys to complete online over a period of approximately six months. As described above, the responses were confidential and anonymous to other participants, but the respondent's identity was known to the researcher. Due to the iterative nature of the Delphi process, participants were not able to withdraw their data from the study after it was submitted online.

Respondents were informed that they might find aspects of the interview and surveys to be distressing due to the sensitive nature of end-of-life discussions with patients. To minimise this risk, respondents were informed of the sensitive nature of the topic in the patient information sheet. Furthermore, they were informed that contact details of local support services were available to them, should they request it at any time during the study. Specialist respiratory nurses are busy health professionals and therefore to minimise interference with their professional and private lives, the online format of the survey allowed them to complete it at a convenient time.

In addition, checking the accuracy of the data or member checking is inherent in the iterative design of the Delphi. As part of the Delphi, data were analysed and sent back to participants to ensure that their views were accurately represented and interpreted.

Potential benefits to taking part included the opportunity to anonymously share thoughts with colleagues about end-of-life discussions. In addition, respondents may have come to have a better understanding of the Delphi process, which may later inform their own research work.

#### **4.11 Conclusions**

The research design and methods considered in this chapter demonstrate that the sequential exploratory mixed methods design for instrument development was most appropriate given the lack of literature on the topic (established in the systematic reviews in Chapters 2 and 3), to address how health professionals know a patient is ready or willing to discuss end-of-life, and to establish a tool to aid them in this discussion. This research design employed the Delphi, which was justified after a critique of alternate consensus methods was presented. Finally, a method used to compare the UK and Canadian Delphi studies was discussed.

The findings of the Delphi studies conducted in the UK and Canada will be presented in chapters five and six. These chapters will include the tool that resulted from each Delphi process. The UK and Canadian Delphi studies will then be compared in chapter seven.

The narrative comparison of Delphi results from the UK and Canada can be found in Chapter 7. The findings from each stage of the research discussed here will be developed into a model of end-of-life discussions in NMRD, which will be presented in section 8.2.1.

## **Chapter 5. A modified Delphi study with specialist respiratory nurses in the UK**

### **5.1 Introduction**

The objectives of this phase of the study were to use the Delphi to establish how health professionals in the UK know a patient with NMRD is ready or willing to discuss end-of-life and the key considerations and topics for such discussions. This is in line with objectives one and two of the doctoral study as listed in 1.5. The findings of this Delphi study address the first aim of the study (to determine how health professionals discuss end-of-life with patients with NMRD) and facilitate the achievement of the second aim (to develop an instrument allowing health professionals to determine constraints and opportunities within the environment to facilitate successful end-of-life discussions with this patient group).

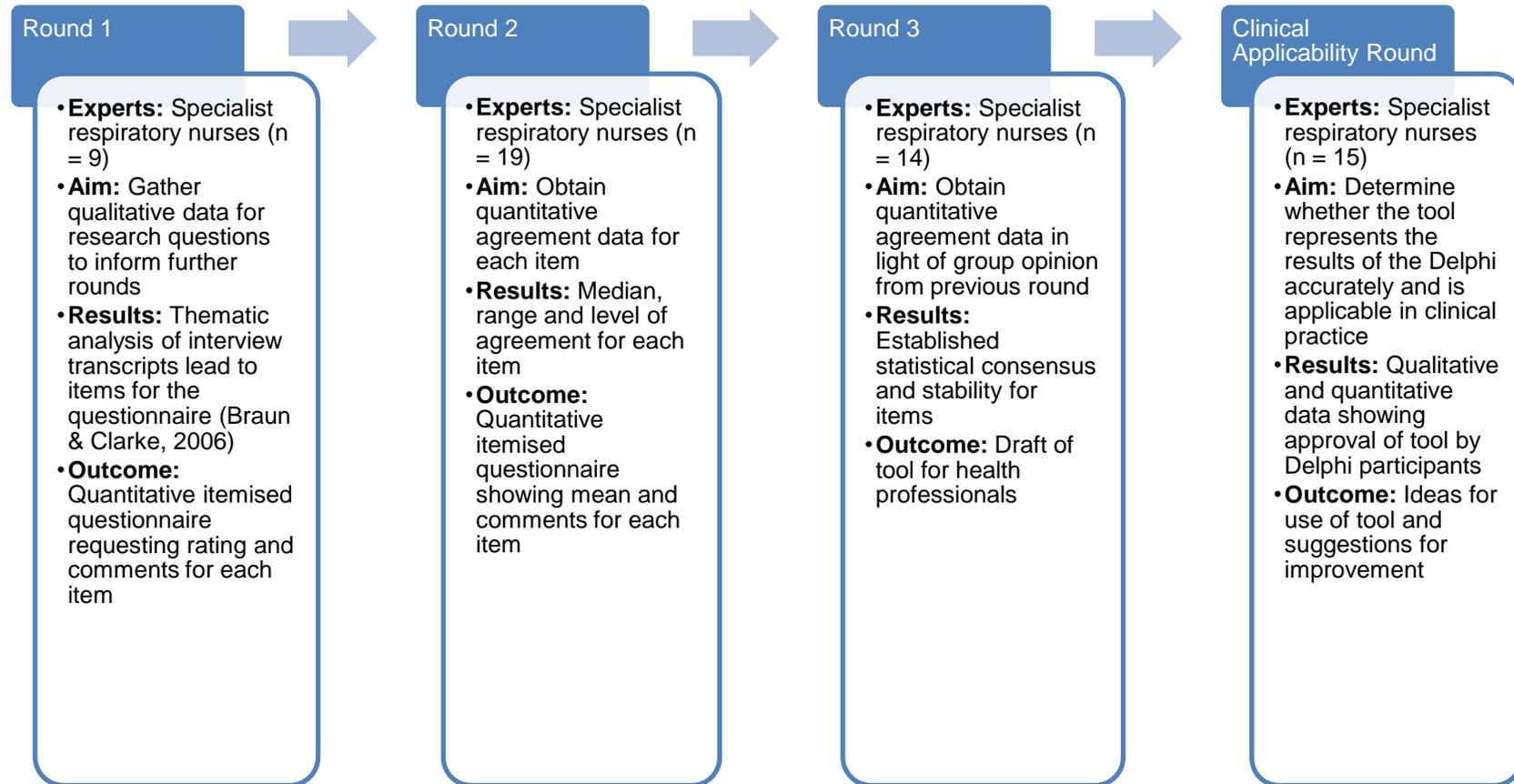
As described in Chapter 4, this Delphi study consisted of one round of qualitative interviews, and three rounds of online questionnaires, and was a 'mixed methods' study (Bowles, 1999). A summary of this process can be found in Figure 5.1. The study was designed to answer three questions as per the objectives of the doctoral study (section 1.4): 1) How do health professionals know a patient is ready or willing to discuss end-of-life?; 2) What are the key considerations in end-of-life discussions with patients with NMRD?; 3) What are the topic areas that need to be addressed in such discussions?

In line with the MRC guidelines for the development of a complex intervention (1.6), the Delphi process resulted in the development of a tool for use by health care professionals in end-of-life discussions for patients with NMRD. The tool summarises the findings of each of the three questions that the study was designed to answer, and once the tool was developed, a

fourth and final questionnaire went to participants to ascertain its usefulness and applicability (Mead and Moseley, 2001).

A description of the recruitment procedures and the participants is included in 5.2. Next, in the findings for each round of the Delphi, as well as a discussion of how this process resulted in the development of the tool described above are presented. Finally, conclusions are made in 5.9. A discussion of how the results of this Delphi study contributed to the development of theory and modelling of the process of end-of-life discussions in NMRD can be found in Chapter 7.

Figure 5.1 UK Delphi overview diagram.

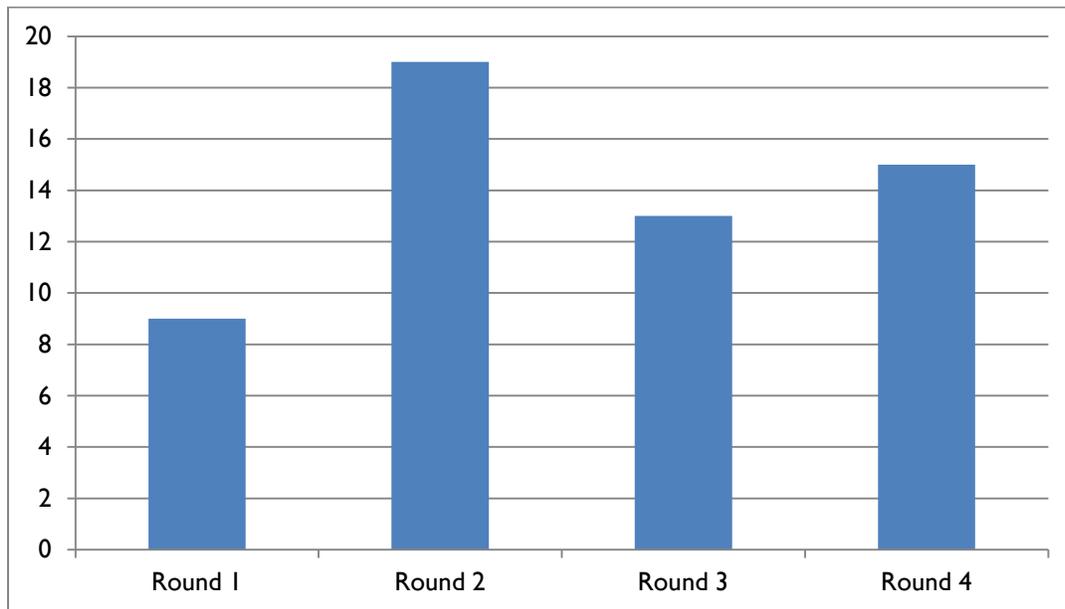


## **5.2 Recruitment and participants**

The purposive sample for this Delphi study consisted of Specialist Respiratory Nurses working in the NHS, whose posts were funded in part or in whole by the British Lung Foundation (BLF). In order to achieve BLF status for their role, these nurses have to demonstrate a level of expertise in respiratory nursing; hence this was considered a useful proxy for expertise in this Delphi study (section 4.8).

Nineteen of a possible forty-five nurses participated in the study, achieving a response rate of 42 percent. The BLF nurse manager considered this a low response rate caused by uncertain conditions in the NHS, mainly job insecurity and understaffing (Jackson 2010). However, the validity of the study was not affected as the number (n=19) is within the ideal number of Delphi participants (Bowles, 1999, Okoli and Pawlowski, 2004, Baker et al., 2006). This issue is addressed in detail in section 4.3.1 and Figure 5.2 shows the number of participants for each round of the Delphi.

**Figure 5.2 UK Delphi participants by round**



The initial recruitment phase took place from September to November 2010, and a total of 11 nurses indicated interest in participating. Recruitment was conducted by sending study information to the nurse manager, who sent it to all BLF Nurses via email. The researcher also attended the BLF nurse study day, to recruit participants in person where an additional eight participants joined. In total, 19 participants completed the consent process, and nine of these people agreed to be interviewed, the remaining 10 consented participants agreed only to complete the online questionnaires.

Of 11 participants who consented to the Delphi before Round 1 began, only nine were selected to be interviewed for the first round: selection for interview was based on their geographic location and work setting to achieve a maximum variation sample (Patton, 2005), as described in section 4.8.1. Demographic details of the participants are provided in Table 5.1.

In the first round of semi-structured interviews, data saturation was reached after nine interviews. Participants who were interviewed for Round 1 (n=9) had a similar demographic

profile to the whole Delphi participant panel (n=19) as shown in Table 5.1. In the following sections, quotes from participants have been anonymised, and assigned a code denoting the country of origin (UK) and a participant number.

**Table 5.1 UK Delphi participant demographic information.**

		<u>Round 1</u>		<u>Rounds 2-4</u>	
		<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
Sex (f)		9		19	
UK Region					
	East Midlands	1	11	1	5
	London	1	11	4	21
	North East	1	11	1	5
	North West	2	22	3	16
	Scotland	2	22	2	11
	South East			1	5
	South West	1	11	3	16
	Wales	1	11	1	5
	Yorkshire			3	16
Education					
	Diploma	2	22	5	26
	Bachelor's	5	55	9	47
	Master's			1	5
	Unknown	2	22	4	21
Age					
	30-39	2	22	5	26
	40-49	6	66	12	63
	50-59	1	11	1	5
	60-65			1	5
Professional Designation					
RGN		9	100	19	100
Professional Role (all that apply)					
	Practitioner	8	88	18	95
	Manager	2	22	3	16
	Educator			1	5
Work Setting					
	Community	6	66	13	68
	Primary Care Trust	3	33	6	32
Years in respiratory health					
	1-3	2	11	3	17
	4-10	2	11	2	11
	11-15	2	11	3	17

	Round 1		Rounds 2-4	
16-19			2	11
20+	5	44	8	44

### 5.3 Round 1 Findings

Thematic analysis of the interview data was guided by the three questions: 1) How do health professionals know a patient is ready or willing to discuss end-of-life?; 2) What are the key considerations in end-of-life discussions in NMRD?; 3) What are the topic areas that need to be addressed in such discussions in line with the objectives of the doctoral study (section 1.5). Specifically, seven items were generated for Question 1, 36 items for Question 2, and 28 items for Question 3. Unlike a typical thematic analysis where only items that were mentioned by more than one participant would be included in the findings (Braun and Clarke, 2006), in this study, all items that were mentioned in the interviews, even by only one participant, were included for consideration by participants in Round 2, and will be described below. Each of the three research questions was a question for the Round 2 survey.

#### 5.3.1 Question 1: How participants knew a patient was ready to discuss end-of-life

Participants were asked directly how they knew a patient was ready or willing to discuss end-of-life. This question was met with a variety of responses, which were grouped into five themes:

- Intuition of nurses
- Body language and patient demeanour
- Clinical indicators
- Verbal cues from the patient
- Response when health professional alludes to end-of-life topic.

## **Intuition of nurses**

Six participants mentioned their use of intuition when negotiating end-of-life discussions. However the word 'intuition' was not always used to describe this phenomenon; it was sometimes referred to as 'just knowing' that the patient was ready to have the discussion; for example, one participant said:

*'there are numbers of patients that I know want to talk, intuition tells me' (UK8).*

In other cases, participants used cues coming directly from their patients to determine readiness to discuss.

## **Body language and patient demeanour**

The body language of the patient was used by participants to determine whether to broach an end-of-life discussion:

*'Some people... just looking... withdraw into their self, or other times ... their body language is quite open.' (UK5).*

Another participant linked body language and the demeanour of the patient to gauge whether or not a patient was ready to discuss:

*'I know by the language they use, by their body language, by their general demeanour. You just know. You just know whether that's a conversation that needs to go further or whether they don't want to go any further with it at that moment, and sometimes they do. Sometimes, people start a discussion about end of life and then realise they can't go any further. So it's picking up the cues, picking up and listening to what they say and respecting... and I mean it's experience I think. Good communication.' (UK8).*

## **Clinical indicators**

One participant outlined in detail the clinical indicators that she and her colleagues used to determine when a patient had reached a stage in their illness when such discussions were appropriate:

*'Well, obviously they've got to be on... we have some clinical indicators that we use....So, poor prognostic factors. So, through spirometry they've got severe COPD, that they've had above three acute exacerbations in the last 12 months, that they have possibly respiratory failure or...that they're on maximum inhaled therapy, whether it be inhaler or nebulised therapy, where they've got a presence of any co-morbidities, especially obviously heart failure. They've been reviewed by a consultant and all surgical options have been explored and you know the most crucial question, would you be surprised if they passed away in the last... in the next 6 to 12 months.'*(UK7)

The use of these indicators was mentioned by eight participants to explain how they knew from a clinical perspective that a patient was ready to discuss end-of-life.

## **Verbal cues from the patient**

Some participants stated that they only knew patients were ready to discuss the end-of-life topic when patients themselves initiated the discussion; specifically, by asking 'am I going to die?'

### **Patient is responsive when the health professional alludes to end-of-life topic**

Some participants indirectly prompted the end-of-life discussion; for example,

*'...quite often it can be prompted, particularly if they've had an episode into the hospital and they've maybe had some treatment that they've maybe not liked.'* (UK9).

These indicators can be divided into two groups: indicators that the patient is *ready* to discuss end-of-life, and indicators that the patient is *willing* to discuss end-of-life.

#### Readiness to discuss end-of-life

- Intuition of nurses
- Patient is responsive when HP alludes to the end-of-life topic
- Clinical indicators
- Body language and general demeanour

#### Willingness to discuss end-of-life:

- Verbal cues from the patient

The distinction between cues indicating readiness and cues indicating willingness was unexpected as the wording of the question was not meant to indicate two separate concepts. However, this is potentially important to the development of theory as part of the tool development process, and as such is discussed in detail in section 8.2.2.

The above themes were transformed into items for the round 2 survey. Participants were asked ‘Which of the following factors indicate that a patient is ready or willing to discuss end-of-life?’ to ensure that both paths toward end-of-life communication were considered. They were given the following options:

- Clinical signs
- Professional intuition
- Cues from the patient such as stating ‘I do not want to go back to hospital’
- Questions from the patient such as asking if s/he is going to die

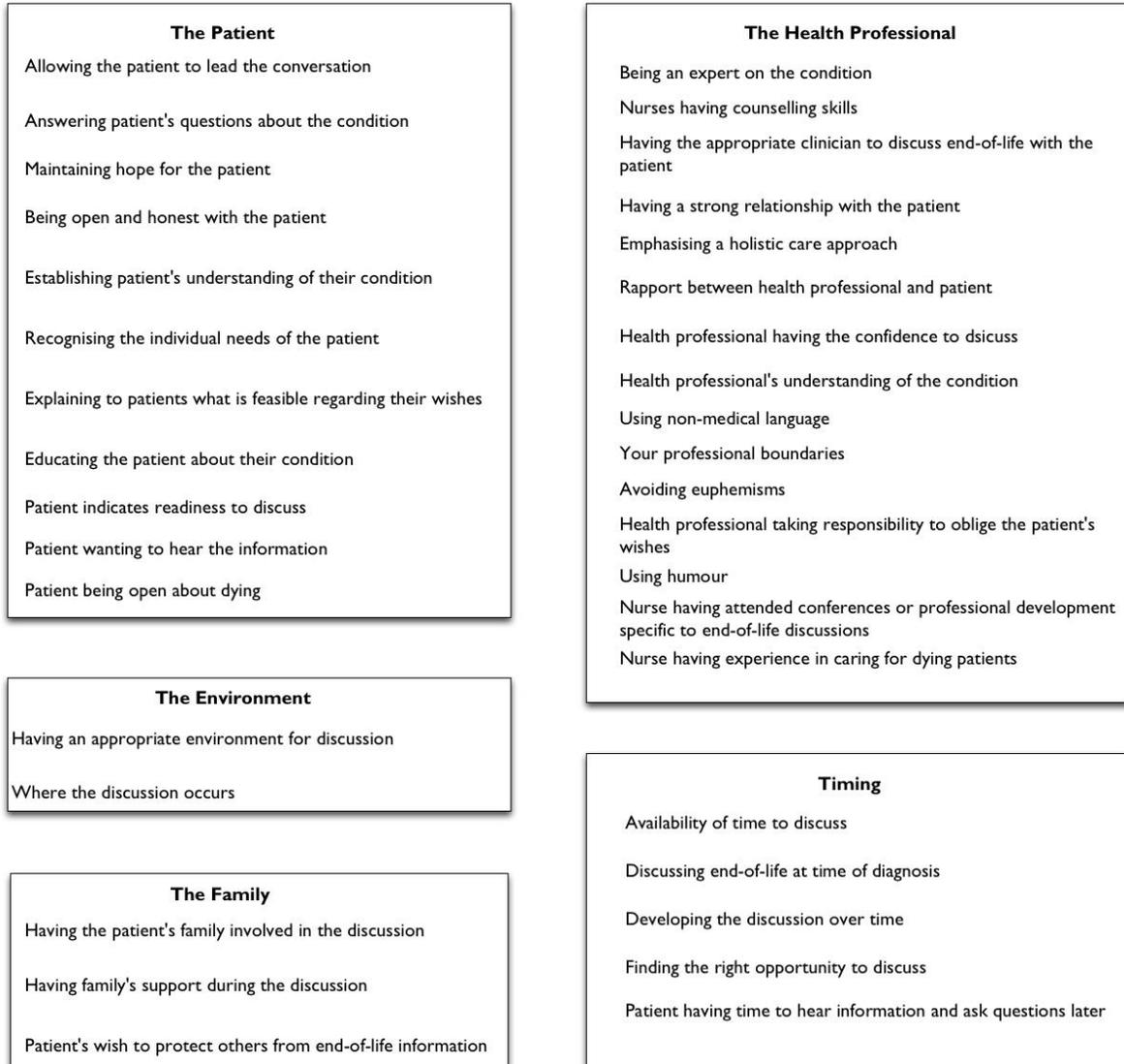
- Body language
- General patient demeanour

Patient is responsive when health-care professional alludes to the end-of-life topic.

### **5.3.2 Question 2: Key considerations in end-of-life discussions**

Participants stated 36 unique items that were categorised into five themes: the patient, the environment, the family, the health professional and timing. These themes and the considerations within each are presented in Figure 5.3.

**Figure 5.3 Themes and categories of key considerations in end-of-life discussions.**



As there are many items in these themes, examples are presented in Figure 5.4 below. Further data are presented in Appendix C. Further clarification or explanation of items was sought using comments in further rounds.

**Figure 5.4 Key considerations when discussing end-of-life: samples from Round 1 of the UK Delphi**

Allowing the patient to lead the conversation	<ul style="list-style-type: none"><li>• ...not just talking to the patient but get... make it a two way conversation and just take guidance from the patient, don't dictate, feel from them. (UK7)</li></ul>
Recognising the individual needs of the patient	<ul style="list-style-type: none"><li>• ...everybody's individual you deal with it you know as you think your relationship with that patient... I don't know quite what the words are, to... each individual will do it slightly differently, or will want something slightly different, so you pick and run with it as it's presented to you. (UK10)</li></ul>
Patient indicates readiness to discuss	<ul style="list-style-type: none"><li>• The patient being ready, the patient indicating that they want to have this discussion, is the most important. (UK8)</li></ul>
Patient being open about dying	<ul style="list-style-type: none"><li>• ...people will talk about it. People can be very open about dying... (UK10)</li></ul>
Where the discussion occurs	<ul style="list-style-type: none"><li>• I think the joy I have from going to people's homes is, there's more time. There's less interruptions, people feel safer because they're in their own environment and that's one thing you do notice when you actually work in the community compared to a hospital, is that you are being invited into their home and therefore you know, that's one thing they are leading the whole consultation because it's in their environment, and so it's definitely a different dynamic when you visit somebody in a home (UK11)</li></ul>
Patient's wish to protect others from end-of-life information	<ul style="list-style-type: none"><li>• I think as well sometimes, that once they acknowledge it, again if there's a family member there, they might be thinking it, but they don't want the carer or the wife or whoever, to know that that's how they're thinking, because it's a kind of helplessness and the loss of hope (UK9)</li></ul>
Having a strong relationship with the patient	<ul style="list-style-type: none"><li>• We've been in their homes, we know their families, you know we've looked at the pictures on the wall. It's all about building relationships and they trust you to look after them, and actually talking about it with us is probably easier than talking about it with anybody else (UK10)</li></ul>
Your professional boundaries	<ul style="list-style-type: none"><li>• ...we then see them again through a nastier exacerbation and things and sometimes again they bounce back and but the disease trajectory with COPD compared to cancer, it's so very different, and can be so much longer, and so you do go on that journey with them for many, many years, but you are the professional at the end of the day, and for your own sanity I suppose, for want of a better word, it's that you have to ensure that you protect yourself. (UK11)</li></ul>

### 5.3.3 Questions 3: Key content of discussion

Participants suggested 28 unique items that were grouped into this category and three sub themes emerged - hospice, perceptions of death and practical needs. Again, a sample of these items is presented in Figure 5.5 below. Examples from all categories and sub categories can be found in Appendix D.

Figure 5.5 Key content when discussing end-of-life: samples from Round 1 of the UK Delphi.



## **5.4 Round 2 Findings**

In general, there was a high level of agreement (more than 70 percent of participants rating the item 'agree' or 'strongly agree' (Downar and Hawryluck, 2010) on many of the items in Round 2: 71 percent of items in Question 1, 83 percent of items in Question 2 and 86 percent of items in Question 3. In Round 2, space for comments on individual items and at the end of each section were well utilised by participants. Table 5.2 reports the median, range and level of agreement for each item in rounds 2 and 3, and Table 5.3 provides a sample of comments from rounds 2 and 3.

**Table 5.2 Quantitative results from Rounds 2 and 3 of the UK Delphi.**

Delphi Item	Round 2			Round 3		
	Median	Range	Level of agreement (%)	Median	Range	Level of agreement (%)
<b>How do health professionals know a patient is ready or willing to discuss end-of-life?</b>						
Clinical signs	2	4	32	2.5	3	35
My professional intuition	4	3	84	4	3	93
Cues from the patient such as stating 'I do not want to go back to hospital'	5	2	95	4	1	100
Patient asks if s/he is going to die	5	2	95	4.5	2	93
Body language e.g.: open posture, appears relaxed	4	4	52	3	3	14
General patient demeanour	4	3	74	3	3	21
Patient is responsive when I allude to the end-of-life topic	4	1	100	4	1	100
Patient refers to their own death				4	2	86
Patient talks about or asks about hospice options				4	2	93
Patient appears to be getting their affairs in order				4	2	93
Family whispers to you in the hall 'John wants to die'				3	4	36
Patient states that they have 'had enough' or that they want to die				4	3	92
Patient asks about intubation in the hospital				4	2	57
Patient does not comply with treatment				3	2	21
Recent death in the family and patient has concerns about the same issue				4	2	78
<b>What are the key considerations in end-of-life discussions in nonmalignant respiratory disease?</b>						
Allowing the patient to lead the conversation	4	2	84	4	2	84
Answering patients questions regarding the condition	5	1	100	5	3	93
Maintaining hope for the patient	3	3	42	4	2	76
Being open and honest with the patient	5	1	100	5	1	100
Establishing the patient's understanding of their condition	5	1	100	4	1	100
Recognising the individual needs of the patient	5	0	100	5	1	100

**Table 5.1 Quantitative results from Rounds 2 and 3 of the UK Delphi (continued).**

Delphi Item	Round 2			Round 3		
	Median	Range	Level of agreement (%)	Median	Range	Level of agreement (%)
Explaining to patients what is feasible regarding their wishes	5	1	100	5	1	100
Educating the patient about their condition	5	2	85	4	1	100
Patient indicates readiness to discuss	5	3	94	4	1	100
Patient wanting to hear the information	4	3	89	4	1	100
Patient being open about dying	5	2	74			
Having an appropriate environment for discussion	5	2	94	4	1	100
Where the discussion occurs e.g. clinic, hospital or patient's home	4	4	79	4	2	77
Having the patient's family involved in the discussion	4	4	52	4	2	61
Having the family's support during the discussion	4	2	74	4	2	92
Patient's wish to protect others from end-of-life information	4	4	58	3	3	23
Being an expert on the condition	4	3	79	4	2	69
Nurses having counselling skills	4	2	90	4	3	61
Having the appropriate clinician to discuss end-of-life with the patient	4	3	79	4	2	83
Having a strong relationship with the patient	4	3	74	4	3	61
Emphasising a holistic care approach	5	1	100	5	1	100
Rapport between health professional and patient	4	1	100	4	1	100
Health professional having the confidence to discuss	5	1	100	4	1	100
Health professional's understanding of the condition	5	1	100	4	1	100
Using non-medical language	5	3	94	4	2	93
Your professional boundaries	4	3	79	4	2	93
Avoiding euphemisms - saying 'dying' or 'death' instead	4	3	58	4	3	62
Health professional taking responsibility to oblige the patient's wishes	4	3	58	4	2	69
Using humour	3	3	21	4	2	54
Nurse having attended conferences or professional development specific to end-of-life discussions	4	3	69	4	3	69
Nurse having experience in caring for dying patients	4	2	89	4	1	100
Discussing end-of-life at the time of diagnosis	3	3	5	3	3	23

**Table 5.1 Quantitative results from Rounds 2 and 3 of the UK Delphi (continued).**

Delphi Item	Round 2			Round 3		
	Median	Range	Level of agreement (%)	Median	Range	Level of agreement (%)
Developing the discussion over time	4	2	95	4	1	100
Finding the right opportunity to discuss	4	2	95	4	1	100
Patient having time to hear information and ask questions later	5	3	84	4	2	93
Availability of time to discuss	5	1	100	4	2	92
Health professional being unafraid of talking about dying whenever the opportunity occurs - from diagnosis onwards when patient initiates				4	2	93
<b>What are the topic areas that need to be addressed in such discussions?</b>						
Introduction of an advance care planning document	4	1	100	4	1	100
The type of care the patient wants	5	2	95	5	1	100
Emergency management preferences	5	3	100	4	1	100
Explaining palliative care	5	1	100	4	1	100
Anticipatory prescribing	4	2	89	4	1	100
Ceiling of treatment	4	2	89	4	1	100
Medication options	4	1	100	4	1	71
Treatment options	4	2	95	4	1	100
Patient goals	5	2	94	4	1	101
Intubation and ventilation options	4	2	89	4	3	84
Preferred place of care	5	1	100	5	1	100
Preferred place of death	5	1	100	5	1	100
When the patient is likely to die	3	4	32	4	2	93
Sedation availability/options	4	2	69	4	2	85
Social services involvement	4	2	94	4	1	100
Spirituality	4	2	89	4	1	100
Transferring to palliative care	4	2	89	4	2	92
Who the patient wants present at the very end-of-life	4	3	74	4	2	69
Dealing with breathlessness	5	2	95	5	3	93

**Table 5.1 Quantitative results from Rounds 2 and 3 of the UK Delphi (continued).**

Delphi Item	Round 2			Round 3		
	Median	Range	Level of agreement (%)	Median	Range	Level of agreement (%)
Explaining hospice (if available)(moved to question 1 in Round 3)	4	1	100			
Options for hospice (if available)(moved to question 1 in Round 3)	4	1	100			
How they feel about death	4	2	95	4	2	92
Reassuring the patient he won't suffer	3	3	32	4	2	54
Understanding of death	4	3	69	3	2	38
Getting affairs in order (moved to question 1 in Round 3)	4	1	100			
Practical equipment needs	5	1	100	4	1	100
Support in the home	5	1	100	4	1	100
Transportation needs to facilitate care	4	2	89	4	2	92
Needs of the partner/significant other				4	1	100
Option to change your mind about end-of-life decisions				4	1	100

**Table 5.3 A selection of comments from Round 2 and 3 of the UK Delphi**

<b>Delphi Item</b>	<b>Round 2 Comments</b>	<b>Round 3 Comments</b>
<b>How do health professionals know a patient is ready or willing to discuss end-of-life?</b>		
<b>Clinical signs</b>	Be led by patient. Patient needs to know that they are severe COPD, make sure that patient is informed of diagnosis. Be there for answering questions and further advice (support when needed), clinical severity does not always represent a willingness to engage	The symptoms don't indicate a willingness to discuss end-of-life however, recognising a deteriorating patient would I hope lead to the professional exploring with the patient if they recognise that deterioration and the possibility of discussing the future or planning ahead.
<b>My professional intuition</b>	'Gut' feeling is helpful, supported by professional expertise, emotional intelligence	Gut feeling is usually recognition of signs from the patient that they want to discuss this.
<b>Patient asks if s/he is going to die</b>	This could be explored to see if want to	Agree that this may be an open door but need to be certain that the patient wants to discuss further, i.e. Use of communication skills, intuition and emotional intelligence but should be taken at their pace
<b>What are the key considerations in end-of-life discussions in nonmalignant respiratory disease?</b>		
<b>Maintaining hope for the patient</b>	Honesty is the best way forward, false hope can be detrimental	Prepare for the worst but hope for the best
<b>Educating the patient about their condition</b>	This depends - hopefully I will have had the opportunity to establish their level of understanding	Identifying what their fears are about dying allows it to be related to symptom control sometimes and is more specific to end-of-life
<b>Patient wanting to hear the information</b>	Patient need realistic information it may not be information that they want to hear	But sometimes you need to discover what information they DON'T want too
<b>Having the family's support during the discussion</b>	Only if patient wishes	Definitely agree two sets of ears are better than one
<b>Being an expert on the condition</b>	You don't need to be an 'expert' to discuss end of life matters	You need to know what you are talking about when dealing with such an emotive subject,
<b>Having a strong relationship with the patient</b>	Helpful in starting conversation	With the right skills I think you can talk to any patient
<b>Using humour</b>	If patient likes or uses humour	Patient led
<b>What are the topic areas that need to be addressed in such discussions?</b>		
<b>Ceiling of treatment</b>	Need to talk about i.e. NIV	Not at the first meeting unless the patient brings up the subject.

#### **5.4.1 Development of Round 3 Questionnaire**

The comments from Round 2 resulted in five items being added to Question 1, one item to Question 2, and two items to Question 3.

After careful consideration and discussion with the three supervisors (who were all nurses), some items that had initially been classified under questions two or three were moved to Question 1. Relocated items were marked with their former category for participants. In addition, some items were re-worded if the comments indicated that they were difficult to understand, or needed to be altered to be more representative of the experience of the nurses. These new, reworded or relocated items were clearly marked as such for the participants in the Round 3 questionnaire.

Items with a mean score of less than two were to be excluded; however, there were no items that met this criterion in the second round of data collection, and therefore all items were reconsidered by participants in Round 3.

#### **5.5 Round 3 Findings**

Individual items, their scores from each round, and notes regarding any changes made to the item can be found in Table 5.2. Items that gained consensus opinion of the participants are listed in Table 5.4. Consensus for each individual item was determined based on:

- items having an agreement (agree or strongly agree) level of 70 percent or more (Downar and Hawryluck, 2010),
- items having a median rating of 4 or above (Chang, Gardner et al.),

- range level of items: 2 or less was considered to indicate strong agreement, but items with a higher range were still considered to have consensus if the percentage of agreement and the median were high enough (Holey, Feeley et al. 2007).

There were fewer comments on items from participants in Round 3, potentially indicating increasing stability. The percentage of items that did not gain consensus was 29 percent, and clear qualitative feedback was provided by participants on these items.

**Table 5.4 Items that reached consensus opinion in the UK Delphi.**

Question	Item	
<p><b>How do you know a patient with nonmalignant respiratory disease is ready or willing to discuss end-of-life?</b></p>	Cues from the patient such as stating ‘I do not want to go to hospital’	
	Patient asks if s/he is going to die	
	Patient is responsive when I allude to the end-of-life topic	
	Patient refers to their own death	
	Patient talks about or asks about hospice options	
	Patient appears to be getting their affairs in order	
	Patient states that they have ‘had enough’ or that they want to die	
	Allowing the patient to lead the conversation	
	Answering the patient’s questions regarding the condition	
	Maintaining hope for the patient that symptoms can be managed effectively, while being honest about the likelihood of progress of the disease	
	Being open and honest with the patient	
	Establishing the patient’s understanding of their condition	
	Recognising the individual needs of the patient	
	Explaining to patients what is feasible regarding their wishes	
	Educating the patient about their condition	
	<p><b>What are the key considerations in an end-of-life discussion in nonmalignant respiratory disease?</b></p>	Patient indicates readiness to discuss
		Patient wanting to hear the information
Having an appropriate environment for discussion		
Where the discussion occurs e.g. clinical, hospital or patient’s home (merged into ‘having an appropriate environment for the discussion’)		
Having the family’s support during the discussion		
Having the appropriate clinician to discuss end-of-life with the patient		
Emphasising a holistic care approach		
Rapport between health professional and patient		
Health professional having the confidence to discuss		
Using non-medical language		
Working within your professional boundaries		
Nurse having experience in caring for dying patients		
Developing the discussion over time		
Finding the right opportunity to discuss		
Patient having enough time to hear information and then ask questions later		
Availability of time to discuss		
Health professional being unafraid of talking about dying whenever the opportunity occurs - from diagnosis onwards when patient initiates		

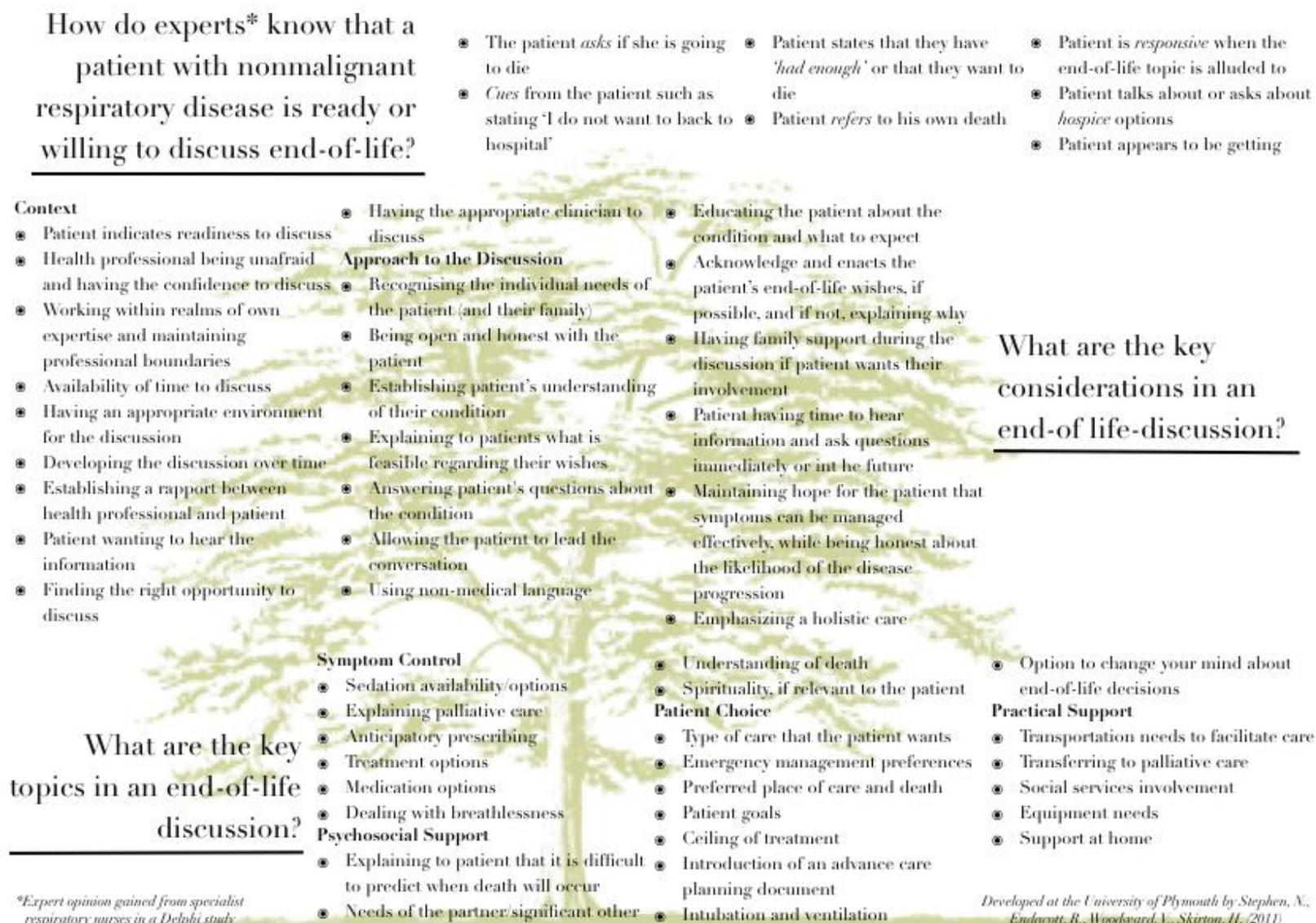
Question	Item
<b>What are the key topics that should be addressed in an end-of-life discussion in nonmalignant respiratory disease?</b>	Introduction of an advance care planning document
	The type of care the patient wants
	Emergency management preferences
	Explaining palliative care
	Anticipatory prescribing
	Ceiling of treatment
	Medication options
	Treatment options
	Patient goals
	Intubation and ventilation options
	Preferred place of care
	Preferred place of death
	When the patient is likely to die
	Sedation availability/options
	Social services involvement
	Spirituality
	Transferring to palliative care
	Dealing with breathlessness
	How they feel about death
	Practical equipment needs
Support in the home	
Transportation needs to facilitate care	
Needs of the partner/significant other	
Option to change your mind about end-of-life decisions	

## 5.6 Tool development

The tool was designed from the list of items that had reached consensus. After the tool was designed, items were reviewed with the researcher's supervisors, and two items were subsequently removed. The item *'health professional being unafraid of talking about dying whenever the opportunity occurs from diagnosis onwards when patient initiates'* was removed as it was very similar to the item *'health professional having the confidence to discuss'*. The latter was rated higher than the first item, and so the lower rated item was removed from the list. Also, *'having a strong relationship with the patient'* was similar to *'rapport between health professional and patient'*, which was rated higher in the previous round, therefore *'having a strong relationship...'* was removed to avoid repetition in the tool. Finally the term used in question 2 *'key components'* was changed to *'key considerations'* as the supervisor felt this was more appropriate for the topic. As the point of this tool was to encourage discussion between health professionals and patients, *'key considerations'* was thought to be a more acceptable term. The results of the tool development process can be found in Figure 5.6.

