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Can the value and acceptability of a patient feedback tool for revalidating psychiatrists be improved for both patients and psychiatrists through its co-production? An action research approach.

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Can the value and acceptability of a patient feedback tool for revalidating psychiatrists be improved for both patients and psychiatrists through its co-production? An action research approach.

by

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- This thesis is dedicated to the memory of my much loved Gran -

Declarations

At no time during the registration for the research degree has the author been registered for any other University award, without prior agreement of the Doctoral College Quality Sub-Committee.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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Abstract

Rebecca Baines

Can the value and acceptability of a patient feedback tool for revalidating psychiatrists be improved for patients and psychiatrists through its co-production? An action research approach.

Background: Co-production is often suggested as an alternative approach to patient feedback design. However, critical exploration of how co-production may affect the perceived value and acceptability of a patient feedback tool is severely limited, particularly in the context of revalidation for practising psychiatrists.

Aim: This research sought to address four research questions: i) how are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists, if at all; ii) what are patient and psychiatrist perceptions, experiences and aspirations for patient feedback tools in revalidation; iii) how do these compare and iv) can co-production improve the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists?

Methods: Seven cycles of action research were conducted in co-production with a mental health patient-research partner.

Results: Patients are rarely involved in the design, delivery or evaluation of patient feedback tools for practising psychiatrists. Comparison of 152 online reviews demonstrates that patients frequently describe different psychiatric care domains with different terminology to that used in existing feedback tools. Inductive thematic analysis of focus groups and interviews with 77 patients and 29 psychiatrists identified a number of shared concerns and suggestions that often related to improving existing feedback design, content and processes. Finally, following a co-production and refinement workshop with 28 participants, 16 patients and psychiatrists stated that co-production had improved the perceived value and acceptability of the patient feedback tool. Benefits of co-production identified by participants included enhanced relevance, provision of more accessible information and increased sense of ownership.

Conclusion: Co-production can enhance the perceived value and acceptability of a patient feedback tool. However, the integration of co-produced knowledge ultimately remains at the organisations’ discretion. Research impacts include the national implementation of the feedback tool and international implementation of the co-produced response framework.

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Abbreviations

AR	Action research
CIS	Critical interpretative synthesis
CPD	Continuing Professional Development
GMC	General Medical Council
HRA	Health Research Authority
PPI	Patient and Public Involvement
UK	United Kingdom

Introduction

About the study

Patient feedback is considered integral to patient safety, quality of care and professional development (Gillespie & Reader, 2018; Griffiths & Leaver, 2018; Marsh *et al.*, 2019). As a result, patient feedback is becoming increasingly prevalent in regulatory processes such as medical revalidation, the United Kingdom's (UK) regulatory system designed to ensure doctors are both up to date and fit to practise (General Medical Council, 2018). However, despite repeated assurances of validity and reliability (Lelliott *et al.*, 2008), the value and acceptability of existing patient feedback tools has recently been called into question (Archer *et al.*, 2018; Sir Keith Pearson, 2017), particularly in the context of psychiatry. Although co-production has been suggested as an alternative approach to patient feedback design, critical exploration of this process and its potential impact is severely limited.

This research therefore sought to explore whether the value and acceptability of a patient feedback tool for revalidation purposes could be improved for both patients and psychiatrists through its co-production. The thesis draws on a critical theory paradigm, historical realism ontology, subjective epistemology (Guba & Lincoln, 1994) and dialectical methodology in the form of co-production and action research. Following the cyclical nature of action research, exploration of patient and psychiatrist experiences, perceptions and aspirations was achieved through the use of qualitative methods including focus groups, semi-structured and think-aloud interviews in seven iterative research cycles as outlined in the organisation of this thesis section below. Importantly, the research design and analysis was conducted in co-production with a volunteer mental health patient research partner. Further information on this relationship is provided below. This research also involved a co-produced activity with both patients and psychiatrists who co-produced a patient feedback tool. As suggested by Waterman et al., this research is therefore best conceptualised as a variation of action research that combines the underpinning ethos of egalitarian and emancipatory philosophy in co-production (Locock & Boaz, 2019; Williams *et al.*, 2020) and the cyclical, action focused process of action research (Waterman *et al.*, 2001).

Terminology

Recognising the variable terminology often used in existing literature, particularly in the field of mental health (Tait & Lester, 2005), this thesis begins by defining its terminology (Table 1).

Table 1 Definition of terms used

Patient	In the absence of a single agreeable term (Towle *et al.*, 2010), this thesis uses the term ‘patient’ to be inclusive of clients, service-users, survivors, citizens, consumers, customers, carers and caregivers. While recognising the important distinctions between these terms (Baggott, 2005; Stickley, 2006), this decision was made as a result of ‘patient’ being the most dominant term used in European policy (Tritter, 2009) and preferred terminology of the patient research partner.
Patient research partner	A fundamental aspect of this research is its co-production with a volunteer mental health patient research partner. The research partner is currently receiving psychiatric care for a number of mental health diagnoses including schizophrenia, psychosis, multiple personality disorder, obsessive compulsive disorder, anxiety and acute paranoia. The term chosen by the patient partner emphasises the underpinning ethos of this relationship, a partnership. For clarity, the patient research partner was not involved as a participant at any stage of this research.
Patient feedback	Similar to the term ‘patient’, the term patient feedback is often used interchangeably to describe a multitude of concepts including patient satisfaction, expectation, experience, preference and patient reported outcomes

	(Baldie *et al.*, 2018). The definition of patient feedback used in this research builds on that provided by Hattie & Timperly (2007) to reflect a more person-centred focus (Hattie & Timperley, 2007). Patient feedback in the context of this research is therefore defined as information provided by a patient based on their experience of an individual healthcare professional, in this instance a psychiatrist. The focus on experience reflects Gillet et al's., (2015) definition of patient experience, satisfaction and expectations: patient experience explores the specific experience of individuals, while patient satisfaction evaluates those experiences. In contrast, patient expectations is a measure of how well an experience met an individual's expectations, which can often be highly variable (Gill *et al.*, 2015).
Value & acceptability	Value is defined as the importance, or usefulness an individual attributes to the tool. The definition of acceptability draws on that provided by van der Vleuten to mean the perceived suitability of the patient feedback tool from a patient and psychiatrist perspective (van der Vleuten, 1996b).
Co - production	Although there is no universally agreed definition (Longtin *et al.*, 2010; Mockford *et al.*, 2012; Pizzo *et al.*, 2015; Towle *et al.*, 2010), co-production can be used to describe both the overall approach to a research project, i.e. "*an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project"* (INVOLVE, 2019a) and the approach to an individual activity within a research project. In this thesis, co-production is used to describe both an individual activity, i.e. the co-production of a patient feedback tool and the overall research approach, i.e. co-producing the research design and analysis process with the mental health patient research partner. This research therefore has two central co-productive elements: the co-production of the research design, focus and analysis with the patient research partner and the co-production of the patient feedback tool with both patients and psychiatrists. All co-production efforts were informed by national guidance provided by INVOLVE (INVOLVE, 2018), a government funded programme established in 1996 to support active public involvement in NHS, public health and social care research.
Action research	Finally, as previously identified, this research draws on the cyclical process of action research. Following their extensive realist review, this research draws on the definition of action

research provided by Jagosh et al, the "*co-construction of research between researchers and people affected by issues under study (e.g. patients, community members, community healthcare professionals) and/or decision makers who apply research findings*" (Jagosh *et al.*, 2012, p.311). It is acknowledged that the definition of action research shares many similarities with that of co-production. However, the cyclical, fluid and flexible process of action research is well suited to the aims and purpose of this research as later described.

A short introduction to the patient research partner, Oriel, is presented below to provide further information about his important role:

> "*My name is Oriel and I am a 61 year old male. My background is in design and architecture. However, following a mental breakdown in 2016 I have been diagnosed with a variety of psychiatric conditions including schizophrenia, psychosis and multiple personality disorder. Rebecca and I met at a homeless hostel in our local city after I had been discharged from the intensive care unit. Since then, I have been involved as an equal partner in this research including its design, analysis and reporting. In this thesis I provide an explanation of my background, my motivations for getting involved and the impact this research has had on me"*

For clarity, Oriel is referred to by name or as the 'patient research partner' throughout the thesis. The student submitting this thesis is referred to as the researcher.

Organisation of the thesis

This thesis begins by contextualising the research study in existing literature, exploring the emergence of patient-centred care, introduction of medical revalidation in 2012 and difficulties encountered as a result of including patient feedback within this process. Chapter one concludes by presenting the overall research aims, objectives, questions and rationale.

Chapter two provides an overview of the philosophical underpinnings of the thesis, its research paradigm, ontology, epistemology and methodology. This is followed by the findings of a systematic review that sought to explore the presence of patient and public involvement in the design, delivery and evaluation of patient feedback tools for practising psychiatrists (cycle one, chapter three). Comparison of the content shared in psychiatric care reviews online with the two most commonly used patient feedback tools for revalidating psychiatrists, (the General Medical Council (GMC) patient feedback questionnaire and ACP 360 designed by the Royal College of Psychiatrists), is then provided in chapter four (cycle two).

Chapters five (cycle three) and six (cycle four) explore patient and psychiatrist perceptions, experiences and aspirations of existing patient feedback tools currently used in the revalidation process. Chapter seven (cycle five) compares these findings, identifying areas of commonality and disparity, while chapter eight (cycle six) documents the co-production and refinement of a patient feedback tool that incorporates research findings from cycles two-six. Chapter nine (cycle seven) evaluates the co-produced tool and two other feedback tools designed with varying levels of patient involvement with both patients and psychiatrists. Finally, chapter ten discusses the key findings of this research and its implications for policy, practice and future research.

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1.0 Background

1.1 Introduction

This chapter explores the emergence of patient-centred care, the introduction of patient feedback within professional regulation and the difficulties encountered as a result of feedback inclusion within this process in the context of psychiatry. The chapter concludes by identifying the gaps in existing knowledge that the thesis seeks to address, its rationale, overall research aims, questions and objectives.

1.1.1 The emergence of patient-centred care

Historically, patients have been subjected to the role of passive participants, dependent on the clinical expertise and knowledge of healthcare professionals (Farre & Rapley, 2017; Kaba & Sooriakumaran, 2007). The term patient is itself problematic due to inherent connotations of passivity, dependency and inaction (Farre & Rapley, 2017; Kaba & Sooriakumaran, 2007; Towle *et al.*, 2010). However, as recognized by Snyder & Engström and others (Britten *et al.*, 2017; Moore *et al.*, 2017), medicine has undergone a "*paradigmatic shift"* in the past 60 years where patients have moved *"from passive recipients, to more autonomous, active and involved"* individuals (Snyder & Engström, 2016, p.3). Such changes are arguably reflected in the rejection of the historical 'biomedical' model with its "*apparent and concomitant abuses"* (Stickley, 2006, p.570) and emergence of patient-centred care as outlined below (Brooks *et al.*, 2017; Mead & Bower, 2000; Snyder & Engström, 2016).

In the biomedical model of care, a patient's report of illness is typically reduced to a set of symptoms and signs that are investigated and interpreted by the doctor alone (Mead & Bower, 2000). The doctor then determines a diagnosis for the presenting pathology, selects an appropriate therapy to treat or restore the diseased process, thereby curing the patient's illness (Mead & Bower, 2000). The inclusion or acknowledgment of patient expertise in the biomedical medical is therefore severely limited. As a result, the biomedical model has faced a number of criticisms including its narrow approach to understanding illness and its depiction of patients as inanimate objects of scientific scrutiny (Borrell-Carrió, Suchman & Epstein, 2004; Farre & Rapley, 2017; Mead & Bower, 2000).

In an attempt to address the dehumanisation of medicine arguably enforced by the biomedical approach (Borrell-Carrió, Suchman & Epstein, 2004), George Engel provided an alternative model of care that emphasised the importance of simultaneously attending to the biological, psychological and social dimensions of health and illness (Engel, 1962). More recently Engel's biopsychosocial model of care has become encompassed by the model of patient-centred care (Kaba & Sooriakumaran, 2007; Lehman, David & Gruber, 2017). As identified by Mead and Bower, patient-centred care differs to the biomedical model in five key ways (Mead & Bower, 2000).

Firstly, patient-centred care challenges the key assumption that "*illness and disease are coterminous*" (Mead & Bower, 2000, p.1068). By doing so, patient-centred care broadens traditional disease taxonomies to encompass biological, psychological and social perspectives, reflecting the subjective and personal nature of health and illness (McWhinney, 1985; Mechanic, 1986). Secondly patient-centred care suggests that "*in order to understand illness and alleviate suffering, medicine must first understand the personal meaning of illness for the patient*" (Mead & Bower, 2000, p.1089). Patients are therefore considered to be an "*experiencing individual, rather than the object of some disease entity*" (Mead & Bower, 2000, p.1089). Thirdly, as stipulated by Mead and Bower, patient-centred care places “*far greater priority”* (Mead & Bower, 2000, p.1090) on the therapeutic alliance (the relationship between a doctor and patient), than that proposed by the biomedical model. For example, “*developing a therapeutic alliance is a fundamental requirement, as opposed to a useful addition”* (Mead & Bower, 2000, p.1090). Furthermore, while the biomedical model typically views the application of diagnostic and therapeutic techniques as fundamentally objective, patient-centred care acknowledges an inherent subjectivity within the doctor-patient relationship, with both doctors and patients influencing one another (Britten *et al.*, 2017; Wolf *et al.*, 2017). Finally, patient-centred care advocates the use of a democratic, equal doctor-patient relationship, challenging the traditional paternalistic model envisaged by Parsons, who suggested authority, power and control inevitably lay with the doctor due to a ‘competence gap’ between the medical expert and lay patient (Parsons, 1951). Collectively, these five dimensions challenge the historical biomedical model, calling for patients to no longer be seen as passive recipients of care, but as active agents of change, signifying a desirable shift from passivity, to activity.

Calls to embrace patient-centred care are indeed not new (Britten *et al.*, 2017). Carl Rogers is often cited as the first person to use the term ‘person-centred’ back in the 1960s (Health Foundation, 2016). Following the emergence of Engel’s biopsychosocial model, the Institute of Medicine included patient-centeredness as one of its six aims for healthcare quality in 2001 (Baker, 2001). Over the course of the next decade, patient-centred care began to emerge with increasing regularity in UK health policy. For example in 2002, the Wanless report focused on enablement and empowerment with patients as partners in care (Wanless, 2002). In 2008, Lord Darzi’s report highlighted the importance of people being involved in decisions about their care (Darzi & Johnson, 2008).

Since then, a variety of high profile malpractice cases have propelled the need for person-centred care and its focus on dignity, respect and involvement (Berwick, 2013; Francis, 2013).

1.1.2 Patient involvement

In England, the emergence of patient and public involvement (PPI) is often traced to the founding of the Community Health Councils in 1973 (Tritter, 2011), with The NHS and Community Care Act of 1990 frequently cited as the first piece of legislation to establish a formal requirement for patient involvement in service planning (Tait & Lester, 2005). Subsequent policies including the Health and Social Care Act (2001, 2012) introduced statutory PPI in service development, delivery and evaluation.

The regulation of healthcare professionals has also seen an increasing shift towards PPI as reported by Lalani et al., (Lalani *et al.*, 2019). Patient involvement in the context of regulation is often achieved through the provision of patient feedback (Lee *et al.*, 2016; Narayanan, Farmer & Greco, 2018; Nurudeen *et al.*, 2015; Salmon & Pugsley, 2017). For example, following its implementation in December 2012, all doctors in the UK are required to collect patient feedback as part of a process called medical revalidation.

Designed to ensure doctors are both up to date and fit to practise (General Medical Council, 2018; Heneghan & Chaplin, 2016; Tazzyman *et al.*, 2017), medical revalidation was implemented by the General Medical Council (GMC) to assure "*patients that their doctor is being regularly checked by their employer and the GMC"* (General Medical Council, 2018). Responding to calls for enhanced accountability and transparency (Baggott, 2005; Crawford *et al.*, 2002; Eriksson, 2013; Gillard *et al.*, 2010; Longtin *et al.*, 2010; Mockford *et al.*, 2012; Stickley, 2006), all doctors with a license to practise in the UK are required to collect six types of supporting information at least one every revalidation cycle, (typically every five years). The information includes:

1. Colleague feedback
2. Significant events
3. Review of complaints & compliments
4. Quality improvement activity
5. Continuing professional development
6. Patient feedback, also referred to as 360-degree or multisource feedback

Once collected, all six types of supporting information are shared and reflected upon during a series of annual appraisals. Following the completion of a revalidation cycle, a Responsible Officer makes a recommendation to the GMC, who then in turn make one of three decisions:

i) To revalidate - no change to licence or registration, doctors are able to continue to practise as usual
ii) To defer the revalidation submission date - doctors are able continue to hold their licence and practise as usual until their new revalidation submission date
iii) Licence withdrawal - doctors must stop practising within the UK with immediate effect (General Medical Council, 2018).

The outcome of revalidation can therefore be significant.

1.1.3 Concerns about revalidation

However, while considered world leading (Sir Keith Pearson, 2017), the introduction of revalidation represents "*the biggest change in medical regulation in over 150 years"* (Eaton, 2010). The implementation of revalidation has also been described as problematic by some (Archer *et al.*, 2018; Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017). Reported difficulties in the implementation of revalidation can often be attributed to the questioning of previously unchallenged roles and responsibilities (Tazzyman *et al.*, 2020). For example, since the Medical Act in 1858, the medical profession has been trusted to operate within a model of self-regulation (Archer & Regan de Bere, 2013). Revalidation directly challenges this approach, representing an erosion of previously held autonomy and independence (Archer & Regan de Bere, 2013). As a result, reports of professional resistance and scepticism are common, with some doctors reporting an undesirable shift in power, autonomy and control (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017).

The perceived purpose of revalidation also appears unclear (Archer *et al.*, 2015; Tazzyman *et al.*, 2017). While frequently defined as a formative process by the GMC, several researchers have identified conflicting discourses of professionalism and regulation (Archer *et al.*, 2015; Tazzyman *et al.*, 2017; Tazzyman *et al.*, 2018), concluding that revalidation is a summative exercise, given its possible outcomes, i.e. licence removal (Archer *et al.*, 2015; Williams, Holmes & Laugharne, 2016). Such confusion has led to the description and in some cases, dismissal of revalidation as a bureaucratic, or "*hoop jumping exercise*" that fails to deliver assured promises of enhanced patient care and care quality (Archer *et al.*, 2016; Sir Keith Pearson, 2017; Tazzyman *et al.*, 2017).

Such findings are concerning as the impact of revalidation and its ability to support professional development, patient safety and quality of care is largely dependent on how it is perceived by those involved and how well it is embedded into daily practice (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017). If stakeholders involved including both patients and healthcare professionals are cynical about its value, anticipated outcomes of enhanced care quality may be severely undermined. Furthermore, if doctors are concerned about the possibility of licence removal, some may be ‘creative’ in the way that they collect, or withhold, supporting information. Despite its detrimental impacts, critical exploration of this practice is severely limited.

1.1.4 Concerns about patient feedback in regulation

The inclusion of patient feedback in healthcare regulation also appears to be particularly problematic. While the collection of patient feedback is common practice in service evaluations, patient feedback for revalidation differs in the sense that it relates to the experience provided by an individual healthcare professional alone. Patient feedback in the context of revalidation is therefore indicative of an individual’s performance and not that of the wider healthcare team or service. This represents a different scope to many of the patient feedback tools that have been extensively researched. Despite this difference, patient feedback for revalidation purposes is typically collected in a similar way to other existing patient feedback initiatives, primarily through paper-based questionnaires that require a set number of responses to ensure sufficient validity and reliability (Campbell *et al.*, 2010; Campbell & Wright, 2012; Narayanan, Farmer & Greco, 2018).

However, the value and acceptability of these tools has recently been called into question (Academy of Medical Royal Colleges, 2018; Archer *et al.*, 2018; Sir Keith Pearson, 2017). Such issues primarily relate to reported difficulties in patient feedback collection, limited patient understanding and perceived value amongst some doctors. For example, although identified as the most helpful type of supporting information in facilitating reflective practice, responses from a national survey of 26,171 UK doctors revealed that patient feedback is considered to be the most problematic type of supporting information to obtain (Archer *et al.*, 2018).