The items on the tool were found to be highly reliable, with Cronbach's Alphas of .85 for Question 1 items, .94 for Question 2 items, and .96 for Question 3 items.

Figure 5.6 Tool developed from the UK Delphi.



## **5.7 Round 4 Findings**

In the fourth round of data collection, participants were provided with a copy of the tool and asked to give their opinion on the potential usefulness of the tool in clinical practice (Mead and Moseley, 2001). The questions and their responses are detailed in Table 5.5.

Participants stated that the tool was an accurate representation of end-of-life discussions in NMRD. In addition, they rated it as 'somewhat to very useful in clinical practice for experienced practitioners and novice practitioners'. Open-ended questions gave participants the opportunity to provide suggestions regarding potential uses for the tool. They suggested possible formats for the tool, such as an interactive website. These suggestions will be used to determine how best to disseminate this information to health professionals in the UK. One of the most prominent suggestions was that the tool could be used to train less experienced health professionals about end-of-life discussions.

**Table 5.5 UK Delphi Round 4 questionnaire results.**

Question	Response	% (number)	n
<b>Does this tool accurately reflect end-of-life discussions in nonmalignant respiratory disease?</b>	Yes	92.3 (12)	13
	Unsure	7.7 (1)	
	No	0	
<b>How useful would the tool be in clinical practice?</b>	Very useful	23.1 (3)	13
	Somewhat useful	76.9 (10)	
	Not useful	0	
<b>As an experienced practitioner, would you use this tool in your clinical practice?</b>	Definitely	15.4 (2)	13
	Very probably	38.5 (5)	
	Probably	23.1 (3)	
	Possibly	15.4 (2)	
	Probably not	7.7 (1)	
	Not at all	0	
<b>Do you think this tool would be useful to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease?</b>	Very useful	91.7 (11)	12
	Somewhat useful	8.3 (1)	
	Not useful	0	
<b>Would you to recommend this tool to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease?</b>	Definitely	23.1 (3)	13
	Very probably	69.2 (9)	
	Possibly	7.7 (1)	
<b>How might you use this tool in your clinical practice? (a sample of participant comments)</b>	<i>'Education and training to junior staff, guide to treatment, support for personal clinical reasoning process, guide to developing local [end-of-life] protocols and procedures'</i>		
	<i>'I think it will be helpful as a prompt to assess whether a patient is ready to discuss end-of-life topics but also to identify whether there are other factors that need to be addressed before these discussions can take place, e.g. understanding their condition'</i>		
	<i>'I would use it during education for other health care professionals and as an aide memoire to add to my medical notes.'</i>		
<b>Is there anything that could be added to or changed about this tool to make it more useful for clinical practice? (a sample of participant comments)</b>	<i>'Could it be in more diagrammatical form, could it be extended to provide examples. If available on the web, could there be hyper links to other useful sites? e.g. GSF, preferred place of care?'</i>		
	<i>'It would be useful if it sat within a framework or pathway for end-of-life in nonmalignant respiratory disease.'</i>		

## **5.8 Discussion**

The findings reveal that health professionals can perceive whether a patient is ready or willing to discuss end-of-life by understanding patient cues. Using this knowledge, health professionals may be able to initiate meaningful end-of-life discussions. The use of participants with knowledge and interest in the topic helps to ensure the content validity of the Delphi, while the use of successive rounds of the questionnaire helps to establish concurrent validity (Goodman, 1987)

Clear qualitative feedback was provided by participants for items that did not gain consensus, however one non-consensus item is interesting, as it is contrary to current guidelines in the UK. This study revealed clear disagreement between experts in the field as to whether clinical indicators helped them to establish whether a patient was ready or willing to discuss end-of-life, revealing lack of clear support for recommendations to use the Gold Standards Framework Prognostic Indicator Guidance to determine when to initiate end-of-life discussions with patients with COPD (2006). Items that did gain consensus, such as the importance of developing the discussion over time and discussing whenever the opportunity occurs after diagnosis (see Table 5.5), show that perhaps such emphasis in the policy guidelines on clinical indicators may inhibit health professionals from starting discussions early in the disease process, rather than allowing for the iterative process of such discussions to occur as mentioned in the end-of-life care strategy (2009).

## **5.9 Conclusions**

Gaining the consensus opinion of specialist respiratory nurses in the UK was essential in order to address objectives one and two of the doctoral study. This led to the development of a tool to help health professionals to determine constraints and opportunities specific to the

UK context to facilitate successful end-of-life discussions. The findings of this phase show that health professionals can be sensitive to patient cues to determine whether they are ready to engage in an end-of-life discussion. This knowledge may help increase professional confidence in interpreting patient cues, and thus ease some of the anxiety that health professionals may have about approaching end-of-life discussions.

For the purposes of gaining further insight into how end-of-life is discussed, the findings of this phase will be compared to the findings of the Canadian Delphi phase in Chapter 7. In addition, the distinction between the concepts of readiness versus willingness to discuss end-of-life emerged, and will be addressed along with the other findings from this phase, in terms of developing theory and constructing a model for such discussions in Chapter 8.

## **Chapter 6. A modified Delphi study with Canadian respiratory health professionals in Canada**

### **6.1 Introduction**

The objectives of this phase of the study, in line with objectives one and two of the doctoral study: to use the Delphi to develop a tool about how health professionals know a patient with NMRD is ready or willing to discuss end-of-life and delineate key considerations and topics for such discussions in the Canadian context.

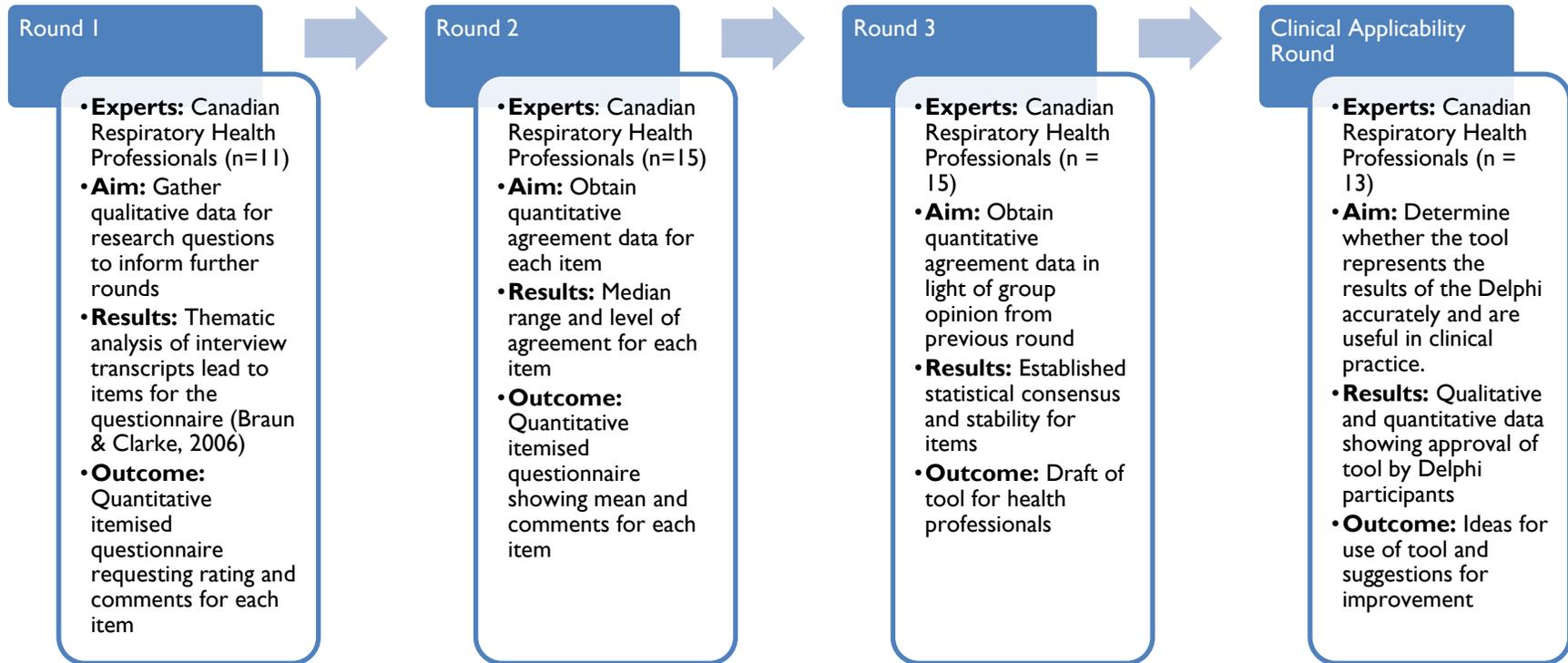
As laid out in Chapter 4 and summarized in section 5.1 for the UK Delphi study, this mixed methods study involved one round of qualitative interviews and three rounds of online questionnaires (Figure 6.1). Details of the Canadian recruitment process and the findings of the study can be found in section 6.2.

In line with the MRC guidelines for the development of a complex intervention (section 1.6), this Delphi study resulted in the development of a tool to aid health professionals in discussing end-of-life in NMRD (section 6.2.4) specific to the Canadian context. The tool is presented in Figure 6.6 along with findings from the clinical applicability and usefulness questionnaire in section 6.2.5. This is followed by a discussion of the findings in section 6.3.

This is followed in section 6.4 by a comparison of the findings of this Delphi study and the UK Delphi presented in Chapter 5 in order to achieve the third overarching study objective (section 1.5) of delineating the difference in end-of-life discussions in NMRD in the UK and Canada. A discussion of how the results of this Delphi and the international comparison

contributed to the development of theory and modeling of the process of end-of-life discussions follows in Chapter 7.

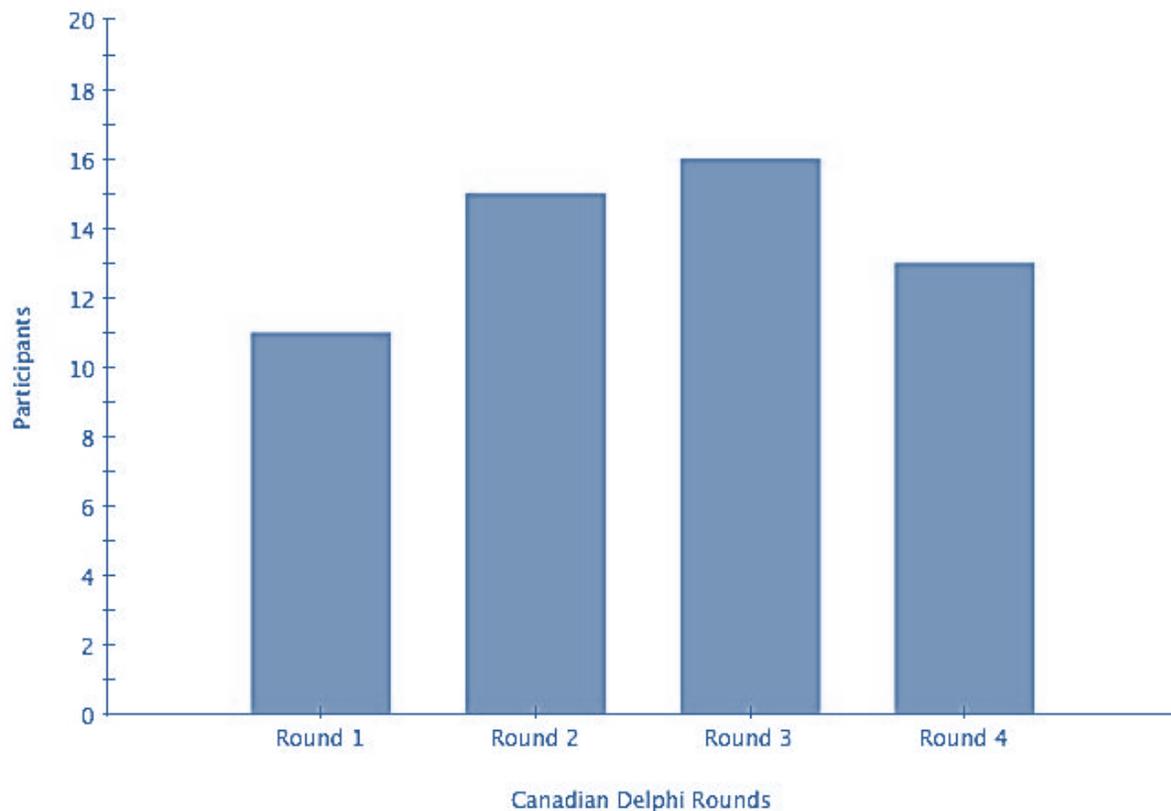
Figure 6.1 Canadian Delphi Overview.



## 6.2 Participants and Findings

Initial recruitment for the Canadian Delphi took place in from August to October 2011, and a total of 18 health professionals indicated interest in participating. As discussed in section 4.10.2, recruitment was conducted by advertising the study in the monthly email newsletter to members of the Canadian Respiratory Health Professionals group. Of the 18 participants, 11 were selected to be interviewed for the first round: selection for the interview was based on geographic location, health profession and work setting to achieve a maximum variation sample (Patton, 2005) (see section 4.9.1). The number of participants for each round of the Delphi is displayed in Figure 6.2, and is well within the idea number of Delphi participants (Bowles, 1999, Okoli and Pawlowski, 2004, Baker et al., 2006).

**Figure 6.2 Canadian Delphi participants by round.**



In the first round of semi-structured interviews (see section 4.4.1), data saturation was reached after 11 interviews. Participants who were interviewed for Round 1 (n = 11) had a similar demographic profile to the whole Delphi participant panel (n = 18). Participant demographic information is presented in Table 6.1. Throughout this chapter, quotes from participants have been anonymised, and assigned a code denoting the country of origin (CAN) and a participant number. Where applicable, a reference to the relevant section of Chapter 4 describing the methods used will be provided.

**Table 6.1 Canadian participant demographic information.**

	Round 1		Rounds 2-4	
	N	%	N	%
Sex (f)	11	58%	18	88%
Province				
Alberta	3	27%	4	22%
British Columbia			2	11%
New Brunswick	2	18%	3	17%
Nova Scotia	1	9%	2	11%
Ontario	3	27%	5	28%
Saskatchewan	2	18%	2	11%
Education				
Diploma	6	55%	8	44%
Bachelor's	3	27%	6	39%
Master's	2	18%	3	17%
Age				
30-39	3	27%	5	28%
40-49	4	36.50%	6	33%
50-59	4	36.50%	6	33%
60-65			1	6%
Professional Designation (all that apply)				
RRT	6	55%	12	67%
COPD Educator	8	73%	14	78%
CAE	7	64%	12	67%
RN	3	27%	3	17%
Nurse Practitioner	1	9%	1	6%
Social Worker	1	9%	2	11%
Professional Role (all that apply)				
Clinical (including counselling)	8	73%	15	83%
Teaching	7	64%	12	67%
Research	3	27%	3	17%
Administration	1	9%	2	11%
Work Setting (all that apply)				
Community	7	64%	10	56%
Hospital	5	45%	7	39%
Outpatient clinic	2	18%	4	22%
Years in respiratory health				
01-Mar	2	18%	3	17%
04-Oct	2	18%	2	11%
Nov-15	2	18%	3	17%
16-19			2	11%
20+	5	45%	8	44%
Years discussing end-of-life				
01-Feb			1	6%
03-May	4	36%	5	28%
06-Oct	3	27%	6	33%
Nov-15	3	27%	4	22%
15-20	1	9%	1	6%
>20			1	6%

### 6.2.1 Round 1

Thematic analysis of the round 1 (see section 4.4.1) interviews resulted in 12 items for Question 1, 47 for Question 2, and 13 items for Question 3. Unlike a typical thematic analysis,

all items that were mentioned in interviewees were included for consideration by participants in the next round (Braun and Clarke, 2006). One additional questionnaire item for Round 2, asking participants to rate their agreement with the following statement was added as: 1b) 'There are situations when 'readiness' is not important; for example, when the topic must be discussed immediately for practical purposes' as this was an idea that was raised by interview participants but did not fit under an existing research question. In total, eleven issues were categorised into Question 1 and one in question 1b; 47 items into Question 2, and 13 into Question 3.

### **Question 1: How participants knew a patient was ready to discuss end-of-life**

Participants were asked directly how they knew that a patient was ready or willing to discuss end-of-life. Participants gave 12 unique responses in this category.

- Clinical indicators; for example, the patient has recently had an acute episode and required hospitalization;
- The health professional uses their emotional intelligence to gauge patient readiness;
- Patient cues such as body language, facial expressions, open personality;
- Patient initiates end-of-life topic with health professional;
- Patient responds when end-of-life topic is alluded to or initiated by the health professional; for example, asking whether the patient has made a will, sharing a personal story about a death in the family where end-of-life decisions were not made, explaining what the first health professional to arrive on the scene would be expected to do in the event of a patient crisis, and that patient wishes would not be met if they had not been expressed;
- All patients are ready if the health professional frames the discussion appropriately;

- You know a patient is ready to discuss because you know them

Several participants who were qualified as COPD educators and discussed end-of-life with patients in respiratory education programme contexts. As such, some responses were categorized under the theme of 'readiness in the patient education context'. The following is a description of each theme and example quotes from interview participants.

### **Clinical indicators**

Two participants mentioned using clinical indicators as a cue to indicate readiness or willingness to discuss. If the patient had recently had an acute episode that required hospitalization, then the health professional would initiate a discussion about what the patient would want next time. One participant said:

*'so i'll look at the clinical stuff and that'll...if I think they're doing poorly I will try to bring it up sooner, um, and I try to make sure I cover, well, I don't get them to fill anything else and hand it back to me, I give them the form and say, you know, discuss this with your family, and with your doctor, make sure that he knows or she knows what kind of care you want, and so I make sure I cover, sort of the levels of advance care directives' (CAN5)*

They also mentioned that the more severe the patient's condition is, the more opportunities there are for discussion.

### **The health professional uses their emotional intelligence to gauge patient readiness**

Three participants discussed using their emotional intelligence to gauge whether someone was ready to discuss.

*'In our clinical team we talk about the emotional intelligence factor, and just being able to connect enough with people' (CAN9).*

Another participant described how she used emotional intelligence to gauge readiness.

*'but you have to really gauge it, you have to be very good, I think at reading people, and knowing how much you can say, or you know, recognizing if you say something and you see a reaction that's not positive, then you know not to go down that path again. It's a delicate dance, it really is.'*(CAN6).

### **Patient cues**

Several participants mentioned the use of cues from the patient such as body language, facial expressions and an open personality as an indicator that they were ready to discuss.

*'Um, definitely an openness to the conversation, you know, you can tell by the energy and by their facial expressions, by their body language whether or not they're ready for that information' (CAN1)*

### **Patient initiates end-of-life topic with the health professional**

Three participants discussed whether or not they had experienced patients initiating the discussion themselves. One participant stated that there was no way to discern readiness unless the patient initiated the discussion themselves. While others stated that they had never experienced a patient who had initiated the topic with them:

*'I have not seen that...I have not had anybody ask me directly or bring it up themselves, it's always - i've always been the one who brought it up.'* (CAN5)

However, when experienced, initiation was not always verbal, in the case of COPD education sessions, attendance to the end-of-life session, and following up with a phone call to the health professional was viewed as initiation.

*'So like, they're ready, because they've showed up to start with. And they're even more ready to talk about it by making the phone call. So it's kind of a dual initiation...yah.'* (CAN4)

### **Patient responds when end-of-life topic is alluded to or initiated by the health professional**

One participant (CAN1) discussed how patients could show an 'openness to the conversation' after she had initiated the topic. Openness could be relayed through facial expressions or body language, and therefore this cue is related to the earlier category of 'patient cues'. This could also mean that the patient accepted the health professional's 'invitation to discuss the topic further', and was willing to 'increase knowledge about their condition'.

### **All patients are ready if the health professional frames the discussion appropriately**

One participant described how any patient would be willing to discuss end-of-life if the discussion was framed appropriately. She said:

*'I can't think of anyone (where) I can honestly say that they were not ready, and even the toughest ones, I can think of a couple men who would just make jokes and 'oh, oh I guess I must be about to fall off the block' and I go 'no, this is not about, you know, and I use a lot of joke and I tend to, I feel, I think I feel good about who I can joke with who I can't, and you know who you can't, you know if they kinda push back with a joke and say 'oh yah, this isn't good, look it, she came here to talk to me about puffers and now suddenly she says I'm dying',*

*and I say 'no I'm not saying you're dying, I could be smoked by a truck when I leave your driveway, but I'm in a bit of a different position, because if I get smoked by a truck, um, you know, I would want everything done, I'm young and have children, and I'm willing to risk the outcome of everything, but, what does everything mean and look like for you, and would you want that, would you want those same things. And if you want what the system provides by default with no communication you're fine, but if you don't want that, then what are the possible decisions.'*(CAN9)

### **You know a patient is ready to discuss because you know them**

This category relates to the emotional intelligence category. One participant discussed how when you know people enough to understand their values and belief systems, and to understand how that influences their decision making, then you can gauge readiness. In addition, participants stated they were able to initiate a discussion once the relationship between health professional and patient had been established.

*'I don't bring it up in the first appointment. It's usually something later once I have a bit of a relationship with them.'* (CAN5)

Some themes related directly to the role of COPD educator in Canada and how readiness may have been expressed in this context.

### **Readiness in the patient education context**

Indicators of readiness in the patient education context included:

- Attending end-of-life session implies readiness to discuss
- Group setting encourages patients to discuss
- Patient follows up on end-of-life information received in education session

- Patients are not given the option of being ready to hear the information in the education context.

An additional item was labelled as question 1b was added as it could not be categorized appropriately under the existing question 1:

- There are situations when 'readiness' is not important such as when the topic must be discussed immediately for practical purposes.

### **Attending end-of-life session implies readiness to discuss**

This category is relevant when a patient has had the opportunity to attend a COPD education program, a service provided by some health regions by certified COPD Educators. There is often a session as part of the programme about end-of-life planning, and by attending this session as they would have been advised of the topic in advance, a patient is indicating an openness to the topic of end-of-life.

*'And in a group situation that we teach once a week, it's part of the curriculum, so it's not a subject that we avoid. So we talk about it, they don't even, it's whether they're ready to talk about or not is...it's almost irrelevant in a group setting, but you do open up for it.'* (CAN7)

### **Group setting encourages patients to discuss**

Again, relating to the context of COPD education sessions, being in a group of other patients with COPD was thought to be a facilitator of readiness or willingness to discuss.

*...even if you don't have that experience, you can relate to somebody else's, and when you relate to somebody else's situation, you set up a rapport with the patient and their family, that they then get an idea, well you know what, you understand, or have an understanding.'*(CAN5)

### **Patient follows up on end-of-life information received in education session**

Another indicator of readiness or willingness relating to COPD education was the possibility of follow-up between the patient and health professional. Patients would have access to the COPD educators running the session and likely be able to make appointments to see them. By doing this in order to address end-of-life issues, patients were thought to be indicating readiness or willingness to discuss.

*'So what I tend to do when I have those clients that come in and that are followed under the practice that I'm participating in, I do follow up and say, you know, was there anything out of the education session that you wanna talk further about, you know, have you looked at...or else I'll even say 'you know, I noticed that you were a little uncomfortable speaking about that, you know, is there anything that I can help you with.' And I try to open that door for them, because sometimes it's an outsider that needs to open that door and they can't talk to their family about it.'* (CAN5)

### **Patients are not given the option of being ready to hear the information in the education context**

One participant mentioned that patients may not be warned in advance about the end-of-life component of their COPD education, and therefore they would not have the option to choose to avoid the subject.

*'Well in our classes I don't really give the option...it's just brought in as part of the discussion and I have to say overall it is well received. I mean I try to keep the topic as upbeat as you possibly could, and simply stating that this is a fact, at some point we're all going to go, so if there is a way that you want to go, then we should start talking about it.'* (CAN2)

An additional item was labelled as question 1b was added as it did not fit with the items above:

**Being ready to discuss end-of-life is not relevant, such as when the topic must be discussed immediately for practical purposes**

This item was developed from comments made by a participant that readiness is not always important, such as when accessing palliative care, the patient has to agree to a 'do not resuscitate' order.

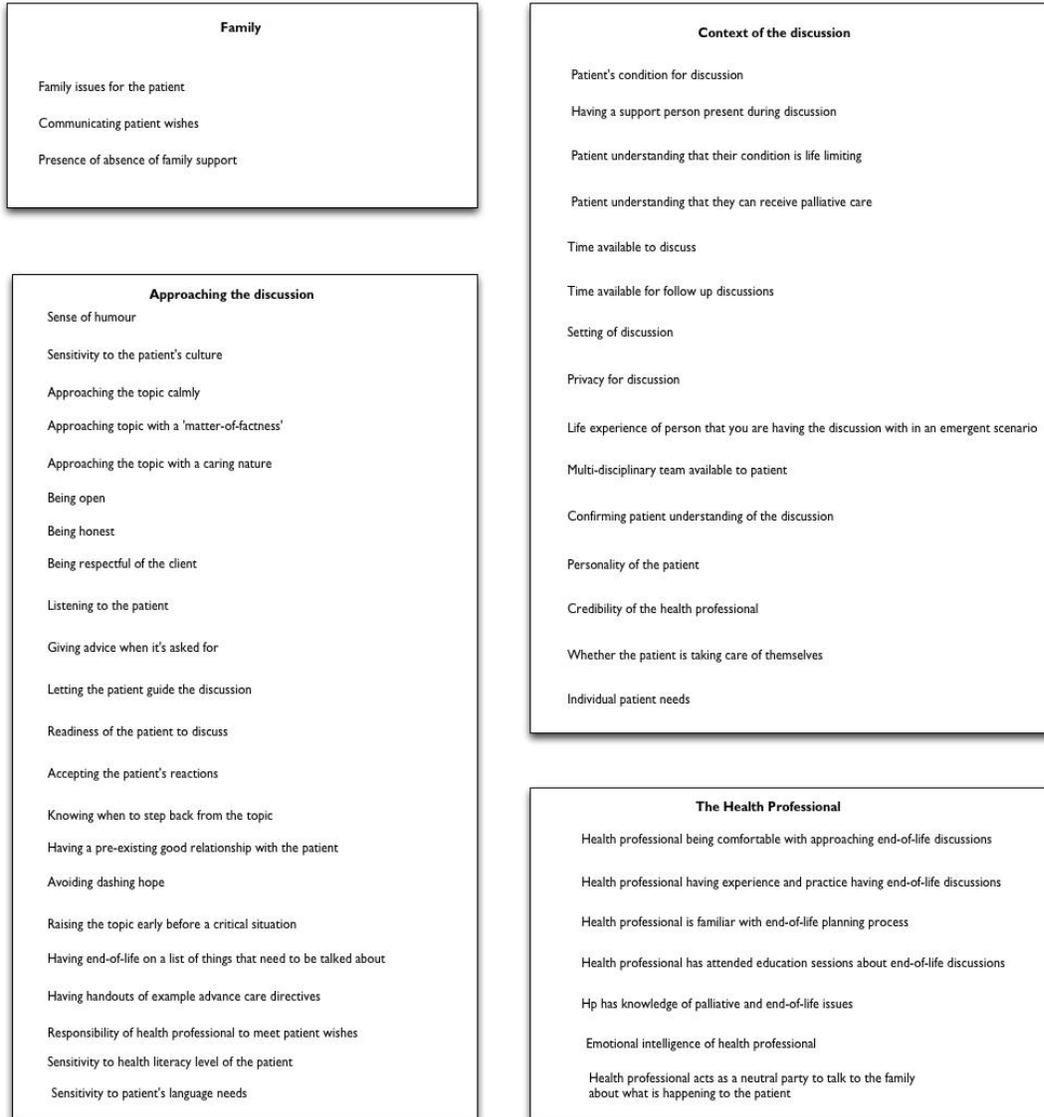
*'but it was something that had to be discussed because we had to register patients um, for the ambulance that they would be a no code if they got called, if the patient agreed to you know, a do not resuscitate, which if they were palliative, they had to, that was the policy here, if you were on the palliative home care team, or on the palliative home care program, you had to agree to um, you know, you weren't going to be resuscitated at all.'* (CAN6)

Another example given is when a home care professional has to ask questions about end-of-life because they need to know practical details if the patient dies while they are there, such as wishes for funeral arrangements.

**Question 2: Key considerations in end-of-life discussions**

Participants stated 47 unique items that were categorized here, and these were subdivided into a further four themes: family, approaching the discussion, the health professional, and the context of the discussion. These themes and the considerations within them are presented in Figure 6.3.

**Figure 6.3 Canadian Delphi themes and categories for key considerations.**



Items requiring further clarification or refinement were developed by having participants provide comments in the next round. A sample of these items and quotes is presented in Figure 6.4. Example quotes from all categories can be found in Appendix E.

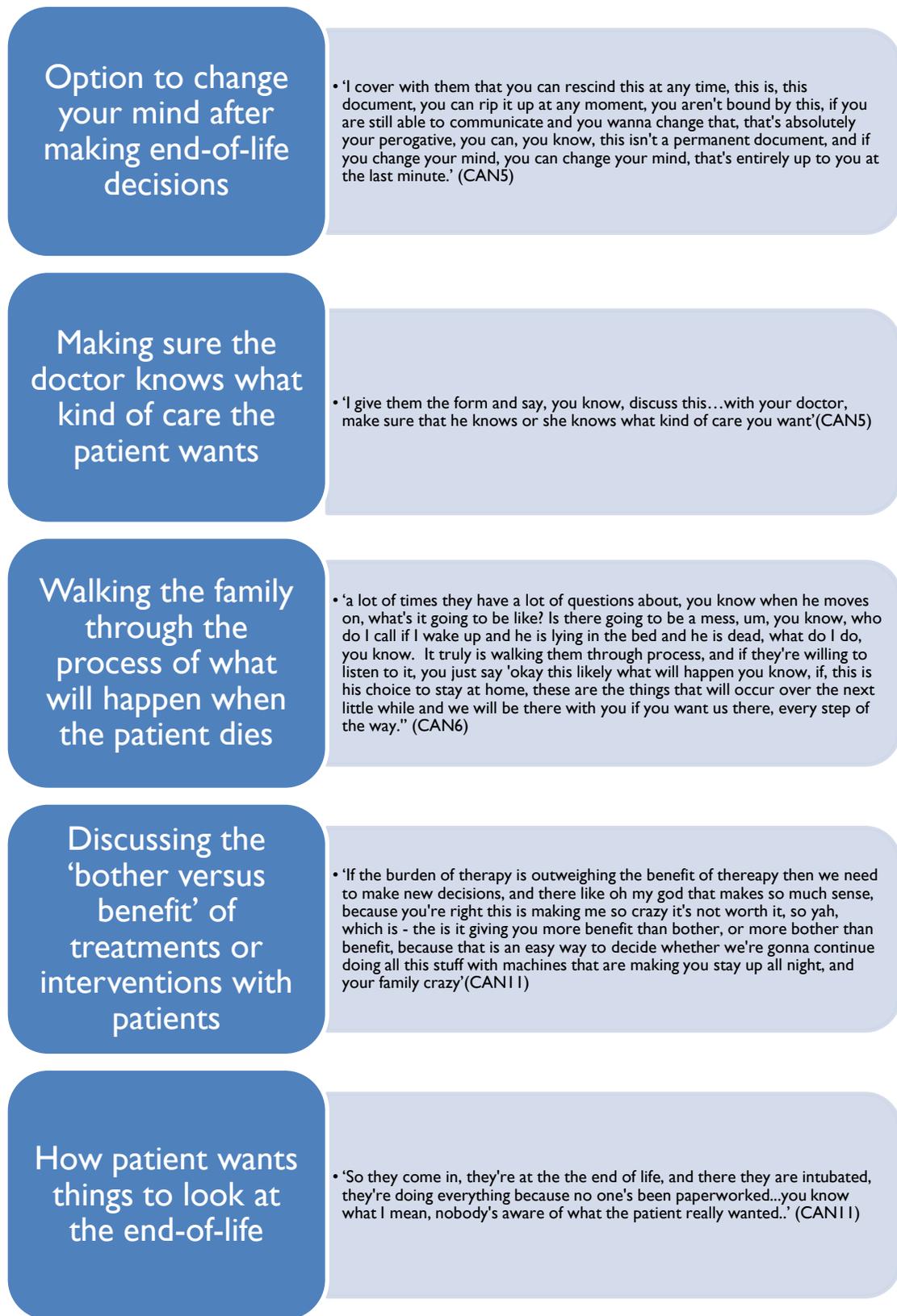
**Figure 6.4 Key considerations in end-of-life discussions: samples from Round 1 of the Canadian Delphi.**

<p>Sense of humour</p>	<ul style="list-style-type: none"> <li>• ‘And i would try and talk about it, and I would bring humour into it a lot of times, whenever I could, because that always sort of breaks the ice a little bit, and makes it easier’ (CAN10)</li> </ul>
<p>Approaching topic with a ‘matter-of-factness’</p>	<ul style="list-style-type: none"> <li>• You just go and you know if you approach the topic...with a matter of factness... I think people respond to that no matter where they are. (CAN1)</li> </ul>
<p>Letting the patient guide the discussion</p>	<ul style="list-style-type: none"> <li>• ‘Letting the patient or whoever you’re talking to about the end-of-life discussion, guide the journey, you know, they are the captain, and going wherever they go. But that doesn’t mean like being a, you know a pushover either. Right? If they’re going down a path um, you can, you know, having that trust, that therapeutic relationship enough to say ‘hey, you know, uh, I don’t know, do you want to think about that a little bit or?’ (CAN1)</li> </ul>
<p>Readiness of the patient to discuss</p>	<ul style="list-style-type: none"> <li>• ‘Um, well definitely the person has to be ready, you can’t force a discussion’ (CAN4)</li> </ul>
<p>Having a pre-existing good relationship with the patient</p>	<ul style="list-style-type: none"> <li>• ‘I think what’s really important i’ve found through the years is getting a relationship with the patient, so that they know that they can trust you, and that um, you know, you’re not just a stranger coming into the house or seeing them in a clinic a situation and they have no relationship, so I think relationships a little bit important’(CAN11)</li> </ul>
<p>Setting of discussion</p>	<ul style="list-style-type: none"> <li>• ‘Whenever you talk about that when you’re in a hospital, they have a tendency not to believe you because when you go to a hospital, you come out better, that’s what most people think. So once the doctors have the initial discussion with them, they are in shock, and if you go in and discuss it, it’s like you know what, I just wanna go home and think about all of this, so it really has to be on their terms.’(CAN6)</li> </ul>
<p>Credibility of the health professional (as recognised by the patient)</p>	<ul style="list-style-type: none"> <li>• ‘Credibility, um, you know, patients will say, some patients will say that they want their physicians to lead this discussion and because their physician is credible, um, so, so I think that’s an important piece’ (CAN9)</li> </ul>

### **Question 3: Key topics for end-of-life discussions**

Participants stated 13 unique items that were categorized here. These items were not subdivided into themes as they were all felt to be sufficiently unique. Again, participants were able to modify or clarify items in the next round by providing comments. A sample of these items and quotes is presented in Figure 6.5. Example quotes from all categories can be found in Figure 6.5.

Figure 6.5 Key topics in end-of-life discussions: samples from Round I of the Canadian Delphi.



### **6.2.2 Round 2**

In the second round, participants had space to provide comments on each item, in addition to rating their agreement on a five-point Likert-type scale. Participants made several comments, and these resulted in one item being added to Question 1, and two items being added to Question 2 for participants to consider in round 3. No new items were added to Question 3. In addition, clarification or modification of items was clearly denoted in the Round 3 survey for participants to consider.

Items with a mean score of less than three were excluded from the following round (section 4.4.2); therefore, four items were removed. In general there was a high level of agreement (more than 70 percent of participants rating the item 'agree' or 'strongly agree' (Downar and Hawryluck, 2010)) on many items in Round 2: 100 percent agreement on question 1b, 81 percent agreement of items in Question 2 and 100 percent agreement of items in Question 3. Question 1 was more contentious with a level of agreement on 33 percent of items. Table 6.2 reports the descriptive statistics for rounds two and three.

### **6.2.3 Round 3**

Participants made 28 percent, 41 percent and 40 percent fewer comments in questions one, two and three respectively. Question 1b had the same number of comments in Round 3. This may indicate that stability of agreement on items increased from Round 2.

Consensus for each item was determined based on (section 4.4.3):

- items having an agreement level of 70 percent or more (Downar and Hawryluck, 2010);
- items having a median rating of 4 or higher (Chang et al.);

- range of scores – items with a range of 2 or less were considered to indicate strong agreement; however, items with a higher range were still considered to have consensus if the percentage agreement and the median were high enough (Holey et al., 2007).

Individual items along with their mean scores from rounds two and three can be found in Table 6.2, and a sample of comments from some items can be found in Table 6.3. Items that gained consensus are listed in Table 6.4.

**Table 6.2 Quantitative results from rounds 2 and 3 of the Canadian Delphi.**

		Round 2			Round 3		
		Median	Range	Level of agreement	Median	Range	Level of agreement
Question 1							
	Clinical indicators	4	4	56%	4	3	75%
	The health professional uses their emotional intelligence to gauge patient readiness	4	2	100%	4	1	100%
	Patient cues	4	2	88%	4	1	100%
	Patient initiates end-of-life topic with health professional	5	2	94%	5	2	94%
	Patient responds when end-of-life topic is alluded to or initiated by the health professional	4	1	100%	4	1	100%
	All patients are ready if the health professional frames the discussion appropriately	2	4	25%	-	-	
	You know a patient is ready to discuss because you know them	3	2	19%	-	-	
	Attending end-of-life session implies readiness to discuss	3.5	2	50%	3	2	25%
	Group setting encourages patients to discuss	3	3	38%	3	3	38%
	Patient follows up on end-of-life information received in education session	4	2	56%	4	3	63%
	Patients are not given the option of being ready to hear the information in the education context	3	4	25%	-	-	
	Comments from family to the health care professional	-	-	-	3	2	38%
Question 1b							
	There are situations when 'readiness' is not important such as when the topic must be discussed immediately for practical purposes	4	3	88%	4	3	88%
Question 2							
	Family issues for the patient	4	3	88%	4	1	100%
	Communicating patient wishes to family	5	1	100%	5	1	100%
	Presence or absence of family support	4	2	94%	4	2	94%
	Sense of humour	3.5	3	50%	4	2	81%
	Sensitivity to the patient's culture	5	1	100%	5	1	100%
	Approaching the topic calmly	5	1	100%	5	1	100%

**Table 6.2 Quantitative results from rounds 2 and 3 of the Canadian Delphi (continued)**

Approaching topic with a 'matter-of-factness'	4	3	56%	3	3	44%
Approaching the topic with a caring nature	5	1	100%	5	1	100%
Being open	5	1	100%	5	1	100%
Being honest	5	1	100%	5	1	100%
Being respectful of the client	5	1	100%	5	1	100%
Listening to the patient	5	1	100%	5	1	100%
Giving advice when it's asked for	4	3	75%	4	2	63%
Letting the patient guide the discussion	4	3	88%	4	2	81%
Readiness of the patient to discuss	4	2	94%	4	2	94%
Accepting the patient's reactions	4	3	94%	4	1	100%
Knowing when to step back from the topic	4	2	94%	4	1	100%
Having a pre-existing good relationship with the patient	4	3	63%	3	3	44%
Avoiding dashing hope	4	3	63%	3	3	31%
Raising the topic early before critical situation	5	2	100%	5	2	75%
Having end-of-life on a list of things that need to be talked about	4	3	88%	4	3	94%
Having handouts of example advance care directives (paper resources)	4	2	94%	4	1	100%
Responsibility of health professional to meet patient wishes	4	3	88%	4	2	75%
Sensitivity to health literacy level of the patient	5	1	100%	5	1	100%
Sensitivity to patient's language needs	5	1	100%	5	1	100%
Health professional being comfortable with approaching end-of-life topic	5	1	100%	5	2	94%
Health professional having experience and practice having end-of-life discussions	4	1	100%	4	3	81%
Health professional is familiar with end-of-life planning process	4	3	94%	4	2	94%
Health professional has attended education sessions about discussing end-of-life	4	2	69%	4	2	88%
Health professional has knowledge of palliative care and end-of-life issues	4	2	100%	4	2	81%
Emotional intelligence of health professional	4	2	94%	4	2	94%
Heath professional acts as a neutral party to talk to the family about what is happening to the patient	4	2	94%	4	2	88%
Patient's condition for discussion	4	3	69%	4	2	75%
Having a support person present during discussion	4	3	56%	4	2	56%
Patient understanding that their condition is life limiting	4	3	75%	3	3	56%
Patient understanding that they can receive palliative care	4	3	81%	4	3	94%

**Table 6.2 Quantitative results from rounds 2 and 3 of the Canadian Delphi (continued)**

Time available to discuss	4.5	2	94%	4	3	94%
Time available for follow up discussions	4	2	88%	4	3	94%
Setting of discussion	4	2	63%	3	2	19%
Privacy for discussion	4.5	2	94%	4	3	75%
Life experience of person that you are having the discussion with in emergency scenario (usually a family member)	4	3	75%	4	2	50%
Multi-disciplinary team available to patient	4	2	94%	4	2	94%
Confirming patient understanding of the discussion	4	1	100%	4	1	100%
Personality of the patient	4	3	75%	3	1	44%
Credibility of the health professional (as recognized by the patient)	4	2	94%	4	1	100%
Whether the patient is taking care of themselves	3	2	25%	-	-	
Individual patient needs	4	2	94%	4	1	100%
The patient's spiritual beliefs and how they may be incorporated into the end-of-life care plan	-	-		4	1	100%
Health care professional checking that day to day as well as longer term needs will be met	-	-		4	2	88%
<b>Question 3</b>						
Patient understanding of their option to make end-of-life choices	5	1	100%	5	1	100%
Patient deciding on a substitute decision maker	4	2	94%	4	2	94%
Patient understanding of the 'chain of command' of decision makers, should there be a dispute when patient is unable to speak for themselves	4	3	94%	4	2	94%
Option to change your mind after making end-of-life decisions	5	3	94%	5	1	100%
Making sure doctor knows what kind of care the patient wants	5	1	100%	5	1	100%
Levels of advance care directives (supportive care only to full resuscitation)	5	2	94%	5	1	100%
Walking the family through the process of what will happen when the patient dies	4	2	81%	4	2	81%
Explaining implications of end-of-life decisions and care to family	5	2	94%	4	1	100%
Discussing the 'bother versus benefit' of treatments or interventions with patients	4	2	88%	4	2	81%
How patient wants things to look at the end-of-life	4	3	75%	4	2	88%
Educating patients about their end-of-life choices and implications	4.5	3	94%	4	1	100%
Goals of care	4.5	2	94%	4	1	100%
Explaining where they are in their disease	4.5	2	88%	4	2	94%

**Table 6.3 Comment samples from Round 2 and 3 of the Canadian Delphi**

Delphi Item	Round 2	Round 3
	How do health professionals know a patient is ready or willing to discuss end-of-life?	
Clinical indicators	An acute episode might signal a good opportunity for a health care professional to approach the topic of end-of-life care with a patient, however it may not correlate into patient readiness or willingness to talk about the topic.	While clinical indicators may indicate that we should start the discussion, it does not mean the patient is ready or willing
The health professional uses their emotional intelligence to gauge patient readiness	Patients give cues and clinicians need to be intuitive enough to hear and read these cues	Agree whole-heartedly with last comment. Emotional intelligence is helpful but it's really about being able to broker a therapeutic relationship and being able to follow up on patients' cues.
	What are the key considerations in end-of-life discussions in nonmalignant respiratory disease?	
Sensitivity to health literacy level of the patient	Vital to assess the patient's understanding by having feedback on what is discussed and frequent checking back with the patient/family. Assessing the patient/family's ability to understand and navigate the health care system, information and able to access what they need is a part of health literacy.	Great comment  If you lose your patient early on because of communication barriers, then the door to these discussions may also be closed.
Emotional intelligence of health professional	Some people are just 'not wired' in an emotional intelligence way to be able to lead these discussions effectively with patients / families. Others are not 'wired' to place various catheters in various body parts. While skills can be taught, it doesn't mean you will excel in it, nor even become proficient. If you are less capable, desirous, etc., it is wise to enable those with capabilities and desires on the team to lead with their skill sets. Being professional enough to admit your limitations is becoming more and more the norm for our professional practice and accepting our limitations. There will always be people better than us and always be people worse than us in doing these things. Being humble enough to admit it, and do something about it is the mark of a graceful practitioner.	I believe that it plays a major role in how a health professional presents themselves in this situation.

**Table 6.4 Items that reached consensus opinion in the Canadian Delphi (continued)**

What are the key topics in end-of-life discussions in nonmalignant respiratory disease

Explaining  
where they are  
in their disease

I believe this is important, however, I have had experiences where clients don't want to know how "bad" they actually are and want the treatment to continue but are comfortable with dying.

Patient dependent, need to watch cues from patient to know when to stop

**Table 6.4 Items that reached consensus opinion in the Canadian Delphi.**

Question	Item
<p>Question 1. How do you know a patient is ready or willing to discuss end-of-life?</p>	<p>Clinical indicators; for example, length of disease process, burden of disease, the patient has recently had an acute episode and required hospitalization.</p>
	<p>The health professional uses their emotional intelligence to gauge patient readiness.</p>
	<p>Patient cues; for example, body language, facial expressions, open personality.</p>
	<p>Patient initiates end-of-life topic with health professional - either directly or indirectly by bringing up death or end-of-life care in relation to something or someone else.</p>
	<p>Patient responds when end-of-life topic is alluded to or initiated by the health professional; for example: asking whether the patient has made a will; sharing a personal story about a death in the family where end-of-life decisions were not made; explaining what the first health professional to arrive on the scene would be expected to do if the patient were in crisis, and that it would be unfortunate if they had wishes that had not been expressed.</p>
<p>Question 1b. There are situations when the patient's 'readiness' to discuss end-of-life is not important, such as when the topic must be discussed immediately for practical purposes.</p>	
<p>Question 2. What are the key considerations in end-of-life discussions?</p>	<p>Family issues for the patient; for example, young children at home, unresolved family problems</p>
	<p>Communicating patient wishes to their family</p>
	<p>Presence or absence of family support in the patient's life</p>
	<p>Sense of humour when appropriate</p>
	<p>Sensitivity to the patient's culture</p>
	<p>Approaching the topic calmly</p>
	<p>Approaching the topic with a caring nature</p>
	<p>Being open</p>
	<p>Being honest</p>
	<p>Being respectful of the patient</p>
	<p>Listening to the patient</p>
	<p>Letting the patient guide the discussion</p>
	<p>Readiness of the patient to discuss</p>
<p>Accepting the patient's reactions</p>	

**Table 6.4 Items that reached consensus opinion in the Canadian Delphi (continued)**

Question 2. What are the key considerations in end-of-life discussions? (continued)	Knowing when to step back from the topic	
	Raising the topic early before a critical situation	
	Having end-of-life on a list of things that need to be talked about	
	Having handouts of examples of advance care directives (paper resources)	
	Responsibility of health professional to meet patient wishes	
	Sensitivity to health literacy level of the patient	
	Sensitivity to patient's language needs	
	Health professional being comfortable with approaching end-of-life topic	
	Health professional having experience and practice having end-of-life discussions	
	Health professional is familiar with end-of-life planning process	
	Health professional has attended education sessions about discussing end-of-life	
	Health professional has knowledge of palliative care and end-of-life issues	
	Emotional intelligence of health professional	
	Health professional acts as a neutral party to talk to the family about what is happening to the patient	
	Patient's condition for discussion; for example, the patient is in the hospital with an acute episode, or patient is trying to get their breathing under control early in the morning	
	Patient understanding that they can receive palliative care	
	Time available to discuss	
	Time available for follow up discussions	
	Privacy for discussion	
	Multi-disciplinary team available to patient	
	Confirming patient understanding of the discussion	
	Credibility of the health professional (as recognized by the patient)	
	Individual patient needs	
	The patient's spiritual beliefs and how they may be incorporated into the end-of-life care plan	
	Health care professional checking that day-to-day as well as longer term needs will be met	
	Question 3. What are the key topics in an end-of-life discussion?	Patient understanding of their option to make end-of-life choices
		Patient deciding on a substitute decision maker
Patient understanding of the 'chain of command' of decision makers should there be a dispute when patient is unable to speak for themselves		
Option to change your mind after making end-of-life decisions		

**Table 6.4 Items that reached consensus opinion in the Canadian Delphi (continued)**

Question 3. What are the key topics in an end-of-life discussion? (continued)	Making sure doctor knows what kind of care the patient wants
	Levels of advance-care directives (supportive care only to full resuscitation)
	Walking the family through the process of what will happen when the patient dies
	Explaining implications of end-of-life decisions and care to family
	Discussing the positive and negative consequences of treatments or interventions with patients *phrase 'bother vs benefit' has been replaced due to participant comments
	How patient wants things to look at the end-of-life
	Educating patients about their end-of-life choices and implications
	Goals of care
	Explaining where they are in their disease; for example: at a stage where there is no cure: focus on symptom management

#### **6.2.4 Tool Development**

The tool development process followed the same procedures as the UK Delphi study. Cronbach's alphas were calculated on each question to determine reliability of the findings. Items in Question 2 and Question 3 were found to be highly reliable with alphas of .86 and .88 respectively (Bland and Altman, 1997). However, items in Question 1 had a very low level of reliability with an alpha of .095. This may be due to the small sample size or it may indicate that this component of the tool requires further refinement (Nunnally and Bernstein, 1994). As part of the development process for complex interventions, this issue will be addressed in the next phases of research as detailed in Chapter 8. Therefore, despite the reliability of Question 1, the tool was created and then sent to one supervisor for comments before being sent out to participants for review. The results of the tool development process are reported in Table 6.5. The tool presented below is different in appearance from the tool resulting from the UK Delphi as it was thought by the author that a pamphlet format may be more effective than a single sheet as it would allow more space and thereby improve readability.

Figure 6.6 Canadian tool for end-of-life discussions in nonmalignant respiratory disease

# *Discussing end-of-life*

IN NONMALIGNANT RESPIRATORY DISEASE  
IN CANADA



DEVELOPED AT PLYMOUTH UNIVERSITY (UK)  
BY NICOLE STEPHEN, RUTH ENDACOTT, VALERIE WOODWARD & HEATHER SKIRTON (2012).

## Considerations for end-of-life discussions

### **Approaching the discussion:**

- Speak calmly
- Demonstrate a caring nature
- Be open
- Be honest
- Be respectful of the patient
- Listen to the patient
- Accept the patient's reactions
- Know when to step back from the topic
- Have a sense of humour when appropriate
- Let the patient guide the discussion
- Could have end-of-life on a list of things that need to be talked about
- Have handouts of example advance care directives or other paper resources
- Confirm patient understanding of the discussion

### **Individual patient needs:**

- Privacy for the discussion
- Sensitivity to their level of health literacy
- Sensitivity to their culture
- Sensitivity to their language needs
- Sensitivity to their spiritual beliefs and how they may be incorporated into the end-of-life care plan
- Emotional intelligence of the health professional
- Patient's condition for discussion e.g. Patient is in the hospital with an acute episode, patient is trying to get their breathing under control early in the morning
- Credibility of the health professional

### **Context of the discussion:**

- Consider presence or absence of family support in the patient's life
- Consider family issues for the patient, e.g. young children at home, unresolved family problems
- Raise the topic early before a critical situation
- The health professional is comfortable with approaching the end-of-life topic
- The health professional has experience and practice having end-of-life discussions
- The health professional is familiar with the end-of-life planning process
- The health professional has attended education sessions about discussing end-of-life
- The health professional has knowledge of palliative care and end-of-life issues
- Patient's understanding that they can receive palliative care
- Ensure time available to discuss
- Ensure time available for follow-up discussions
- Multi-disciplinary team available to the patient
- Patient's understanding of their option to make end-of-life choices

### **Health professional's role:**

- Help the patient determine how to communicate their wishes to the family
- To help meet the patient's wishes
- Act as a neutral party to talk to the family about what is happening to the patient
- Checking that day to day and longer term

HOW DO EXPERTS* KNOW A PATIENT IS READY OR WILLING TO DISCUSS END-OF-LIFE?	
<p>Clinical indicators, e.g.</p> <ul style="list-style-type: none"> <li>• Length of disease process;</li> <li>• Burden of disease;</li> <li>• The patient has recently had an acute episode and required hospitalization.</li> </ul>	<p>Patient initiates end-of-life topic with health professional</p> <p>Either directly or indirectly by bringing up death or end-of-life care in relation to something or someone else</p>
<p>The health professional uses their emotional intelligence to gauge patient readiness</p>	<p>Patient responds when end-of-life topic is alluded to or initiated by the health professional, e.g.</p> <ul style="list-style-type: none"> <li>• Asking whether the patient has made a will;</li> <li>• Sharing a personal story about a death in the family where end-of-life decisions were not made;</li> <li>• Explaining how if the patient were in crisis what the first health professional to arrive on the scene would be expected to do, and that it would be unfortunate if they had wishes that were not expressed and therefore not met in this type of situation</li> </ul>
<p>Patient cues, e.g.:</p> <ul style="list-style-type: none"> <li>• Body language;</li> <li>• Facial expressions;</li> <li>• Open personality.</li> </ul>	
<p><i>*Expert opinion gained from a panel of Canadian Respiratory Health Professionals who regularly discuss end-of-life in their practice</i></p>	

## Topics to include in end-of-life discussions

### With the patient

- ▶ Patient deciding on a substitute decision maker
- ▶ Patient understanding of the ‘chain of command’ of decision makers, should there be a dispute when the patient is unable to speak for themselves
- ▶ The option to change his or her mind after making end-of-life decisions
- ▶ Making sure the doctors know what kind of care the patients wants
- ▶ Levels of advance care directives (supportive care only to full resuscitation)
- ▶ The positive and negative consequences of treatments or interventions with patients

- ▶ How the patient wants things to look at the end-of-life
- ▶ Educating patients about their end-of-life choices and implications
- ▶ Goals of care
- ▶ Explaining where they are in their disease e.g. No cure, focus on symptom management

### With the family

- ▶ Walking the family through the process of what will happen when the patient dies
- ▶ Explaining implications of end-of-life decisions and care to family

### **6.2.5 Round 4**

After the tool had been developed, participants were provided with a digital copy and asked to give their opinion on the usefulness of the tool in clinical practice (Mead and Moseley, 2001) (section 4.5). The questions that they were asked along with their responses are in Table 6.5.

A majority (86%) of participants felt that the tool was an accurate representation of end-of-life discussions in non-malignant respiratory disease. They also stated that it would be somewhat-to-very-useful in clinical practice, as well as for a reference for both expert practitioners and less experienced practitioners.

**Table 6.5 Round 4 questionnaire and results**

Question	Response	%	n
Does this tool accurately reflect end-of-life discussions in nonmalignant respiratory disease?	Yes	86% (12)	14
	No	7% (1)	
	Unsure	7% (1)	
How useful would the tool be in clinical practice?	Very useful	36% (5)	14
	Somewhat useful	64% (9)	
As an experienced practitioner, would you use this tool in your clinical practice?	Definitely	29% (4)	14
	Very Probably	7% (1)	
	Probably	29% (4)	
	Possibly	21% (3)	
	Probably not	14% (2)	
Do you think this tool would be useful to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease? Would you to recommend this tool to a clinician with little experience with end-of-life discussions in non-malignant respiratory disease?	Very useful	57% (8)	14
	Somewhat useful	43% (6)	
	Definitely	43% (6)	14
	Very probably	7% (1)	
	Probably	21% (3)	
	Possibly	21% (3)	
How might you use this tool in your clinical practice? (a sample of participant comments)	<i>'To get coworkers engaged in end of life discussions with their patients'</i>		
	<i>'Because I am in the process of moving to another job, this tool would be very useful in orienting new staff. There has been huge reluctance and, consequently, resistance, for other staff to take over this responsibility. I am anticipating this tool would be very useful in the transition.'</i>		
	<i>'If I come across a "difficult" situation where I feel it might be challenging to discuss the issue.'</i>		
	<i>'I would use it in my COPD education class and Pulmonary Rehab class to help raise their awareness and open discussion with family members and their (Doctor).'</i>		
	<i>'available as electronic medical record compatible, or downloadable to put into patient charts... Much needed and helpful for hopefully thousands of people and more.'</i>		
Is there anything that could be added to or changed about this tool to make it more useful for clinical practice?	<i>'Specific examples of how to start an End-of-Life conversation would be great. Or examples of how to respond to different reactions that patients may have to the topic.'</i>		

### 6.3 Discussion

This study builds on the Delphi study conducted in the UK. Again, it is the first study known to the author that resulted in a tool specifically to help health professionals discuss end-of-life in NMRD. While items related to Question 1 did gain consensus, there was a lower percentage agreement in this category than others, therefore the findings in this category might require further development. However, in all areas a fairly high level of agreement in Round 2, and higher level of agreement in Round 3 shows that the findings are stable (Holey et al., 2007), and that they represent a range of health professionals.

The findings of this phase show that emotional intelligence of health professionals may be an important factor in approaching end-of-life discussions. The idea that health professionals use their emotional intelligence to gauge patient readiness gained consensus among the participants. Emotional intelligence is defined as an ability (Mayer and Salovey, 1997), a set of traits and abilities (Bar-On, 2005) or a combination of skills and competencies (Goleman, 1998), however, a convergent definition does not exist (Bulmer Smith et al., 2009). While there is a lack of overall agreement on the definition, emotional intelligence is thought to be an essential part of decision making for nurses as they may contextualize decision making, leading to more empathetic and patient-centred decisions, and as such may have a positive impact on patient outcomes (Bulmer Smith et al., 2009).

Interestingly, patient education activity was not seen as the context where discussions took place, or that assumptions about patient readiness could be made, but rather where the end-of-life topic was introduced to patients, and where they could begin to consider their

options. This may be contrary to the idea that if patients have attended education sessions, then they have addressed end-of-life issues and communicated their wishes to the relevant health professionals and their families. Lists of factors to consider and topics to cover during end-of-life discussions were also established, and may give less experienced healthcare professionals some guidance on how to approach this topic. This study has also identified the importance of the recognition of cultural issues for patients and families as well as health literacy levels when approaching end-of-life discussions.

The findings of this Delphi were similar to the UK findings and were also consistent with the literature, however some differences between findings reflect the difference in culture in each country. Items such as 'sensitivity to patient culture', 'health professional being comfortable when approaching end-of-life topic' and 'health literacy of the patient' highlight differences between health professionals in each country. These differences will be discussed further in section 7.2.

#### **6.4 Conclusions**

Gaining the consensus opinion of respiratory health professionals in Canada was necessary in order to meet objectives one and two of the doctoral study. This process resulted in a tool specific to the Canadian context that can help health professionals determine the constraints and opportunities when discussing end-of-life.

The findings of this phase also brought to light differences between UK and Canadian panels, which will be discussed in Chapter 7. As outlined in chapter one, the findings of this phase of

the study will be compared to the UK study in Chapter 7. This will lead to the development of a theory and constructing a model for end-of-life discussions in Chapter 8.

## **Chapter 7. Comparison of findings from the UK and Canada**

The objective of this phase of the study, as listed in section 1.5, was to delineate differences in end-of-life discussions in nonmalignant respiratory disease between the UK and Canada.

The international comparison was conducted as a way to find innovative ways to meet the needs of people with COPD who are facing the end-of-life as it contributes an in-depth understanding of the issues by examining different cultures. It is also highly relevant when considering the increasingly multi-cultural client group in both the UK and Canada. As discussed in Chapter 1, the UK and Canada were chosen as countries to compare because of the recent quality of end-of-life care rankings of first (UK) and ninth (Canada) (Murray, 2010)) and the similarities between the two healthcare systems (government funded, nationalised and freely accessible)(see Table 1.3). In addition, both countries have a similar disease epidemiology (Department of Health, 2010, Canadian Lung Association, 2008).

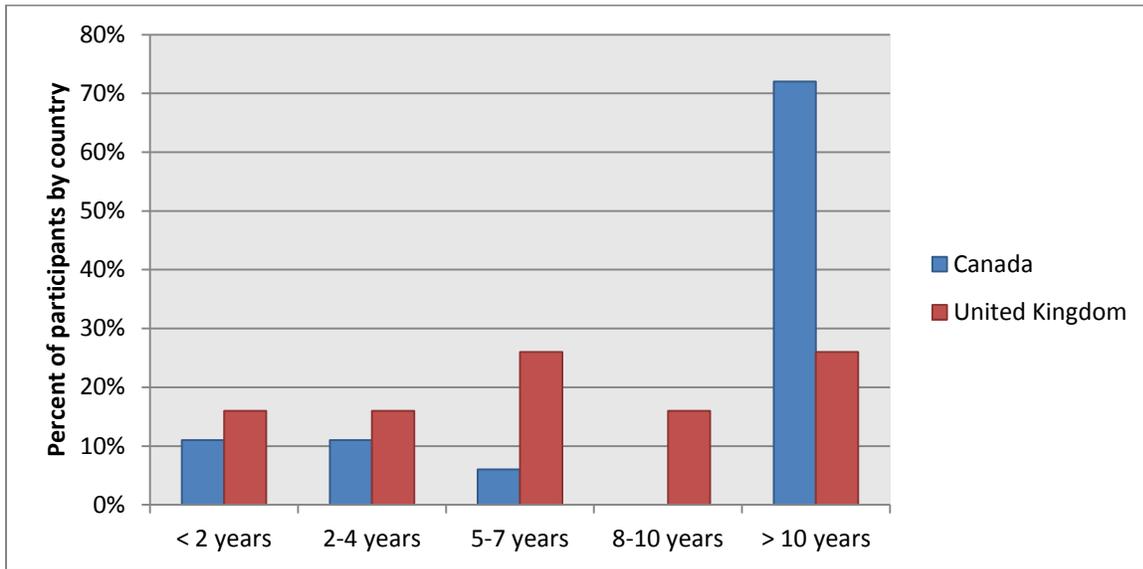
In section 7.1.1 the characteristics of the Delphi panels will be compared and discussed, and this will be followed by a comparison of the results of the UK and Canadian Delphi studies in section 7.1.2. The results of these comparisons will be discussed in section 7.2, and the chapter will be concluded in section 7.3.

### **7.1.1 Characteristics of the Delphi Panels**

The recruitment of health professionals in the UK and Canada took place through professional associations in each country. The details of the recruitment strategy for each Delphi study are detailed in section 4.9.

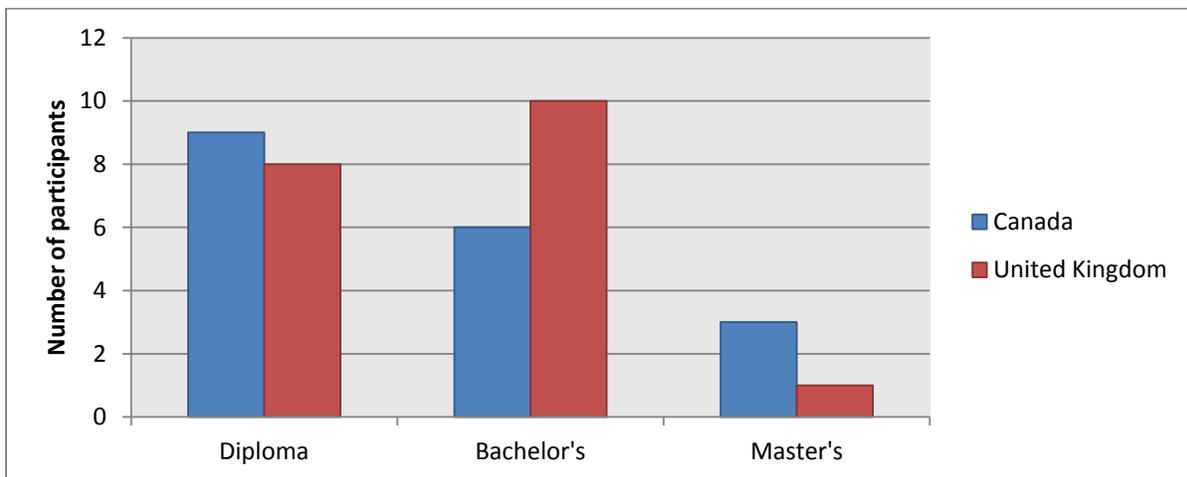
Overall, the Canadian panel was more experienced in respiratory care than the UK panel, with 72 percent of the Canadian panel having more than 10 years experience in respiratory care, compared with 26 percent of UK participants. Figure 7.1 shows participant experience by country.

**Figure 7.1 Years of participant experience by country.**



The educational levels also varied slightly between panels. More UK panelists reported a bachelor's degree as their highest level of education (27% UK, 16% Canada), while more Canadians reported a Master's degree as their highest level of education (8% Canada, 3% UK). Figure 7.2 shows the highest level of education reported by country.

**Figure 7.2 Highest level of education reported by participants by country.**



Data from the CRHP show that 11 percent of all members report a Master's degree as their highest level of education; unfortunately this information was not available for the BLF nurse population. While there are several differences between the groups, they are comparable as each panel represented how care is provided in their respective countries.

### **7.1.2 Comparison of Delphi Study Results**

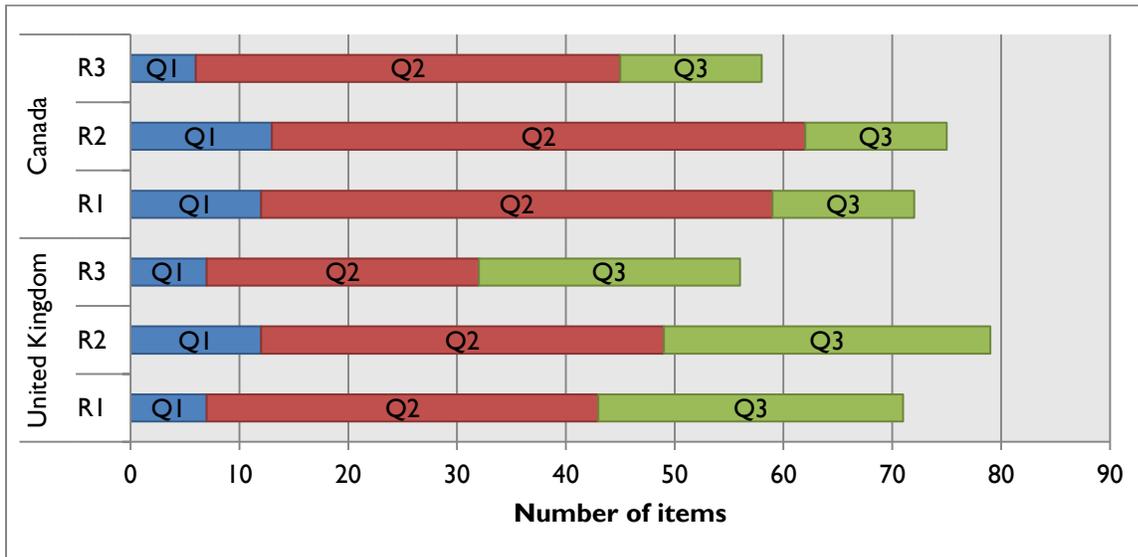
The results from the UK and Canadian Delphi studies are compared in the form of a narrative discussion regarding items that appear to be related to each other (section 7.1.2). Items from each Delphi were 'matched' thematically by inserting all Delphi consensus items into a table, and then looking for thematic similarities. Then all systematic review findings were entered into the table and again analysed for thematic similarities. The discussion of 'matched items' is followed by a narrative discussion of items that were not matched between Delphi studies. A discussion of implications of these findings and how the findings of this comparison contributed to the development of the theory of end-of-life discussions in NMRD can be found in Chapter 8.

#### **Matched items in the UK and Canadian Delphi Studies**

Given the similarities in prevalence, health systems and end-of-life care policies discussed in section 1.2, there was limited agreement between the Delphi panels from the two countries. Of 56 consensus items from the UK Delphi, only 22 had matching items from the Canadian Delphi. First, these matched items have been tabulated and briefly discussed, followed by tables and discussion of non-matched items from both Delphi studies in the next

section. Figure 7.3 shows the number of items from each round in the UK and Canadian Delphi studies.

**Figure 7.3 Number of Delphi items in each round by country.**



The matched items are organised by question as per the Delphi studies, and presented in Table 7.1, Table 7.2 and Table 7.3.

As shown in Table 7.1, the first matched item is that patient cues (verbal or non-verbal) indicate to health professionals that a patient is ready or willing to discuss end-of-life. However, it seems that the UK health professionals relied on verbal cues, while Canadians looked for non-verbal cues. Both of these items must be perceived by the health professional, thereby putting the onus on them to respond to such cues and may rely on the emotional intelligence of that individual.

The UK panel also listed several specific examples of how patients may initiate the discussion themselves, or verbal indicators, while the Canadian panel stated simply that the patient may initiate the topic themselves, directly or indirectly. The specific examples provided by the UK panel may be more helpful for novice practitioners, while the Canadian version leaves more room for interpretation and flexibility, and as such again may be highly dependent on the emotional intelligence of the health professional. The issue of emotional intelligence will be discussed in 8.2.2.

**Table 7.1 Matched items for Question 1: How do health professionals know a patient is ready or willing to discuss end-of-life?**

UK Item	Canadian Item
Cues from the patient such as stating 'I do not want to go to hospital'	Patient cues: for example, body language, facial expressions, open personality
Patient is responsive when I allude to the end-of-life topic	Patient responds when end-of-life topic is alluded to or initiated by the health professional
Patient states that they have 'had enough' or that they want to die	Patient initiates end-of-life topic with health professional – either directly or indirectly by bringing up death or end-of-life care in relation to something or someone else
Patient asks if s/he is going to die	
Patient refers to their own death	
Patient talks about or asks about hospice options	

Within the category of considerations in end-of-life discussions, there were several matches between the Canadian and UK Delphi studies as shown in Table 7.2.

The items *Allowing the patient to lead the conversation* (UK), and *letting the patient guide the discussion* (Canada) indicates that the discussion should be on the patient's terms. This may pertain to the idea of readiness versus willingness to discuss as raised in the UK Delphi as the

discussion would likely be shaped by the level of readiness or the willingness of the patient. Indeed, the level of readiness is another item that was matched in both Delphis. This issue is discussed in section 8.2.2.

Regarding the *presence or absence of family support in the patient's life (Canada)*, or *having the family's support during the discussion*, these may not seem to be the same, however they were matched because they both raise the issue that the absence or presence of family must be a consideration when having a discussion, as this would raise further considerations such as whether the patient needed the health professional to act as an advocate for their views with the family, or whether the patient wanted family members to be involved in decision making. The issue of family can be associated with cultural consideration and is discussed as further in section 8.2.2.

Three items from the Canadian Delphi were matched to the UK item *nurse having experience in caring for dying patients*. The Canadian panel divided the issue of experience into three areas: familiarity with the end-of-life process, experience and practice having discussions and knowledge of palliative care and end-of-life issues. This specificity of what experience in end-of-life discussions entails is potentially helpful for novice practitioners trying to gain such experience, as well as for educators. The assignment of a key health professional to discuss end-of-life with patients has been raised throughout this study, and this item may be helpful in determining who is most appropriate to be assigned on a team. This issue pertains to end-of-life policies in health care organisations and is addressed further in 8.2.2.

**Table 7.2 Matched items from Question 2: Key considerations for end-of-life discussions.**

<b>UK Item</b>	<b>Canadian Item</b>
Allowing the patient to lead the conversation	Letting the patient guide the discussion
Being open and honest with the patient	Being open/being honest (2 items)
Recognising the individual needs of the patient	Individual patient needs
Patient indicates readiness to discuss	Readiness of the patient to discuss
Where the discuss occurs e.g. clinical, hospital or patient's home (merged into 'having an appropriate environment for the discussion')	Privacy for discussion
Having the family's support during the discussion	Presence or absence of family support in the patient's life
Health professional having the confidence to discuss	Health professional being comfortable with approaching end-of-life topic
Nurse having experience in caring for dying patients	Health professional is familiar with end-of-life planning process/ Health professional having experience and practice having end-of-life discussions/ Health professional has knowledge of palliative care and end-of-life issues (3 items)
Patient having enough time to hear information and then ask questions later	Time available for follow up discussions
Availability of time to discuss	Time available to discuss

In the category of key topics in end-of-life discussions there were six matching items between the UK and Canadian Delphi studies, as compared to 18 UK items that were not matched in this category. This may be reflective of the impact of policy differences between countries as to what the important issues to address are, or cultural differences between populations. These issues are discussed in 8.2.2.

**Table 7.3 Matched items from Question 3: Key topics for end-of-life discussions.**

<b>UK Items</b>	<b>Canadian Items</b>
Introduction of an advance care planning document	Levels of advance care directives (supportive care only to full resuscitation)
The type of care the patient wants	How patient wants things to look at the end-of-life
Explaining palliative care	Patient understanding that they can receive palliative care
Patient goals	Health professional checking that day-to-day as well as longer term needs will be met
Spirituality	The patient's spiritual beliefs and how they may be incorporated into the end-of-life care plan
Option to change your mind about end-of-life decisions	Options to change your mind after making end-of-life decisions

### **7.1.3 Unmatched items in UK and Canadian Delphi Studies**

Unmatched items for each Delphi question are listed in Table 7.4, Table 7.5, and Table 7.6. Overall, these items reveal key differences between the UK and Delphi panel findings, which is essential for meeting the third objective of delineating the differences in end-of-life discussions for patients with NMRD. The items will be summarized here and discussed in depth in Chapter 8.