Similar concerns have also been raised by Sir Keith Pearson in his independent review of revalidation, concluding that:

> "*While statistically valid, I am not convinced that a set of questionnaires, usually numbering around 40 or 50 and often collected on a single day in each five year cycle provides sufficient quality and breadth of information, to enable a doctor to reflect properly on their interaction with patients*" (Sir Keith Pearson, 2017)

Such statements challenge previously accepted conclusions that revalidation and its associated feedback processes are underpinned by rigorous processes due to their "*robust psychometric properties*" (Campbell *et al.*, 2010; Heneghan & Chaplin, 2016; Hill *et al.*, 2012; Lelliott *et al.*, 2008). Furthermore, in 2018 the Academy of Medical Royal Colleges reported extensive "*difficulties with the distribution, collection, analysis and reporting"* of existing patient feedback tools (Academy of Medical Royal Colleges, 2018), highlighting the severity and timeliness of the topic at hand.

The motivation for including patient feedback in the regulation of healthcare professionals also appears unclear. While not discouraging the importance of including patient voices in healthcare regulation, some researchers suggest that the mandatory inclusion of patient feedback is symptomatic of a 'target culture' that fails to critically consider why such involvement may be important, what impact it hopes to achieve and how such impacts can best be achieved (Tritter, 2009). Patient feedback is often included as a necessity to conform to existing, mandatory agendas, as opposed to intrinsic or educational motivations (Tritter, 2009). As a result, Sibley and colleagues recently likened the increasing collection of patient feedback as an "*avalanche …with experience now tracked, monitored and measured to an almost obsessive degree"* (Sibley, Earwicker & Huber, 2018, p.4329).

Some researchers have therefore questioned the ethics of collecting mandatory, or extrinsically motivated patient feedback that leads to minimal direct benefit (Edwards & Staniszewska, 2000; Williams, Coyle & Healy, 1998). Sheard et al., recently reported that all patient feedback tools must have the ability to be meaningfully used by those providing frontline care. Otherwise it becomes "*unethical to ask patients to provide feedback which will never be taken into account"* (Sheard et al., 2019, p.51). Despite such concerns, the collection of patient feedback has been described as its *"own self-perpetuating industry"* (Sheard et al., 2019, p.46).

Although related to the use of patient feedback more broadly, other reported concerns of patient feedback include: biased patient selection (Asprey *et al.*, 2013; Baldie *et al.*, 2018; Carter *et al.*, 2016; Gayet-Ageron *et al.*, 2011); limited opportunities to form specific actions due to a predominant focus on numerical scores (Asprey *et al.*, 2013; Edwards *et al.*, 2011; Jones *et al.*, 2019); perceived relevance to local contexts (Jones *et al.*, 2019); and biased patient responses (Carter *et al.*, 2016; Edwards & Staniszewska, 2000; Fernandes *et al.*, 2019; Lelliott *et al.*, 2008; Narayanan, Farmer & Greco, 2018) with quantitative scores often providing an overly optimistic view of care that inhibits learning, change and development (Edwards *et al.*, 2011; Staniszewska & Henderson, 2004). For example, Williams et al., reported that while patients indicated they were 'satisfied', or 'highly satisfied' with aspects of their care in a validated questionnaire, when given the opportunity, patients also described critical feelings towards the same aspects of care during a qualitative interview, signifying a discrepancy between quantitative scores and qualitative reports (Williams, 1994). Williams et al concluded that had the quantitative scores been used in isolation, a seemingly positive, yet inaccurate evaluation of care would have been provided (Williams, 1994). Such disparities have been widely reported in a number of other areas including marketing, dentistry and sociology (Edwards, Staniszewska & Crichton, 2004). Patient feedback tools can therefore act as a form of censorship, as opposed to empowerment, if considered to be of limited value and acceptability by those involved (Edwards & Staniszewska, 2000).

1.1.5 Patient feedback within psychiatry

Finally, as previously mentioned, the collection of patient feedback for revalidation purposes appears particularly problematic in the context of psychiatry (Archer *et al.*, 2018). For example, research conducted by Baines et al., suggests that despite asking a comparable number of patients, psychiatrists (n=1,761/26,171) received a significantly lower feedback response rate in comparison to all other surveyed specialties with the exception of pathology and public health (Baines *et al.*, 2019c). Doctor survey respondents stated that patients had difficulty understanding the purpose, target and content of existing patient feedback tools with several respondents commenting that a fear of "*being done*" (potential repercussions for future health care) deterred patient engagement and feedback authenticity. Similarly, many survey respondents viewed existing patient feedback tools as "*administratively burdensome and time consuming,*" with some respondents acknowledging that "*many of* [their] *colleagues have filled these* [feedback questionnaires] *up themselves to satisfy the college. It's* [patient feedback] *a futile exercise… with no value*" (Baines *et al.*, 2019c, p.573). In one instance, the inclusion of patient feedback in revalidation was described as “*degrading to the role of a psychiatrist*” (Baines *et al.*, 2019c, p.573). Such defensive attitudes have been reported elsewhere (Tazzyman *et al.*, 2017), with some healthcare professionals considered more willing than others to accept such involvement (Tritter, 2009).

1.1.6 Difficulties of patient feedback in psychiatry

Existing literature provides some insight into why patient feedback may be perceived as particularly difficult in psychiatry. Some researchers suggest that reported difficulties can be attributed to assumed biases following psychiatric diagnoses, issues of patient capacity and acknowledged difficulties of raising concerns while experiencing mental ill health (Berzins *et al.*, 2018; Eriksson, 2013). However, other researchers suggest that reported challenges can be attributed to the historical, social and cultural context of psychiatric care (Dabby, Tranulis & Kirmayer, 2015; Ma, 2017; Vigo, 2016). Specifically, the inherent power hierarchies that exists between patients and psychiatrists (Dabby, Tranulis & Kirmayer, 2015; Stickley, 2006). For example, as identified by Stickley et al,:

> “*As with any national institution, power struggles are inevitable. However, these struggles are more poignant in psychiatry with its history of enforced treatment and abuse…In no other arena in health care has there been the equivalent of what we now call the user/survivor movement”* (Stickley, 2006, p.570)

Psychiatry is the only speciality where it is possible to treat and hold someone against their will (Heneghan & Chaplin, 2016). Similarly, mental health services are the only current exception to the ‘free choice offer’ that states a patient has the right to choose any provider in England for a first outpatient appointment (Isaac, 2016). When admitted, a patient’s health, routine, status and possibility of discharge is therefore often dependent on a psychiatrist alone, with no alternative service provider to turn to. As a result, psychiatrists are often considered to “*differ from other physicians by virtue of the power they possess over their patients”* (Szasz, 1994, p.137). The intricate interaction of professional, cultural, historical, legal and social contexts can therefore be described as particularly inherent in psychiatric care (Davies, 2001; Sitzia & Wood, 1997).

Furthermore, although now nearly sixty years on since the emergence of the Survivors movement in the 1960’s, the cultural, societal and systemic stigmatisation faced by psychiatric patients was recently defined as a public health crisis in 2016 (Hatzenbuehler, Phelan & Link, 2013; Vigo, 2016). This is in part due to the disproportionate problems faced by mental health patients including: reduced employment and educational opportunities (Davies, 2001; Thornicroft *et al.*, 2016); increased poverty (Beresford & Wallcraft, 1997); health and social care inequalities (Dabby, Tranulis & Kirmayer, 2015; Farrelly *et al.*, 2015; Mitchell, Lord & Malone, 2012) and increased rates of morbidity (Dabby, Tranulis & Kirmayer, 2015; Thornicroft *et al.*, 2016; Vigo, 2016). There is also increasing evidence to suggest that psychiatric patients experience stigma and discrimination in the healthcare setting, with individual healthcare professionals playing an integral role in both the mitigation and perpetuation of such attitudes and behaviours (Dabby, Tranulis & Kirmayer, 2015; Thornicroft *et al.*, 2016; Vigo, 2016).

Other suggested reasons for the reported difficulty of collecting patient feedback in a psychiatric setting includes the disparity between the historical silencing of the patient voice in psychiatric care and its now mandatory status (Steslow, 2010). In his examination of oral testimonies in mental health since 1948, Davies describes how:

> “*Psychiatry itself and the historiography of psychiatry have in many ways silenced the patient… Case notes, for example, privilege the voices of psychiatrists and tend to report patients’ voices as signs of illness or cure, rather than communication in their own right”* (Davies, 2001, p.267)

Steslow’s autobiographical account of psychiatric care also provides a vivid description of the silencing and passivity encountered by some psychiatric patients:

> “*What I found distressing—was not the involuntary commitment, but rather the distinct feeling of being unheard. Everything I said or did was taken to be a product of my illness and categorized accordingly. I had questions and worries and thoughts and even a good deal of imagination, but I was cut off from all meaningful conversation by the veil of my diagnosis, through which my speech and behaviours passed before doctors and nurses heard, saw and interpreted them. There was a clear and distinct vocabulary being used to talk about my experience and that vocabulary was not mine…”* (Steslow, 2010, p.30)

As a result, some authors conclude that over time, the voices, behaviours and narratives of psychiatric patients have become unfairly marginalised, demonised, or worse still, removed altogether (Davies, 2001).

1.1.7 Why is it important to explore patient feedback in psychiatric care?

Some authors suggest that exploring patient feedback in the context of psychiatry is of paramount importance for the following reasons. Firstly, psychiatry is unique in the sense that patients may receive care against their will (Heneghan & Chaplin, 2016). Such circumstances may have important implications for providing patient feedback on the experience provided by an individual psychiatrist as required in medical revalidation. Secondly, while considered important in all healthcare settings, the therapeutic relationship, (arguably the focus of patient feedback in revalidation), is considered critical in mental health and psychiatric care (Gunasekara, Patterson & Scott, 2017; Lelliott *et al.*, 2008; Perry *et al.*, 2013). Santos recently described the therapeutic relationship “*as the most important element of psychiatric care”*

(Santos, 2017, p.3). However, despite its acknowledged importance, limited research has explored the components of an effective and valued therapeutic relationship within psychiatry, particularly from a patient perspective or from individuals with a psychotic disorder (Brenner, 2017; Farrelly & Lester, 2014). Furthermore, the provision of patient feedback has been linked to a number of positive outcomes including: enhanced treatment adherence and efficiency (Gondek *et al.*, 2016; Klingaman *et al.*, 2015); reduced clinical relapse rates, hospital admission rates and resource expenditure (O'Regan & Ryan, 2009); heightened patient empowerment and autonomy (Berzins *et al.*, 2018; Brooker & Dinshaw, 1998; Gondek *et al.*, 2016); development of accessible services (Beattie *et al.*, 2014; Berzins *et al.*, 2018) and enhanced patient safety and quality of care (Beattie *et al.*, 2014; Cooper, 2016; Krägeloh *et al.*, 2015; Luxford, Safran & Delbanco, 2011). Finally, evidence suggests that the continued use of ineffective patient feedback methods has been shown to be detrimental to the overall quality of care received (Thornicroft *et al.*, 2008). Identifying ways in which the value and acceptability of existing patient feedback tools could be improved is therefore imperative.

1.2 Rationale

The rationale for this research stems from identified policy, practical and methodological driven needs.

1.2.1 Policy and practical driven needs

Firstly, the value and acceptability of existing patient feedback tools used in the revalidation of psychiatrists has recently been called into question (Academy of Medical Royal Colleges, 2018; Archer *et al.*, 2018; Sir Keith Pearson, 2017). However, research exploring patient feedback tools from both a patient and professional perspective is severely limited (Crawford *et al.*, 2011). Secondly, Sir Keith Pearson and others have called for existing patient feedback tools to be strengthened and developed (Archer *et al.*, 2018; Sir Keith Pearson, 2017), with a more nuanced understanding of factors that support and inhibit their perceived value and acceptability currently required (Gayet-Ageron *et al.*, 2011; Hill *et al.*, 2012), given their increasing use in regulatory decisions (Salmon & Pugsley, 2017). Similarly, despite growing interest in doctor-patient communication and the unique context of psychiatric care, research in a psychiatric setting is considered to be limited (Berzins *et al.*, 2018), or 'neglected' by some (Bramesfeld *et al.*, 2007; Santos, 2017), highlighting the necessity of this research.

1.2.2 Methodological

Furthermore, the exclusive approach used to design and evaluate many patient feedback tools has been repeatedly criticised (Boardman, 2018; Crawford *et al.*, 2011; Edwards & Staniszewska, 2000; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a). As stated by Davidson, traditional approaches to feedback design:

> "*Have neglected to invite the perspective or input of the person with the disorder, further exacerbating the passive and helpless role of the mental health patient"* (Davidson et al., 1997, p.767)

Despite acknowledged disparities between the domains of care valued by patients and those valued by healthcare professionals (Crawford *et al.*, 2011; Farrelly & Lester, 2014; Trujols *et al.*, 2013), existing feedback tools have often been criticised for their reliance on the assumption that the inquirer, often a researcher or clinician, knows what is important to ask and how best to ask it (Edwards, Staniszewska & Crichton, 2004). As a result, several researchers have acknowledged a need to identify and explore domains of care that are meaningful from both a patient and professional perspective (Eiring *et al.*, 2015; Trujols *et al.*, 2013). However, to date, such explorations have been severely limited (Boardman, 2018; Crawford *et al.*, 2011; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a), highlighting a further need for this research.

Moreover, as stated by Eiring et al. "*to know what matters most to the person in front of you, you have to ask"* (Eiring *et al.*, 2015, p.11). Some researchers have suggested that this may best be achieved through co-production (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a). For example:

> "*Mental health has, as yet, not focused sufficiently on the patient perspective. To improve this situation, service users and carers need to be involved in the entire process of developing, testing and measuring outcomes. This means listening effectively to the patient voice by developing a co-productive approach…"* (Boardman, 2018, p.5)

Similarly, as suggested by Brooker and Dinshaw:

> "*Psychiatrists can often feel as disempowered as the patients they serve and as such, think that they are powerless to bring about change. The fact that their views are being sought gives a powerful message to them that they hold many of the keys to quality improvement within their own hands*" (Brooker & Dinshaw, 1998, p.70)

Evidence suggests working with both patients and psychiatrists may help to achieve a greater sense of ownership, perceived usefulness (Riiskjær *et al.*, 2010), trust and engagement (Carter *et al.*, 2016). However, similar to the examination of care domains from both a patient and psychiatrist perspective, limited research has explored whether the co-production of a patient feedback tool can enhance its perceived value and acceptability, highlighting a further gap in existing knowledge and understanding that this research seeks to address.

Finally, while the longevity of a patient feedback tool can be considered beneficial, there is an acknowledged risk of relying on historical data to establish theories of care quality, with what constitutes care quality from a patient perspective likely to change over time (Beattie *et al.*, 2014; Biringer *et al.*, 2017). There is increasing evidence to suggest that repeated patient feedback measures lose their effectiveness over time (Riiskjær *et al.*, 2010), with additional items often added to conform to current healthcare policies, as opposed to patient experience and determinants of care quality (Beattie *et al.*, 2014). As a result, Beattie et al., recommends a re-examination of patient feedback tools every couple of years (Beattie *et al.*, 2014). The ACP 360 tool designed by the Royal College of Physiatrists, one of the most commonly used patient feedback tools for revalidating psychiatrists, has received limited attention since its conception in 2005 (Lelliott *et al.*, 2008), further emphasising the timeliness of this research.

1.3 Gaps in existing understanding

For clarity, this research seeks to address the following gaps in existing knowledge and understanding:

1. Critical exploration of whether patients are involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists given identified methodological criticisms outlined above (Biringer *et al.*, 2017; Boardman, 2018; Crawford *et al.*, 2011; Trujols *et al.*, 2013) and limited research into this area (Barbato *et al.*, 2014; Bjertnaes, Iversen & Kjollesdal, 2015; Delaney, Johnson & Fogg, 2015)
2. Critical exploration of patient and psychiatrist perceptions, experiences and aspirations for patient feedback tools used in the revalidation of psychiatrists following the limited amount of research into this area (Boardman, 2018; Crawford *et al.*, 2011; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a)

3. Critical exploration of whether the value and acceptability of a patient feedback tool for revalidating psychiatrists can be improved through its co-production, responding to repeated calls for such an approach to be undertaken (Berzins *et al.*, 2018; Gunasekara, Patterson & Scott, 2017; Williams, Coyle & Healy, 1998)

1.4 Research aims

The aims of this research are to therefore:

1. Identify the extent to which patients and the public are involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists
2. Explore and compare patient and psychiatrist experiences, perceptions and aspirations for patient feedback tools for revalidation purposes
3. Co-produce a patient feedback tool with both patients and psychiatrists
4. Explore the impact, if any, of co-production on the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists

1.5 Research questions

Following the aims identified above, the research questions this thesis seeks to address are as follows:

1. How, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists?
2. What are patient and psychiatrist perceptions, experiences and aspirations for patient feedback tools in the revalidation process?
3. How do these perceptions, experiences and aspirations differ if at all?
4. Can the perceived value and acceptability of a patient feedback tool be improved for both patients and psychiatrists through its co-production?

1.6 Objectives

Finally, the objectives of this research are to:

1. Identify and explore the extent to which patients and the public are involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists
2. Identify and explore patient aspirations, experiences and perceptions of the two most commonly used patient feedback tools in the revalidation of psychiatrists
3. Identify and explore psychiatrist aspirations, experiences and perceptions of the two most commonly used patient feedback tools in their revalidation
4. Compare and contrast patient and psychiatrist experiences to identify areas of divergence and commonality
5. Co-produce a patient feedback tool based on patient and psychiatrist aspirations, experiences and perceptions
6. Evaluate how, if at all, the co-production of a patient feedback tool affects its perceived value and acceptability amongst patients and psychiatrists.

2.0 Methods

Having situated the thesis in existing literature (chapter one), this chapter seeks to explore the paradigm, methodology and methods used in this research.

2.1 Introduction

This research is grounded in a critical theory research paradigm, draws on a historical realism ontology, subjective epistemology and dialectic methodology in the form of co-production and action research. Justification for these decisions stems from the belief that excluding either patients and/or psychiatrists from the research process would perpetuate, or create an additional hierarchy, leading to the continuation of exclusive research practice and knowledge generation. As a result, this research is comprised of seven inter-related cycles (Figure 1) that primarily draw on qualitative methods to enable participants to express their views and opinions in their own words (Staniszewska & Henderson, 2004). The seven cycles used in this research are:

1. Cycle one: a systematic literature review exploring the presence of patient and public involvement in the design, delivery and evaluation of patient feedback tools for practising psychiatrists
2. Cycle two: comparison of psychiatric care reviews shared online with the two most commonly used patient feedback tools for revalidating psychiatrists
3. Cycle three: qualitative exploration of patient experiences, perceptions and aspirations of patient feedback tools for revalidating psychiatrists
4. Cycle four: qualitative exploration of psychiatrist experiences, perceptions and aspirations of patient feedback tools for revalidating purposes
5. Cycle five: comparison of patient and psychiatrist experiences, perceptions and aspirations

6. Cycle six: co-production of a patient feedback tool for revalidating psychiatrists building on findings from cycles one-five
7. Cycle seven: evaluation of the co-produced tool in comparison to two other feedback tools designed with varying levels of patient involvement and exploration of the potential impact of co-production on the perceived value and acceptability of a patient feedback tool from both a patient and psychiatrist perspective.

Figure 1 outlines the research question each cycle seeks to address, its relationship to the overall research questions, methods and analysis techniques used. Further information regarding the recruitment method, sample size, inclusion/exclusion criteria and method justification are provided in the write up of each cycle to avoid duplication.

The remainder of this chapter explores the methodological considerations of this research beginning with its research paradigm, ontology (what is the nature of reality and what is there that can be known about it?), epistemology (what is the nature of knowledge? How does the knower come to know what they know?) and methodology (what approach can be used to find out what is known?). These discussions have been included to provide the reader with an overview of the assumptions that may underpin this research process. For purposes of transparency, a biography of both the patient research partner and researcher has also been provided below.

2.2 Research paradigm

A research paradigm is understood to be the basic belief system, or worldview, that guides the researcher in their ontological, epistemological and methodological selections (Guba & Lincoln, 1989; Guba & Lincoln, 1994). While there is limited consensus around the terminology and classification of philosophical perspectives, this research draws on the widely cited work of

Guba and Lincoln and their four research paradigms: i) positivism, ii) post-positivism, iii) critical theory and iv) constructionism (Guba & Lincoln, 1994). Each paradigm and their corresponding ontological, epistemological and methodological positions are shown in Figure 2.