**Table 7.4 Unmatched items for Question 1: How health professionals know a patient is ready or willing to discuss end-of-life.**

UK Items	Canadian Items
Patient appears to be getting their affairs in order	Clinical indicators e.g. length of disease process, burden of disease, recent acute episode
	The health professional uses their emotional intelligence to gauge patient readiness
	There are situations when the patient's readiness to discuss end-of-life is not important, such as when the topic must be discussed immediately for practical purposes

Interestingly, the unmatched item 'clinical indicators' was proposed in early rounds of Question 1 in the UK Delphi, as was the use of intuition (relating to emotional intelligence) by health professionals, but neither gained consensus. In addition, the idea that there are emergency scenarios where the debate as to whether a patient is ready or willing is not relevant was novel in the Canadian Delphi.

The first four listed under the UK heading in Table 7.5 point to the educational role of health professionals for patients. This was not emphasized in the considerations of the Canadian Delphi perhaps because of the 'patient education context' section of Question 1. This difference demonstrates in the delivery of patient education in each country and implications are discussed in section 8.2.2.

**Table 7.5 Unmatched items for Question 2: Key considerations in end-of-life discussions.**

<b>UK Items</b>	<b>Canadian Items</b>
Answering the patient's questions regarding the condition	Family issues for the patient e.g. young children at home, unresolved family problems
Establishing the patient's understanding of their condition	Communicating patient wishes to their family
Explaining to patients what is feasible regarding their wishes	Sense of humour when appropriate
Educating the patient about their condition	Sensitivity to the patient's culture
Patient wanting to hear the information	Approaching the topic calmly
Having an appropriate clinician to discuss end-of-life with the patient	Approaching the topic with a caring nature
Emphasising a holistic care approach	Being respectful of the patient
Rapport between health professional and patient	Listening to the patient
Using non-medical language	Accepting the patient's reactions
Working within your professional boundaries	Knowing when to step back from the topic
Developing the discussion over time	Raising the topic early before a critical situation
Finding the right opportunity to discuss	Having end-of-life on a list of things that need to be talked about
	Having handouts of examples of advance care directives (paper resources)
	Responsibility of health professional to meet patient wishes
	Sensitivity to health literacy level of the patient
	Sensitivity to patient's language needs
	Health professional has attended education sessions about discussing end-of-life
	Emotional intelligence of the health professional
	Health professional acts as a neutral party to talk to the family about what is happening to the patient
	Patient's condition for discussion e.g. the patient is in the hospital with an acute episode or patient is trying to get their breathing under control early in the morning
	Multi-disciplinary team available to the patient
	Confirming patient understanding of the discussion
	Credibility of the health professional (as recognized by the patient)

The item 'having the appropriate clinician to discuss end-of-life with the patient' implies that this clinician has been assigned to the patient, or has a certain level of expertise or knowledge of the patient. What is not clear is whether the term 'appropriate' means from the view of other health professionals, or whether it is from the patient. If it is from the patient's view, then this item might be related to the Canadian item 'credibility of the health professional (as recognised by the patient)', but this cannot be assumed. The issue of the confidence of health professionals, again perhaps to assume they are the appropriate person, is raised. This is also associated with communication between health professionals to determine who this appropriate person is, so that they may acknowledge and carry out their role to discuss end-of-life with the patient as addressed in section 8.2.2.

Referring to the unmatched item; consideration of the rapport between the patient and the health professional', it is important to note here that this item is not about the necessity of the existence of a rapport, but rather considering whether such a rapport exists before having a conversation. This is indirectly associated with several items from the Canadian Delphi regarding specifics on how to approach the discussion that may help to establish a rapport, or at least make the patient comfortable such as 'approaching the topic calmly, with a caring nature, being respectful of the patient, listening to the patient, accepting the patient's reactions, using a sense of humour and knowing when to step back from the topic. Again, these Canadian items imply the existence of emotional intelligence in the health professional, and the explicit use of such intelligence when approaching end-of-life discussions, as will be discussed in section 8.2.2.

Using non-medical language was another UK item that was not matched in the Canadian Delphi. However, this item may correspond to the issue of sensitivity to the health literacy level of the patient, as well as sensitivity to the patient's language needs. While the latter item likely refers to the patient's language of origin, sensitivity to both aspects may imply the avoidance of the use of non-medical language. The issue of language is also connected to the unmatched Canadian item 'sensitivity to the patient's culture'. These items are dealt with in section 8.2.2.

The UK item of *working within your professional boundaries* was unique to the UK panel. However, it brings to light an issue of whether professional boundaries are different for Canadian and UK health professionals. Several of the Canadian health professionals shared in Round I interviews how they used their own personal experiences with death when discussing end-of-life with patients (section 6.2.1 – framing the discussion appropriately). This was contrary to UK health professionals, who stated that to bring their own personal beliefs or experiences to patient conversations would be taboo and inappropriate. This points to a potential difference in the openness of health professionals in each country and the potential impact that this may have on end-of-life discussions.

One issue that was raised in several items in the Canadian Delphi was the role of the health professional to mediate between the patient and their family, in some cases acting as an advocate on the patient's behalf. Another item exclusive to the Canadian Delphi findings was the training and experience of the health professional, and again the explicit statement regarding the emotional intelligence of the health professional. The feeling of responsibility for the health

professional to meet the patient’s wishes once they were communicated was also unique to the Canadian Delphi. While health literacy, language and culture have already been mentioned, the *patient’s physical condition for discussion* was also raised as a consideration in the Canadian Delphi. Finally, the availability of a multi-disciplinary team was an item raised only in the Canadian Delphi.

**Table 7.6 Unmatched items from Question 3: Key topics in end-of-life discussions.**

<b>UK Items</b>	<b>Canadian Items</b>
Emergency management preferences	Patient understanding of their option to make end-of-life choices
Anticipatory prescribing	Patient deciding on a substitute decision maker
Ceiling of treatment	Patient understanding of the ‘chain of command’ of decisions makers should their be a dispute when the patient is unable to speak for themselves
Medication options	Making sure doctor knows what kind of care the patient wants
Treatment options	Walking the family through the process of what will happen when the patient dies
Intubation and ventilation options	Explaining implications of end-of-life decisions and care to family
Preferred place of care	Discussing the positive and negative consequences of treatments or interventions with patients
Preferred place of death	Educating patients about their end-of-life choices and implications
When the patient is likely to die	Goals of care
Sedation availability/options	Explaining where they are in their disease; for example: at a stage where there is no cure: focus symptom management
Social services involvement	
Transferring to palliative care	
Dealing with breathlessness	
How they feel about death	
Practical equipment needs	
Support in the home	
Transportation needs to facilitate care	
Needs of the partner/significant other	

The unmatched items for Question 3 from the UK and Canada are highly distinguishable. The UK consensus items are all practicalities regarding current and planned end-of-life care,

while the Canadian items are all related to confirming understanding with patients and clarifying understanding with other health professionals and family members. Again, this difference could be related to the roles that health professionals hold in each country. While all items relate to education, the UK findings seem more in-line with a case management support approach, compared to the Canadian findings, which seem to be more related to the provision of psychosocial support.

## **7.2 Discussion**

There was an interesting difference in the educational role of health professionals in each country. Several items from the UK panel were related to this role, and the Canadian Delphi resulted in an entire subcategory of findings regarding the patient education context.

In Canada, most patients attend sessions related to their COPD run by a certified COPD educator, which is a specific qualification to perform this role. Often, information about end-of-life care is provided, although it is may be delivered in an informational ,rather than a conversational, context. This is in contrast to one-on-one patient education, which is the primary method delivered by the British Lung Foundation Nurse Programme.

One key difference between the findings of the Delphi panels was related to the educational role of health professionals for patients. It was clear from the UK items such as *answering the patient's questions regarding the condition, establishing the patient's understanding of their condition and educating the patient about their condition* that educating the patient is a part of the role of health professionals in the UK. However, in the Canadian Delphi, an entire sub-

section of responses to Question 1 was related to the patient education context, pointing to the difference in delivery of patient education in non-malignant respiratory disease.

An Evaluation of the British Lung Foundation Nurse Programme (2008) stated that education was delivered one-to-one to patients and also in group contexts, while in Canada a range of health professionals deliver educational interventions to patients and there is a professional designation 'COPD educator' held by several participants (Stolikova et al 2013). The issue of patient education and the potential implications for end-of-life communication are discussed in Chapter 8.

Sensitivity to patient culture was an item from the Canadian Delphi that did not arise in the UK Delphi. This highlights the important consideration that patients come from various cultural backgrounds and health professionals should not assume that patients' values are consistent with those that guide western-based medicine, as cultural variants are highly likely to have a direct impact on how patients and their families understand death (Bullock, 2011).

The item *Health professional having experience and practice having end-of-life discussions* gained consensus in the Canadian Delphi. This may relate to the provider's personal or professional experience. This item had developed out of several participants in Round 1 stating that they shared their personal experiences of death and dying with their patients as examples of why end-of-life discussions are important, in addition to emphasis on the idea that you get better at discussions as you practice them. Along with the item *Health professional being comfortable with approaching end-of-life topic*, this brings in an important point about professional

boundaries in end-of-life communication in Canada. Using personal experience may be something that is not often discussed in the literature, or recommended because of the potential for this to go wrong, however, when done appropriately it can be a very effective way to start an open and honest discussion about end-of-life with patients as was relayed by the participants. Interestingly, there are currently no guidelines issued by the Nursing and Midwifery Council specifically related to self-disclosure, unlike Canadian nursing bodies such as the College of Registered Nurses of British Columbia and Nova Scotia (College of Registered Nurses of British Columbia, 2006), which have issued specific guidance on self-disclosure in nurse-client relationships. For example:

*'Self-disclosure occurs when the nurse shares personal information with a client. Self-disclosure may be used in moderation as long as it is focused on the needs of the client. In these situations disclosing personal information may have the therapeutic intent of reassuring, counselling or building rapport with clients. Disclosing personal information that is lengthy, self-serving or intimate is never acceptable.'* (Nurse-Client Relationships, College of Registered Nurses of British Columbia, p. 13)

This relates to the social penetration theory and the norm of reciprocity from the communication literature. Social penetration theory, often described using the onion metaphor, suggests that there are layers upon layers of self-disclosure (Bylund et al., 2012). Surface levels of information are regularly shared with others, but the intermediate and central layers containing private information are not until they are revealed as relationships develop through reciprocal self-disclosure. However, patients and providers are unlikely to regularly have reciprocal levels of disclosure, leading to a violation of the normal pattern of social penetration

(Bylund et al., 2012). Therefore, perhaps some self-disclosure of provider's experiences with making end-of-life decisions may help to encourage patients to do the same.

One interesting consideration in end-of-life discussions in the Canadian Delphi was health literacy of the patient. This was not mentioned in the UK Delphi, however it is an important issue. Health literacy is defined as 'The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course' (Rootman and Gordon-El-Bihbety, 2008, p. 11). Approximately 55 percent of Canadians between the ages of 16 to 65 scored below Level 3 on the International Adult Literacy and Skills Survey Health literacy scale (Learning, 2007). Only one in eight adults (12%) over the age of 65 appears to have adequate health literacy skills (Rootman and Gordon-El-Bihbety, 2008) which is concerning given that patients with lower health literacy are more likely to be hospitalized, have poorer understanding of treatment and lower adherence to medical regimens (Mahadevan, 2013). This is particularly important in COPD as this group have complex treatment regimens, and often have multiple meetings with a range of healthcare professionals (Roberts et al., 2008), while cognitive impairment in elderly patients may be an additional barrier to understanding (Allen and Ragab, 2002).

As an example of the prevalence of limited health literacy, it was shown that 59.2 percent of COPD patients did not understand the term 'exacerbation', and only 1.6 percent could explain the term correctly (Kessler et al., 2006). A minimum of 15 percent of patients may have diminished literacy and it is emphasized in the health literacy literature that the 'magnitude' of low health literacy should be recognized rather than trying to identify specific

individuals. Therefore, strategies to improve understanding for all patients such as decision aids, pictograms, leaflets and videos may be helpful to use in consultations (Roberts et al., 2008).

### **7.3 Conclusions**

In order to meet the third objective of the doctoral study: to delineate the differences between end-of-life discussions in NMRD in Canada and the UK, a comparison of results of the UK and Canadian Delphi studies was conducted and findings were briefly discussed in section 6.4. While differences in the literature from each country are delineated in chapter 3, further differences between the UK and Canada regarding patient education and the roles of the health professional regarding providing psychosocial support and cultural issues in each country were highlighted from this comparison of Delphi studies. The findings also demonstrated that issues such as patient culture and health literacy levels are key issues that perhaps are not properly addressed by health professionals in the UK. The discrepancies between findings in each country highlight the benefit of conducting international comparative studies as a way to provide insight into practice and inform future developments in each country, as well as to determine the best solutions for individuals with complex needs and their families (Higginson, 2005). The way that these findings and others from this phase contribute to the development of theory and construction of the model of end-of-life discussions is delineated in Chapter 8.

## **Chapter 8. Discussion**

### **8.1 Introduction**

The findings of each of the four phases of this study have been discussed in relation to the previous literature in sections 2.5, 3.6, 5.8 and 6.3. As per the MRC guidelines for the development of complex interventions, the key findings of each phase will be translated into a theoretical model of end-of-life discussions in NMRD. In this chapter, first, the aims and objectives of the study will be reviewed as a reminder to the reader in section 8.2. This will be followed by the presentation of the theoretical model of end-of-life discussions in NMRD (section 8.2.1) and an examination of each of the components of this model in relation to the current literature (section 7.2.2). Conclusions and recommendations resulting from the study are presented in Chapter 8.

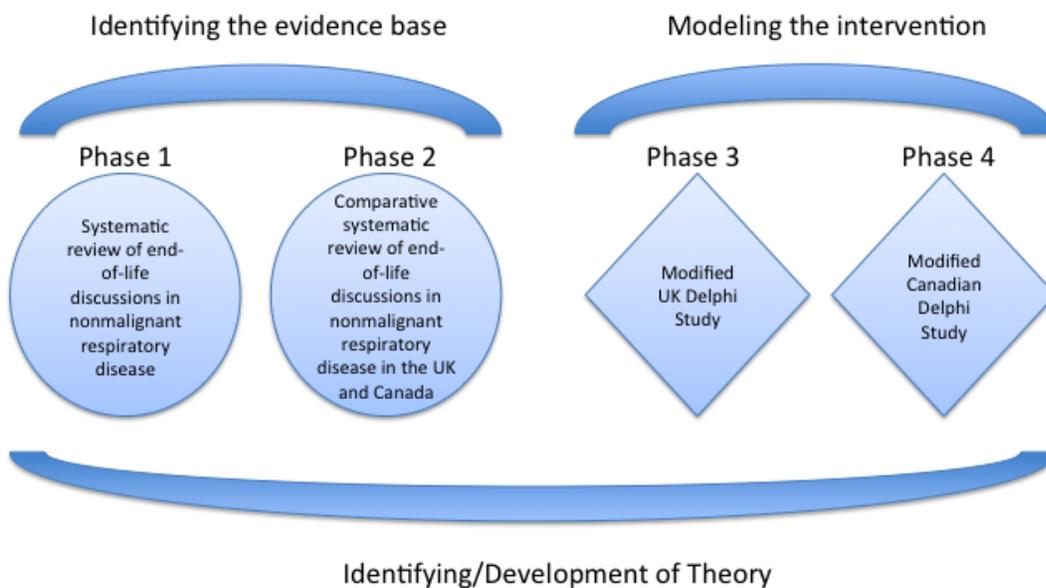
### **8.2 Study Aims and Objectives Reviewed**

As outlined in the introduction chapter, the aims of this doctoral study were to: 1) determine how health professionals discuss end-of-life with patients with NMRD in the UK and Canada, and 2) develop an instrument allowing health professionals to determine constraints and opportunities within the environment to facilitate successful end-of-life discussions with this patient group in the UK and Canada. The study aims were addressed through the following objectives: a) establish and validate how health professionals know a patient with NMRD is ready or willing to discuss end-of-life, b) establish and validate the key considerations and key

topics in such discussions as defined by health professionals in the field, and delineate the differences in end-of-life discussions for patients with NMRD in the UK and Canada.

The aims and objectives were achieved through four phases of study including two systematic reviews and two Delphi studies. Figure 8.1 summarises this process.

**Figure 8.1 Four phases of a study to develop a complex intervention adapted from MRC (2008).**



The study was designed to achieve the development phase for complex interventions as outlined by the MRC (2008), and included identifying the evidence base, modelling the intervention and developing a theory.

The following theoretical model encapsulates the findings relating to the first study aim of how end-of-life is discussed in NMRD that emerged from each phase of the study. The tools that were developed as a result of the UK and Canadian Delphi study to model the intervention achieve the second aim of the study are presented in Figure 5.6 and Figure 6.6. The plans for the piloting and evaluation of these tools as per the next stages of developing an intervention (Figure 1.1) are discussed in detail in the recommendations for research in section 9.5 of Chapter 8.

### **8.2.1 Theoretical Model of Findings – facilitators and barriers to end-of-life discussions in nonmalignant respiratory disease**

Several themes were identified throughout the systematic reviews and Delphi studies that contributed to the model. In the first systematic review the responsibility of the health professional to initiate the discussion, along with the patient's desire for end-of-life information were identified as issues in end-of-life discussions. The first systematic review also brought forth the importance of the recognition of facilitators and barriers for individuals discussing end-of-life, and the importance of having an ongoing discussion over time, and power issues between health professionals and patients in such discussions.

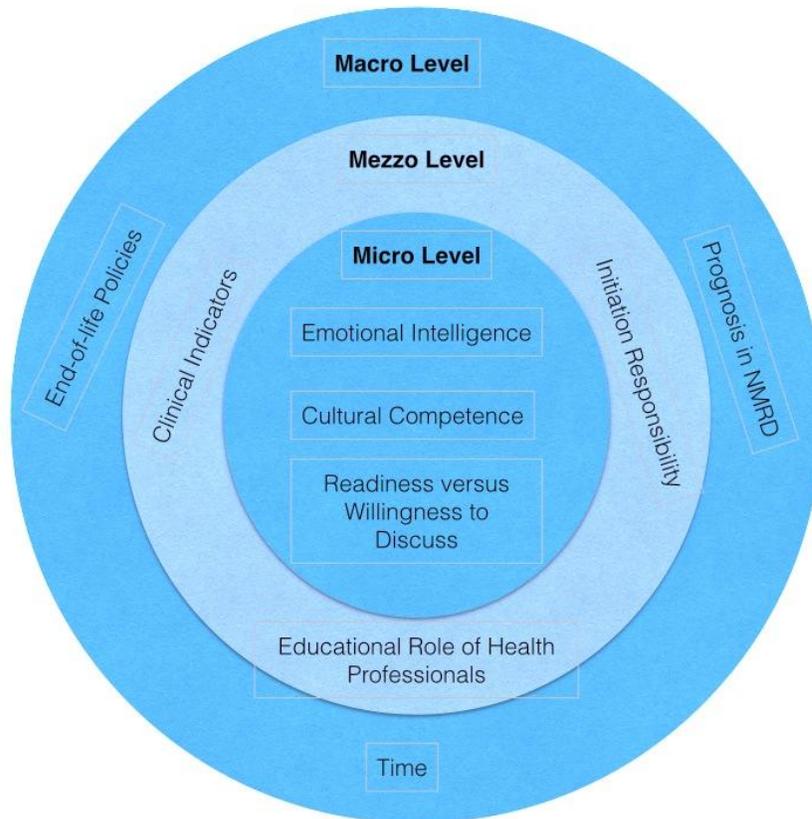
The second systematic review identified the use of clinical indicators as a contentious issue in end-of-life discussions, as well as the complication surrounding providing patients with a prognosis in NMRDs. The relation of end-of-life policies to the occurrence of discussions was also raised, in relation to the use of advance care planning documents. The significance of the role of family, as well as sensitivity to cultural issues was also identified through this review.

While again, the issue of the health professional's responsibility to initiate end-of-life discussions was evident throughout the findings of the second systematic review.

The findings of the Delphi studies conducted in phases 3 and 4 of the doctoral study complimented and built on the findings of the systematic reviews. The importance of the role of health professionals as educators in end-of-life discussions evident in both studies, as was the importance of recognising cultural, spiritual and individual needs for patients. Interestingly, the use of emotional intelligence by health professionals to gauge end-of-life discussions was raised in each Delphi study, yet the UK findings focused exclusively on perceiving verbal cues, while the Canadian study focused on the perception of non-verbal cues. Finally, the differentiation between readiness and willingness to discuss emerged as an important issue in the analysis of the UK Delphi findings, and is believed to be a key issue in end-of-life discussions.

These issues, along with the key theme of time that was evident throughout the phases of the study will be discussed in the following sections in relation to the theoretical model of end-of-life discussions in NMRD that has been developed as a result of the findings.

**Figure 8.2 Theoretical model of how health professionals discuss end-of-life in nonmalignant respiratory disease.**



This model presented in Figure 8.2 is based on the systems theory of social work, which is an organizing conceptual framework for understanding individuals within their environment (1983). This model applies to all health professionals, not just social workers, and it was thought that the multi-level system model would be helpful to explain the considerations that need to be made regarding the individual in the larger social context in relation to end-of-life discussions in non-malignant respiratory disease. Systems theory is useful for understanding the dynamics of

an individual patient in order to make sense of problems and develop balanced intervention strategies (Meyer, 1983).

This model is divided into three systems – macro, mezzo and micro. Briefly, Microsystems refer to small social systems like individuals and health professionals, mezzo systems typically include groups, and networks, and macro systems are large systems like communities and organizations (Friedman and Neuman, 2011). In this system, the macro level, which can represent health care in general, the health system in a given country and the society in which it functions includes three components: end-of-life policies; prognosis issues in non-malignant respiratory disease; and the notion of time. Policies related to end-of-life care govern end-of-life discussions as they dictate priorities and access to resources for health professionals, patients and families. For example, as discussed in the introduction, the fact that 76 percent of adult inpatient specialist palliative care units in the UK are run by charities, will dictate availability to patients in certain areas, and therefore whether inpatient palliative care is offered as an option to patients during end-of-life discussions.

At the Macro level, discussions related to end-of-life in non-malignant respiratory disease are also determined by the difficulties in providing a prognosis for this type of disease. As addressed in the introduction chapter, the problems related to providing a prognosis, along with the lack of a consistent disease trajectory can severely hamper end-of-life discussions (Clayton et al., 2005).

The notion that time is passing for people and health professionals working with a life limiting condition is key and relates to policies, the use of clinical indicators or not, the issue of providing a prognosis and the responsibility to initiate a discussion. Time also provides a specific problem in certain environments such as hospitals where health professionals state that sufficient time to discuss end-of-life issues is not allocated in their clinical practice.

Next, at the Mezzo level, which includes the role of the health professional with a given patient and within a given institution are three important components of end-of-life discussions in non-malignant respiratory disease: the use of clinical indicators to signal timing for end-of-life discussions, the responsibility to initiate end-of-life discussions, and the educational role of health professionals. As discussed in sections 5.3.1, 5.86.2.1, the use of clinical indicators to indicate the timing of end-of-life discussions arose as a contentious issue throughout the doctoral study. It gained consensus in the Canadian Delphi, but not in the UK Delphi, but is identified as a key trigger for end-of-life care in policy (2006). As a part of this model of end-of-life discussions, it is present as something that must be considered by health organisations and the health professionals within them.

Next, the issue of whose responsibility is it to initiate end-of-life discussions arose throughout the study. As discussed in section 3.5.4, this is another issue that must be considered when approaching end-of-life discussions and is in the mezzo section as again it applies to both health organisations and the health professionals within them. In section 3.6 it was recommended that a key health professional be assigned to each non-malignant respiratory

disease patient with the explicit responsibility for end-of-life discussions, with a clear understanding of the components within the Macro and Micro Levels.

The role of health professionals as educators for patients with non-malignant respiratory disease was significant in the Delphi findings in both the UK and Canada. This educational role may include formal education sessions for groups of patients, as well as informal education such as answering patient and family questions about their condition, explaining palliative care, and accessibility of services. This educational role arose as highly imperative as it is can be the gateway to end-of-life discussions, and the processes that occur at the micro level.

The issue of emotional intelligence at the Micro Level is a key component. This issue came out in both Delphi studies. While the Canadian Delphi panel agreed that the health professional uses emotional intelligence to gauge patient readiness (section 6.3), the UK Delphi stated that the health professional must perceive verbal cues from patients (section 5.8). It seems clear that emotional intelligence is not only related to gauging patient readiness, but also to the educational role of health professionals and cultural competence.

The next key issue that arose throughout the findings of this doctoral study was cultural awareness or cultural competence including health literacy and language. In this discussion it is important to distinguish that culture can mean the culture within a family, within a group of individuals, or even within a particular hospital. The key issues here are the role of family and end-of-life discussions and this came out in the systematic reviews and the Delphi studies as something that could either be beneficial or detrimental to the end-of-life discussion.

Within the consideration of cultural issues, the consideration of the health literacy of the family and patient was brought forward as an issue. This could involve ensuring that the patient understands their condition, which also relates to the role of the health professional as an educator, but also to providing information using non-medical language and providing ample opportunity for the patient and family to ask questions.

The use of the terms 'readiness' and 'willingness' were not initially meant to conceptually distinguish between readiness versus willingness, instead it was meant to provide further explanation to the reader to Question 1. However throughout analysis of the data it turned out that there was a difference between readiness and willingness to discuss (section 5.3). It transpired that this is a key distinction when perceiving the ability of a patient to have an end-of-life discussion and therefore it is one of the key aspects of this model of end-of-life discussions in NMRD.

This model is not meant to be prescriptive as it has been established that formal processes for discussion are problematic (section 1.4). Indeed many components could easily be placed within an additional level, such as emotional intelligence and cultural competence, which could be related to how health professionals are trained at the macro level. Therefore each component should be thought of as equally important when approaching end-of-life discussions in non-malignant respiratory disease. This model simply identifies the key components identified in this doctoral study that must be considered in such discussions, and may be helpful when addressing the education of health professionals down to approaching a discussion with an individual patient or family. Each of the considerations in this model will be

discussed in relation to their contexts in current end-of-life policy and research in the sections that follow.

In addition to the tools developed for the UK and Canada outlining 'how health professionals know a patient is ready or willing to discuss end-of-life', this model helps to understand the issues at hand when approaching such discussions. The considerations and topics for discussion make up the components of end-of-life discussions. The model can be viewed as per Donabedian's (1973) model of patient-professional communication and Roter and Fallowfield's (1998) view of patient centered medicine, as raised in section 1.4, where the different perspectives of health professionals and patients may create obstacles in communication. The model proposed here may help health professionals to gain insight into the perspective of the patient, leading to more patient-centered consideration of psychosocial consequences and allowing them to make choices appropriate to their individual context. It is hoped that this would thereby enable more successful communication about end-of-life.

## **8.2.2 Context of Findings within the Model**

### **Emotional intelligence**

The idea that health professionals use their emotional intelligence to gauge patient readiness gained the consensus opinion of the participants, as did the need to interpret verbal and non verbal cues from patients. Bulmer Smith et al. (2009) review the concept of emotional intelligence and examine the various definitions put forth by the key scholars in the field who define it as an ability (Mayer and Salovey, 1997), a set of traits and abilities (Bar-On, 2005), or a

combination of skills and competencies (Goleman, 1998), and state that a convergent definition does not exist (Bulmer Smith et al., 2009). However, it is thought to include the ability to know and manage one's own emotions, expressing empathy to others and the ability to recognize subtle cues of changes of emotions in others (Goleman, 1995).

Emotional intelligence of nurses may have a positive impact on patient outcomes, as nurses who enter the patient's home as guests are often confronted with emotionally charged situations and therefore they must be prepared to manage their own and others' emotions (Bulmer Smith et al., 2009, Davies et al., 2010). Emotions are key indicators of the moral aspects of a situation where a decision must be made, therefore can contextualise decision-making processes and ultimately help the health professional to be more empathetic and patient focused (Freshwater and Stickley, 2004, Evans and Allen, 2002, Gooch, 2006).

In concordance with the findings of this study, being able to recognize the right timing to have end-of-life discussions has been described as a skilled process of 'feeling your way', which includes knowing the patient, and possessing emotional intelligence (Crawford, 2010). The discussion of end-of-life topics may bring forward deep fears or feelings of the health professional (Teasdale et al., 2001). The possession and development of emotional intelligence are fundamental for growth for nurses and other health professionals (Heffernan 2010), but in order to enable growth, formal and informal supervision and reflection processes are an essential part of the process (Davies et al., 2010, Teasdale et al., 2001).

## **Educational role of health professionals**

Patient education emerged as a key issue throughout the doctoral study. Several consensus items in both Delphi studies included items related to patient education such as:

- Explaining palliative care
- Answering patient questions about the condition
- Educating patient about the condition.

In addition, a lack of consensus in one area of the Canadian Delphi brought to light that assumptions may be made, particularly in the patient education context, of which we should perhaps be aware.

Patient education has been defined as the ‘teaching or training of patients regarding their own health needs’, and more specifically as providing disease specific information and skills by Bodenheimer (2002). Patient education interventions may range from the provision of leaflets to educational programmes that involve several sessions on various topics.

An Evaluation of the British Lung Foundation Nurse Programme (2008) found that the most important elements of the BLF Nurse role were clinical activities and patient education.

The principle method of education was one-to-one education supplemented by printed materials, while they also reported delivering group education (Angus Forbes, 2008). Education was for both patients and carers and other health professionals. It was delivered formally and informally. An important part of this education was establishing the Breathe Easy groups for patient support throughout the UK. Indeed, this is reflected in the literature stating that

educating patients has historically been a key feature of nursing practice (Henderson, 1966), and that patients may find nurses more approachable for information than physicians (Collins, 2005). However, the demographics of the Canadian Delphi study show that a range of health professionals, often respiratory therapists, in Canada deliver educational interventions to patients, and this is supported by a study by Stoilkova et al. (2013). A recent systematic review found that it is difficult to assess whether the profession of the health professional delivering the education was important for the effectiveness of the intervention, as many studies do not report the profession of the health professional (Coster and Norman, 2009).

Round I interviews of the Canadian Delphi revealed that often respiratory patient education programmes include a session about end-of-life decision making; however, the experts did not agree that attending such a session meant that patients were necessarily ready to discuss end-of-life (section 6.2.1).

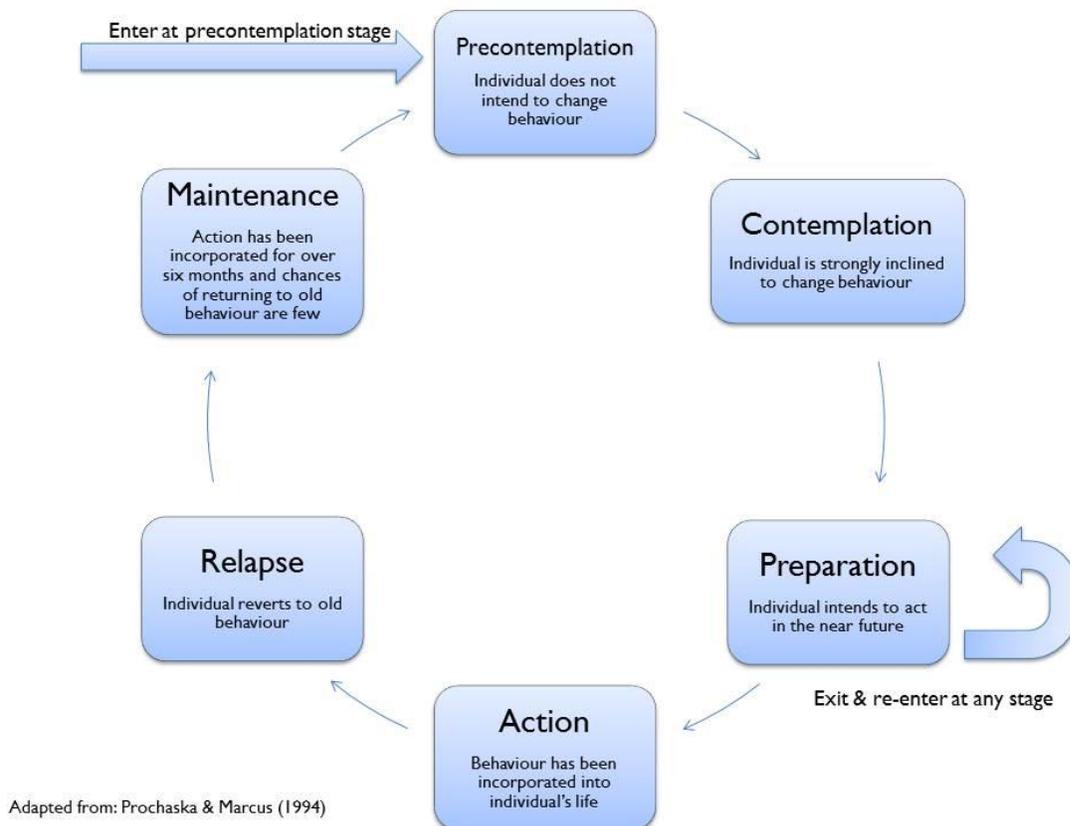
Therefore, as patient education is also a large part of the role of BLF nurses (Angus Forbes, 2008), and is essential for COPD patients, perhaps it can be viewed as part of the process to move patients to moving patients towards readiness to discuss (as discussed in the following section). However, in patient education, the level of health literacy of the patient must be taken into consideration. Patients with lower health literacy have been found to have higher rates of hospitalization, poorer health outcomes, increased mortality, a poorer understanding of the disease process (Eckman et al., 2012) and therefore it is essential that patient education interventions be targeted to the health literacy level of the individual patient,

and that a lack of interest or participation by the patient not be necessarily dismissed for this reason.

### **Readiness versus willingness to discuss end-of-life**

The previous section regarding the educational role of health professionals brings us back to the concept of readiness, as raised in the UK Delphi Chapter (section 5.3). The concept of readiness is part of the transtheoretical stages of change model proposed by Prochaska et al. (1994). This model is focused on the decision making process of the individual and relates to intentional change, assuming that change in behaviour occurs through a cyclical process.

**Figure 8.3 Transtheoretical stages of change model.**



Through the lens of this model, Patients may be guided toward readiness to discuss end-of-life by the health professional using a semi-structured approach, such as the one discussed in Rizzo (2010). Perhaps then this stage of the patient education process does not indicate readiness, but is a stepping stone in preparation to discuss. Attending the education may be part of the stage that Fowler (1998) describes when the patient realizes that making a change would be beneficial. Alternatively, it would be explained by Prochaska et al. (1994) as the pre-

contemplation phase is where the patient increases their awareness of the benefits of discussing end-of-life.

This could be directly related to the lack of consensus that the participants had on the item that a patient following up on information from such an education session implies readiness to discuss (Table 6.4). Instead, this could be part of the contemplation phase (Prochaska et al., 1994) where the patient is seeking more information, but is not necessarily ready to address this issue.

In both of these situations in the patient education context, it is up to the health professional to assist patients to move toward the next stage of behavioural change - the preparation and action phases (Prochaska et al., 1994). Therefore, it is important that health professionals are aware of the concept of readiness, how it can be established, and the stages of change transtheoretical model, so that they can apply it in their work, and perhaps design their patient education programmes around it.

Understanding ways patients indicate readiness or willingness to discuss can help to facilitate end-of-life conversations. Differentiation of the concepts of readiness and willingness when discussing end-of-life may be an important distinction.

The concept of readiness in the context of patient behavior is discussed by Fowler (1998), Medvene et al. (2007) and Rizzo et al. (2010). While Fowler (1998) gives a clear definition of readiness in the context of patient behavior, Medvene et al. (2007) and Rizzo et al. (2010) view patient readiness as a continuum within the Stages of Change Transtheoretical

Model (TTM) (Prochaska and DiClemente, 1985). Informed by the stages of change theory (Prochaska and DiClemente, 1985), stages of readiness theory (Rohren et al., 1994) and reversal theory (Lafreniere, 1993), Fowler (1998) claims that there are five elements that indicate a person's readiness: 1) The person realizes that change would be beneficial; 2) The person has identified barriers to change and is willing to remove these barriers; 3) The person has taken responsibility for making the change; 4) The person is in control of their own behavior; 5) The person must want to take action. With this approach, health professionals are looking for indication of readiness rather than guiding patients toward it. This is compared to the purely TTM approach, where health professionals guide patients toward readiness by assisting them to weigh the pros and cons of changing their behavior (deciding to talk about/make plans for end-of-life) using a semi-structured approach.

Therefore, while Fowler (1998) gives an explicit definition of readiness, Rizzo et al. (2010) and Medvene et al. (2007) link explicit readiness with the preparation ('someone intends to take action but is not yet ready to make change' (Prochaska and DiClemente, 1985)) and the action stage of TTM (where 'behaviour is modified enough to produce clinically-significant change'(Prochaska and DiClemente, 1985)). Fowler (1998) believes that the role of the health professional is to identify readiness in their patients, while Rizzo et al. (2010) and Medvene et al. (2007) view the health professional as someone to guide the patient toward readiness. This is compared to the concept of willingness, which is not influenced by the health professional, but is instead spontaneously exhibited by the patient.

The concept of 'willingness' to communicate has been identified as the likelihood that a person will initiate communication when there is opportunity to do so (Burgoon, 1976, McCroskey and Baer, 1985, MacIntyre, 1994). While willingness to communicate is acknowledged to be a personality trait, there is high variation across situations (McCroskey and Richmond, 1987). It has been found that a person's willingness to communicate about their health is related to the amount of health information they desire, as well as their assertiveness in communicating with health professionals, and this may vary on a daily basis. Therefore, willingness is not influenced necessarily by the health professional, as compared to the concept of readiness, which is something that the health professional may help the patient to move toward (Wright et al., 2007). The indicators from the Delphi study that demonstrate a patient is ready to discuss end-of-life are summarised in Table 8.1 Indicators of 'readiness' and 'willingness' to discuss end-of-life from the UK Delphi. Table 8.1.

**Table 8.1 Indicators of 'readiness' and 'willingness' to discuss end-of-life from the UK Delphi.**

'Readiness' indicators	'Willingness' indicators
<ul style="list-style-type: none"> <li>• Verbal cues from the patient such as stating 'I do not want to go to hospital'</li> <li>• Patient is responsive when I allude to the end-of-life topic</li> <li>• Patient appears to be getting their affairs in order</li> </ul>	<ul style="list-style-type: none"> <li>• Patient asks if s/he is going to die</li> <li>• Patient refers to their own death</li> <li>• Patient talks about or asks about hospice options</li> <li>• Patient states that they have 'had enough' or they want to die</li> </ul>

## **Cultural competency**

The recognition of the culture of the patient and the family has been established as a key component of end-of-life discussions in NMRD. In this discussion, culture refers to “patterns of explanatory models, beliefs, values and customs” (Crawley, 2005) which are expressed either materially (such as in dress, diet or ritual practices) or nonmaterially (such as in language, social order or kinship systems) (Crawley, 2005); while ethnicity is a way of grouping people based on historical identity, geographic identity or shared cultural patterns (Crawley et al., 2002). In the UK, the term ‘minority ethnic group’ is used for purposes of official classification by the Office for National Statistics to describe groups of people who do not identify themselves as ‘white British’ (Evans et al., 2011). The author would like to acknowledge that while it is essential to understand differences between cultural and ethnic groups, it is also important to understand how individuals within such groups vary, and not use a prescriptive approach (Kwak and Haley, 2005).