2.2.1 Critical paradigm

Due to its consideration and questioning of historical exclusion, inequality and marginalisation (Stickley, 2006), this research is situated within a critical paradigm. While plausible, a positivist paradigm was considered inappropriate for the purposes of this research for the following reasons. Firstly, positivist research typically considers reality to be objective, as opposed to socially constructed with individuals subjected to the social facts that exercise coercive control over them (Durkheim *et al.*, 1938). This approach arguably enforces notions of passivity and inaction that the researcher seeks to avoid (Edwards & Staniszewska, 2000). Secondly, positivist research typically seeks to explain, or uncover general laws that govern human behaviour as opposed to describe and understand why individuals view and act in the world in the way that they do. Given the lack of existing research that explores patient and psychiatrist experiences of patient feedback tools (Boardman, 2018; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a), critical theory and its interest in description and understanding was considered to be more appropriate for the purposes of this research. Positivist research also typically considers knowledge to be independent of context and time-free, as opposed to time-bound, with the researcher often positioned in a privileged point of observation (Hudson & Ozanne, 1988). Such an approach is arguably at risk of perpetuating exclusive research practice that prioritises traditionally held notions of knowledge, expertise and reliability at the expense of others.

Furthermore, although plausible, a constructionist approach was felt to be unable to provide the desired level of critique and change that is possible in a more critical paradigm. A critical paradigm and its desire to create a more democratic approach that facilitates the co-production, as opposed to assumption of knowledge (Scotland, 2012) was therefore selected as the appropriate paradigm for this research.

2.3 Ontology

This research draws on historical realism as its ontological position. Defined by Guba and Lincoln, historical realism suggests that "*a reality is assumed to be apprehendable that was once plastic, but that has, over time been shaped by a congeries of social, political, cultural, economic, ethnic and gender factors and then crystallised into a series of structures that are now (inappropriately) taken as 'real'. For all practical purposes the structures are 'real', a virtual or historical reality*" (Guba & Lincoln, 1994, p.110). The researcher understands this to mean that a version of reality exists, but is shaped by social, political and cultural influences, so aspects of the truth or reality have become accepted, unquestioned and unchallenged. Given the historical, cultural and political treatment of psychiatric patients and more recent developments of regulatory changes as previously described (chapter one), the selection of historical realism appears to be justifiable for the purposes of this research.

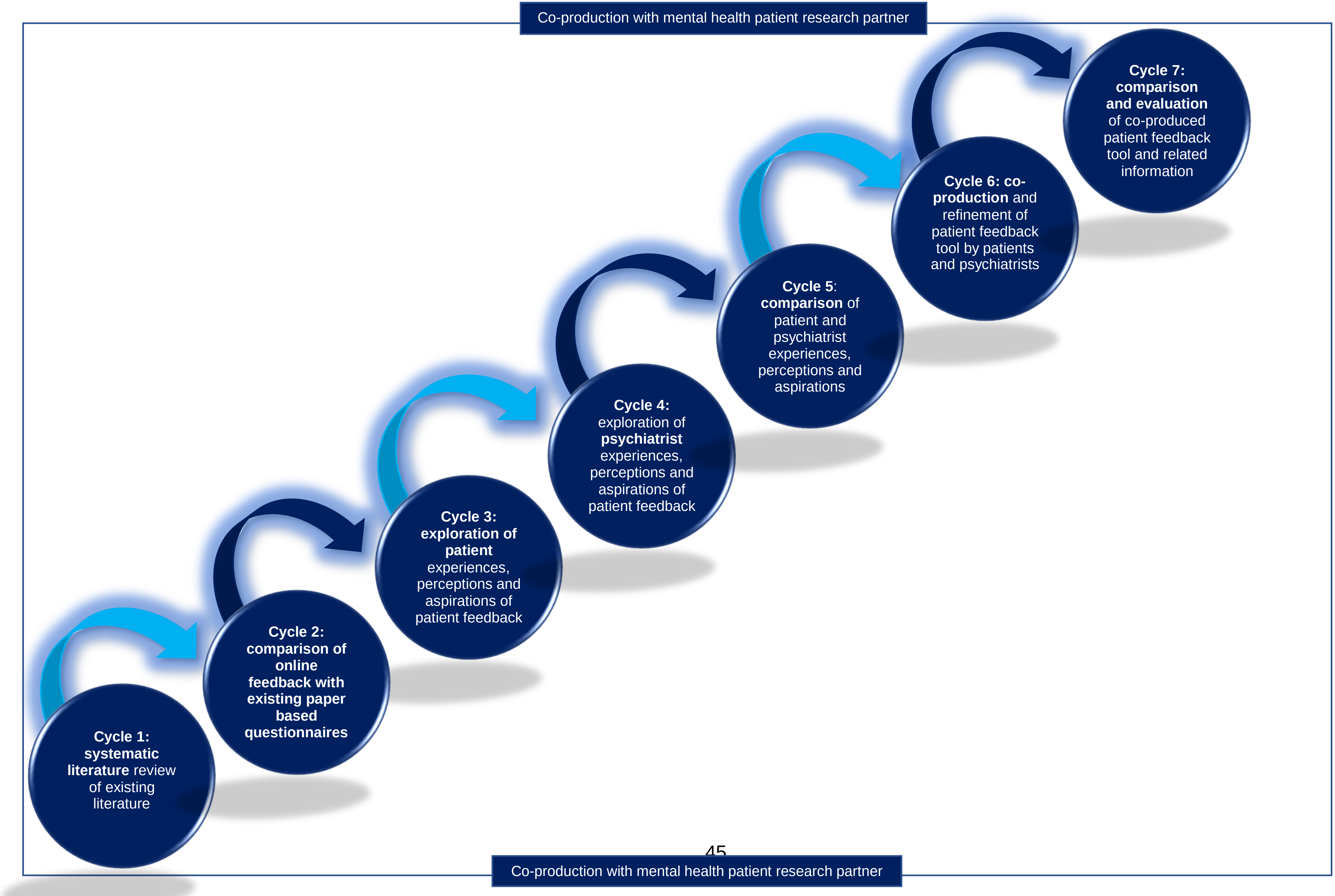
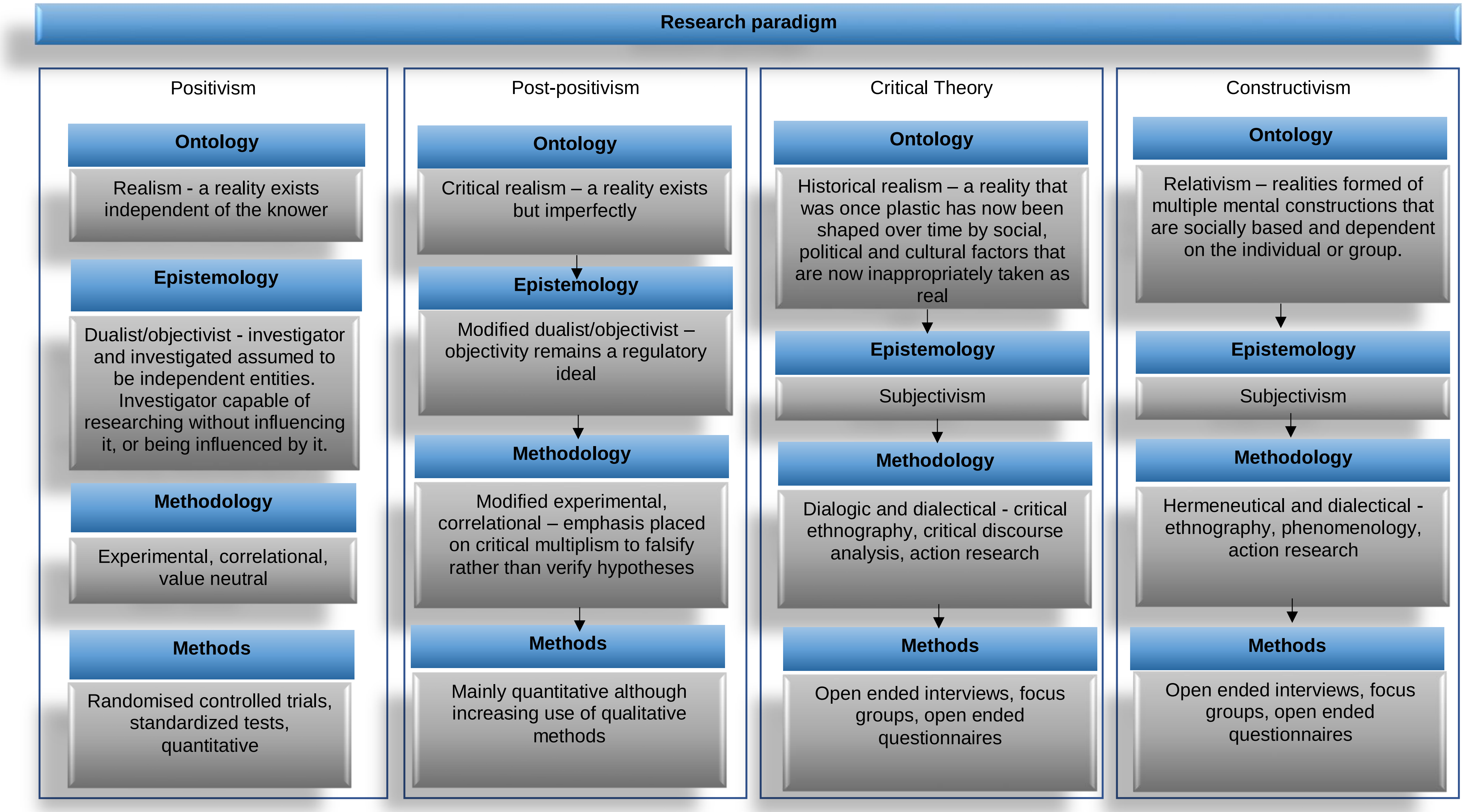


Figure 1 Research process

Cycle	Cycle question(s)	Overall research question*	Methods	Recruitment	Anticipated sample size	Analysis
1	How, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists?	1	Systematic review	N/A	N/A	Thematic & Critical Interpretative Synthesis
2	What do patients share online about psychiatric care experiences? How, does this compare, if at all, to the content used in the two most commonly used patient feedback tools for revalidating psychiatrists?	2&3	Qualitative observational design	Online feedback posted on national website Care Opinion	N/A	Framework
3	What, if anything, would patients like to give their feedback on? What behaviours, attributes and skills are considered most conducive to the therapeutic relationship? What, if anything, would motivate patients to give their feedback? How do patients perceive the two most commonly used patient feedback tools in the revalidation of psychiatrists?	2	Focus groups & semi-structured interviews	Volunteer purposeful sampling	54-60 Focus groups (n=6, 6-8 participants each), interviews (n=18)	Thematic
4	What ,if anything would psychiatrists find most helpful to receive patient feedback on for revalidation purposes? What, if anything, could make patient feedback more meaningful for psychiatrists for revalidation purposes? How do psychiatrists perceive and experience the two most commonly used patient feedback tools for revalidating psychiatrists?	2	Focus groups & semi-structured interviews	Volunteer purposeful sampling	30-42 Focus groups (n=3, 6-8 participants each), interviews (n=12)	Thematic
5	How do patient and psychiatrist perceptions, experiences and desires of patient feedback tools for revalidation purposes differ, if at all?	3	N/A	N/A	N/A	Framework
6	What do patients and psychiatrists co-produce when creating a patient feedback tool for revalidation purposes? How, if at all, does this compare to the ACP 360?	2,3 &4	Focus groups	Volunteer purposeful sampling	6-8 participants (n=4-6 patients, n=2 psychiatrists)	Thematic
7	How do patients and psychiatrists perceive, understand and experience three patient feedback tools and their accompanying information sheets? What impact, if any, does co-production have on the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists?	4	Semi-structured interviews	Volunteer purposeful sampling	12 (n=6 patients, 6 psychiatrists)	Thematic

*1: How, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists? Research question 2: What are patient and psychiatrist perceptions, experiences and aspirations for patient feedback tools in the revalidation process? Research question 3: How do these perceptions, experiences and aspirations differ between patients and psychiatrists if at all? Research question 4: Can the perceived value and acceptability of a patient feedback tool be improved for both patients and psychiatrists through its co-production?

Table 2 Research cycle questions, methods, recruitment and analysis



Research paradigm

	Positivism	Post-positivism	Critical Theory	Constructivism
Ontology	Realism - a reality exists independent of the knower	Critical realism – a reality exists but imperfectly	Historical realism – a reality that was once plastic has now been shaped over time by social, political and cultural factors that are now inappropriately taken as real	Relativism – realities formed of multiple mental constructions that are socially based and dependent on the individual or group.
Epistemology	Dualist/objectivist - investigator and investigated assumed to be independent entities. Investigator capable of researching without influencing it, or being influenced by it.	Modified dualist/objectivist – objectivity remains a regulatory ideal	Subjectivism	Subjectivism
Methodology	Experimental, correlational, value neutral	Modified experimental, correlational – emphasis placed on critical multiplism to falsify rather than verify hypotheses	Dialogic and dialectical - critical ethnography, critical discourse analysis, action research	Hermeneutical and dialectical - ethnography, phenomenology, action research
Methods	Randomised controlled trials, standardized tests, quantitative	Mainly quantitative although increasing use of qualitative methods	Open ended interviews, focus groups, open ended questionnaires	Open ended interviews, focus groups, open ended questionnaires

Figure 2 Research paradigms, their ontology, epistemology, methodology and methods (Adapted from Guba and Lincoln 1994)

2.4 Epistemology

This research draws on a subjectivist epistemology. Defined by Guba and Lincoln as the belief that “*the investigator and the investigated object are assumed to be interactively linked, with the values of the investigator inevitably influencing the inquiry”* (Guba & Lincoln, 1994, p.110), a subjective epistemology differs to an objectivist epistemology that asserts it is possible and indeed mandatory, for an observer to be objective and distanced from its subject (Beresford, 2013; Guba & Lincoln, 1989). Such an approach is believed to have important implications for the credibility of research by some, with subjective research often considered to be inferior, or anecdotal in comparison to its objective counterparts (Beresford, 2013; Waterman *et al.*, 2001).

However, such claims have consistently been challenged. For example, Beresford argues that the shorter the distance between direct experience and its interpretation, the less distorted, inaccurate and damaging the resulting knowledge may be (Beresford, 2013). Furthermore, first hand, or experiential knowledge is highly valued in day-to-day life. Despite this, traditional positivist research often invalidates such experiences. As a result, many people who have been discriminated against, or oppressed as a result of their experiences, identity, or diagnoses, are often considered to be less reliable or valid in comparison to other knowledge sources (Beresford, 2013). People can often therefore experience further discrimination and invalidation, highlighting the risk research can play “*in the othering of people”* (Beresford, 2013, p.147).

Recognising the detrimental impact discrimination has for psychiatric patients and the reported silencing of patient expertise as previously described (Steslow, 2010), an objectivist approach was considered inappropriate and potentially damaging for the purposes of this research. In line with the emergence of patient-centred care, wider cultural and societal attitudes of inclusion and collaboration (Rycroft-Malone *et al.*, 2016; Salmon & Pugsley, 2017), this research used a subjective epistemology that focused on the exploration of subjective experiences, aspirations and perceptions.

With this in mind, Sutton and Austin state that it is important for researchers to be transparent about their position to provide context for the reader and the opportunity to consider how this may influence the research process (Sutton & Austin, 2015). The biographies of the patient research partner and researcher are therefore provided below (the patient research partner has given his consent for this information to be made publically available):

2.4.1 Patient research partner biography

> "*My name is Oriel, a single sixty year old male helping Rebecca as a patient research partner. I was introduced to Rebecca in 2016 and since then have been working with her on a continuous basis working with her and contributing on a regular basis both to relevant papers and to research carried out in relation to this thesis.*
>
> *My own background is in architecture and design, working on both private and commercial projects for clients associated with the creative world of music, TV and film with a typical project lasting 24/36 months. My last project was on going (2015-2016) when I experienced a complete nervous breakdown resulting in a prolonged period of hospitalisation (including a stay in an I.C.U.). A culmination of stress, anxiety, depression and as it transpired, much deeper rooted issues, a persistent depression was soon diagnosed but it wasn't until 2018 that I was referred for a psychiatric report.*
>
> *I should mention that no blame should be attached to the medical team at that time for any delay in referral. In fact, I had earlier been referred for psychiatric counselling while recovering in hospital. Unfortunately the process had been intimidatory, off hand, lacking in empathy, contradictory and rude (including one psychiatrist choosing to wear reflective sunglasses in my presence whilst carrying out a conversation) and I had determined not to reveal anything further regarding my circumstances thereafter to the members of my medical team.*
>
> *It was only when I was introduced to a consultant psychiatrist, compassionate and empathetic that I relented and, explaining my*

circumstances, persistent voices, two particular characters, each a presence who has formed part of my life for over forty years and acute paranoia, that a complete diagnosis was possible. I present with multiple-personality disorder, psychosis, schizophrenia, depression and am also being treated for acute anxiety and post-traumatic stress disorder having unfortunately suffered an abusive childhood where - for a period of time - I was routinely raped as part of my life.

I share my life now with a constant presence whose name is Amber and as a writer she identifies as Electra Della Francesca. An unwanted presence exists called Banin, a voice of evil intent whom both Amber and I are in conflict with. I am currently placed with a team and am benefiting from deep therapy conducted by a clinical psychologist in conjunction with care provided by a consultant psychiatrist, psychologist and care co-ordinator.

A goal exists if you like, which would allow me to deal with the unwanted persistent voices or even negate them ridding myself and Amber of Banin and integrate Amber into my future life. She is a presence I would feel incomplete without, all that and build a world, a future life, beyond therapy.

My current team are warm, embracing, caring, empathetic, exceptionally compassionate and understanding and each day I am awe struck by what they do… Unfortunately, as I have previously stated, a stark contrast to the care I had received from my previous psychiatric team.

I have stated this in order that I may tell you that I have as a patient, with often debilitating circumstances, a claim like all other psychiatric patients - to speak. Should our voice be heard, or do we sit huddled and ashamed? A hundred thousand, maybe more, clamour to say no and not just because our voice casts a light on deficiencies in the exercise of psychiatric treatment. No, it is and because correctly perceived, it is an empowering voice and not just for patients but for all professionals alike.

As for the future, ask me what I've done with my life and this, my heart and mind speaking, a non-academic but persistent, relevant voice answers this… That this research will set fire to the ground, bring a certainty of knowledge which I hope inspires. This research has given me a voice and if this sounds heartfelt and easy speech, it's underpinned by years of hard work, aspirations, research and a passion born of a desire to make sure the mistakes of yesterday, the conferences and dreams of today, become the realities of tomorrow."

2.4.2 Researcher biography

"*I am entering this research as a young, white, female, self-funded doctoral research student, with no medical background who works full time as a research assistant at the University of Plymouth. I recognise that there may be stark differences in access to social, cultural and material resources between myself, patients and healthcare professionals. My association with the University of Plymouth may be both helpful and harmful depending on people's previous experience with the University and perceptions of Universities as an institution more broadly.*

The training I have received as a doctoral research student and research assistant may also be problematic. To date, my research training and experience has upheld traditional notions of rigour, knowledge and expertise, with limited room for innovation, questioning or alternative ways of thinking. I often feel at odds with the 'top down' approach widely promoted in academic institutions, i.e. the professional, researcher, or clinician knows what is best and how best to ask it. I believe people outside the institution have significant expertise and knowledge, but have repeatedly seen first-hand, that such knowledge is not always welcomed nor appreciated. The repeated dismissal of including alternative perspectives in research and practice has most likely shaped my worldview in the sense of championing and proactively seeking more collaborative ways of working.

It is also important to recognise that I have no personal experience of receiving psychiatric care. I do however have extensive experience of supporting immediate family members and friends through psychiatric care and have a decade's worth of experience working with people considered to be 'mentally ill' in a volunteering and work-related capacity. This has provided me with extensive experience of talking to people with mental health issues and feeling comfortable in psychiatric care settings. This may be beneficial in the context of this research and has given me some understanding of the language used in psychiatric care, although not all of it.

Finally, as previously mentioned, I am not medically trained. Previous research experiences and general media coverage has identified the increasing pressure healthcare professionals are under given recent funding cuts and such considerations are often at the forefront of my mind. However, following repeated discussions with both healthcare professionals and patients during a previous research study (Archer et al., 2018), I have become aware of a prevailing 'us and them' mentality between patients and healthcare professionals, with each group often attributing blame to the 'other'. Through these discussions I feel limited conversations have been allowed, or encouraged, to take place between the two communities to explore one another's experiences and desires, particularly in a non-clinical setting. Despite this, the desire to both receive and deliver high quality psychiatric care experiences remains a common thread across both parties.

> *Similar to seeking more collaborative ways of working, previous research experience in this area has likely shaped my thinking and motivation for exploring the topic of patient feedback in the context of psychiatry.*
>
> *With this in mind, I recognise the importance of sharing my world view clearly, openly and honestly and continuously reflecting on my position. I have therefore kept a reflective diary throughout the research process to further facilitate reflexivity and maintain transparency"* (Appendix 1).