The recognition of the cultural beliefs, values and patterns of behaviour in patients and their families is of essential importance when planning end-of-life care as these cultural variants are likely to determine how specific groups make sense of life and death, and how they make end-of-life decisions. As the population in the UK and in Canada becomes more diverse, it is less likely that patients and families values, structures and functioning will be consistent with those upon which traditional Western medicine is based. Therefore, in order to meet the needs of patients and their families, cultural competence on the part of health professionals is essential (Bullock, 2011).

While the influence of culture and ethnicity on end-of-life decision making has been acknowledged in the literature, particularly since the Macpherson Report highlighting the disparities for health care for minorities in the UK (1999), there has been limited uptake of advance care planning by minority groups in Canada and the UK (Johnstone and Kanitsaki, 2009, Evans et al., 2012). In the UK, several policy initiatives related to ensuring equal access for minority ethnic groups to end-of-life care services such as the End-of-life Care Strategy (2008) state the importance of sensitivity to cultural and religious differences, and highlights the need for cultural competency training in order to provide culturally sensitive care (Johnstone and Kanitsaki, 2009). Despite such initiatives, health professionals are often unaware of, and surprised by the extent that patients and families of such groups distrust the medical system and feel unsafe within it (Johnstone and Kanitsaki, 2009). As a result, health professionals may be exasperated by what they may view as hostile resistance regarding end-of-life planning, and an incapability to understand and accept the benefits of such planning and discussion. On the other side, patients and families feel perplexed by the health professionals incapability of understanding the meaning of their actions which are meant to protect their loved ones (Johnstone and Kanitsaki, 2009). It is with this view that patients from minority groups are fearful that policies related to end-of-life care and planning may not benefit them, but work to their detriment (Baker, 2002).

One of the key misunderstandings that arises is that in some cultures, discussing death and terminal illness is interpreted as an immediate death sentence. This was identified as the 'Nocebo' phenomenon by Helman (1990), which is the negative effect that beliefs and

expectations can have on health outcomes, the reverse effect of the 'placebo effect', where inappropriate disclosures regarding end-of-life is problematic because of the potentially harmful 'nocebo' effect that may be triggered. As a result, disclosures that are culturally inappropriate can be perceived and experienced as 'authoritarian, paternalistic, disrespectful and demeaning, and received with shock and dismay', despite the good intentions of the health professional who is coming from a place of compassion and ethical practice (Candib, 2002, p. 222) This may explain why in some groups the family acts as a gatekeeper to ensure that any disclosures that are made do not result in a loss of hope for the patient ((Johnstone and Kanitsaki, 2009, McGrath et al., 2005, Kwak and Haley, 2005).

A hindrance in end-of-life discussions is the lack of understanding by health professionals of the dominance of the Western bioethical view. (Johnstone and Kanitsaki, 2009). The primary feature of this viewpoint is the overriding concept of autonomy, which some groups may feel is alienating and oppressive (Candib, 2002). Therefore, the mainstream view of autonomy must include respecting the cultural values of individuals, and their right to cultural liberty (the right to maintain their ethnic, linguistic and religious identities) (Johnstone and Kanitsaki, 2009). In some cases, the ultimate expression of autonomy may be the choice not to make a decision, but to waive their right to autonomy to another person (Candib, 2002).

These issues of poor communication between health professionals and patients and families from minority ethnic groups were repeatedly emphasized in a systematic review of the primary research on minority ethnic groups and end-of-life care from the UK by Evans et al. (2012). This review highlighted the specific issues of differences in social taboos about death

and illness, the lack of information in appropriate languages and formats, the inadequate provision of interpreting and advocacy services and difficulties in understanding and communicating verbally and nonverbally. It is clear that understanding cultural values, attitudes and behaviours can help to create more positive interactions with patients and their families and ultimately result in better patient outcomes (Reith and Payne, 2009). There are several examples of ethnic variation in end-of-life preferences in the literature (Bowman and Singer, 2001, Carrese and Rhodes, 1995, Matsumura et al., 2002, Perkins et al., 2002, Murphy et al., 1996) however, due to the scope of this discussion, the findings of these studies will not be discussed here.

However, the issue of providing culturally competent care is problematic in itself as the literature makes recommendations regarding this issue, but not how to achieve it (Evans et al., 2011). There is no consensus on a definition of cultural competence and a lack of information regarding what should be included in training programmes for cultural competence. In addition, many health professionals were unaware of the training that was available and many did not desire detailed information on cultural practices. Such training programmes were often criticized as creating stereotypes. There were also no studies that evaluated the effect of training on patient outcomes (Evans et al., 2012). One definition by an organization that places extreme importance on cultural competency is the National Association of Social Workers (US) (2007). This organisation also provides standards for cultural competence in practice: “the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a

manner that recognizes, affirms, and values the worth of individuals, families and communities, and protects and preserves the dignity of each” (p. 12). However, this is an American definition, and may not necessarily be adopted by the UK and Canada, however this issue is outside the scope of this thesis.

Indeed, the UK End-of-life Strategy (2009) highlights the need for ‘spiritual, religious and cultural care competencies’ to be adopted within all core training. However in a scathing critique of the document, Evans et al. (2011) points out that these needs were not repeated in the sections of the strategy that identified core principles and competencies or education, in fact, no mention of minority ethnic groups was made in these areas or improving the environments and future research.

As discussed here, and identified in each phase of the doctoral study, cultural competence is essential to end-of-life communication in NMRD. While it seems simple to recommend that health professionals need to be trained to recognize patterns of explanatory models, beliefs, values and customs (Crawley, 2005), and act in way that respects and values the culture of each patient and family they encounter, much work must be done to determine how to put this into practice. This may start with the End-of-life Strategy in the UK, and an understanding of the dominant Western bioethical view that pervades health practice and may unintentionally exclude minority groups from receiving appropriate end-of-life care and communicating about this care in health contexts. Recommendations related to cultural competence will be made in section 9.4.

## **Initiation responsibility**

The findings clearly demonstrate that there is a lack of agreement about who is responsible for initiating end-of-life discussions. This ambiguity may be specific to COPD as the UK Cancer Palliative Care guidelines state that key information should be delivered by the most senior health professional available, and that health professionals should be about to respond appropriately to patient concerns (National Institute for Clinical Excellence (NICE), 2004). The Canadian guidelines for COPD state that physicians have a responsibility to help patients and caregivers with COPD to plan for the end-of-life and to access support (O'Donnell et al., 2008).

A study of GPs and nurses in the community found that both groups of health professionals tended to wait for patients to raise issues regarding advance care planning before approaching the topic (Munday et al., 2009). In addition, Abarshi et al. (2011) found that GPs discussed end-of-life issues more with patients with cancer than with other conditions. The UK End-of-life Strategy (2008) states that discussions about end-of-life should be undertaken by health professionals who are trained in communication skills, assessment, care planning, and symptom management as related to end-of-life care (Department of Health, 2009). However, the End-of-life Strategy also notes that providing such training for health professionals should be a priority in education, perhaps explaining why health professionals may currently be lacking the necessary skills.

While the nurses in the UK Delphi study are responsible for initiating end-of-life discussions with their patients, this may not be representative of most nurses or health professionals and depending on the care context, non-physician health professionals may

instead be responsible for following up on end-of-life discussions after bad news has been received by the patients from physicians (Reinke et al., 2010). However, it has been argued that often the nurse has a leading role in communication between patient, family members and staff. Often nurses spend more time with patients and families than other health professionals, thereby creating more opportunities to develop a rapport (Hidalgo Kehoe, 2006), and are also more likely to be present at the moment of death than physicians and for these reasons in acute care settings, nurses play a crucial role in initiating end-of-life discussions (Crump et al., 2010). The nursing role is in contrast with the role of the physician, who may hesitate to discuss end-of-life because of the unpredictability of death, particularly with certain conditions like COPD which are known to have an unpredictable disease trajectory (Murray et al., 2005, Clabots, 2012). In addition, physicians may be overly optimistic about the time that patients with a terminal illness have to live, and therefore may not see the need to initiate end-of-life discussions (Vigano et al., 2000).

Regardless of the type of health professional initiating the discussion, Crawford (2010) states that it is the role of the health professional to create an open environment for discussion to allow patients to share their feelings and have productive end-of-life discussions. A recent Canadian study found that less than 10 percent of elderly patients admitted to the hospital had communicated their end-of-life wishes to nurses, social workers or spiritual care workers. Given that this population has unmet needs in regards to emotional, psychological, spiritual and informational care, it is recommended that non-physician led initiatives toward such discussions in the community rather than in acute care contexts may be more sensible. However ensuring

that preferences are documented and then communicated across contexts is essential (Heyland, 2013).

A study of community nurses found that this group acknowledged their key role in starting end-of-life discussions, they were concerned with ability to time such discussions sensitively, as well as the difficulty of raising such topics in a culture that predominantly does not promote the open discussion of death (Seymour et al., 2010). In addition, facilitating potentially time consuming end-of-life discussions for nurses in the community with unpredictable workloads proved difficult (Burt et al., 2008).

### **Clinical indicators**

While the Canadian Delphi identified the use of clinical indicators to indicate readiness or willingness to discuss end-of-life, the UK Delphi study revealed clear disagreement between participants as to whether clinical indicators helped them to establish whether a patient was ready or willing to discuss end-of-life, revealing lack of clear support for recommendations to use the Gold Standards Framework Prognostic Indicator (2006). Other items that did gain consensus, such as the importance of developing the discussion over time and discussing whenever the opportunity occurs after diagnosis show that perhaps such emphasis in the policy guidelines on clinical indicators may inhibit health professionals from starting discussions early in the disease process, rather than allowing for the iterative process of such discussions to occur as mentioned in the end-of-life care strategy. In fact, it has been recently recommended that the Prognostic Indicators for COPD should be tested to determine at which point they may trigger a discussion about end-of-life (Blackmore et al 2011). Overall, this study points toward

the idea that health professionals can perceive whether a patient is ready or willing to discuss end-of-life, particularly within the model presented above. Therefore, using this knowledge instead of clinical or prognostic indicators may be the way forward for initiating meaningful end-of-life discussions.

### **End-of-life policies**

The use of advance care planning documents was raised as an important consideration throughout the study. Participants of Canadian Delphi study discussed how they were mandated as part of a hospital intake to do an advance care plan, regardless of patient readiness or willingness to discuss. In the UK, the 'Preferred Priorities of Care' (PPC) document is a patient held rather than institutionally held document that identifies a patient's preferences and wishes at the end-of-life. The factsheet about the PPC states that it is a tool to facilitate end-of-life discussions, but also states that it is up to the individual whether information in the document is shared with family and health professionals (NHS).

This difference in policy may be related to accessibility of palliative care services. In some health regions in Canada, to access palliative care services, patients must sign a DNR and agree that they will not receive active treatment (Hodgson, 2012). Therefore, end-of-life discussions may become more important or essential to have in order to start receiving palliative care services. This is contrasted with the availability of services in the UK, where patients can receive active and palliative treatment at the same time, therefore making the end-of-life discussion less essential or urgent even for those receiving palliative care services.

The Canadian approach may be problematic in NMRD when there is rarely a clear transition point from active to palliative care, and therefore concurrent services may be most appropriate (Coventry et al., 2005). The difference between these two countries points to the necessity of two separate tools for discussing end-of-life.

### **Prognosis issues in nonmalignant respiratory disease**

The difficulty in providing a prognosis for patients with NMRD emerged throughout the study as a reason that end-of-life discussions do not occur and is widely acknowledged in the literature (Pinnock et al., 2011, Curtis et al., 2004, Dean, 2008). Specifically, in COPD, identifying patients who are in the last year of life (based on disease parameters) is largely unsuccessful (Celli et al., 2004, Small et al., 2009), and a recent systematic review found that while there are several high quality prognostic tools in existence, neither clinicians or tools can predict with certainty how long a person will live (Yourman et al., 2012). However, these findings are contrasted with the idea that the problem with prognostication in NMRD is the lack of simple, well validated, prognostic models with good calibration, reliability and generalizability (Coventry et al., 2005, Puhan et al., 2009). In addition, current models of prognostication do not consider the role of social factors. For example, in the context of cancer care, patients spiritual beliefs have been shown to be predictive of clinical outcomes and these are unlikely to be taken into account by prognostic tools (Coventry et al., 2005).

Such uncertainty with prognostication seems to negatively effect communication about end-of-life and ultimately limits access to palliative care services (Curtis et al., 2008). Health professionals may feel anxious about delivery information to patients when prognosis is

uncertain (Crawford, 2010), and patients with COPD are more likely than patients with cancer or AIDS to express concern regarding the amount of information that they have received about their condition, including treatment, prognosis and advance care planning (Curtis et al., 2002). It seems that this issue of prognostication must not be viewed by health professionals as a barrier to discussing end-of-life. This view implies that clinical indicators must signal that end-of-life discussions should occur and it has been shown here that this is not necessarily an indicator to readiness or willingness to discuss end-of-life.

## **Time**

The issue of time arose in every stage of this study, from finding the right opportunity to discuss, to developing discussions over time and having multiple discussions, to the problem of time constraints in medical practice. This is clearly an overarching issue in end-of-life discussions. While the limited literature indicates that patients with COPD prefer to wait until their condition is advanced to discuss end-of-life (Momen et al., 2012), other studies indicate the importance of considering the individual needs of the patient before making this judgment (Crawford, 2010). The recent systematic review by Momen et al. (2012) states that discussions should be patient centred and that the timing, content and pace should be decided by the patient, but this is concerning as it may be interpreted as guidance that the patient is responsible for initiating such discussions, which has been established previously in this discussion as highly problematic.

### **8.3 Transferability**

Initially, the literature about end-of-life communication in malignant diseases was not included in this thesis. This was due to the different disease trajectory between conditions, the difference in patient awareness of the fatality of their disease and the lack of resources available to broaden the scope of this thesis to include such literature. However, in this discussion some literature related to malignant conditions will be brought in to demonstrate that despite the differences stated above between conditions, similarities between patients in each condition may contribute to the transferability of these findings to be useful for working with patients with malignant conditions.

For example, research with patients with cancer shows that, like patients with nonmalignant respiratory disease, patients want to have conversations about end-of-life care with their health professionals and often expect the health professional to initiate the discussion (Steinhauser et al., 2000, Wenrich et al., 2001, Jefford & Tattersall, 2002). As a result of this expectation, patients with cancer do not always discuss end-of-life with their clinician, despite a desire to do so (Gattellari et al., 1999, Gattellari et al., 2002, The et al., 2001). Similar to non-malignant respiratory disease, it is thought that conversations about end-of-life care are beneficial as they may result in a greater chance of patients' wishes being met (Detering et al., 2010), better quality of life (Temel et al. 2010), less use of futile life sustaining treatment (Wright et al., 2008), more use of hospice care (Wright et al., 2008), reduced distress for the family (Wright et al., 2008) and reduced resource use overall (Teno et al., 2007). However,

health professionals, particularly physicians, are uncomfortable with raising this topic, due to the highly emotive nature of this subject (Bernacki et al., 2013).

However, despite similarities, there are some key differences in care between lung cancer patients and patients with nonmalignant respiratory disease as found by Partridge et al. (2009), which has been discussed previously. In addition, Epiphaniou et al. (2014) found in the UK that while patients with lung cancer have access to a key worker who coordinates care between settings, referred patients to palliative care services in the community, helped with financial issues and provided support, while COPD patients did not have a key worker. This has the potential to influence end-of-life discussions due to the nature of the key worker relationship. This area of research also demonstrates the importance of different considerations in such discussions for patients from different conditions. For example, Murray and colleagues (2004) found that different disease trajectories lead to different patterns of spiritual needs – patients with cancer had needs regarding recognising the imminence of dying, while nonmalignant patients had needs regarding feelings of isolation, hopelessness and a loss of confidence. In addition, recent research exploring needs of patients with advanced cancer in the USA and Australia for a question prompt list to discuss end-of-life care found that tailoring a communication aide for individual populations was highly appropriate given the differences of their findings between countries (Walczak et al., 2013) as well as complex cultural influences on end-of-life decision making (Michael et al., 2013).

## **8.4 Conclusions**

This chapter presents a theoretical model of the findings of the four phases of the doctoral study and then contextualizes these findings in relation to the existing literature and finally addresses the potential transferability of these findings. Conclusions and recommendations based on the findings of the study, in addition to a critical appraisal where the strengths and limitations of the study are discussed are presented in Chapter 8.

## **Chapter 9. Conclusion and recommendations**

### **9.1 Introduction**

This chapter builds on the previous discussion chapter (Chapter 7) to explicate the original contribution of this study to knowledge regarding end-of-life discussions in NMRD, as well as to provide recommendations based on the findings for practice, education, policy and finally future research.

### **9.2 Contributions of the study to theory, methods and practice**

As discussed in the introduction chapter the authors of a recent study concluded that future research should examine international differences as well as patient specific facilitators and barriers to end-of-life discussions (Janssen et al., 2011). In addition, the authors of a recent integrative review found that further investigation was required to address the complex personal, provider and system elements involved in COPD (Disler et al., 2012). This doctoral study answers the call of both studies and extends on elements of previous work regarding end-of-life discussions in NMRD, including COPD. It is novel in the exploration of indicators of readiness or willingness to discuss end-of-life and contributes a theoretical model of facilitators and barriers to end-of-life discussions in NMRD and the development of tools to address discussing end-of-life with this specific patient population in the UK and Canada, and in the international comparison of two Delphi study findings. Ultimately, the first stage of development of a complex intervention for end-of-life discussions in NMRD has been completed through this work.

### **9.2.1 Theory**

The theoretical model of findings summarises the facilitators and barriers to end-of-life discussions that emerged in this study using a systems theory perspective and identifies items that can be either facilitators or barriers to discussion at the Macro, Mezzo and Micro levels. This model can be employed by health professionals to investigate the facilitators and barriers to discussion in their own context. Particularly, the model establishes the importance of cultural competence, which is currently lacking in the literature, particularly as COPD is poised to become the third most common cause of death in the world . While a recent Delphi Study by Junger et al. (2012) with members of the European Association of Palliative Care acknowledged the differences in cultural needs dependent on country, the literature on facilitators and barriers, particularly in non-malignant respiratory disease has not widely acknowledged the importance of cultural competency with individual patients and families.

### **9.2.2 Methods**

This doctoral study contributes to research methods by comparing two Delphi studies that were conducted in separate countries in order to develop a tool and discern the specific concerns of health professionals in each country. Specifically, comparing the results of two Delphi studies is not common in the literature, and comparing the findings of two panels from different countries is entirely novel. To the author's knowledge a comparison of Delphi panels has only been carried out by Duffield in (1993), and Kennedy in (2000). Members of different disciplines are rarely included on one Delphi panel and therefore the range of professionals included in the Canadian Delphi is a unique aspect of the methods used in this study.

Comparing Delphi studies can add validity to their findings (Duffield, 1993) and by comparing international panels, allows for the understanding of cross-country differences and similarities, providing insight into practice in each country. The findings from this study point to the benefit of using international comparative studies to bring awareness and comprehension to areas in need of development and to help find innovative solutions for complex situations.

### **9.2.3 Practice**

This is the first study to develop a tool that includes items on how health professionals know that a patient is ready or willing to discuss end-of-life in NMRD. The findings reveal that health professionals can perceive whether a patient is ready or willing to discuss end-of-life by understanding patient cues. Using this knowledge, health professionals may be able to initiate meaningful end-of-life discussions. In addition, the findings regarding considerations in end-of-life discussions and topics for such discussions from both Delphi studies are consistent with the current literature (Buxton et al., 2010, Gore et al., 2000, Spence et al., 2009), however, this is the first study to develop a tool specific to the patient population to be developed further for use by health professionals in clinical practice.

### **9.3 Critical appraisal of the study**

The four phases of data collection in this study including two systematic reviews and two Delphi studies enabled the aims and objectives of the study to be met. By identifying the state of the science in the literature, and then establishing an expert consensus on the topic, a greater understanding of end-of-life discussions in non-malignant respiratory disease was developed. Ultimately, the findings of the study as a whole has resulted in a model of how end-

of-life is discussed in this patient group in the UK and Canada, as well as the development two tools to aid health professionals approach end-of-life discussions. This development process, in line with the MRC guidelines for complex interventions, will provide a building block towards a validated instrument to use with this patient group.

Through the use of systematic reviews, an evidence base regarding how end-of-life is discussed in non-malignant disease in general and specifically in respiratory diseases worldwide and also specific to the UK and Canada has been established. Many end-of-life interventions and services have been designed specifically for patients affected by cancer, and have been 'adapted' in some way to extend to other patient groups. However, the literature related to discussing end-of-life in non-malignant respiratory disease is often focused on the difficulties due to the unpredictable disease trajectory and it is clear that this patient group has very different needs and often much less resources available to them related to end-of-life. Therefore, throughout this study, literature related to cancer was purposely excluded.

After the findings of the systematic reviews indicated a lack of literature regarding how health professionals know a patient was ready or willing to discuss as well as further investigation required regarding key considerations and topics when discussing end-of-life with this patient group, the use of the Delphi method was considered most appropriate to establish expert consensus on these topics. However, there were some limitations regarding the sample selection. In addition to the recruitment advertising through the British Lung Foundation and the Canadian Health Professionals group, a snowball sampling method could have been used to have experts in the field identified by other health professionals.

In the UK, the expert views are from nurses who work primarily in the community and have established relationships with their patients. However, the majority of contact that patients with non-malignant respiratory disease have with health care professionals is in a primary care setting, and trends in health care provision at the time of writing (Spence et al., 2009) are moving towards blurred primary/secondary care boundaries. Furthermore, in Canada, the sample could have consisted of only one type of health professional in order to be able to make more definite conclusions from the Canadian Delphi data, but perhaps this would not have reflected the diversity of health professional that conducts end-of-life discussions in non-malignant respiratory disease in Canada. In addition, it must be acknowledged that differences in findings may be partly due to the diversity of Canadian health professionals, however as this was a pragmatic, service based study, it was appropriate to use more than one group.

Finally with regarding to the samples it must be acknowledged that in any study where participants are self-selecting, it is most likely the case that they have a particular interest in the topic. In fact, more than one participant described end-of-life communication as her 'pet topic' and was very eager to share her views. While this is not major limitation, particularly given the nature of the Delphi to gain a consensus opinion from experts in the area, it does mean that a wide range of experiences may not be identified. However, there are already several studies that address the reasons why health professionals do not address this topic (Janssen et al., 2011, Abarshi et al., 2011, Crawford, 2010, Anselm et al., 2005).

As mentioned previously, the systematic review process that was meant to inform the initial Delphi questionnaire did not return any findings related to readiness or willingness to discuss end-of-life, therefore the decision was made to interview participants for the first round of Delphi data collection instead. Alternatively, an initial Delphi questionnaire from what was found through the systematic review with regards to key considerations and topics could have been used in the first round in addition to interviews to address the readiness/willingness component. This could have resulted in more commonalities in the first round of the Canadian and UK Delphi data and may have enabled more in depth statistical comparison between studies.

Another option would have been to use a structured interview guide rather than a topic guide for the Round I Delphi interviews. This would have enabled a more straightforward analysis, and perhaps would have resulted in more comparable data between the Canadian and UK Delphis. However, allowing participants to explore the topic using the topic guide did result in a wealth of data and so perhaps the trade-off of a inability to statistically compare UK and Canadian Delphi data was sensible.

In hindsight, the topic of the entire study should have been specific to COPD rather than non-malignant respiratory disease. This would have allowed for a more focused comparison with the relevant literature in the systematic reviews. Also, would have provided clarity for Delphi participants as to which aspects of their job to focus on. Some of the Canadian Delphi participants worked with patients with cystic fibrosis, and due to the early onset and likely mortality rate of this disease, considerations may not be the same for these patients.

While the data analysis process was rigorous and guided by literature from the field there was a minor oversight, which was that there was not a common baseline mean score for eliminating items in Round 2 of the Delphi studies. Ultimately, this did not affect the results of the study as only consensus items and non-consensus items were compared narratively rather than statistically. Finally, the mean statistic was used to determine whether items moved from one round to the next in the Delphi studies. In hindsight, it would have been prudent to use the median statistic instead to be consistent with the median statistic that was used to establish consensus.

#### **9.4 Recommendations for Practice, Education and Policy**

In light of the findings of this study, a number of recommendations can be made for end-of-life discussions in non-malignant respiratory disease, the education of health professionals regarding end-of-life communication with this group as well as policy related to this topic.

##### **9.4.1 Recommendations for end-of-life discussions**

- Emotional intelligence should be used to gauge patient readiness for end-of-life discussions, and these discussions should be followed by informal and formal supervision and reflection processes.
- Patient education should be used by health professionals as a stepping stone towards moving patients forward toward the next stage of behaviour change to be ready to address end-of-life issues. As such, health professionals must be made aware of the concept of readiness and the stages of change transtheoretical model and how it applies to the patient education context.

- Patient education interventions must be targeted to the health literacy level of the individual patient, and a lack of interest or participation in end-of-life issues must not be immediately dismissed as such before their level has been established.
- Where a health professional perceives that a patient is not ready to discuss, the health professional may guide the patient towards readiness by using the Transtheoretical Stages of Change Model.
- Health professionals should be aware of the concept of readiness, how it can be established and apply this knowledge when designing patient education programmes.
- Health professionals should be aware of the concept of willingness, and be wary of approaching end-of-life discussions when the patient does not appear willing to discuss end-of-life.
- The recognition of the cultural beliefs, values and patterns of behaviour of patients and their families should be used to understand how individual patients and families may make end-of-life decisions.
- To avoid missing opportunities, or approaching the topic insensitively, health professionals should not rely on clinical indicators or the existence of a poor prognosis as a signal to initiate discussions and instead use indications of patient readiness as established by the current research.

#### **9.4.2 Recommendations for the education of health professionals**

- Further development of expert to novice transfer of knowledge regarding end-of-life communication through use of tools such as the one developed in this study, and perhaps mentorship programmes.
- More emphasis on emotional intelligence and communication skills during training of health professionals has been highlighted in the literature as beneficial, but specific needs are not addressed. Based on the findings of this study cultural competence training must be a priority, but definitions of what this would involve and what should be included in such training require more research, such training may include awareness of dominance of western medical model and focus on autonomy creating 'problematic' relationships with ethnic minority groups.

#### **9.4.3 Recommendations for Policy**

- The assignment of a key health professional to each patient with non-malignant respiratory disease may improve the likelihood of end-of-life discussions and resolve ambiguity about initiation responsibility and ensure that wishes are communicated between settings.
- The UK End-of-life Strategy (Department of Health, 2009) should be updated to include competencies regarding cultural competence, emotional intelligence and understanding of readiness to discuss.

## **9.5 Recommendations for research**

The MRC Guidance for Developing and Evaluating Complex Interventions (2008) suggests a five stage process for the development, evaluation and implementation of complex health related interventions. As discussed in the introduction and research design and methods chapters the focus of this doctoral study was to develop an intervention, and further stages in the process are required to prepare the intervention for use in clinical practice. A potential piloting and evaluation phase is briefly described below for each tool in the UK and Canada. Only the UK proposed pilot and evaluation studies are described below. However, similar pilot and evaluation studies would be carried out in Canada, with some modification for the Canadian context.

### **9.5.1 Pilot study to evaluate the effectiveness of a tool in improving end-of-life communication between health professionals and patients with COPD.**

This pilot study would aim to determine how the tool can be used by health professionals in practice, and to determine how best to administer the outcome measures in the planned randomised control trial. Health professional participants in each location would be asked to attend an education session about the tool and how to use it in practice. Then, they would be asked to use the tool with patients with COPD over the period of one year. Participants would also be asked to reply to questions relating to outcome measures to determine how the tool was used. The information gathered in the pilot study will be used to design a cluster randomized trial with several PCTs in England, Scotland, Wales and Northern Ireland. Further explanation of this pilot study is included in Appendix G.

### **9.5.2 A Systematic Review of Interventions For Health Professionals to Improve end-of-life Communication**

The objective of this systematic review is to review the effectiveness of end-of-life communication skills training programmes for health professionals on improving communication about end-of-life between health professionals and patients, and to identify experience of learning about end-of-life communication and changed perceptions as a result of such training. This review will be used to inform the educational session in the pilot study, and to determine how best to educate health professionals about this end-of-life communication tool. The protocol for the systematic review developed using the JBI method of systematic reviews (The Joanna Brings Institute, 2008) and includes the PICO outline for inclusion criteria, the search strategy, the assessment of methodological quality, data collection and methods for data synthesis are outlined in Appendix H.

### **9.6 Study Conclusion**

In this study the author examined how end-of-life is discussed in NMRD. The findings and the theoretical model that resulted from the study highlight the complex and dynamic process of end-of-life discussions specific to NMRD. This model consists of nine key areas that can act as facilitators or barriers to discussing end-of-life including: prognosis, end-of-life policies, time, clinical indicators, initiation responsibility, the educational role of health professionals, emotional intelligence, cultural competence and readiness versus willingness to discuss. The four phase, mixed methods design for instrument development was successful in leading to the development of two country-specific tools to assist health professionals in approaching end-of-

life discussions in NMRD. These tools are ready for the next stages of development for use by health professionals as a complex intervention, and recommendations for how this could be achieved using a pilot study, leading to a cluster randomized trial and a systematic review were provided.

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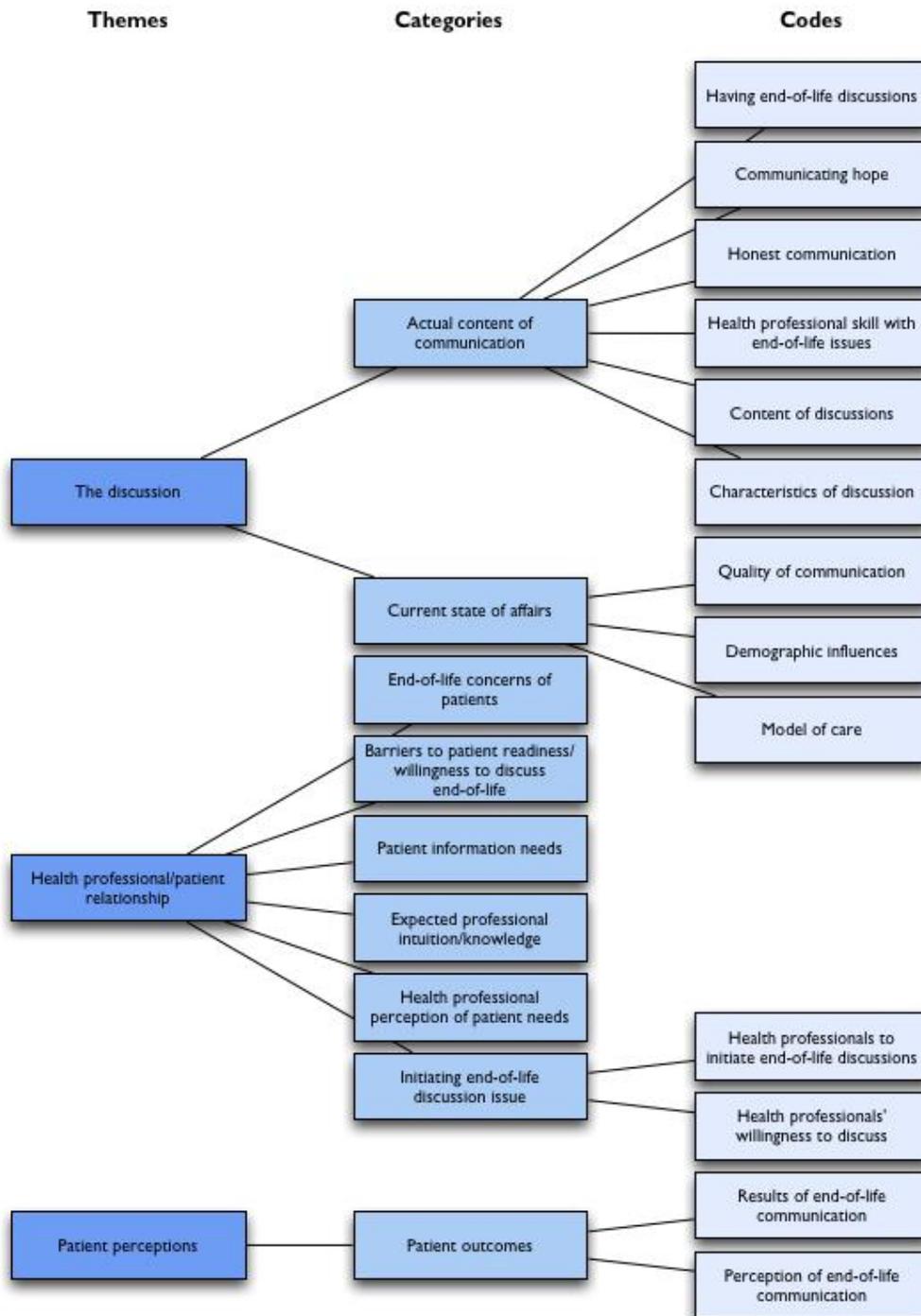
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## Appendix A. Themes, categories and codes from the systematic review (Chapter 2)



## Appendix B. Evidence of ethical approval

### South West 4 REC

(formerly Southmead REC)  
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17 August 2010

Mrs Nicole Stephen  
PhD Student  
University of Plymouth  
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Drake Circus  
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PL4 8AA

Dear Nicole

**Study title:** Readiness/willingness to discuss end-of-life in nonmalignant disease  
**REC reference:** 10/H0102/11  
**Amendment number:** 1  
**Amendment date:** 20 July 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 17 August 2010.

#### Ethical opinion

Favourable Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Consent Form: with Biographical data	1	20 July 2010
Protocol	2	20 July 2010
Notice of Substantial Amendment (non-CTIMPs)	1	20 July 2010
Covering Letter		20 July 2010

## Appendix C. UK Delphi Round I – Key considerations: quotes from each item

UK Delphi Round I – Key considerations: quotes from each item.

<b>The patient</b>	
Allowing the patient to lead the conversation	...not just talking to the patient but get... make it a two way conversation and just take guidance from the patient, don't dictate, feel from them. (ARI)
Answering patient's question about the condition	...because they want to know more about the condition as a rule. They tend to ask the questions anyway. (ZWR)
Maintaining hope for the patient	We'll do our best to try and keep things at bay and hopefully keep you as well as we can, but actually, this is going to progress. So I really think at any point, you should really be thinking about... but you know, for real kind of end of life discussions, it should be... you know you're going to be picking your most... the patients that are more [unintelligible 11:57] to it, that you think are going to be heading down that kind of slippery slope. (KMI)
Being open and honest with the patient	There's no point hiding things from the patient, because like I said, they don't have the trust in you if you hide things from them. (ZWR)
Establishing patient's understanding of their condition	...establish the patient understands what you're talking about (KMI)
Recognising the individual needs of the patient	...everybody's individual you deal with it you know as you think your relationship with that patient... I don't know quite what the words are, to... each individual will do it slightly differently, or will want something slightly different, so you pick and run with it as it's presented to you. (ASI)
Explaining to patients what is feasible regarding their wishes	...but you have to instil some realism into that, because you know with the best will in the world, if you want to die at home, but your family just can't cope with that, then it's a real dilemma because we can't provide 24 hour, seven day a week care in the domiciliary setting. (SPI)
Educating the patient about their condition	Well why am I not getting any better question, or, I've been given this treatment by my doctor but I actually don't feel any better, and to kind of... you know, sort of take it from there to say well, why do you think that is, that you're not getting any better. Can you think... and then to sort of lead them into me trying to give them very sort of simple explanations, that it's not getting better and this is why, but this is what we can do for you... (KMI)
Patient indicates readiness to discuss	The patient being ready, the patient indicating that they want to have this discussion, is the most important. (SPI)
Patient wanting to hear the information	...the patient being receptive and willing and them wanting to know... (IBI)

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UK Delphi Round I – Key considerations: quotes from each item.

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Patient being open about dying ...people will talk about it. People can be very open about dying... (ASI)

The environment

Having an appropriate environment for discussion e.g. privacy, quiet I would say the environment, setting the right environment, to a point, as much as you possibly you can. You know, privacy, dignity, respect, quiet. That sort of thing, and sometimes relatives present, and sometimes not (SPI)

Where the discussion occurs e.g. clinic, hospital or patient's home I think the joy I have from going to people's homes is, there's more time. There's less interruptions, people feel safer because they're in their own environment and that's one thing you do notice when you actually work in the community compared to a hospital, is that you are being invited into their home and therefore you know, that's one thing they are leading the whole consultation because it's in their environment, and so it's definitely a different dynamic when you visit somebody in a home (SJP)

The family

Having the patient's family involved in the discussion ...(if the) pt does not have family around makes it more difficult to give them bad news (NDI)

Well, I mean obviously if the family members are present or there, then I would... with the patient's consent, would include them in the discussions. (KMI)

Having family's support during the discussion I think good family support makes things quite a bit easier as well, so you know that you're not just having this conversation and then going away and leaving them to sit on their own and dwell about everything, but then on the other hand, that's what some people want (ARI)

Patient's wish to protect others from end-of-life information I think as well sometimes, that once they acknowledge it, again if there's a family member there, they might be thinking it, but they don't want the carer or the wife or whoever, to know that that's how they're thinking, because it's a kind of helplessness and the loss of hope (KMI)

The health professional

Being an expert on the condition ...you want to discuss it with family; I think if you're coming from an informed position as an expert, then you would hope that people would recognise that (KMI)

Nurses having counseling skills ...basic counselling skills, have to be reinforced at every level of training (SJP)

Having the appropriate clinician to discuss end-of-life with the patient ...you need the appropriate skills and experience to be able to enter those discussions. (SJP)

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UK Delphi Round I – Key considerations: quotes from each item.