Patient research partner recruitment

The patient research partner was recruited on a volunteer basis through a chance meeting. We met during a previous research project exploring patient involvement in revalidation. Oriel was living in the homeless hostel where I was running a focus group. Oriel expressed an interest in the other work I was doing and we agreed to meet at his local library the following week to discuss some initial PhD ideas. Following this informal meeting, Oriel asked if could be involved. Since then, we have met every two weeks at the same time, same place for the duration of this PhD with the exception of interruptions caused by Covid-19. Oriel's involvement in this research has been entirely voluntary.

2.5 Methodology

This research adopts a dialectical methodology in the form of co-production (Hartley & Benington, 2000) and action research (Reason & Bradbury, 2005). A dialectical methodology is one that focuses on expressions and the conversational nature of inquiry (Ball, 1979). Given its co-production with a patient research partner, inclusion of a co-produced activity, (creation of a patient feedback tool with both patients and psychiatrists) and construction of seven inter-related research cycles, this research is best conceptualised as a combination of both action research and co-production (Waterman *et al.*, 2001). It draws on the cyclical and practical nature of action research (Reason & Bradbury, 2005) and the emancipatory ethos of co-production (Locock & Boaz, 2019; Williams *et al.*, 2020). While often conflated in existing literature and practice (Kagan, 2013), an overview of co-production and action research is discussed in turn below.

2.5.1 Co-production

Encouraged by recent health policy and legislation, the active involvement of patients and members of the public as equal partners in research is increasing on an international scale (Carr & Patel, 2016; Mjøsund *et al.*, 2017; Rolfe *et al.*, 2018; Staniszewska *et al.*, 2007). Following the seminal work of Arnstein's ladder (1969), patient involvement was previously described as a typology of levels, i.e. consultation, collaboration and user-controlled. However, more recently, INVOLVE, the UK's national advisory group has defined co-production as:

> "*An approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance"* (INVOLVE, 2018, p.5)

Efforts are therefore required "*to redress power differentials"* (INVOLVE, 2018, p.5), reflecting what Maiter et al. (2008) refer to as the ethic of reciprocity (Maiter *et al.*, 2008).

Similar to action research, co-production is considered to be principle driven (INVOLVE, 2019a). Its key principles include:

- The sharing of power
- Including all perspectives and skills
- Respecting and valuing the knowledge of all those working together on the research
- Reciprocity
- Building and maintaining relationships.

2.5.2 Action Research

Often attributed to the work of Kurt Lewin in the 1940's (Greenwood & Levin, 2006; Reason & Bradbury, 2005), action research focuses on practical change and knowledge (Greenwood, Whyte & Harkavy, 1993; MacDonald, 2012; McNiff & Whitehead, 2011). Described as a family of approaches (McNiff & Whitehead, 2011; Reason & Bradbury, 2005) that seeks to "*involve, empower and improve"* aspects of an individual's world (Koshy, Koshy & Waterman, 2010), a multitude of terms have been used interchangeably to describe action research including participation research, participatory action research, community-based study, co-operative enquiry, action science, action learning, social action research, empowerment evaluation, community engaged research and community-based participatory research. This has caused much confusion in its application and implementation (Kidd *et al.*, 2018; Koshy, Koshy & Waterman, 2010; Minkler, 2000; Waterman *et al.*, 2001).

However, sharing many similarities with the definition of co-production identified above, a recent systematic review by Jagosh defined action research (AR) as:

> "*The co-construction of research between researchers and people affected by the issues under study, e.g. patients, community members, healthcare professionals and/or decision makers"* (Jagosh et al., 2012, p.311)

Action research is therefore considered to be:

> "*Problem focused, context specific and future orientated… with an explicit critical value basis founded on a partnership between action researchers and participants, all of whom are involved in the change process"* (Waterman *et al.*, 2001, p.iii)

As such, action research is often depicted as a cyclical process (Koshy, Koshy & Waterman, 2010), involving exploration, identification, analysis, reflecting, acting and reporting. While helpful in facilitating understanding, the cyclical pattern of AR is often iterative, fluid and responsive (Koshy, Koshy &

Waterman, 2010), making it difficult to present in written reports (Waterman *et al.*, 2001).

2.5.3 How do co-production and action research differ to traditional research?

Although similar, it is important to consider how co-production and AR differ to other research methodologies. Firstly, in co-production and AR, research is carried out *with* or *by* patients and members of the public as opposed *to, about,* or *for them* (INVOLVE, 2018; Smith *et al.*, 2010). While this may be considered to be an issue of semantics, the difference in meaning is substantial (Baines & Regan de Bere, 2018). Secondly, co-production and AR methodologies are organised around a process of action and change, inverting the traditional research agenda of generating knowledge that then becomes actioned through knowledge exchange (Kidd *et al.*, 2018). Thirdly, co-production and AR typically present knowledge in the form of personal experience narratives, giving voice to those who have historically, politically and culturally been silenced by conventional structures of social inquiry (Winter & Munn-Giddings, 2001). By doing so, these methodologies seek to share power by privileging local voices, cultures and wisdom throughout the research process, as opposed to reproducing worldviews that privilege the dominant and the powerful (Baum, MacDougall & Smith, 2006; Kidd *et al.*, 2018; Smith *et al.*, 2010; Waterman *et al.*, 2001). Within AR and co-production, the researcher is also often conceptualised as a facilitator, as opposed to expert, contrasting with the privileged position of observer as previously outlined in the positivist paradigm (Kidd *et al.*, 2018; Stringer, 2007). Finally, co-production and AR embrace emancipatory and a social justice agenda (Baum, MacDougall & Smith, 2006), highlighting a key difference in the location of power (Cornwall & Jewkes, 1995;

Smith *et al.*, 2010). As such, AR is often considered to be a "*critique, or challenge to dominant positivist social science research as the only legitimate and valid source of knowledge"* (Maguire, 1987, p.10).

2.5.4 Justification for chosen methodology

Justification for choosing a dialectic methodology in the form of co-production and AR stems from their ability to:

1. Facilitate empowerment (Gillard *et al.*, 2010; Gillard *et al.*, 2012; Kagan, 2013; MacDonald, 2012; Winter & Munn-Giddings, 2001), emancipation (Reason & Bradbury, 2005; Tangvald-Pedersen & Bongaardt, 2017) and democratisation by equalising scientific rigour, clinical and patient expertise (Baum, MacDougall & Smith, 2006; Smith *et al.*, 2010; Waterman *et al.*, 2001)
2. Enhance research quality by ensuring research relevance and appropriateness (Cornwall & Jewkes, 1995; Jagosh *et al.*, 2012; Kagan, 2013; Locock & Boaz, 2019; Staniszewska *et al.*, 2007)
3. Increase the quality and richness of data collection and analysis (Gillard *et al.*, 2012; Greenwood & Levin, 2006; Jagosh *et al.*, 2012; Locock *et al.*, 2019; Mjøsund *et al.*, 2017; Reason & Bradbury, 2005)
4. Generate capacity, skills, confidence and competence among communities (Jagosh *et al.*, 2012; Kagan, 2013)
5. Facilitate recruitment rates (Boardman, 2018; Jagosh *et al.*, 2012)
6. Strengthen academic-community relationships (Jagosh *et al.*, 2012)
7. Enhance research sustainability and likelihood of outcomes being successfully implemented (Cornwall & Jewkes, 1995; Jagosh *et al.*, 2012; Pizzo *et al.*, 2015)

8. Provide an opportunity to stimulate the development of alternative ideas and innovative approaches (Alderson *et al.*, 2019; Kagan, 2013; Pizzo *et al.*, 2015; Staniszewska *et al.*, 2007)

Other justifications for the adoption of co-production and AR include their ability to facilitate an active, as opposed to passive role for individuals who have historically been marginalised (Brydon-Miller, 1997) or ‘othered’ (Beresford, 2013; Holt *et al.*, 2019; Robert *et al.*, 2015; Rycroft-Malone *et al.*, 2016). The disruption to the historical practice or assumption that the observer (often a researcher or clinician) knows best is also a desirable outcome of co-production and AR (Haywood *et al.*, 2015; Kidd *et al.*, 2018; Trujols *et al.*, 2013), as is their response to increasing calls for meaningful involvement (Biringer *et al.*, 2017; Tangvald-Pedersen & Bongaardt, 2017), particularly in a mental health setting (Baum, MacDougall & Smith, 2006; Eiring *et al.*, 2015; Kidd *et al.*, 2018; Lambert & Carr, 2018). As suggested by Cornwall & Jewkes, conventional researchers:

> “*Are coming to realise that working with the voiceless is infinitely more rewarding than working on them”* (Cornwall & Jewkes, 1995, p.1674)

2.5.5 Limitations and difficulties of AR and co-production

While the benefits of co-production and AR are well documented, their limitations, complexities and ‘messiness’ (Baum, MacDougall & Smith, 2006) must also be acknowledged (Cornwall & Jewkes, 1995; Lambert & Carr, 2018; Waterman *et al.*, 2001). For researchers who are used to defining and controlling research, “*co-production can be both intimidating and liberating”* (Kagan, 2013, p.4). Similarly, AR can leave researchers “*feeling exposed and rudderless”* (Smith et al., 2010, p.407). Both methodologies are complex, time consuming and require a shift in existing relationships and practices (Cornwall &

Jewkes, 1995; MacDonald, 2012; Mathie *et al.*, 2020; Mathie *et al.*, 2017). For example, research that actively involves patients and/or members of the public can be significantly limited by institutional control, including the maintenance of professional or service power (Boylan *et al.*, 2019; Lambert & Carr, 2018; Locock *et al.*, 2017; Stickley, 2006). Traditional rules and roles can inhibit the way researchers work equally and collaboratively with patients and members of the public, undermining best practice. Furthermore, the way researchers are traditionally trained can make it hard for them to relinquish control and embrace 'other', or 'local' knowledge as their knowledge is typically seen as 'superior' in training models (Cornwall & Jewkes, 1995). As stated by Smith et al., in order to be successful, researchers working within a dialectical methodology such as AR and co-production:

> "*Must be committed to working outside the ivory tower mind-set that privileges certain kinds of knowledge and experience…it requires a willingness to follow unexpected paths as they emerge"* (Smith et al., 2010, p.415)

Finally, affiliations with a university can be problematic (Smith et al., 2010). Community members may be highly sceptical of whether it is worth investing their time and energy into a project (Cornwall & Jewkes, 1995), making recruitment and sustained recruitment difficult at times. The complex relationship between communities and university researchers must therefore be navigated carefully and sensitively.