Having a strong relationship with the patient	We've been in their homes, we know their families, you know we've looked at the pictures on the wall. It's all about building relationships and they trust you to look after them, and actually talking about it with us is probably easier than talking about it with anybody else (ASI)
Emphasising a holistic care approach	Well, I think we do, but it's more as in, like their wellbeing, like their overall feelings, and wellbeing and how comfortable they are. (IBI)
Rapport between health professional and patient	...advantageous to know the patient, to have built some kind of rapport with them before you start embarking on it. (KMI)
Health professional having the confidence to discuss	I think a lot if it depends on how you feel yourself about how confident the person who's delivering the discussion feels (DWI)
Health professional's understanding of the condition	And it's now that I feel equipped, that I can answer those questions for them and sit down with the knowledge and be able to address the issues with the patients. (IBI)
Using non-medical language	I think patients are brought up to a clinic, told that you're... told in very medical language that you have this condition, probably not given a huge opportunity to ask an awful lot of questions and sent on their way, you know and I don't know if it's... if that's likely to change, and it probably happens to lots of things, but I think we are very bad at using jargon that patients don't understand. (KMI)
Your professional boundaries	...we then see them again through a nastier exacerbation and things and sometimes again they bounce back and but the disease trajectory with COPD compared to cancer, it's so very different, and can be so much longer, and so you do go on that journey with them for many, many years, but you are the professional at the end of the day, and for your own sanity I suppose, for want of a better word, it's that you have to ensure that you protect yourself. (SJP)
Avoiding euphemisms – saying the words 'death' or 'dying' instead	They don't like using the word dying very much... They always have some euphemistic phrase (ASI)
Health professional talking responsibility to oblige the patient's wishes	I sometimes feel, how can I honour what they tell me, can I possibly give them what they want and that... and once you've had the conversation, you know what they want, there's a huge pressure and obligation to... I feel, to ensure that they get what they want and that's sometimes very difficult. (SPI)
Using humour	...you can take it as a joke - very often we deal with that first response as humour 'oh well I hope not quite yet because there's all the paperwork to sort out' (ASI)

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UK Delphi Round I – Key considerations: quotes from each item.

Nurse having attended conferences or professional development specific to end-of-life discussions	I think having been to those two study days was a great benefit to me, particularly the Impress one because I was put in a position where I had to speak to ‘a patient’ and it made me recognise that actually, yes, I can talk to patients about this. It’s just recognising that they’re all different. Not all of them want to hear what you have to say, so you don’t have to tell them everything. I’m not there to frighten people. There’s always another day I can go back when they’re ready to have a bit more information from me. (DWI)
Nurse having experience in caring for dying patients	...with experience and you know getting into different situations, that you build that experience up as well...(ARI)
<b>Timing</b>	
Discussing end-of-life at time of diagnosis	...really to be honest, at the point that these patients are diagnosed, whenever that is. I mean, obviously somebody who can be diagnosed and still have a very good quality of life and a very long life still to come, but you know I think patients who... particularly that we see, that come into secondary care, they tend to be further down the line and I think if we’re as honest with them as possible that yeah, we can still treat you, however they need to know that this condition will deteriorate. (KMI)
Developing the discussion over time	...we’d be ongoing and that’s the nature of our work really, is that we see people repeatedly, over and over and as they get nearer to death we would see them more often and so these discussions develop, because again, people forget what you tell them. (ASI)
Finding the right opportunity to discuss	It’s really hard. I try and instigate a visit when I know they’re going to be on their own, so that they have the opportunity (SPI)
Patient having time to hear information and ask questions later	...allow the patient the time to go away and then come back and ask what does this all mean. (KMI)
Availability of time to discuss	I would make sure I had the time. If I went to a patient and even if I was busy, I wouldn’t leave that patient until I knew I had finished. If that conversation started, I would have the time to do it (IBI)

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## Appendix D. UK Delphi Round I – Key content: quotes from each item

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### UK Delphi Round I Key considerations: sample quotes from each item

Introduction of an advanced care planning document	It's the National Council of Palliative Care, and it's called Planning for Your Future Care, A Guide, and it goes through what is advanced care planning, the aspects of it, having open conversations, exploring all your options, about refusing treatments, lasting power of attorney, that's all I think it goes through. (ZWR)
The type of care the patient wants	...if things deteriorate again and you don't want to go into hospital, what would you like to happen (IBI)
Emergency management preferences	You know, would they want to be aggressively managed, would they want an IV attempt or, so I suppose if they don't want to be resuscitated, where would they want to die. (KMI)
Explaining palliative care	They tend to avoid the subject. They play down their symptoms a lot. You know, they tell you that they're feeling fine when you can see the relatives sat next to them sort of shaking their head and disagreeing with what they're saying and it's just slowly you've got to just explain to them and explain to them as well, that because they're going on the palliative care case load doesn't mean to say that they're dying now, which is a lot... it's something that a lot of the patients have got in their head isn't it, they think palliative care like the cancer is, end of life care, rather than advancing disease. (ZWR)
Anticipatory prescribing	So, anticipatory prescribing is very important, but that doesn't have to be done immediately. (ASI)
Ceiling of treatment	But one of the big issues for us really is about the ceiling of treatment because a lot of these COPD patients, we manage at home as much as possible. It's the best place for them, unless they have a hypercap in, in which case they may benefit from non-invasive ventilation, which is not a pleasant experience and these... this is a difficult one really, as you're wanting to know whether, if it gets to that stage, whether they want to take advantage of having non-invasive vent or they just want to pass away peacefully. (SPI)
Medication options	...we can get medication to ease the anxiety and the breathlessness. (IBI)
Treatment options	Different treatment options (IBI)
Patient goals	...have they got any goals, anything that... in other... anything they would like to do or achieve or see or fulfill. You know, other things that they still want to do, because although we're talking end of life, we are still talking... it's still their life, there's still got to be some quality in it, what do they want and what do they not want. (KMI)
Intubation and ventilation options	...intubation... (NDI)

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UK Delphi Round I Key considerations: sample quotes from each item

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Preferred place of care	...where their preferred place of care would be (SPI)
Preferred place of death	...do they want to die at home, or do they want to die at hospital, or do they want to go into a hospice or maybe respite care somewhere. (ASI)
When the patient is likely to die	...they'll all want to know when and you can't say when (ASI)
Sedation availability/options	...how they feel about the use of opiates, morphine, syringe drivers, whether they want to be... you know I've had patients say oh I just want to be sedated. I don't want to know anything about it, and yet I've had other patients that say well no, I want to be you know, I want to be as alert as I can, right to the last minute, and that can be... that can happen. That can be facilitated. (SPI)
Social services involvement	...social services, you know do they need any help or can they go to the hospice for a bit, you know to respite. (ASI)
Spirituality	That's what I would say more for spiritually. Yes, and also like if they're needing to... if they want to see any of their own... like their faith, if they want to deal with anything like that, yes, but spiritually I would say is more to me about their overall wellbeing, and how they are actually dealing with things. Are they dealing with it, or do they need further assistance to deal with that, and is there somebody they need to speak to. (IBI)
Transferring to palliative care	It's quite a hard discussion to have with some of them. I mean, some of the patients are aware, because we don't lie to them, we do tell them it's a progressive condition. So they can see things are getting worse and their conditions are deteriorating. So, some of them are quite happy to be moved across [to palliative care]. Some of them find it quite a difficult transition and you know, it's another six months before they accept it. (ZWR)
Who the patient wants present at the very end-of-life	Who would they want to have with them? (KMI)
Dealing with breathlessness	And overwhelmingly they talk about breathlessness and they're fighting for breath, and they just can't bear the thought that it would be even worse. And then we talk about, well, can you remember going into hospital when you had your last exacerbation? And they have no memory of it. So I reassure them by saying, you know, there are things that we can give you that will help to relieve breathlessness, but the chances are you'll not be aware of it. (DWI)
Hospice	
Explaining hospice (if available)	...what kind of care they would get if they do eventually go to the hospice (IBI)
Options for hospice (if available)	...hospice or respite care...(NDI)

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UK Delphi Round I Key considerations: sample quotes from each item

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Perceptions of death

How they feel about death ...how they feel about death...what their fears are (SPI)

Reassuring the patient s/he won't suffer I've recently nursed a chap that's just died aged 58 and his father died of COPD in his late fifties and his brother died of COPD in his early sixties and his... a lot of the conversations that we had about death were really discussing his previous experiences of horrendous respiratory death, many years ago and ensuring that he had confidence that's not the way it was going to be for him (SPI)

Understanding of death ...enabling people as much as I can, to be in control, in as much as I can, because some people will not want to do that and you have to respect that as well (SJP)

Practical needs

Getting affairs in order Have they managed to get all their affairs into order? (KMI)

Practical equipment needs ...practical stuff like beds, commode, all that sort of stuff that the district nurses can order (ASI)

Support in the home What would you like us to do and then we would be able to say well we can get district nurses in, we can get your GP involved (IBI)

Transportation needs to facilitate care well how am I going to get there, because the physical effort of getting themselves to that place and everything that that involves, is the next hurdle that you have to try and overcome. (KMI)

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## Appendix E. Canadian Delphi Round I Key considerations: quotes from each item

Canadian Delphi Round I Key considerations: quotes from each item	
<b>The Family</b>	
Family issues for the patient	'You know, sometimes it is and sometimes you do have to push the envelope a little bit and say 'hey your pulmonary function is really low, and I know that you don't feel that but um, maybe we need to start having some discussions because you have little ones at home' you know, where it involves young children, then you push the envelope a little bit quicker, you put a little bit more pressure because the stakes are higher, you know. (CAN1)
Communicating patient wishes to family	'this is what she wants, she didn't want to go to the city or she wants to stay here, she doesn't want to be intubated' (CAN5)
Presence or absence of family support	'to prepare them, and to encourage them to bring their support person if they want them' (CAN4)
<b>Approaching the discussion</b>	
Sense of humour	'And i would try and talk about it, and I would bring humour into it a lot of times, whenever I could, because that always sort of breaks the ice a little bit, and makes it easier' (CAN10)
Sensitivity to the patient's culture	'of course there's gonna be huge differences when you think about the um issues of, um, what patients are comfortable, whether it has to do with um, their own culture, and cultural acceptances, um, we've had difficulties, for example, with Native American people wanting to do smudging and things like that, and the process that they're dying, and that's been a barrier because of now the smoking cessation and the requirements for having nonsmoking and those things are not available, and those cultural things can be big barriers' (CAN10)
Approaching the topic calmly	'You just go and you know if you approach the topic with um a calmness... (CAN1)
Approaching topic with a 'matter-of-factness'	You just go and you know if you approach the topic...with a matter of factness... I think people respond to that no matter where they are. (CAN1)
Approaching the topic with a caring nature	You just go and you know if you approach the topic ... with a caring nature, I think people respond to that no matter where they are. (CAN1)
Being open	'I mean I don't know how much it plays into it but it's just, it's not something that I can um, it's not something that I have a problem discussing I guess, is really, i'm very open about and I think that my clients know that about me'(CAN7)
Being honest	'I believe in presenting it in a respectful manner, I don't believe in sugar coating it. I tell people I'm not going to lie to you, and they seem - no one has ever gotten offended with that. They say 'okay, thank you' right...because the stakes are high and it is what it is, sort of a thing.' (CAN1)

Canadian Delphi Round I Key considerations: quotes from each item

Being respectful of the client	‘You know, and taking that time to ask questions, you know, I think those are all really, those are all really important things, because everyone just wants to be heard, and they want to know that they are important, that they count. Especially, man, especially at the end of your life, you know, if any time were more important, this is the time right? People, I think health professionals need to honour that, and respect that, and know the difference between, or know when to push it and when not to, when to step back, so...yah.’ (CAN1)
Listening to the patient	(When I’ve asked patients) you know, when people talked about it with you, what was helpful and what was not helpful (they said): ‘When they listen to me, when they actually listened to me and they heard what I was saying and not what they wanted to hear, or they didn’t have an agenda when they came into the room and they got mad at me because I didn’t follow that agenda’ (CAN1)
Giving advice when it’s asked for	‘giving advice when it’s only asked for’ (CAN1)
Letting the patient guide the discussion	‘letting the patient or whoever you’re talking to about the end-of-life discussion, guide the journey, you know, they are the captain, and going wherever they go. But that doesn’t mean like being a, you know a pushover either. Right? If they’re going down a path um, you can, you know, having that trust, that therapeutic relationship enough to say ‘hey, you know, uh, I don’t know, do you want to think about that a little bit or?’ (CAN1)
Readiness of the patient to discuss	‘Um, well definitely the person has to be ready, you can’t force a discussion’ (CAN4)
Accepting the patient’s reactions	‘But, it is, it’s surprising sometimes when people are kind of, quite shocked about ‘why are you talking to me about this?’. And there’s a disconnect between, sometimes, between um, so, you know, we kind of guide them, wherever they are in that journey, we meet them where they’re at.’ (CAN1)
Knowing when to step back from the topic	‘People, I think health professionals need to honour that, and respect that, and know the difference between, or know when to push it and when not to, when to step back, so...yah’. (CAN1)
Having a pre-existing good relationship with the patient	‘I think what’s really important I’ve found through the years is getting a relationship with the patient, so that they know that they can trust you, and that um, you know, you’re not just a stranger coming into the house or seeing them in a clinic a situation and they have no relationship, so I think relationships a little bit important’(CAN1)
Avoiding dashing hope	‘Um, I’m very forthright and very honest in my answers. If somebody asks me a question they’re going to get the truth. I’ve never been one to dash hope, but hope is a very hard thing to bring up when you’re talking about death, and when you’ve got the patient that says ‘I know I’ve only got three months but I’m gonna try and fight this and see if I can live longer’, you know it’s probably not going to happen, but you say to them ‘we can help you by teaching you things, by providing you this, and offering you this, and aiding you this way just to make it comfortable, and I know you’re going to have good days, you’re gonna have bad days and you’re gonna have days you wish you were gonna be dead’(CAN6)

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Canadian Delphi Round I Key considerations: quotes from each item

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Raising the topic early before critical situation	'I usually frame it in the reality that if i'm a healthcare professional out visiting with them in their home, that if something were to happen, if I were to arrive and they were feeling quite short of breath or they were having chest pain or they were having those things...I'm the first responder, i'm the one who is in their home and I usually try to talk to them a little bit about what the default expectations for me as a healthcare professional will be if I come across a crisis. And usually the discussion sorta slides into 'you know, i've known you for quite a long time, and if I were to arrive and there was some sort of medical emergency I would think it was really unfortunate that I didn't have a chance to talk to you about what your expectations would be and what you would want from me, how you would want me to advocate for you on your behalf for all the times that we've had on this couch and had conversations about a bazillion things, this is something I think we should chat about, and not necessarily today, but over the next few visits about what would you like to know and talk about the what if kinda stuff' (CAN9)
Having end-of-life on a list of things that need to be talked about	'I show them my sheet of things i'm supposed to cover, and i'll say, 'you know, we're supposed to talk about this, it can be uncomfortable for some people, but have you ever thought about this or is this something you have questions about', and that will usually open the door there.' (CAN5)
Having handouts of example advance care directives (paper resources)	'I like having a handout, a couple of handouts about um advance care directives or examples of those to show to people and uh, as sort of a starting point for conversation, um, and I do like having it on our list of things to talk about because it's an easier, it's easier for me I guess, I don't know if it's easier for them, it's easier for me to bring it up then, you know, 'it's not that I think you're sick, it's just that we're supposed to talk about this'. So it helps to have that printed on our form, of you know, we talked about all this and this is the one thing we haven't talked about and...uh, so that helps, that helps me bring it up, and then having some paper resources to give them helps too.' (CAN5)
Responsibility of health professional to meet patient wishes	'I think it's thier right, um I think that they have every right to have their wishes met, and so that is part of our responsibility to make sure those are met, and the thing that's very important for me, because this did not happen for me, is I think everyone has, families have the right to say goodbye to patients and I don't think they know their family members are dying or at an end stage of life, and so it's not even ever given them the ability to say goodbye because nobody's ever talked to the family members about what we're doing and what that means, and so our patients will just get sicker and sicker and sicker, and honestly from having been a family member, and not knowing what's going on, my god, come on, let's include them too, and let them know what we're doing, what it means and where this patient is actually, I mean, I deal with respiratory failure, that is end-of-life, you know, and I don't think we're giving it the importance that it deserves, is my feeling.' (CAN11)

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Canadian Delphi Round I Key considerations: quotes from each item

Sensitivity to health literacy level of the patient	'health literacy and understanding certainly...that has rarely been addressed, um, and a lot of it is out of sheer ignorance, um, of these discussions, of the need for these discussions, um, in Canada we have, well in Ontario we have, uh, um power of attorney for personal care, and most people at this point in time when they have done wills, also have done this power of attorney for personal care, which will bring up some of that, but it is very poorly explained in the provincial literature, nor do they really have a good basic standard, from which to do, and there are lots of different standards or bases on which either various hospitals or groups have put together, discussions about living wills, um, and what kinda things, could be discussed, should be discussed, or based on um, health concerns, um, perhaps those kind of things could be worked on together, so that's a health literacy thing that is not only systemic from medical issues and legal issues, and family dynamics, it's putting all those parts together, and getting that information out in a comprehensive and yet understandable way to the majority of the population is a big issue.' (CAN10)
Sensitivity to patient's language needs	'language can be a huge barrier'(CAN6)
<b>The Health Professional</b>	
Health professional being comfortable with approaching end-of-life topic	'a greater degree of comfort, you know, switching in and out of conversations and you know, not being scared or apprehensive...I think is a skill that you develop' (CAN1)
Health professional having experience and practice having end-of-life discussions	'I think the more you do it, the more comfortable you are. And the more easy the conversations come and the more experience you get too, you know' (CAN1)
Health professional is familiar with end-of-life planning process	'they'll book an appointment with me to go into it in more detail - they want to see a copy of the living will, they want to see what types of things that they could be asking for, they wanna discuss those details. They want to discuss details about palliative care in our health region, you know, um how to access it.' (CAN4)
Health professional has attended education sessions about discussing end-of-life	'a bunch of us had gone to a conference, and this one physician started his lecture with...'if you don't talk to your patients about end-of-life, who is?'. And I thought, oh my goodness you're absolutely right' (CAN4)
Health professional has knowledge of palliative care and end-of-life issues	'you're switching over from regular home care to another team, to palliative home care and you know it's palliative, and you know what that means, you know that means end-of-life, you know that means that um, that this is another chapter in your life now, it's a shift right, and so some people are quite okay with that, and quite um, relieved with it, but some people it creates a lot of anxiety and apprehension, and they're just not ready for it yet.' (CAN1)
Emotional intelligence of health professional	'effective communication, um, i'd say emotional intelligence, because there's some really really bright clinicians who just can't read people at all' (CAN9)
Health professional acts as a neutral party to talk to the family about what is happening to the patient	'a lot of times they want to have the homecare person because it's the neutral party who is going to tell them the truth.' (CAN6)

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Canadian Delphi Round I Key considerations: quotes from each item

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<b>Context of the discussions</b>	
Patient's condition for discussion	'Somebody has a chronic disease and if they've had repeated admissions to hospital and each time you see them they're physical condition is declining, and their disease is worsening, then um, that's certainly the time to talk to people' (CAN12)
Having a support person present during discussion	'You know and it should be noted that it's not just the person with chronic lung disease, sometimes it's their support person who makes the call. Yah, so it varies' (CAN4)
Patient understanding that their condition is life limiting	'the shortness of breath will get worse and worse and worse, to the point where you will have difficulty speaking. Before you get to that point, you want to discussions with your family about what you would like done in your final days. And you know again, we put the ball right back in the court. You're relatively - you don't feel like it, but you're relatively healthy now, so have those discussions now.' (CAN4)
Patient understanding that they can receive palliative care	'They want to discuss details about palliative care in our health region, you know, um how to access it.' (CAN4)
Time available to discuss	'it's only when you actually sit there with the client and you actually have the time, and i'm talking I probably spend anywhere from 7 to 20 minutes before a physician sees them, so you, in that time I have to gather an awful lot of information, but I also have to pick and choose as to what I can expand on as well.'(CAN7)
Time available for follow up discussions	'It may be discussed with their physician, whether it's their primary care physician or their respirologist, but alot of the times I don't see them after they've seen the respirologist at that visit, so it's not until the next time I would see them that i'll say - or that i'll see that the respirologist has written end-of-life care was discussed, so if that's been discussed, a lot of the times I bring that up, in the conversation that I have the next visit, because I want them to be able to understand that it was discussed and it is something that needs to be looked at.'(CAN7)
Setting of discussion	'Whenever you talk about that when you're in a hospital, they have a tendency not to believe you because when you go to a hospital, you come out better, that's what most people think. So once the doctors have the initial discussion with them, they are in shock, and if you go in and discuss it, it's like you know what, I just wanna go home and think about all of this, so it really has to be on their terms.'(CAN6)
Privacy for discussion	'And often privacy can be issues when you have people who are in ward rooms, how do you get privacy to discuss things when they are basically immobile. You know, um, so how do you do that well, how do you do that in an emergency setting when it's like a curtain that's separating you as well, and there's a lot of noise going on. A lot of the time you need some privacy and quiet time, you need a quiet room to be able to go and discuss those things, some people are capable of moving to those places and other people are not, so there's a lot of issues that need to be looked at in those factors.'(CAN10)

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Canadian Delphi Round I Key considerations: quotes from each item

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Life experience of person that you are having the discussion with in emergency scenario (usually a family member)	'just today actually I just got off the phone with an 18 year old who is power of attorney for her father who's in his early 60s, and it's a question of how much is understood, and um, life experiences that the person has had that you're having the discussion with and how ready are they to say yes let's just keep them comfortable.' (CAN12)
Multi-disciplinary team available to patient	'we need to have group discussions and patients need to perceive that they can have discussions within the teams, um, with anyone in the team and it will be shared to the point where it's not only getting information from the physicians, but the patient will know that they'd be getting information in discussions and it's equally valid between any team member.'(CAN9)
Confirming patient understanding of the discussion	'Ensuring patient understanding (having the patient tell you what they understand about what you've discussed' (CAN12)
Personality of the patient	'Just personality, the person's personality. I mean you talk to some people and it doesn't matter how you say things, you know you're never going to get through to them, you have to realize that and understand that you just kinda quit. I mean not everybody wants to hear it, you know, our job is to explain it and tell it. But, once you say it once, and if they don't want to hear it again, you don't bring it up again. Unless they approach it, and sometimes that's the only way you can do it' (CAN6)
Credibility of the health professional (as recognised by the patient)	'credibility, um, you know, patients will say, some patients will say that they want their physicians to lead this discussion and because their physician is credible, um, so, so I think that's an important piece' (CAN9)
Whether the patient is taking care of themselves	'Or if the patient is at um, high risk for um, not suicide I wouldn't say, but if because of their denial they're neglecting themselves, then you push the envelope a little bit further, right, you bring up the conversations more' (CAN1)
Individual patient needs	'it's really tough because you have to guage every single person differently, it's like you have to feel them out first and see where they're at with things, and see how far you can go before you watch the reaction in their face go to you know' (CAN6)

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## Appendix F. Canadian Delphi Round I Key topics: sample quotes

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### Canadian Delphi Round I Key topics: sample quotes

Patient understanding of their option to make end-of-life choices	'But the older group... now that group is quite anxious to know the truth, and they also want to know what it means by what we're doing. And they wanna have a choice. They don't all want us to give them all this stuff. And, and so, they seem to be more willing to go through what the consequences are of not pursuing intervention, and then making some new decisions at that point. Not necessarily with me but with their doctors, so they'll hear our schpeil about why we think they should go on this stuff, but also consequences of not going on it, and then they seem to make a decision and then they're gonna pursue speaking about this in more detail and getting some written direction down with their physicians.' (CAN11)
Patient deciding on a substitute decision maker	'I talk about substitute decision maker, and with the Ontario booklet they have the little wallet card that you can actually write in your substitute decision maker, and a phone number.' (CAN2)
Patient understanding of the 'chain of command' of decision makers, should there be a dispute when patient is unable to speak for themselves	'briefly discuss that there's sort of a chain of command when it comes to making a decision, and that if you think your spouse is the one and only who could give an answer, that's not necessarily the case....should there be any dispute.' (CAN2)
Option to change your mind after making end-of-life decisions	'I cover with them that you can rescind this at any time, this is, this document, you can rip it up at any moment, you aren't bound by this, if you are still able to communicate and you wanna change that, that's absolutely your perogative, you can, you know, this isn't a permanent document, and if you change your mind, you can change your mind, that's entirely up to you at the last minute.' (CAN5)
Making sure the doctor knows what kind of care the patient wants	'I give them the form and say, you know, discuss this...with your doctor, make sure that he knows or she knows what kind of care you want'(CAN5)
Levels of advance care directives (supportive care only to full resuscitation)	'I make sure I cover, sort of the levels of advance care directives, the form that we have has supportive care only, um, I forget what the second level is, and the third level is sort of full resuscitation'(CAN5)
Walking the family through the process of what will happen when the patient dies	'a lot of times they have a lot of questions about, you know when he moves on, what's it going to be like? Is there going to be a mess, um, you know, who do I call if I wake up and he is lying in the bed and he is dead, what do I do, you know. It truly is walking them through process, and if they're willing to listen to it, you just say 'okay this likely what will happen you know, if, this is his choice to stay at home, these are the things that will occur over the next little while and we will be there with you if you want us there, every step of the way.'" (CAN6)
Explaining implications of end-of-life decisions and care to family	'nobody's ever talked to the family members about what we're doing and what that means, and so our patients will just get sicker and sicker and sicker, and honestly from having been a family member, and not knowing what's going on, my god, come on, let's include them too, and let them know what we're doing, what it means and where this patient is actually, I mean, I deal with respiratory failure, that is end-of-life, you know, and I don't think we're giving it the importance that it deserves, is my feeling' (CAN11)

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<p>Discussing the 'bother versus benefit' of treatments or interventions with patients</p>	<p>'If the burden of therapy is outweighing the benefit of thereapy then we need to make new decisions, and there like oh my god that makes so much sense, because you're right this is making me so crazy it's not worth it, so yah, which is - the is it giving you more benefit than bother, or more bother than benefit, because that is an easy way to decide whether we're gonna continue doing all this stuff with machines that are making you stay up all night, and your family crazy'(CAN11)</p>
<p>How patient wants things to look at the end-of-life</p>	<p>'So they come in, they're at the the end of life, and there they are intubated, they're doing everything because no one's been paperworked...you know what I mean, nobody's aware of what the patient really wanted..' (CAN11)</p>
<p>Educating patients about their end-of-life choices and implications</p>	<p>'I start with 'have you ever thought of, or have you ever discussed with your family, should you become so will that we would have to consider life support for you, or that if your heart should stop, would you want us do the compressions like you've seen on TV?', and then I go on to say 'there's pros and cons to both, the pro is, you may live longer, the con is, you may have to go down into the intensive care unit on a breathing machine where you will be tied down and you can't talk and you'll have to be fed through a tube, and you're dependent on care, totally'. Um, so that's sort of how I frame it.' (CAN12)</p> <p>'we made some goals of getting him out of the house so he could have a life' (CAN11)</p>
<p>Explaining where they are in their disease e.g. no cure, focus on symptom management</p>	<p>'Somebody has a chronic disease and if they've had repeated admissions to hospital and each time you see them they're physical condition is declining, and their disease is worsening, then um, that's certainly the time to talk to people.'(CAN12)</p>

## **Appendix G. Protocol for proposed pilot study**

This pilot study would aim to determine how the tool can be used by health professionals in practice, and to determine how best to administer the outcome measures in the planned randomised control trial. The pilot study would be conducted in two PCTs in England where several BLF nurses are in practice. At the time of writing this would likely in Liverpool and Southampton as these two areas have the highest number of nurses registered with the BLF (Liverpool (12), Southampton (8)). A researcher in each area would be employed to carry out the administration of the project. The pilot study would only include patients with a diagnoses of COPD at any stage in their disease and would be carried over one year. The limit of only COPD patients, rather than any patient with NMRD would be imposed during the pilot study in order to simplify recruitment and to provide clarify for health professional participants as to which patients they should be using the tool with.

Health professional participants in each location would be asked to attend an education session about the tool and how to use it in practice. This session will be informed by the findings of the proposed systematic review.

Several copies of the tool, with a set of questions printed on the back will be provided to participants. The questions on the back will relate to outcome measures one and two.

The pilot study will have three outcome measures:

1. A question about whether the health professional used the tool when meeting with a patient, and whether or not they decided to initiate a discussion or not based on guidance from the tool, with room for comments.
2. A question about whether the tool increased their confidence in initiating an end-of-life discussion, asking them to rate their confidence level on a scale of 1-10. This will be compared with a rating of confidence approaching end-of-life discussions at the beginning of the study to enable establish a baseline confidence rating.
3. The Quality of Communication Questionnaire (Engleberg, 2006) would be used by the researcher on a follow-up visit to patients with which end-of-life discussions have been initiated by the health professional. This validated questionnaire includes two scales: the General Communication Skills scale and the Communication about End-of-Life scale. This measure will be used to determine whether patients who have health professionals who have used the tool to guide an end-of-life discussion have a high score. The scores could be compared with the COPD patient data provided by (Engleberg, 2006) to determine whether the scores using this intervention are higher, but in the randomized control trial following the pilot study, the outcome measure would also be applied on a control group receiving no intervention and this is where the meaningful data will emerge.

The information gathered in the pilot study will be used to design a cluster randomized trial with several PCTs in England, Scotland, Wales and Northern Ireland. Details of the cluster randomized trial are not able to be explicated until after the pilot study has been carried out.

## **Appendix H. Protocol for proposed systematic review**

The objective of this systematic review is to review the effectiveness of end-of-life communication skills training programmes for health professionals on improving communication about end-of-life between health professionals and patients, and to identify experience of learning about end-of-life communication and changed perceptions as a result of such training. This protocol was developed using the JBI guidelines for protocol development (JBI, 2008).

### **Inclusion criteria**

#### **Types of participants**

The quantitative and qualitative components of this review will consider studies that include health professionals (physicians, nurses and allied health professionals) currently in education or already qualified and practicing.

#### **Types of intervention(s)/phenomena of interest**

- The quantitative component of the review will consider studies that evaluate educational interventions to improve end-of-life communication.
- The qualitative component of this review will consider studies that investigate educational interventions to improve end-of-life communication
- The quantitative component of the review will consider studies that evaluate educational programmes to teach health professionals about how to communicate with patients about end-of-life.

- The qualitative component of this review will consider studies that investigate students' experiences of undertaking training about how to communicate with patients about end-of-life issues.

### **Types of outcomes**

This review will consider studies that include the following outcome measures:

- reported increase in confidence to have end-of-life discussions with patients
- reported increase in end-of-life discussions after education programme
- reported increase in palliative care uptake in patients

### **Types of studies**

The qualitative component of the review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. In the absence of research studies, other text such as opinion papers and reports will be considered.

The quantitative component of the review will consider both experimental study designs including randomised controlled trials, non-randomised controlled trials, quasi-experimental, before and after studies, prospective and retrospective cohort studies, case control studies and analytical cross sectional studies for inclusion.

## **Search strategy**

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilised in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English will be considered for inclusion in this review. Studies published 2000-2013 will be considered for inclusion in this review.

The databases to be searched include: MedLine, CINAHL, Embase, JBI Library, Cochrane Collaboration, TRIP. The search for unpublished studies will include: Google (Scholar), Mednar, WorldWideScience, PsychExtral, OAlster, SIGLE Initial keywords to be used will be: education, medical education, communication, education, end-of-life.

## **Assessment of methodological quality**

Quantitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MASARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Quantitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

### **Data collection**

Quantitative data will be extracted from papers included in the review using the standardised data extraction tool from JBI-MAStARI. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

Qualitative data will be extracted from papers included in the review using the standardised data extraction tool from JBI-QARI. The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives.

## **Data synthesis**

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorising these findings on the basis of similarity in meaning (Level 2 findings). These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Quantitative papers will, where possible be pooled in statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. Effect sizes expressed as odds ratio (for categorical data) and weighted mean differences (for continuous data) and their 95 percent confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard Chi-square and also explored using subgroup analyses based on the different quantitative study designs included in this review. Where statistical pooling is not possible the

findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorising these findings on the basis of similarity in meaning (Level 2 findings). These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form

## BLF Delphi Round 2

1.

\* 1. Please enter your first and last name.

First name

Last name

\* 2. Have you been interviewed by Nicole in round one of the Delphi (telephone interview)?

Yes

No

## BLF Delphi Round 2

2.

- \* 1. Have you filled out the consent form and biographical information pages? *If not you will be redirected to provide consent and biographical information before continuing with the Delphi Round Two survey.*

Yes

No

## BLF Delphi Round 2

### 3. Consent form

Please take time to read and sign this page. You may not proceed to the survey until it has been completed.

- \* 1. I confirm that I have read and understand the information sheet dated 20 July 2010 for the study "Readiness/Willingness to discuss end-of-life in nonmalignant disease". I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. *Please initial box if you are in agreement with this statement.*

- \* 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my legal rights being affected. *Please initial below if you agree with this statement.*

- \* 3. I understand that I can withdraw my data up until it becomes anonymised. *Please initial below if you agree with this statement.*

- \* 4. I give consent for anonymised quotes from my responses to be used in publications/reports. *Please initial below if you agree with this statement.*

- \* 5. I agree to take part in the above study. *Please initial below if you agree with this statement.*

- \* 6. Please type your name below as your electronic signature and today's date.

- \* 7. Please enter the email address where you would like the next questionnaire to be sent.

## 4. Biographical Questionnaire

\* 1. What year were you born?

\* 2. Please indicate your ethnicity:

Other (please specify)

\* 3. What type of setting do you work in? (e.g. PCT, community, hospital ward, etc.)

\* 4. What town or city do you work in?

\* 5. How many years of respiratory nursing experience do you have?

Less than 2 years

2-4 years

5-7 years

8-10 years

More than 10 years

\* 6. What are your nursing qualifications? (choose all that apply)

RN

RGN

BA (Hons) in Nursing

BSc in Nursing

Diploma in Nursing

Other (please specify)

Other (please specify)

7. What are your post registration qualifications? OR What post registration qualification are you working towards?

## BLF Delphi Round 2

\* 8. What is your current job title?

\* 9. Which of the following best describes the main focus of your current post?

Practitioner

Educator

Researcher

Manager

Other (please specify)

Other (please specify)

# BLF Delphi Round 2

## 5. Letter to participants

Dear Participant,

Thank you for agreeing to take part in this Delphi study about end-of-life care discussions with patients with nonmalignant respiratory disease.

A major aim of this study is to gather the knowledge and opinions of health professionals on how they know a patient is ready or willing to discuss their end-of-life care preferences.

As an expert in your field your opinions on this topic are extremely valuable to us, and we thank you for your time.

Once you have completed the Delphi Round Two survey, please press the exit button to submit your responses electronically over a secure connection provided by the website. If possible, please complete this survey by **December 17** as online access may be disabled after this time. If you are unable to do so, then please let us know and we will make arrangements to accommodate your needs if possible.

Please don't hesitate to contact me if you have any questions, or concerns about the study or if you have technical difficulties with the online questionnaire at [nicole.stephen@plymouth.ac.uk](mailto:nicole.stephen@plymouth.ac.uk).

Thank you again for your participation.

Kind Regards,

Nicole Stephen

# BLF Delphi Round 2

## 6. Question One

Which of the following factors indicate that a patient is ready or willing to discuss end-of-life? Please indicate your level of agreement with each statement below.

\* 1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Clinical signs e.g.: spirometry indicates severe COPD, 3 acute exacerbations in 12 months, on maximum therapy.	jq	jq	jq	jq	jq

Additional comments

\* 2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
My professional intuition	jq	jq	jq	jq	jq

Additional comments

\* 3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Cues from the patient such as stating 'I do not want to go back to hospital'	jq	jq	jq	jq	jq

Additional comments

\* 4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient asks if s/he is going to die	jq	jq	jq	jq	jq

Additional comments

\* 5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Body language e.g.: open posture, appears relaxed	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
General patient demeanour	ja	ja	ja	ja	ja

Additional comments

\* 7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient is responsive when I allude to the end-of-life topic	ja	ja	ja	ja	ja

Additional comments

**8. Are there any factors not included here that indicate to you that a patient is ready or willing to discuss end-of-life? (please explain below)**

# BLF Delphi Round 2

## 7. Question Two

Which of the following factors are important when conducting an end-of-life discussion? Please indicate your level of agreement with each statement below.

Factors relating to: THE PATIENT

\* 1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Allowing the patient to lead the conversation	jq	jq	jq	jq	jq

Additional comments

\* 2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Answering patient's question about the condition	jq	jq	jq	jq	jq

Additional comments

\* 3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Maintaining hope for the patient	jq	jq	jq	jq	jq

Additional comments

\* 4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being open and honest with the patient	jq	jq	jq	jq	jq

Additional comments

\* 5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Establishing patient's understanding of their condition	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Recognising the individual needs of the patient	jq	jq	jq	jq	jq

Additional comments

\* 7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining to patients what is feasible regarding their wishes	jq	jq	jq	jq	jq

Additional comments

\* 8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Educating the patient about their condition	jq	jq	jq	jq	jq

Additional comments

\* 9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient indicates readiness to discuss	jq	jq	jq	jq	jq

Additional comments

\* 10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient wanting to hear the information	jq	jq	jq	jq	jq

Additional comments

\* 11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient being open about dying	jq	jq	jq	jq	jq

Additional comments

Factors related to: THE ENVIRONMENT

# BLF Delphi Round 2

★ 12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having an appropriate environment for discussion e.g. privacy, quiet	ja	ja	ja	ja	ja

Additional comments

★ 13.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Where the discussion occurs e.g. clinic, hospital or patient's home	ja	ja	ja	ja	ja

Additional comments

**Factors related to: THE FAMILY**

★ 14.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having the patient's family involved in the discussion	ja	ja	ja	ja	ja

Additional comments

★ 15.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having family's support during the discussion	ja	ja	ja	ja	ja

Additional comments

★ 16.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient's wish to protect others from end-of-life information	ja	ja	ja	ja	ja

Additional comments

**Factors related to: THE HEALTH PROFESSIONAL**

★ 17.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being an expert on the condition	ja	ja	ja	ja	ja

Additional comments

# BLF Delphi Round 2

\* 18.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurses having counselling skills	jq	jq	jq	jq	jq

Additional comments

\* 19.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having the appropriate clinician to discuss end-of-life with the patient	jq	jq	jq	jq	jq

Additional comments

\* 20.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having a strong relationship with the patient	jq	jq	jq	jq	jq

Additional comments

\* 21.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Emphasising a holistic care approach	jq	jq	jq	jq	jq

Additional comments

\* 22.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Rapport between health professional and patient	jq	jq	jq	jq	jq

Additional comments

\* 23.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional having the confidence to discuss	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 24.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional's understanding of the condition	jq	jq	jq	jq	jq

Additional comments

\* 25.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Using non-medical language	jq	jq	jq	jq	jq

Additional comments

\* 26.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Your professional boundaries	jq	jq	jq	jq	jq

Additional comments

\* 27.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Avoiding euphemisms - saying the words 'dying' or 'death' instead	jq	jq	jq	jq	jq

Additional comments

\* 28.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional taking responsibility to oblige the patient's wishes	jq	jq	jq	jq	jq

Additional comments

\* 29.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Using humour	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 30.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurse having attended conferences or professional development specific to end-of-life discussions	jq	jq	jq	jq	jq

Additional comments

\* 31.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurse having experience in caring for dying patients	jq	jq	jq	jq	jq

Additional comments

**Factors related to: TIMING**

\* 32.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Discussing end-of-life at time of diagnosis	jq	jq	jq	jq	jq

Additional comments

\* 33.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Developing the discussion over time	jq	jq	jq	jq	jq

Additional comments

\* 34.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Finding the right opportunity to discuss	jq	jq	jq	jq	jq

Additional comments

\* 35.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient having time to hear information and ask questions later	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 36.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Availability of time to discuss	jq	jq	jq	jq	jq

Additional comments

**37. Are there any factors that have not been included here that are important when conducting an end-of-life discussion? (please explain below)**

# BLF Delphi Round 2

## 8. Question Three

Which of the following would you include in an end-of-life discussion? Please indicate your level of agreement with each statement below

\* 1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Introduction of an advance care planning document	jq	jq	jq	jq	jq

Additional comments

\* 2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
The type of care the patient wants	jq	jq	jq	jq	jq

Additional comments

\* 3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Emergency management preferences	jq	jq	jq	jq	jq

Additional comments

\* 4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining palliative care	jq	jq	jq	jq	jq

Additional comments

\* 5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Anticipatory prescribing	jq	jq	jq	jq	jq

Additional comments

\* 6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Ceiling of treatment	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

\* 7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Medication options	jq	jq	jq	jq	jq

Additional comments

\* 8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Treatment options	jq	jq	jq	jq	jq

Additional comments

\* 9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient goals	jq	jq	jq	jq	jq

Additional comments

\* 10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Intubation and ventilation options	jq	jq	jq	jq	jq

Additional comments

\* 11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Preferred place of care	jq	jq	jq	jq	jq

Additional comments

\* 12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Preferred place of death	jq	jq	jq	jq	jq

Additional comments

\* 13.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
When the patient is likely to die	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

★ 14.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Sedation availability/options	jq	jq	jq	jq	jq

Additional comments

★ 15.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Social services involvement	jq	jq	jq	jq	jq

Additional comments

★ 16.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Spirituality	jq	jq	jq	jq	jq

Additional comments

★ 17.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Transferring to palliative care	jq	jq	jq	jq	jq

Additional comments

★ 18.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Who the patient wants present at the very end-of-life	jq	jq	jq	jq	jq

Additional comments

★ 19.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Dealing with breathlessness	jq	jq	jq	jq	jq

Additional comments

**HOSPICE**

# BLF Delphi Round 2

\* 20.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining hospice (if available)	jq	jq	jq	jq	jq

Additional comments

\* 21.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Options for hospice (if available)	jq	jq	jq	jq	jq

Additional comments

## PERCEPTIONS OF DEATH

\* 22.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
How they feel about death	jq	jq	jq	jq	jq

Additional comments

\* 23.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Reassuring the patient s/he won't suffer	jq	jq	jq	jq	jq

Additional comments

\* 24.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Understanding of death	jq	jq	jq	jq	jq

Additional comments

## PRACTICAL NEEDS

\* 25.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Getting affairs in order	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 2

★ 26.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Practical equipment needs	ja	ja	ja	ja	ja

Additional comments

★ 27.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Support in the home	ja	ja	ja	ja	ja

Additional comments

★ 28.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Transportation needs to facilitate care	ja	ja	ja	ja	ja

Additional comments

## 9. Thank you

You have completed round two of the Delphi study.

Thank you very much for your participation. You will be notified via email when the next questionnaire is ready for your participation.

To exit the survey, click exit below.

# BLF Delphi Round 3

## Welcome!

### Round Three of the Delphi Study

Dear Participant,

The purpose of this round of the Delphi is to give you a chance to see how other participants have responded to each item.

Please review each item, considering the mean score and the comments from the previous round. Based on this information re-consider your opinion and then rate the item. Also, feel free to add any comments that you feel may clarify the item, but note that comments are not required.

You may notice that some items have been moved from one question to another, and some items have been added from suggestions made in the previous round. In such cases, there will be no prior information such as a mean or comments provided, and therefore you should rate the item based on your professional experience.

Please would you be kind enough to complete the survey by 28TH JANUARY - please contact me if you have any questions, technical difficulties or problems with completing the survey before 28 January as it is very important to the validity of the study that you are able to respond.

Sincerely,

Nicole Stephen  
nicole.stephen@plymouth.ac.uk

**1. First name:**

**2. Last name:**

# BLF Delphi Round 3

## Question One

Which of the following factors indicate that a patient is ready or willing to discuss end-of-life?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

1.

**Mean** (average rating in previous round)

3.32 (undecided)

**Comments from previous round**

- Clinical symptoms don't indicate willingness to discuss end-of-life
- Exacerbations and decreased time between them is one main factor -not getting better
- Be lead by patient. Patient needs to know that they are severe COPD, make sure that patient is informed of diagnosis. Be there for answering questions and further advice (support when needed)
- Clinical severity does not always represent a willingness to engage
- These signs do not mean much to the patient
- Helpful but not sensitive enough

1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Clinical signs e.g. spirometry indicates severe COPD, 3 acute exacerbations in 12 months, on maximum therapy	jq	jq	jq	jq	jq

Additional comments

2.

**Mean** (average rating in previous round)

4.16 (agree)

**Comments from previous round**

- sometimes
- sometimes
- "Gut" feeling is helpful. Supported by professional expertise, emotional intelligence

2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
My professional intuition	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

3.

**Mean** (average rating in previous round)

4.53 (agree)

**Comments from previous round**

- Can be a prompt to follow

3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Cues from the patient such as stating 'I do not want to go back to hospital'	jq	jq	jq	jq	jq

Additional comments

4.

**Mean** (average rating in previous round)

4.74 (agree)

**Comments from previous round**

- If they ask, the door is open
- This gives an opportunity to discuss end of life. Be lead by the patient. As questions which will prompt the patient. Sometimes patient wants to know but hasn't confidence to ask the question.
- This could be explored to see if they want to

4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient asks if s/he is going to die	jq	jq	jq	jq	jq

Additional comments

5.

**Mean** (average rating in previous round)

3.42 (undecided)

**Comments from previous round**

- Not necessary a sign willing to discuss end-of-life

5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Body language indicates openness to discussion e.g.: open posture, appears relaxed <i>changed from: Body language</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

6.

**Mean** (average rating in previous round)

3.79 (undecided)

**Comments from previous round**

- No comments

6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
General patient demeanour	jq	jq	jq	jq	jq

Additional comments

7.

**Mean** (average rating in previous round)

4.47 (agree)

**Comments from previous round**

- If patient is responsive - take it further with discussion, look for patient reaction and participation
- Another helpful clue for nurses

7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient is responsive when I allude to the end-of-life topic	jq	jq	jq	jq	jq

Additional comments

8.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient refers to their own death previously 2.11 'patient being open about dying'	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

9.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient talks about or asks about hospice options <i>previously 3.20/21 'patient talking about/asking about hospice options'</i>	jq	jq	jq	jq	jq

Additional comments

10.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient appears to be getting their affairs in order <i>previously 3.25 'Getting affairs in order'</i>	jq	jq	jq	jq	jq

Additional comments

11.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Family whispers to you in the hall 'John wants to die' <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

12.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient states that they have 'had enough' or that they want to die <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

13.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

13.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient asks about intubation in the hospital <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

14.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

14.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient does not comply with treatment <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

15.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

15.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Recent death in the family and patient has concerns about the same issue <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

## Question Two

Which of the following factors are important when conducting an end-of-life discussion?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

1.

**Mean** (average rating in previous round)

4.05 (agree)

**Comments from previous round**

- This varies patient to patient
- You need to get decisions made so open questions but you need to guide sometimes
- It is fine to initiate an end-of-life discussion but progress should be lead by the patient
- Usually from cues or leading questions
- Let them lead, however prompt to expand discussion further
- They may want to, listen a lot, resist temptation to take
- Patient can initiate the conversation but probably not leading
- Patient starts the conversation but practitioner leads the discussion
- Some patients will prefer to be 'led' or are not sure how to lead the conversation

1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Allowing the patient to lead the conversation	jq	jq	jq	jq	jq

Additional comments

2.

**Mean** (average rating in previous round)

4.58 (agree)

**Comments from previous round**

- Always answer patient questions as fully as possible or sign post when appropriate
- They may need to understand more to deal with it

2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Answering patient's questions about the condition	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

3.

**Mean** (average rating in previous round)

3.47 (undecided)

**Comments from previous round**

- Honesty is the best way forward. False hope can be detrimental
- Realistic goals
- Hope that symptoms can be managed effectively
- Give facts, evidence based answers i.e. in COPD explain it is a progressive disease
- Difficult one
- You don't generally give patients false reassurance
- This could be unrealistic
- If they are going to die what hope can one maintain?
- Not sure - hope for what?

3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Maintaining hope for the patient that symptoms can be managed effectively, while being honest about the likelihood of disease progression <i>previously: Maintaining hope for the patient</i>	jq	jq	jq	jq	jq

Additional comments

4.

**Mean** (average rating in previous round)

4.89 (agree)

**Comments from previous round**

- Always best
- Treat carefully when being open and honest. Answer questions with tact and appropriateness
- I think this is important, but sometimes they don't want to know
- Even if that means saying 'I don't know'

4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being open and honest with the patient	jq	jq	jq	jq	jq

Additional comments

5.

**Mean** (average rating in previous round)

4.79 (agree)

**Comments from previous round**

- No comments

# BLF Delphi Round 3

5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Establishing patient's understanding of their condition	jq	jq	jq	jq	jq

Additional comments

6.

**Mean** (average rating in previous round)

5.0 (strongly agree)

**Comments from previous round**

- and families
- May be other than health issues, may need to refer on

6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Recognising the individual needs of the patient (and their family where applicable) <i>previously: recognising the individual needs of the patient</i>	jq	jq	jq	jq	jq

Additional comments

7.

**Mean** (average rating in previous round)

4.84 (agree)

**Comments from previous round**

- Make sure any decisions are communicated to multidisciplinary team and family if appropriate
- What is realistic and conceivable

7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining to patients what is feasible regarding their wishes	jq	jq	jq	jq	jq

Additional comments

8.

**Mean** (average rating in previous round)

4.37 (agree)

**Comments from previous round**

- Specific to end-of-life care
- Be lead by patient
- What to expect
- This depends - hopefully I will have had the opportunity to establish their level of understanding

# BLF Delphi Round 3

## 8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Educating the patient about their condition and what to expect <i>previously: educating the patient about their condition</i>	jq	jq	jq	jq	jq

Additional comments

## 9.

**Mean** (average rating in previous round)

4.58 (agree)

**Comments from previous round**

- Patients may have no insight into the risk of their mortality and therefore may be unlikely to raise end-of-life discussion themselves
- Take the opportunity. Be lead by patient. Prompt patient to take discussion wider if appropriate.
- Some patients will never be ready
- Not always obvious - goes back to intuition

## 9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient indicates readiness to discuss	jq	jq	jq	jq	jq

Additional comments

## 10.

**Mean** (average rating in previous round)

4.32 (agree)

**Comments from previous round**

- Patient needs realistic information but it may not be information that they want to hear
- They may want to hear but they may find difficult to understand or accept
- Some patients will never be ready
- You still need to start the conversation to establish what they don't want to hear

## 10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient wanting to hear the information	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

11.

**Mean** (average rating in previous round)

4.63 (agree)

**Comments from previous round**

- Environment is important but this may alter person to person. Some patients wish family to be present
- Sometimes we have to make use of the opportunity rather than setting the scene
- Important to discuss in an environment suitable for the patient and the patient knowing what the discussion is about to be able to choose the right environment
- Wherever patient is comfortable
- No disruptions if possible
- But not always possible

11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having an appropriate environment for discussion	jn	jn	jn	jn	jn

Additional comments

12.

**Mean** (average rating in previous round)

4.11 (agree)

**Comments from previous round**

- Not sure what this question is asking...best for health professional or patient?
- Appropriateness to patient
- Sometimes due to patient's condition you have to do where's available - you would prefer at home - sometimes too poorly
- Wherever best opportunity occurs
- Better in their own environment

12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Where the discussion occurs e.g. clinic, hospital or patient's home	jn	jn	jn	jn	jn

Additional comments

# BLF Delphi Round 3

13.

**Mean** (average rating in previous round)

3.63 (undecided)

**Comments from previous round**

- With patients prior consent to which family member
- Varies patient to patient
- If patient consents
- It should be up to the patient if they want their next of kin present
- Only if patient wishes
- Can vary from individual cases but some may benefit from family being present to reinforce info
- Should be led by the patient, if they would like somebody to be present
- Patient's decision
- Some patient want to discuss stuff without relatives present so some discussion with patient some with relatives and some with both so everyone knows how they feel
- Find out patients wishes first encourage family involvement
- This depends on patient's wishes and need for privacy
- Depends if patient wants family involved in discussion
- Only once I've had the discussion with the patient first

13.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having the family involved in the end-of-life discussion if the patient wishes <i>previously: Having the patient's family involved in the discussion</i>	jn	jn	jn	jn	jn

Additional comments

14.

**Mean** (average rating in previous round)

4.11 (agree)

**Comments from previous round**

- If patient wishes this
- If they want to be
- Is always helpful to support the patient and because two sets of ears are often better than one
- Depends on situation
- Patient's decision
- This depends on patient's wishes and need for privacy
- Can be helpful but not imperative

# BLF Delphi Round 3

14.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having family support during the discussion if patient wants their involvement <i>previously: Having family's support during the discussion</i>	jq	jq	jq	jq	jq

Additional comments

15.

**Mean** (average rating in previous round)

3.63 (undecided)

**Comments from previous round**

- Depends on individual situation
- I recommend that patients be honest with those closest to them to allow them time to adjust. Having a patient try to protect relatives is almost as difficult as the next of kin trying to persuade me not to be honest with a patient
- May not be ready to share info, can be done later
- Need patient to realise all information given is confidential, although may wish to guide patient if it is in the best interest. Therefore important to recognise patients ability to retain information and make informed decisions
- Patient's decision
- Can you find out why
- Important but as a topic for discussion

15.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient's wish to protect others from their end-of-life wishes (keeping information from the family if the patient wishes) <i>previously: Patient's wish to protect others from end-of-life wishes</i>	jq	jq	jq	jq	jq

Additional comments

16.

**Mean** (average rating in previous round)

4.0 (agree)

**Comments from previous round**

- I do not feel like an expert - I am still learning
- All end-stage organ failure can apply across the board. However, being a respiratory specialist, I may be able to offer more info than a generalist
- You don't need to be an 'expert' to discuss end of life matters.
- I don't think this is essential
- Need not be expert in specific condition but expert in needs of long term conditions

# BLF Delphi Round 3

16.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being an expert on the condition	jq	jq	jq	jq	jq

Additional comments

17.

**Mean** (average rating in previous round)

4.05 (agree)

**Comments from previous round**

- Not necessarily from a course. Natural skills are sometimes better
- Or at least excellent communication skills but who can measure this?
- Nurses develop communication skills from training. Communication is one of the most important skills.
- Definitely very helpful as sometimes can feel out of depth
- In an ideal world but often patients will ask the most difficult question of the most junior member of staff

17.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurses having attended counselling skills training previously: Nurses having counselling skills	jq	jq	jq	jq	jq

Additional comments

18.

**Mean** (average rating in previous round)

4.11 (agree)

**Comments from previous round**

- But they have to be good at breaking bad news - some are hopeless!
- Be lead by patient. It may be better from GP in some cases
- May think that consultant may be and they may not necessarily have skills
- The most appropriate person may not be acceptable to the patient
- Who decides who is appropriate - may be me, may be GP or PI nurse

18.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having the appropriate clinician to discuss end-of-life	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

19.

**Mean** (average rating in previous round)

3.84 (undecided)

**Comments from previous round**

- Occasionally the consultant may be best placed but other health care professionals who know the patient can offer on-going support
- Each patient is an individual - one clinician to discuss end of life may not be appropriate for another
- Can make easier
- Helpful in starting conversation

19.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having a strong relationship with the patient	jq	jq	jq	jq	jq

Additional comments

20.

**Mean** (average rating in previous round)

4.68 (agree)

**Comments from previous round**

- Addressing all patients issues
- The bedrock of all we do, I hope

20.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Emphasising a holistic care approach	jq	jq	jq	jq	jq

Additional comments

21.

**Mean** (average rating in previous round)

4.47 (agree)

**Comments from previous round**

- Led by patient
- Very important

21.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Rapport between health professional and patient	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

22.

**Mean** (average rating in previous round)

4.84 (agree)

**Comments from previous round**

- Staff who are not confident should acquire relevant skills and experience
- The time to discuss at numerous times - it requires a lot of time

22.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional having the confidence to discuss	jq	jq	jq	jq	jq

Additional comments

23.

**Mean** (average rating in previous round)

4.63 (agree)

**Comments from previous round**

- No comments

23.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional's understanding of the condition	jq	jq	jq	jq	jq

Additional comments

24.

**Mean** (average rating in previous round)

4.48 (agree)

**Comments from previous round**

- Depends on patient's knowledge/background/education
- Keeping simpler for patient
- In any discussion!

24.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Using non-medical language	jq	jq	jq	jq	jq

Additional comments

25.

**Mean** (average rating in previous round)

4.16 (agree)

**Comments from previous round**

- What boundaries? Something like this is difficult to separate yourself from
- I'm not re what professional boundaries you refer to

# BLF Delphi Round 3

25.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Working within realms of own expertise and maintaining professional boundaries <i>previously: Your professional boundaries</i>	jq	jq	jq	jq	jq

Additional comments

26.

**Mean** (average rating in previous round)

3.68 (undecided)

**Comments from previous round**

- Varies person to person
- What does the patient call it.
- Some patients may be in denial so would these terms be more appropriate?? Then again, who are we to decide that patients need to know? Maybe they already do but do not want to hear...
- Depends on the type of personality some patients don't mind hearing dying
- Tempting to do this to make easier?
- Depends on patient and carer
- Depends

26.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Echoing patient's language for death and dying words <i>previously: Avoiding euphemisms - saying the words 'dying' or 'death'</i>	jq	jq	jq	jq	jq

Additional comments

27.

**Mean** (average rating in previous round)

3.63 (undecided)

**Comments from previous round**

- Two way process
- Try to undertake wishes
- If facilities available to do so /explain to patient why if not possible
- Depends upon the wishes.....
- Within their professional boundaries
- Depends
- You must acknowledge their wishes but be honest and not collude where their wishes are not practical, etc.

# BLF Delphi Round 3

27.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional acknowledges and tries to undertake patient's end-of-life wishes if facilities are able to do so, and if not explaining why <i>previously: Health professional taking responsibility to oblige the patient's wishes</i>	jq	jq	jq	jq	jq

Additional comments

28.

**Mean** (average rating in previous round)

3.05 (undecided)

**Comments from previous round**

- Where appropriate
- Varies person to person
- If patient likes or uses humour
- If appropriate
- Depends on relationship with patient and their personality
- Sometimes depends on the situation
- Can vary... one patient may be happy to talk openly and 'make light' of the situation whereas this can be very inappropriate with a different patient
- Required to be led by patient
- Appropriateness with patient
- Again this depends on the type of patient your relationship with the patient
- Depends on circumstances
- But appropriately

28.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Using humour when appropriate to the individual <i>previously: using humour</i>	jq	jq	jq	jq	jq

Additional comments

29.

**Mean** (average rating in previous round)

3.68 (undecided)

**Comments from previous round**

- Experience of situations and empathy just as important as theoretical knowledge
- Especially to know what local and national guidelines, etc are available
- Some nurses it comes naturally having courses helps increase confidence
- Does make easier
- But should not stop you from having the conversation

# BLF Delphi Round 3

29.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurse having attended conferences or professional development specific to end-of-life discussions	jq	jq	jq	jq	jq

Additional comments

30.

**Mean** (average rating in previous round)

4.16 (agree)

**Comments from previous round**

- For own personal strength in dealing with how we can cope
- Helps nurse confidence

30.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Nurses having experience in caring for dying patients	jq	jq	jq	jq	jq

Additional comments

31.

**Mean** (average rating in previous round)

2.74 (disagree)

**Comments from previous round**

- Should be introduced as part of the discussion regarding ongoing progressive illness and may require discussion in the future
- Varies person to person
- But should be told treatable but not curable
- Not really best time but I do discuss it briefly not in depth
- Patients may be inclined to 'give up' - again, can vary...
- Not necessarily but important patients recognise it is a long-term condition
- We need to get confident in starting at discussions at diagnosis
- Not appropriate at all
- Depends on disease severity at diagnosis
- Depends on patient
- Difficult to balance the need for patients to understand the disease is life limiting with giving a bleak picture and no hope

31.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Discussion of life-limiting nature of disease at time of diagnosis <i>previously: discussing end-of-life at time of diagnosis</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

32.

**Mean** (average rating in previous round)

4.32 (agree)

**Comments from previous round**

- More comfortable
- This depends on patients

32.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Developing the discussion over time	jn	jn	jn	jn	jn

Additional comments

33.

**Mean** (average rating in previous round)

4.32 (agree)

**Comments from previous round**

- Should be over time

33.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Finding the right opportunity to discuss	jn	jn	jn	jn	jn

Additional comments

34.

**Mean** (average rating in previous round)

4.42 (agree)

**Comments from previous round**

- Different patients ask different questions
- All questions should be addressed at time

34.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient having time to hear information and ask questions immediately or in the future <i>previously: patient having time to hear information and ask questions later</i>	jn	jn	jn	jn	jn

Additional comments

# BLF Delphi Round 3

35.

**Mean** (average rating in previous round)

4.63 (agree)

**Comments from previous round**

- Sometimes the right for patients is never, the right time for us so being honest about what you can discuss and how to come back to it

35.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Availability of time to discuss	jq	jq	jq	jq	jq

Additional comments

36.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- not applicable

36.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional being unafraid of talking about dying whenever the opportunity occurs - from diagnosis onwards when patient initiates <i>*new item added from participant comments</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

## Question Three

Which of the following would you include in an end-of-life discussion?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

1.

**Mean** (average rating in previous round)

4.83 (agree)

**Comments from previous round**

- No comments

1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
The type of care that the patient wants	jq	jq	jq	jq	jq

Additional comments

2.

**Mean** (average rating in previous round)

4.37 (agree)

**Comments from previous round**

- At some point - probably not first meeting
- If that's what the patient wanted

2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Introduction of an advance care planning document	jq	jq	jq	jq	jq

Additional comments

3.

**Mean** (average rating in previous round)

4.47 (agree)

**Comments from previous round**

- No comments

3.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Emergency management preferences	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

4.

**Mean** (average rating in previous round)

4.68 (agree)

**Comments from previous round**

- No comments

4.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining palliative care	jn	jn	jn	jn	jn

Additional comments

5.

**Mean** (average rating in previous round)

4.39 (agree)

**Comments from previous round**

- Later in discussions
- Not first off

5.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Anticipatory prescribing	jn	jn	jn	jn	jn

Additional comments

6.

**Mean** (average rating in previous round)

4.16 (agree)

**Comments from previous round**

- Need to talk about i.e. NIV

6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Ceiling of treatment	jn	jn	jn	jn	jn

Additional comments

7.

**Mean** (average rating in previous round)

4.32 (agree)

**Comments from previous round**

- No comments

# BLF Delphi Round 3

7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Medication options	jq	jq	jq	jq	jq

Additional comments

8.

**Mean** (average rating in previous round)

4.33 (agree)

**Comments from previous round**

- No comments

8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Treatment options	jq	jq	jq	jq	jq

Additional comments

9.

**Mean** (average rating in previous round)

4.63 (agree)

**Comments from previous round**

- No comments

9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient goals	jq	jq	jq	jq	jq

Additional comments

10.

**Mean** (average rating in previous round)

4.32 (agree)

**Comments from previous round**

- No comments

10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Intubation and ventilation	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

11.

**Mean** (average rating in previous round)

4.84 (agree)

**Comments from previous round**

- No comments

11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Preferred place of care	jq	jq	jq	jq	jq

Additional comments

12.

**Mean** (average rating in previous round)

4.89 (agree)

**Comments from previous round**

- No comments

12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Preferred place of death	jq	jq	jq	jq	jq

Additional comments

13.

**Mean** (average rating in previous round)

3.17 (undecided)

**Comments from previous round**

- No just that they are dying
- This is very difficult to predict in this condition
- This is impossible to predict
- Difficult to predict and patients can become very fixed on this time span
- I would not be able to say
- They always ask this but how do we know?!
- In a non malignant case it is difficult to predict when death is likely to occur
- This is too difficult to predict
- Difficult to quote

13.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining to patient that it is difficult to predict when death is likely to occur <i>previously: When the patient is likely to die</i>	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

14.

**Mean** (average rating in previous round)

4.21 (agree)

**Comments from previous round**

- No comments

14.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Sedation availability/options	jq	jq	jq	jq	jq

Additional comments

15.

**Mean** (average rating in previous round)

4.42 (agree)

**Comments from previous round**

- If appropriate, patient needs to know options available

15.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Social services involvement	jq	jq	jq	jq	jq

Additional comments

16.

**Mean** (average rating in previous round)

4.37 (agree)

**Comments from previous round**

- Led by patient and family
- Define spirituality. It means different things to different people and is much more than just religion
- Only if the patient wants to include this
- If appropriate

16.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Spirituality, if relevant to the patient/family <i>previously: Spirituality</i>	jq	jq	jq	jq	jq

Additional comments

17.

**Mean** (average rating in previous round)

4.26 (agree)

**Comments from previous round**

- We have end-of-life coordinator
- Only if patients want this option

# BLF Delphi Round 3

17.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Transferring to palliative care	jq	jq	jq	jq	jq

Additional comments

18.

**Mean** (average rating in previous round)

4.26 (agree)

**Comments from previous round**

- Only if patient initiates discussion
- Explain this is not always possible
- May not be possible to achieve

18.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Who the patient wants present at the very end-of-life	jq	jq	jq	jq	jq

Additional comments

19.

**Mean** (average rating in previous round)

4.84 (agree)

**Comments from previous round**

- No comments

19.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Dealing with breathlessness	jq	jq	jq	jq	jq

Additional comments

20.

**Mean** (average rating in previous round)

4.21 (agree)

**Comments from previous round**

- No comments

20.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
How they feel about death	jq	jq	jq	jq	jq

Additional comments

# BLF Delphi Round 3

21.

**Mean** (average rating in previous round)

3.42 (undecided)

**Comments from previous round**

- This needs to be explained that we will do the utmost to ensure this won't occur but cannot guarantee
- Important not to give false hope. I explain that we will do our utmost to prevent suffering and that often it is relatives that are distressed due to potential loss etc
- Could I offer this?? I would hope so but if the patient does not want palliative care involvement, could I guarantee this?
- Difficult to predict 100%. It is an aim for all patients to die without suffering
- Explain they will have symptoms we help ease them
- Not sure this can be done
- Can't do that as the end can be unpredictable
- Hard to predict process

21.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Explaining to patient that everything will be done to prevent suffering at the end-of-life <i>previously: Reassuring the patient s/he won't suffer</i>	jn	jn	jn	jn	jn

Additional comments

22.

**Mean** (average rating in previous round)

3.95 (undecided)

**Comments from previous round**

- May be more appropriate to sign post patient if they wish to discuss this further due to personal belief

22.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Understanding of death	jn	jn	jn	jn	jn

Additional comments

23.

**Mean** (average rating in previous round)

4.63 (agree)

**Comments from previous round**

- No comments

23.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Practical equipment needs	jn	jn	jn	jn	jn

Additional comments

# BLF Delphi Round 3

24.

**Mean** (average rating in previous round)

4.58 (agree)

**Comments from previous round**

- No comments

24.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Support in the home	jñ	jñ	jñ	jñ	jñ

Additional comments

25.

**Mean** (average rating in previous round)

4.37 (agree)

**Comments from previous round**

- If necessary

25.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Transportation needs to facilitate care	jñ	jñ	jñ	jñ	jñ

Additional comments

26.

**Mean** (average rating in previous round)

not applicable

**Comments from previous round**

- Not applicable

26.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Needs of the partner/significant other <i>*new item added from participant comments</i>	jñ	jñ	jñ	jñ	jñ

Additional comments

27.

**Mean** (average rating in previous round)

Not applicable

**Comments from previous round**

- Not applicable

# BLF Delphi Round 3

27.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Option to change your mind about end-of-life decisions	jq	jq	jq	jq	jq
<i>*new item added from participant comments</i>					

Additional comments

# BLF Delphi Round 3

## Survey Complete!

Many thanks for participating in Round 3 of the Delphi study. You will receive a link to the fourth and final round of the Delphi in February.

**\*1. Please enter your first and last name:**

First name

Last name

**\*2. Have you been interviewed by Nicole?**

Yes

No

**\* 1. Have you filled out the consent form and biographical information questionnaire? *If not you will be redirected to provide consent and biographical information before continuing with this survey.***

Yes

No

## Consent form

Please take time to read and sign this page. You may not proceed to the survey until it has been completed.

**\* 1. I confirm that I have read and understand the information sheet dated 16 June 2011 for the study "Willingness/readiness to discuss end-of-life with nonmalignant disease patients". I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. Please initial box if you are in agreement with this statement.**

**\* 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my legal rights being affected. Please initial below if you agree with this statement.**

**\* 3. I understand that I can withdraw my data up until it becomes anonymized. Please initial below if you agree with this statement.**

**\* 4. I give consent for anonymized quotes from my responses to be used in publications/reports. Please initial below if you agree with this statement.**

**\* 5. I agree to take part in the above study. Please initial below if you agree with this statement.**

**\* 6. Please type your name below as your electronic signature and today's date.**

**\* 7. Please enter the email address where you would like the next questionnaire to be sent.**

# Biographical Survey

Please answer the following questions so that we can learn more about you.

## \* 1. Please provide your contact and location information

**Name:**

**Organization (if applicable):**

**Address:**

**Address 2:**

**City/Town:**

**Email Address:**

## \* 2. Which province or territory do you work in?

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

## \* 3. What year were you born?

## \* 4. What is your first language?

- French
- English
- Other (please specify)

**\*5. Which language do you use primarily when speaking with patients?**

- English
- French
- Other (please specify)

**\*6. Please tell me about your education and professional designation(s) *Please check all that apply***

- Diploma
- Bachelor's
- Master's
- MD
- PhD
- CAE
- COPD Educator
- RN
- RRT
- PT
- Pharmacist
- Social Worker
- Other (please specify)

**\*7. Please provide the year that you obtained the degrees or designations above: (e.g. Bachelor's/1996)**

**\*8. Where do you practice as a respiratory health professional? *check all that apply***

- University
- Community
- Hospital
- Outpatient clinic
- Other (please specify)

**9. What are your practice activities? Check all that apply**

- Teaching
- Research
- Administration
- Clinical
- Counselling
- Other (please specify)

**\*10. What is your current job title?**

**\*11. How many years of experience do you have as a respiratory health professional?**

*Please enter a number between 0 and 50*

**\*12. How many years of experience do you have discussing end-of-life with patients with nonmalignant respiratory disease? Please enter a number between 0 and 50**

Thank you for completing the consent form and biographical questionnaire. You will now enter the survey.

## Letter to participants

Dear Participant,

Thank you for agreeing to take part in this Delphi study about end-of-life care discussions with patients with nonmalignant respiratory disease.

A major aim of this study is to gather the knowledge and opinions of Canadian health professionals on how they know a patient is ready or willing to discuss their end-of-life care preferences. As an expert in your field your opinions on this topic are extremely valuable to us, and we thank you for your time.

The items on the following survey have been taken from interviews conducted with health professionals, and this is your chance to agree or disagree on their opinions based on your experience. When possible, interviewees' own words have been used. Please rate your agreement with each item, and provide comments as you wish. Your anonymous comments will be visible to other participants in the next questionnaire.

Please try to relate your answers to your experience with patients with nonmalignant respiratory disease exclusively.

Please don't hesitate to contact me if you have any questions, or concerns about the study or if you have technical difficulties with the online questionnaire.

Thank you again for your participation.

Kind Regards, Nicole Stephen

## Question 1

**Which of the following factors indicate that a patient is ready or willing to discuss end-of-life?** Please indicate your level of agreement with each statement below and provide comments if you would like to clarify or modify an item

### \*1. Clinical indicators

*e.g. the patient has recently had an acute episode and required hospitalization*

Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

### \*2. The health professional uses their emotional intelligence to gauge patient readiness

Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

### \*3. Patient cues

*e.g. body language, facial expressions, open personality*

Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

### \*4. Patient initiates end-of-life topic with health professional

Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*5. Patient responds when end-of-life topic is alluded to or initiated by the health professional**

*examples:*

- - *asking whether the patient has made a will;*
- - *sharing a personal story about a death in the family where end-of-life decisions were not made;*
- - *explaining how if the patient were in crisis what the first health professional to arrive on the scene would be expected to do, and that it would be unfortunate if they had wishes that were not expressed and therefore not met in this type of situation.*

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*6. All patients are ready if the health professional frames the discussion appropriately**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*7. You know a patient is ready to discuss because you know them**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**Readiness in the patient education context**

**\*8. Attending end-of-life session implies readiness to discuss**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments

**\*9. Group setting encourages patients to discuss**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments

**\*10. Patient follows up on end-of-life information received in education session**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments

**\*11. Patients are not given the option of being ready to hear the information in the education context**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments

**12. Are there any factors not included here that indicate to you that a patient is ready or willing to discuss end-of-life? *Please explain below.***

## Question 1b

**\*1. There are situations when 'readiness' is not important such as when the topic must be discussed immediately for practical purposes**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

## Question 2

**Which of the following factors are important when conducting an end-of-life discussion?** Please indicate your level of agreement with each statement below and comment if you would like to clarify or modify an item

### **Family:**

#### **\* 1. Family issues for the patient**

*E.g. young children at home*

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

#### **\* 2. Communicating patient wishes to family**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

#### **\* 3. Presence or absence of family support**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

### **Approaching the discussion:**

#### **\* 4. Sense of humour**

Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*5. Sensitivity to the patient's culture**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*6. Approaching the topic calmly**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*7. Approaching topic with a 'matter-of-factness'**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*8. Approaching the topic with a caring nature**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*9. Being open**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*10. Being honest**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*11. Being respectful of the client**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*12. Listening to the patient**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*13. Giving advice when it's asked for**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*14. Letting the patient guide the discussion**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*15. Readiness of the patient to discuss**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*16. Accepting the patient's reactions**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*17. Knowing when to step back from the topic**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*18. Having a pre-existing good relationship with the patient**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*19. Avoiding dashing hope**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*20. Raising the topic early before critical situation**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*21. Having end-of-life on a list of things that need to be talked about**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*22. Having handouts of example advance care directives (paper resources)**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*23. Responsibility of health professional to meet patient wishes**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*24. Sensitivity to health literacy level of the patient**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*25. Sensitivity to patient's language needs**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**The Health Professional:**

**\*26. Health professional being comfortable with approaching end-of-life topic**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*27. Health professional having experience and practice having end-of-life discussions**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*28. Health professional is familiar with end-of-life planning process**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*29. Health professional has attended education sessions about discussing end-of-life**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*30. Health professional has knowledge of palliative care and end-of-life issues**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*31. Emotional intelligence of health professional**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*32. Health professional acts as a neutral party to talk to the family about what is happening to the patient**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**Context of the discussion:**

**\*33. Patient's condition for discussion**

*e.g. patient is in the hospital with an acute episode, or patient is trying to get their breathing under control early in the morning*

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*34. Having a support person present during discussion**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*35. Patient understanding that their condition is life limiting**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*36. Patient understanding that they can receive palliative care**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*37. Time available to discuss**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*38. Time available for follow up discussions**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*39. Setting of discussion**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*40. Privacy for discussion**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*41. Life experience of person that you are having the discussion with in emergency scenario (usually a family member)**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*42. Multi-disciplinary team available to patient**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*43. Confirming patient understanding of the discussion**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*44. Personality of the patient**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*45. Credibility of the health professional (as recognized by the patient)**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*46. Whether the patient is taking care of themselves**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\*47. Individual patient needs**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**48. Are there any considerations not included here that are important when conducting an end-of-life discussion? Please explain below.**

### Question 3

**Which of the following topics would you include in an end-of-life discussion?** *Please indicate your level of agreement with each statement below and comment if you wish to clarify or modify any items.*

**\*1. Patient understanding of their option to make end-of-life choices**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*2. Patient deciding on a substitute decision maker**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*3. Patient understanding of the 'chain of command' of decision makers, should there be a dispute when patient is unable to speak for themselves**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*4. Option to change your mind after making end-of-life decisions**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*5. Making sure doctor knows what kind of care the patient wants**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*6. Levels of advance care directives (supportive care only to full resuscitation)**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*7. Walking the family through the process of what will happen when the patient dies**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*8. Explaining implications of end-of-life decisions and care to family**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*9. Discussing the 'bother versus benefit' of treatments or interventions with patients**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*10. How patient wants things to look at the end-of-life**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\*11. Educating patients about their end-of-life choices and implications**

- Strongly agree     Agree     Undecided     Disagree     Strongly disagree

Comments:

**\* 12. Goals of care**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**\* 13. Explaining where they are in their disease e.g. no cure, focus on symptom management**

- Strongly agree       Agree       Undecided       Disagree       Strongly disagree

Comments:

**14. Are there any topics not included here that are important to discuss when conducting an end-of-life conversation? Please explain below.**

## Thank you!

You have completed round two of the Delphi study.

Thank you very much for your participation. You will be notified via email when the next questionnaire is ready for your participation. To exit the survey, click exit below.

## Welcome!

### Round Three of the Delphi Study

Dear Participant,

The purpose of this round of the Delphi is to give you a chance to see how other participants have responded to each item.

Please review each item, considering the mean score and the comments from the previous round. Based on this information re-consider your opinion and then rate the item. Also, feel free to add any comments that you feel may clarify the item, but note that comments are not required.

You may notice that some items have been moved from one question to another, and some items have been added from suggestions made in the previous round. In such cases, there will be no prior information such as a mean or comments provided, and therefore you should rate the item based on your professional experience.

Please would you be kind enough to complete the survey by DECEMBER 24th - please contact me if you have any questions, technical difficulties or problems with completing the survey by December 24th as it is very important to the validity of the study that you are able to respond.

Sincerely,

Nicole Stephen  
nicole.stephen@plymouth.ac.uk

**1. First name:**

**2. Last name:**

## Question One

### Which of the following factors indicate that a patient is ready or willing to discuss end-of-life?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

\*\*\*Please note that changes to items are indicated by [ ]

1.

**Mean** (average rating in previous round)

3.41 (undecided)

#### Comments from previous round

- Once the client has settled and their condition has stabilized, during the hospitalization and opportunity to discuss end of life care would be appropriate.
- This is dependant on whether it is their first episode or not, if they have been admitted several times before then they may be willing to discuss end of life issues.
- An acute episode might signal a good opportunity for a health care professional to approach the topic of end-of-life care with a patient, however it may not correlate into patient readiness or willingness to talk about the topic.
- I don't necessarily agree that any clinical indicator (such as having had an AECOPD) means patients "are ready and willing" to discuss end-of-life but I do believe that having recently had an AECOPD provides an opening for initiating discussions around patients' goals of care and could include discussions about end-of-life care.
- Not enough information is given with just an exacerbation.

1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Clinical indicators	<input type="radio"/>				
<i>e.g. [length of disease process, burden of disease], the patient has recently had an acute episode and required hospitalization</i>					

Additional comments

2.

**Mean** (average rating in previous round)

4.24 (agree)

#### Comments from previous round

- You have to be able to read people to bring up this delicate topic, without that you can come across rude, offensive and inconsiderate.
- Patients give cues and clinicians need to be intuitive enough to hear and read these cues.
- not enough information - while EI [emotional intelligence] is helpful, it should be based on information gleaned from time spent with the client, taking in patient cues and discussions

**2.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
The health professional uses their emotional intelligence to gauge patient readiness	<input type="radio"/>				

Additional comments

**3.**

**Mean** (average rating in previous round)

4.18 (agree)

**Comments from previous round**

- Take your cues from the patient, they will indicate when they are ready to talk.
- some patient cues can be contrary to what the patient is actually saying.... congruent patient cues along with verbal interaction are needed to be able to judge appropriately. These cues, however can be more accurate than words, at times, and a HCP may take these cues along with other EI [emotional intelligence] gleaned to decide to introduce the topic.

**3.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient cues	<input type="radio"/>				

*e.g. body language, facial expressions, open personality*

Additional comments

**4.**

**Mean** (average rating in previous round)

4.53 (strongly agree)

**Comments from previous round**

- If the client brings this at any point in your time together it is a strong indicator that the client is interested and the information should be discussed.
- What better time than now!
- However, in my experience, at times, patient introducing the topic may be feeling pushed by family or others to open the topic and be internally, quite hostile to the discussions.

**4.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient initiates end-of-life topic with health professional [either directly or indirectly by bringing up death or end-of-life care in relation to something or someone else]	<input type="radio"/>				

Additional comments

**5.**

**Mean** (average rating in previous round)

4.41 (agree)

**Comments from previous round**

- Again, emotional intelligence and client cues are needed to continue a more comfortable discussion.

**5.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Q27. Patient responds when end-of-life topic is alluded to or initiated by the health professional



*examples:*

- asking whether the patient has made a will;
- sharing a personal story about a death in the family where end-of-life decisions were not made;
- explaining how if the patient were in crisis what the first health professional to arrive on the scene would be expected to do, and that it would be unfortunate if they had wishes that were not expressed and therefore not met in this type of situation.

Additional comments

**6.**

**Mean** (average rating in previous round)

3.12 (undecided)

**Comments from previous round**

- A client may be attending the session because a family member has pressured them into it.
- Attendance may be out of curiosity it does not guarantee they are accepting of their prognosis or the reality ahead of them.

6.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Attending [a group] end-of-life [education] session implies readiness to discuss	<input type="radio"/>				

Additional comments

7.

Mean (average rating in previous round)

3.18 (undecided)

Comments from previous round

- However not all clients will participate in group discussion and it is important for the facilitator to be aware of this during the discussion so a follow up can be arranged.
- Depends on the individual (how comfortable they are in sharing) as well as the cohesiveness of the group
- I've never participated in a group setting like this - I imagine that would be an advantage of a COPD class...
- In my experience one on one is much better to discuss these issues, however, having a small family group is often ideal.
- Depends on the personality on the patient; the group setting may be too intimidating, or it may help normalize feelings and encourage participation.
- Many will feel more comfortable in a group setting when discussing death and concerns, however, not all personality types respond well in this setting. Some 1:1 discussions are better in this subgroup. In other cases, the introduction of the topic in a 1:1 setting may help ease a client into a group setting for ongoing discussions and support.

7.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Group setting encourages patients to discuss	<input type="radio"/>				

Additional comments

8.

Mean (average rating in previous round)

3.76 (undecided)

Comments from previous round

- For the clients that I see routinely a follow up is done, if the client is referred by another physician I may never see them again.

8.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient follows up on end-of-life information received in education session [with educator or any other HCP]	<input type="radio"/>				

Additional comments

9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Comments from family to the HCP ***new item from participant comments	<input type="radio"/>				

Additional comments



## Question 1b

1.

**Mean** (average rating in previous round)

4.06 (agree)

**Comments from previous round**

- I don't believe 'is not important' applies to a situation in which the topic must be discussed ie a crisis - this is not an unimportant situation.
- "Practical" is open to interpretation so sometimes one must be "practical" but usually some time can be given for patient to "come to terms"
- I agree that there are times in crisis that these issues must be discussed. Even if goals of care have been discussed in the past, goals of care can change and are influenced by so many things so, in crisis situations, these goals need to be revisited. In the end, some clinicians pursue these discussions in very tactful/respectful ways and others are downright abusive!
- impending acute respiratory and/or cardiac failure. This is when I broach topic by stating: I have seen these symptoms in 100s of clients and I expect that we will be facing major decisions. As a Health Care Team member, we want to ensure that your wishes and desires are known and are followed. There is nothing worse than having patient families unaware of your wishes, or indeed, fighting over what they believe your wishes are about life saving measures, and as a team, we want to ensure that we are following what you want and that we are all, along with you and your family, on the same page. I then go on to discuss the specifics of a DNR and implications for each part - intubation, mechanical ventilation, defibrillation, cardiac and other drugs, and if discussion time permits, decisions re feeding tubes, IVs for fluids and comfort measures desires of the client, etc.
- For the clients that I see routinely a follow up is done, if the client is referred by another physician I may never see them again.

1.

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

There are situations when [the patient's] 'readiness' [to discuss end-of-life] is not important such as when the topic must be discussed immediately for practical purposes



Additional comments

## Question Two

### Which of the following factors are important when conducting an end-of-life discussion?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

\*\*\*Please note that changes to items are indicated by [ ]

1.

**Mean** (average rating in previous round)

4.06 (agree)

**Comments from previous round**

- Clarifying this with the client should be part of end of life discussions. While this (young children at home) is rarely the case of a chronic lung disease client, more often it is about a family member in disagreement, or out of the family communication group who the client wants to touch base with and try to reconcile with prior to their death. This has had implications for life support in my experience - clients going on/off modified life support (biPAP) while awaiting arrival of family member to reconcile, see for 1 last time. Whether this is appropriate or not, is case sensitive and open for ethical discussion.

1.

Strongly agree      Agree      Undecided      Disagree      Strongly disagree

Family issues for the patient



*E.g. young children at home, [unresolved family problems]*

Additional comments

2.

**Mean** (average rating in previous round)

4.65 (strongly agree)

**Comments from previous round**

- I agree that the family needs to understand the clients wishes and respect them whenever possible.
- Imperative aspect of discussions. If it is perceived by the client that this will be a difficult discussion for the client to make alone with the family, support should be available for the client to discuss with the HCP, or have the HCP broach the subject, stating that it is the wish of the client to discuss this with family. This way, the HCP can be 'the bad guy' and take pressure off of the client. This way the HCP can also be available for responding when questions are asked, or clarifying meanings of discussions, including family health literacy issues, cultural sensitivities, etc.

2.

Strongly agree      Agree      Undecided      Disagree      Strongly disagree

Communicating patient wishes to family



Additional comments

**3.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- End of life needs to be discusses with or without family present if the client is willing to discuss it.
- Whenever possible eliciting family support when it is supportive is of huge importance. 'Family' may be defined in different terms for different clients and discussing 'what this looks like' for the client is one of the first discussions needed. It should include Power of Attorney whether they are 'family' or not.

**3.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Presence or absence of family support [in the patient's life]	<input type="radio"/>				
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Additional comments

**4.**

**Mean** (average rating in previous round)

3.47 (undecided)

**Comments from previous round**

- This has to be used judiciously - it depends on the group so much.
- if appropriate for the patient
- Depends on your relationship with the patient, patient personality, type of situation (clinic visit, hospital setting, change in health status)

**4.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Sense of humour [when appropriate]	<input type="radio"/>				
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Additional comments

**5.**

**Mean** (average rating in previous round)

4.59 (strongly agree)

**Comments from previous round**

- Vital need to be addressed. Eliciting supportive 'family' help in this is vital for after care of the family as well.

**5.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Sensitivity to the patient's culture	<input type="radio"/>				
--------------------------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Additional comments

**6.**

**Mean** (average rating in previous round)

4.59 (strongly agree)

**Comments from previous round**

- Un-rushed and calmness is vital, otherwise, discussions can be seen as 'wanting to get the HCPs own way of doing things', or 'not in the client's best interest', or uncaring, or impression to family and patient that the 'imminence of death is sooner than we think' and is more apt to bring on panic - poor decision making is often done in these circumstances and should be avoided.

**6.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Approaching the topic calmly	<input type="radio"/>				

Additional comments

**7.**

**Mean** (average rating in previous round)

3.59 (undecided)

**Comments from previous round**

- I believe it is individual client bases, however in a group session, presenting with an open attitude will allow for clients to comfortably ask questions.
- This may be seen as being too business-like for such a sensitive topic and may, therefore, shut people down instead of encouraging participation
- Very important for some people to "take out the emotional component"
- This will depend on the patient and how they react, this type of approach does not work if you bring it up right after a diagnosis or Dr. appointment that had bad news.
- Absolutely. Statistics from resuscitation attempts from the ACLS manual can be used as factual information that may help to break patient's 'TV-version' of always a 'good ending' with resuscitation attempts, where as, matter of factness re patient's desires being met and remaining family's meeting of goals about a 'good death' are good discussion starters.... everyone has a story about a 'bad death'.

**7.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Approaching topic with a 'matter-of-factness'	<input type="radio"/>				

Additional comments

**8.**

**Mean** (average rating in previous round)

4.76 (strongly agree)

**Comments from previous round**

- They can sense when you really " care"
- Vital need, a part of good communication skills.

**8.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Approaching the topic with a caring nature	<input type="radio"/>				

Additional comments

**9.**

**Mean** (average rating in previous round)

4.82 (strongly agree)

**Comments from previous round**

- Vital need, a part of good communication skills.

9.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being open	<input type="radio"/>				

Additional comments

10.

Mean (average rating in previous round)

4.76 (strongly agree)

Comments from previous round

- Vital need.

10.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being honest	<input type="radio"/>				

Additional comments

11.

Mean (average rating in previous round)

4.82 (strongly agree)

Comments from previous round

- Do not pity but show true compassion
- Vital need - part of good communication.

11.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Being respectful of the client	<input type="radio"/>				

Additional comments

12.

Mean (average rating in previous round)

4.82 (strongly agree)

Comments from previous round

- Perhaps most important is to listen
- Vital need, a part of good communication skills.

12.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Listening to the patient	<input type="radio"/>				

Additional comments

13.

Mean (average rating in previous round)

3.88 (undecided)

Comments from previous round

- What kind of advice? I would hesitate to make suggestion - I would definitely provide information in order for the patient and family are better prepared to make decisions
- The role of the health professional to provide as much information the patient needs, so that the patient can make an informed decision.
- Vital need, a part of good communication skills. Sometimes, giving information, even when it's not asked for can broach areas of discussion that the client/family has been avoiding. On the other hand, being honest and discussing with the pt/family that you feel uncomfortable in this area of discussion is important too and leading them to another person with expertise in that area is a honest and professional way of handling these discussions.

13.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Giving advice when it's asked for

Additional comments

14.

Mean (average rating in previous round)

4.12 (agree)

Comments from previous round

- It depends on the level of the discussion.
- Although sometimes you have to be the one to start the discussion.
- We have a responsibility to help them through these discussions. Even though they can lead at times and we stay open, etc...they "don't know what they don't know" so it should be our responsibility as clinicians to help direct these discussions, to probe gently when more information is required so that we can better understand and support their decision-making processes.
- Vital need, a part of good communication skills. However, as per the 'advice-giving' response, it may also be important here to guide the discussion to broach a topic that the patient/family has been avoiding, but doing so in a caring supportive way. The ability to pull back and get permission to re introduce it at another time is also important. There are times that I will introduce a 'touchy' topic and state that the physician will need to know about your wishes/desires around topic X. There are pros and cons about topic X and I suggest you take some time and discuss it with your family and be prepared to discuss it later with the physician at your next meeting. In the mean time, i am willing to be a resource for any questions you may have about this topic and you may contact me in the following way.

14.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Letting the patient guide the discussion

Additional comments

15.

Mean (average rating in previous round)

4.35 (agree)

Comments from previous round

- It is always best to have the patient (and preferably patient/family) ready to discuss. However, sometimes, a gentle introduction is needed, stating something like... "We normally have these discussions at this point of your care, however, I sense that you do not feel ready to discuss this at this time... am I correct? Different people are more or less comfortable with these discussions. What makes this a difficult topic for discussion for you to talk about?" (elicits clients feelings and past history with the topic, so it is a bit less of a 'hot' button trigger). Introducing the topic through a 3rd-hand approach can be helpful - client seeing discussions with another patient, or another family member, discussions of death of a pet in the past, etc.

**15.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Readiness of the patient to discuss	<input type="radio"/>				

Additional comments

**16.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- If the patient is violent one must try to understand from where that is coming but protection of all in danger of being hurt by this violence must be initiated
- As a HCP, I've seen all kinds of reactions. Being prepared for handling them is imperative. Discussions may follow, but acknowledging the emotions are a part of good communication and 'normalizing' the discussions for the client/ family.

**16.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Accepting the patient's reactions	<input type="radio"/>				

Additional comments

**17.**

**Mean** (average rating in previous round)

4.35 (agree)

**Comments from previous round**

- Recognition of negative reactions or 'discussion stoppers' is imperative. Knowing what to do about them is the next step and may be multifaceted. Knowing when to step back is only one part of this next step. EI [emotional intelligence] processes of assessing the patient/family and when to break off the discussions and change the topic is needed. In rare circumstances, stopping the meeting may be necessary. When/if appropriate, stating an expectation that you are always available to discuss further, or answer questions they may have at any time can be valuable to the patient/family, whether they have questions alone or together. Being ready to apologize for discomfort caused may be needed, depending on the circumstances.

**17.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Knowing when to step back from the topic	<input type="radio"/>				

Additional comments

**18.**

**Mean** (average rating in previous round)

3.71 (undecided)

**Comments from previous round**

- What is a 'good relationship'? Being seen as a credible source of information would be more of a factor, I feel.
- The better the relationship with the patient/family, the more ideal the circumstances for discussion. Finding 'common ground' or common values is always a 1st step, even if you have not had time to develop the good relationship as you'd like to.

**18.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having a pre-existing good relationship with the patient	<input type="radio"/>				

Additional comments

**19.**

**Mean** (average rating in previous round)

3.71 (undecided)

**Comments from previous round**

- This is an unfortunate choice of words - I don't believe any HCP worth their salt would intentionally dash hope.
- this is a tough one when death is inevitable, you don't want to destroy the time left
- Vital need. Without hope, spirits can be crushed utterly. Finding things to be hopeful for can be a big part of the patient's/ family's expectations and modus operandi. Often these hopes and expectations become more centred and smaller in scope, more intimate with time, in the client's 'shrinking world'. Looking for appropriate areas for values and hope can be a daily adventure. Celebrating them daily can bring joy in even the most difficult circumstances.

**19.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Avoiding dashing hope	<input type="radio"/>				

Additional comments

**20.**

**Mean** (average rating in previous round)

4.53 (strongly agree)

**Comments from previous round**

- Need to use the word "early" with caution I think. I think it would be best to stick with something like, "it's best to raise the topic at a time when the patient can appreciate that it's relevant" i.e., when a patient has had an exacerbation that required a hospitalization, this may be a good time to chat about their experience, what was good, what wasn't, how things could have been different, etc...
- Whenever possible this should ALWAYS be the case. It is without exception, more difficult to discuss when time is of essence and people are rushed into decisions that they (especially family) may regret later. We want to avoid having team members and/or family on different pages, opening up the possibility for conflict, now or in the future.

**20.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Raising the topic early before critical situation	<input type="radio"/>				

Additional comments

**21.**

**Mean** (average rating in previous round)

4.12 (agree)

**Comments from previous round**

- This allows the client to be prepared for the topics that will be discussed during the appointment time or in group sessions
- a great idea, but I don't have such a list
- I don't think it's necessarily a discussion about "end-of-life". Who wants to talk about "end-of-life"? In my experiences in palliative care, patients think palliative care is for "when you're dying" and therefore they don't necessarily want palliative care services or decline them. When I explain that Palliative care, in my mind, is about providing good care and good symptom control in a disease/illness where there is no cure, they are much more willing to accept palliative care services. I think we can talk about end-of-life issues but the discussion should be seen as flushing out "goals of care".
- Absolutely. End of life discussions are about Life discussions and have a wide range of possibilities to discuss. While not everyone is comfortable with this topic, it can often be broached in context of other discussions. As HCPs we are concerned about the whole pt's life and quality of life, to best enhance where we can, as the patient / family allows.

**21.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Having end-of-life on a list of things that need to be talked about	<input type="radio"/>				
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Additional comments

**22.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- would be nice
- Patients and families often have difficulty emotionally handling these topics. Some may 'forget' or disassociate partially and not remember discussions. Having paper to go back to , with pens available for notes to the pt/family to write down may help them to come back to the topic on their own and check back and explore more in depth and come back with further questions. It helps clarity and ensures all topics are covered without omitting an area of discussion.

**22.**

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Having handouts of example advance care directives (paper resources)	<input type="radio"/>				
--	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Additional comments

**23.**

**Mean** (average rating in previous round)

4.12 (agree)

**Comments from previous round**

- I have seen where patient and or family wishes have been ignored by MDs. The law covers a lot of this, but there is still a lot of 'grey areas'. Clarifying 'wishes' into 'decisions' are a part of the HCP's responsibility. Some may be achievable, others may not be - eg, wish to be made comfortable is perhaps 98% achievable; wish to avoid death is 100% unachievable. Wish to be kept alive until arrival of person Y may be achievable but at what cost, is the patient/family willing for the consequences of waiting/not waiting?

**23.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Responsibility of health professional to meet patient wishes	<input type="radio"/>				

Additional comments

**24.**

**Mean** (average rating in previous round)

4.53 (strongly agree)

**Comments from previous round**

- Vital to assess the patient's understanding by having feedback on what is discussed and frequent checking back with the patient/family. Assessing the patient/family's ability to understand and navigate the health care system, information and able to access what they need is a part of health literacy. Ensuring these needs are met in a way that the client /family can understand and use is needful, to the extent that the patient/family wants to be able to access it. - needs great assessment and communication skills on the part of the HCP.

**24.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Sensitivity to health literacy level of the patient	<input type="radio"/>				

Additional comments

**25.**

**Mean** (average rating in previous round)

4.59 (strongly agree)

**Comments from previous round**

- Vital need, just as vital as cultural needs, whether verbal or non-verbal. Finding a translator with the above skills is even more difficult. The use of music and art and these music & art therapy can be an international language that can help with some of this and is often overlooked during palliation.

**25.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Sensitivity to patient's language needs	<input type="radio"/>				

Additional comments

**26.**

**Mean** (average rating in previous round)

4.53 (strongly agree)

**Comments from previous round**

- Recognizing this is a learned response - I feel that, the more a HCP is involved with these discussions, the more comfortable they feel
- Vital need. Just because a HCP has an "MD" behind their name, doesn't mean that they are the best one to having these discussions. EI [emotional intelligence], aptitude, training, personality and experience all weight heavily on the individuals abilities in this area. Learn the strengths of your team and use people in their strengths! Being willing to acknowledge our weaker areas is part of being a HC Professional and working as a team brings strength to the team to function appropriately for the patient/family.

**26.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional being comfortable with approaching end-of-life topic	<input type="radio"/>				

Additional comments

**27.**

**Mean** (average rating in previous round)

4.41 (agree)

**Comments from previous round**

- This is a skill. In the US, I believe the "Respecting Choices" program has ACP trainers that assist clinicians in building their skills for ACP discussions. I find it interesting that all our staff have to do yearly CPR re-training and yet we don't think about the importance of helping our staff to build the communications skills they may need to lead or initiate ACP discussions. Some HCP are simply not equipped to have these discussions (they don't want to and patients wouldn't want them to). Maybe we need to seek out clinical leaders for this and nurture their skills.
- Vital need. Just because a HCP has 'experience and practice' at leading discussions, doesn't mean that they are good at it, even though they think they may be. Getting feedback after the fact from family members and others on the health care team is invaluable for honing our skills, and could/should be a part of the followup with the family and team. Being willing to acknowledge our weaker areas and to learn from reflective practice with feedback is part of being a HC Professional and working as a team brings strength to the team to function appropriately for the patient/family and to grow in our abilities.

**27.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional having experience and practice having end-of-life discussions	<input type="radio"/>				

Additional comments

**28.**

**Mean** (average rating in previous round)

4.24 (agree)

**Comments from previous round**

- While you may have small role in the scheme of the end-of-life discussions, knowing the process and where your role fits is in important. Working as a team is important, knowing that there are other parts that need to be addressed and your scope in the whole process is 1 or more parts, working within that scope is important.

**28.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Health professional is familiar with end-of-life planning process	<input type="radio"/>				

Additional comments

**29.**

**Mean** (average rating in previous round)

4.06 (agree)

**Comments from previous round**

- This would be great - I have not seen any at conferences or know of any workshops. I have attended sessions relating to the importance of having end-of-life discussions, and have not attended any workshops that practically walk a HCP through a number of different discussions to role play how these discussions can be done with empathy.
- Formal education processes may/ may not be important. Attending various discussions is an education in itself, when done correctly, but doesn't make you an expert in and of itself. Most of us have not had the opportunity to have didactic education sessions presented to us; thus we learn more 'old school' by experience gleaned with good and not so good experiences. Learning from these experiences through reflective learning is vital then. Just because there are courses doesn't mean that you can invalidate good experience either. The 2 may go hand in hand. Analogy: You may have received 100% in your university education about playing violin, but you are not a good player .... vs. you are good at playing violin, but that doesn't mean you are a good teacher of violin.... v.s. You may be a great teacher of violin but you flunked university courses and you are not a concertmaster or soloist, but you play in an orchestra and can impart what is needed to have a student become a great one!

**29.**

Strongly agree                  Agree                  Undecided                  Disagree                  Strongly disagree

Health professional has attended education sessions about discussing end-of-life

Additional comments

**30.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- Having knowledge does not ensure you have ability, however, it can be a starting point for some, and can become more and more important as you grow in your practice.

**30.**

Strongly agree                  Agree                  Undecided                  Disagree                  Strongly disagree

Health professional has knowledge of palliative care and end-of-life issues

Additional comments

**31.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- #26 to #34 are not rated higher as the HCP must be able to learn on the job regardless of what background formal education on the topic they have received
- Some people are just 'not wired' in an EI [emotionally intelligent] way to be able to lead these discussions effectively with patients / families. Others are not 'wired' to place various catheters in various body parts. While skills can be taught, it doesn't mean you will excel in it, nor even become proficient. If you are less capable, desirous, etc, it is wise to enable those with capabilities and desires on teh team to lead with their skill sets. Being professional enough to admit your limitations is becoming more and more the norm for our professional practice and accepting our limitations. There will always be people better than us and always be people worse than us in doing these things. Being humble enough to admit it, and do something about it is the mark of a graceful practitioner.

**31.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Emotional intelligence of health professional	<input type="radio"/>				

Additional comments

**32.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- While it is desirous to be neutral, we really need to admit to ourselves our own cultural and experiential biases that have made us whom we have become. Can we fully be neutral, No. Can we try to put aside our acknowledged biases and experiences, Yes, for the betterment of the patients and families we serve..... Sometimes, we have to be patient advocates when the family is opposing what the patient wishes, especially when the patient is less able to express their own views (health/illness vs. communication difficulties). Trying to find common ground is always a good starting point. In the end, it is the patient's life and often their own decision with the POA (power of attorney) interpretation at the end.

**32.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Heath professional acts as a neutral party to talk to the family about what is happening to the patient	<input type="radio"/>				

Additional comments

**33.**

**Mean** (average rating in previous round)

4.0 (agree)

**Comments from previous round**

- It depends on the severity and acuity of the episode.
- These discussions need to take place in the right place, at the right time, and by the right person. Being aware of the patient's physical ability to engage in such as discussion in critically important.
- Never ideal to start conversations at this point, but if not discussed before, it often must be broached with some urgency but without being rushed if possible. If unable to discuss at the time with patient or family, often bringing it up after successful outcome, or partially successful outcome may bring about good opportunity.... "You had a tough time this morning. I could see that you were struggling and apprehensive about what was happening and decisions that had to be made. I need you to know that this will not be the last time you experience something like this. You will have more and more of these episodes as time goes on. We got through this one OK, but I need to discuss with you about how you thought about what went on, what went well, what didn't .I'd like to have some discussions about what you have decided as a result of what we've gone through... what we should do for next time, and the time after that... we want to be on the same page and don't want to do what you don't want have done. Let's talk."

**33.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient's condition for discussion	<input type="radio"/>				

*e.g. patient is in the hospital with an acute episode, or patient is trying to get their breathing under control early in the morning*

Additional comments

**34.**

**Mean** (average rating in previous round)

3.71 (undecided)

**Comments from previous round**

- It helps, however not always necessary.
- This is very individual as well as having cultural issues
- sometimes this discussion is better without family present
- Some of our patients don't have support people. Some may feel more comfortable freely discussing their views/beliefs in the absence of their support person. Depends on the person.
- Not necessarily. Some patients may prefer to have the first discussion alone (there are some interesting relationships out there where, with some caregivers, patients struggle to articulate their wishes with coercion). I depends on the situation.
- You did not specify support person for the client or the HCP. I advocate both. A second set of ears and eyes who is also trained may bring a further sense of validity and they may be able to interject appropriately. A patient's support person may/may not be family. Being sensitive to this is vital and needful as the support person will be the one left behind after the death. A support person may also be a clergy member, a family member or friends, or a therapist.

**34.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Having a support person present during discussion [for the patient]	<input type="radio"/>				

Additional comments

**35.**

**Mean** (average rating in previous round)

3.94 (undecided)

**Comments from previous round**

- I believe, generally, this discussion should not be dependent upon the presence or absence of a life-limiting condition.
- some know but appear not to , seems to be a defensive position
- End of life discussions can and should occur at any time, and not just in times of crises.
- Many patients don't even know what "COPD" means. Many don't realize that it is progressive and life limiting. It will be difficult for patients to appreciate discussions around goals of care (including goals for end-of-life care) if they don't have an understanding of the disease process/trajectory.
- I have seen many patients who are in denial of their limitations. This topic has been introduced and patients can gradually realize that this is a deteriorating process that leads to death in some form. Looking at life limiting aspects of any life, whether physical limitations, mental or emotional is useful and a part of the natural consequences of living. Broaching it like this can be the platform to start discussions. Eventually, the patient must be able to express, as a part of "acceptance" that their life is limited by their condition.

**35.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient understanding that their condition is life limiting	<input type="radio"/>				

Additional comments

**36.**

**Mean** (average rating in previous round)

4.12 (agree)

**Comments from previous round**

- By having conversations earlier on, it allows the patient to make decisions without distress, under pressure, in crises, etc.
- As I have mentioned before, many patients do not really understand what palliative care is all about. I make a point of chatting with my patients about this so they understand what palliative care is.
- palliative care' has different meaning for different clients. Clarifying their expectations and hope around end of life care can lead to successful good death, whether at home in palliative care, in hospital in palliative care, or in a palliative care unit, or indeed, if they choose, through full treatment up until the point of death. Informing patients that they have these choices is part of our responsibilities as HCPs.

**36.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient understanding that they can receive palliative care	<input type="radio"/>				

Additional comments

**37.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- Time needs to be made to have these discussions
- If the patient is deteriorating very quickly, end of life discussions should occur for practical reasons.
- Many clinicians use the excuse that they don't have enough time. I think that discussing goals of care is a process and not an event and therefore, I think this can be discussed in bits and pieces. For example, how many times do clinicians do vital signs (and sometimes for no good reason)...this time could be better spent talking about goals of care.
- being sensitive to the patient's volume of time and the actual timing of discussions for the optional time of day, location, etc. is important for the patient to be able to receive and interact appropriately, be given the time to ask questions and ability to come back later with more discussions or questions as they choose is vital for clients.

**37.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Time available to discuss	<input type="radio"/>				

Additional comments

**38.**

**Mean** (average rating in previous round)

4.06 (agree)

**Comments from previous round**

- Depends on the situation. If able, follow up discussions are important.
- This is an essential part of End of Life discussions. It is also a requirement of DNR discussions to allow patients/ family know that they can change their mind and communicate their changes as they wish. Some team members may be more or less available for discussions and scheduling of the follow ups may be limited based on client preference of team member (MD, for example may be less available than an at-the-bedside practitioner) and their availability.

**38.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Time available for follow up discussions	<input type="radio"/>				

Additional comments

**39.**

**Mean** (average rating in previous round)

3.88 (undecided)

**Comments from previous round**

- Sometimes the opportunity is there and the setting is not important.
- setting is often not an option - discussion takes place in patient room
- Discussions can occur anywhere.
- The setting is critical I think.
- While there is no ideal place or setting for these discussions, in a busy ER room with lots of noise, less privacy and more interruptions is always more difficult. Being sensitive to client needs in all these areas is vital and when possible should be accommodated to the best of our abilities.

**39.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Setting of discussion	<input type="radio"/>				

Additional comments

**40.**

**Mean** (average rating in previous round)

4.41 (agree)

**Comments from previous round**

- This is driven by the patient and family somewhat
- While there is no ideal place or setting for these discussions, in a busy ICU Ward room or ER room with only curtains, lots of noise, less privacy and more interruptions is always more difficult. The patient needs to be able to determine for themselves whom they want in the room during the discussions. Being sensitive to client needs in all these areas is vital and when possible should be accommodated to the best of our abilities.

**40.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Privacy for discussion	<input type="radio"/>				

Additional comments

41.

**Mean** (average rating in previous round)

3.82 (undecided)

**Comments from previous round**

- It must be recognized that this can impact the discussion greatly!!
- Life experience with the Client or the Family member has huge effects on the discussions. Listening to their experiences, correcting any misconceptions they have had as a result of their experiences and validating their experiences are all a part of the processes involved.

41.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Life experience of person that you are having the discussion with in emergency scenario (usually a family member)

Additional comments

42.

**Mean** (average rating in previous round)

4.06 (agree)

**Comments from previous round**

- Integral - day to day HCP involved is often the person of choice of the patient, the physician, clergy, music and or art therapist, palliative care coordinator are some of the possibilities

42.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Multi-disciplinary team available to patient

Additional comments

43.

**Mean** (average rating in previous round)

4.18 (agree)

**Comments from previous round**

- Integral to ensure patient is on the same wavelength, and/or the POA [power of attorney].

43.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Confirming patient understanding of the discussion

Additional comments

44.

**Mean** (average rating in previous round)

3.88 (undecided)

**Comments from previous round**

- This is part of the assessment of the patient's needs, based on their personality

**44.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Personality of the patient	<input type="radio"/>				

Additional comments

**45.**

**Mean** (average rating in previous round)

4.29 (agree)

**Comments from previous round**

- If a client is going to have meaningful discussions, the pt has to believe in the HCP, no matter who they are. If that person is NOT the person who has the aptitude/expertise, however in these discussions, accommodations and/or improvisation with that person may be helpful.

**45.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Credibility of the health professional (as recognized by the patient)	<input type="radio"/>				

Additional comments

**46.**

**Mean** (average rating in previous round)

4.24 (agree)

**Comments from previous round**

- Keeping on checking back with the patient is vital to make sure that their day to day and longer term needs are being met. It is always more difficult to assess as the patient becomes less and less competent to communicate effectively. Needs may be physical, emotional and spiritual.

**46.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Individual patient needs	<input type="radio"/>				

Additional comments

**47.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
The patient's spiritual beliefs and how they may be incorporated into the end-of-life care plan. <i>***new items added from participant comments</i>	<input type="radio"/>				

Additional comments

**48.**

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

Health care professional  
checking that day to day  
as well as longer term  
needs will be met \*\*\*new  
items added from  
participant comments

Additional comments

## Question Three

### Which of the following would you include in an end-of-life discussion?

Please read the mean (average) rating and consider the comments made by participants in the previous round before indicating your level of agreement with each item below.

\*\*\*Please note that changes to items are indicated by [ ]

1.

**Mean** (average rating in previous round)

4.59 (strongly agree)

**Comments from previous round**

- Again, important for patients to appreciate that there will inevitably be choices that need to be made and that knowing what they would choose is important.
- within confinements of POA law and pt competence

1.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient understanding of their option to make end-of-life choices	<input type="radio"/>				

Additional comments

2.

**Mean** (average rating in previous round)

4.24 (agree)

**Comments from previous round**

- The client needs to feel comfortable with their decision as well the substitute decision maker needs to be aware of the clients wishes.
- Vital in transition time; needs to be someone the patient is comfortable with; best if decided before a stressful time. Communication of patient's decision to family members is also crucial to avoid conflict.

2.

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient deciding on a substitute decision maker	<input type="radio"/>				

Additional comments

3.

**Mean** (average rating in previous round)

4.18 (agree)

**Comments from previous round**

- Very important in family dynamics.

**3.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Patient understanding of the 'chain of command' of decision makers, should there be a dispute when patient is unable to speak for themselves	<input type="radio"/>				

Additional comments

**4.**

**Mean** (average rating in previous round)

4.47 (agree)

**Comments from previous round**

- Part of POA law

**4.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Option to change your mind after making end-of-life decisions	<input type="radio"/>				

Additional comments

**5.**

**Mean** (average rating in previous round)

4.76 (strongly agree)

**Comments from previous round**

- Vital, but in my experience, MDs may not take the time needed for this part which can lead to dissatisfaction of patient and family members when delays are experienced because of this missed step.

**5.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Making sure doctor knows what kind of care the patient wants	<input type="radio"/>				

Additional comments

**6.**

**Mean** (average rating in previous round)

4.53 (strongly agree)

**Comments from previous round**

- Communication of expectations and pros/cons of each decision is helpful to avoid misunderstandings.

**6.**

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Levels of advance care directives (supportive care only to full resuscitation)	<input type="radio"/>				

Additional comments

7.

Mean (average rating in previous round)

4.12 (agree)

Comments from previous round

- If they ask, otherwise no
- It depends of what and how much information the patients wants to know.
- Integral to family support

7.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Walking the family through the process of what will happen when the patient dies	<input type="radio"/>				
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Additional comments

8.

Mean (average rating in previous round)

4.47 (agree)

Comments from previous round

- Integral to family support

8.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Explaining implications of end-of-life decisions and care to family	<input type="radio"/>				
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Additional comments

9.

Mean (average rating in previous round)

3.94 (undecided)

Comments from previous round

- I'm not sure I understand this phrase so I am not sure how to respond
- If patient asks I would tell them how most patients report bother vs benefit
- "bother vs. benefits" - I've never heard it put this way before. "Bother" seems like a funny word here - bother for whom? I think discussing "risks/benefits" is appropriate and patients can understand this.
- Not sure what is fully meant by this, but pt desires for Rx/interventions should be top priority when available.

9.

Strongly agree                      Agree                      Undecided                      Disagree                      Strongly disagree

Discussing the [positive and negative consequences] of treatments or interventions with patients <i>phrase 'bother vs benefit' has been replaced due to participant comments</i>	<input type="radio"/>				
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Additional comments

10.

**Mean** (average rating in previous round)

4.12 (agree)

**Comments from previous round**

- Brings hope and comfort when assured that this is what they will get.

10.

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

How patient wants things to look at the end-of-life



Additional comments

11.

**Mean** (average rating in previous round)

4.35 (agree)

**Comments from previous round**

- Integral to the process

11.

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

Educating patients about their end-of-life choices and implications



Additional comments

12.

**Mean** (average rating in previous round)

4.41 (agree)

**Comments from previous round**

- Integral to the process; and to keep the goals flexible

12.

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

Goals of care



Additional comments

13.

**Mean** (average rating in previous round)

4.35 ( )

**Comments from previous round**

- I believe this is important, however, I have had experiences where clients don't want to know how "bad" they actually are and want the treatment to continue but are comfortable with dying.
- I stress the symptom management part vs no cure as sometimes, talk of transplantation does enter the discussion
- Very important, quite often they are unaware
- We should always be focused on providing patients with a good quality of life and minimizing symptom burden whether they are approaching end of life or not. Patients do need to understand however the limitations of some of our treatments but that our goal to keep them comfortable is constant and that may mean employing some different types of interventions.
- Integral to the process

**13.**

Strongly agree

Agree

Undecided

Disagree

Strongly disagree

Explaining where they are in their disease e.g. no cure, focus on symptom management

Additional comments

## Survey Complete!

Many thanks for participating in Round 3 of the Delphi study. You will receive a link to the fourth and final round of the Delphi in February.