2.6 Methods

Linked to the information above, this research uses primarily qualitative methods in the form of focus groups, semi-structured and think aloud interviews (Van Someren, Barnard & Sandberg, 1994; Willis, 2004). Such methods have been identified as particularly useful when exploring human experiences, beliefs and attitudes (Staniszewska & Henderson, 2004; Willig, 2013), providing invaluable

> “*Access to people’s ideas, thoughts and memories in their own words, rather than the words of the researcher”* (Reinharz & Davidman, 1992, p.19)

As a result, qualitative methods are often considered to provide richer insights into complex social processes and experiences (Waterman *et al.*, 2001) than those achieved by quantitative methods which typically seek to predict and control (Edwards & Staniszewska, 2000). Qualitative methods have also been identified as particularly useful when the topic at hand, such as the exploration of patient feedback tools from both a patient and professional perspective or definition of psychiatric care experience is relatively unknown or under-explored (Edwards & Staniszewska, 2000). Furthermore, previous research considers the use of qualitative methods as essential (Corstens *et al.*, 2014) in understanding the meaning of patient care and experience from a patient’s perspective (Gilburt, Rose & Slade, 2008; Gunasekara, Patterson & Scott, 2017; Trujols *et al.*, 2013). Further justification for the use of qualitative methods, their strengths and limitations and relevance to this research are provided in the write up of each research cycle to avoid repetition.

2.6.1 Rigour in qualitative research

Finally, evaluation of rigour in qualitative research has traditionally drawn on terms associated with a positivist paradigm (Noble & Smith, 2015). As a result, qualitative research is often criticised for failing to demonstrate sufficient rigor, or integrity (Mays & Pope, 2000; Seale & Silverman, 1997). However, such criticisms often arise when qualitative research is evaluated using the same criteria as that applied to quantitative research (Krefting, 1991; Shenton, 2004). As a result, Lincoln and Guba provide an alternative approach to establishing trustworthiness as opposed to rigour in qualitative research that parallels those of the conventional positivist paradigm: credibility (in preference to internal validity), transferability (in preference to external validity), dependability, (in preference to reliability) and confirmability (in preference to objectivity) (Guba & Lincoln, 1989). Table 3 outlines each of these criteria, their relationship to a positivist paradigm and the steps taken to ensure trustworthiness within this thesis.

Table 3 Trustworthiness criteria as proposed by Guba and Lincoln (1989)

Positivist criteria	Trustworthiness criteria	Trustworthiness criteria met in this study
Internal validity	Credibility - Prolonged engagement - Persistent observation - Triangulation - Peer debriefing - Negative case analysis - Member checks	Triangulation - Method triangulation, source triangulation and analyst triangulation (through involvement of patient research partner in analysis process, involvement of both patients and psychiatrists, comparison of patient and psychiatrist research findings and use of focus groups, semi-structured and think aloud interviews) Peer debriefing - Review of data collection, analysis and reporting through supervision and patient research partner - Sharing of research findings with Royal College of Psychiatrists and community groups Negative case analysis - Identification and sharing of experiences in research write up that contrasted against majority views Member checks - Copy of transcript sent to participant's to ensure accuracy and intended meaning - Sharing of final report with community groups - Clarifying questions and probes asked
External validity	Transferability - Thick descriptive data	Dense description of research method and context - Provision of verbatim quotes
Reliability	Dependability - Audit trail of process	- Maintaining accurate records of data management and collection
Objectivity	Confirmability - Audit of product	- Acknowledgement of study's limitation in discussion

2.7 Ethics

This research received ethical and regulatory approval from the University of Plymouth Health and Human Sciences Research Ethics Committee (reference number- 17/18-846, 08/11/2017) and the Health Research Authority (reference number -17/YH/0353) (Appendix 2,3,4 & 22).

2.8 Summary

In conclusion, this research is grounded in a critical paradigm, draws on a historical realism ontology, subjective epistemology and dialectic methodology in the form of co-production and action research, using primarily qualitative methods. This research is best conceptualised as combination of action research and co-production given its cyclical nature, process of action and change, co-produced activity and co-production with a mental health patient research partner. Justification for these selections stems from acknowledged methodological limitations in existing research and the importance of including marginalised voices in research (Beresford, 2013; Holt *et al.*, 2019; Rycroft-Malone *et al.*, 2016). The setting, recruitment, sample size, inclusion/exclusion criteria and analysis technique used for each research cycle is provided in their corresponding chapters beginning with cycle one below - a systematic review exploring the presence of patient and public involvement in the design, delivery and evaluation of patient feedback tools for practising psychiatrists.

3.0 Cycle 1 - How, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists?

3.1 Introduction

The exclusion of patients in the design, delivery and evaluation of patient feedback tools has been repeatedly identified as problematic (Boardman, 2018; Zendjidjian *et al.*, 2015a). Despite reported disparities between doctor and patient perspectives (Crawford *et al.*, 2011; Farrelly & Lester, 2014; Trujols *et al.*, 2013), many existing patient feedback tools appear to rely on the assumption that they include the behaviours and domains of care quality considered to be of most importance from a patient perspective (Boardman, 2018; Edwards & Staniszewska, 2000; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a). However, critical examination of this belief is severely limited (Biringer *et al.*, 2017; Boardman, 2018; Crawford *et al.*, 2011; Trujols *et al.*, 2013), as is the extent to which patients are involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists (Barbato *et al.*, 2014; Bjertnaes, Iversen & Kjollesdal, 2015; Delaney, Johnson & Fogg, 2015).

This research cycle therefore sought to explore how, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists. If found to be rarely involved, more collaborative ways of designing patient feedback tools could be explored.

The systematic review undertaken as part of this research thesis has been published in the *Journal of Health Services Research* and can be found here (Baines *et al.*, 2018a).

3.2 Methods

A systematic review was conducted to collate and organise existing literature. The researcher acknowledges that reviews typically prioritise the knowledge shared and created by academics and healthcare professionals in peer-reviewed literature. In order to address this issue, grey literature was also included as later explained. Furthermore, at his request, the patient research partner was involved throughout the analysis process providing additional insight and expertise.

To ensure the review was undertaken with sufficient rigour, the review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram (Moher *et al.*, 2009) and guidance set out by the Centre for Reviews and Dissemination (Khan *et al.*, 2001). The review's protocol was also published on the PROSPERO register (Registration number CRD42016050533).

3.2.1 Search strategy

Peer-reviewed literature

Search terms listed in Table 4 were designed and reviewed using the Peer Review of Electronic Search Strategies (PRESS) guidance (Sampson *et al.*, 2009), a set of recommendations concerning the information that should be used to evaluate electronic search strategies. A scoping exercise revealed the need to produce an extensive list of patient synonyms to remain sensitive to different contexts (Table 4). As advised by an information specialist, agreed search terms were used to systematically search: MEDLINE; PubMed; PsycINFO; Embase, CINAHL and Cochrane Library databases. Database searches were also supplemented by reference list searches of included studies.

Grey literature

Grey literature, defined as ‘that which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers ’(GreyNet, 1999), was also searched using Google to ensure sufficient coverage beyond peer-reviewed literature. Screening was limited to the first 10 pages in order to maintain a manageable sample size.

Table 4 Search term strategy

Setting: Psychiat* OR inpatient OR mental health NOT child

AND

Perspective: Patient* OR user* OR “service user” OR service-user OR client OR consumer OR survivor* OR representative* OR citizen OR family OR relative* OR carer*

AND

Intervention: “multisource feedback” OR “multi-source feedback” OR “360 degree feedback” OR “360 degree evaluation” OR MSF OR “performance feedback” OR “patient feedback” OR “patient experience” OR “patient survey” OR “patient questionnaire” OR “online feedback”

AND

Evaluation: “professional development” OR regulation OR behaviour OR attitude OR change OR improve OR quality of care OR learn OR reflect OR impact OR outcome OR “patient safety”

3.2.2 Inclusion criteria

Articles were reviewed independently by the researcher and patient research partner using a two-stage process. Firstly, the title and abstracts of all identified articles were screened using a pre-defined inclusion criteria form created by both the patient research partner and researcher (Table 5). Rayyan, a web application for systematic reviews was used by the researcher to facilitate this process (Mourad Ouzzani *et al.*, 2016). Abstracts of identified articles were provided in paper form for the research partner. If a decision could not be made during this first stage, the full article was retrieved. Full texts of identified articles were then reviewed for inclusion. Discrepancies would have been resolved with reference to a third reviewer although this process was not required.

To develop a manageable focus, studies: not in the English Language, published prior to 2007; with a specific focus of child, Dementia/Alzheimer's disease or learning difficulties were excluded as these areas are likely to require tailored patient feedback activities beyond the focus of this thesis and review. All study designs with the exception of opinion pieces, commentaries or letters were included. The date parameters of 2007-2017 were selected to ensure only the most contemporary information was included. Similarly, only English language studies were included as an accurate translation could not be provided due to resource constraints.

For clarity, due to the focus of this research, articles that described the experience or evaluation of a mental health service only and not that of an individual psychiatrist were excluded. Inclusion decisions are documented in Figure 3 and Figure 4 for purposes of transparency.

Table 5 Inclusion criteria form

Is the study published between 2007 and 2017?	
Yes (proceed)	No (reject)
Is the study available in English?	
Yes (proceed)	No (reject)
Does the study talk about the experience, design and/or use of patient feedback for a practising psychiatrist?	
Yes (proceed)	No (reject)
Does the study solely focus on psychiatric care associated with children/dementia/Alzheimer’s or learning difficulties?	
Yes (reject)	No (include)

3.2.3 Data analysis and synthesis

Data was analysed using inductive thematic analysis as outlined by Braun and Clarke (Braun & Clarke, 2006) and synthesised using critical interpretative synthesis (CIS) (Dixon-Woods *et al.*, 2006; Gysels, Evans & Higginson, 2012). Data analysis was supported through the use of Nvivo 11 software (NVivo 11, 2012) with copies of included articles being provided in paper form for the patient research partner. A comprehensive coding framework was developed by both the patient research partner and researcher during two of our regular meetings. This was achieved by the patient research partner and researcher through the repeated readings of two included articles to ensure content familiarity, independent marking of initial thoughts and ideas in the right hand margins of the printed articles and independent transformation of these ideas into broader overarching themes in the left hand margin. Once completed, the patient research partner and researcher discussed and compared their initial thoughts, themes and theme definitions. Through this process we created a coding framework that was then used by the researcher to individually analyse and compare emerging themes across included studies. At his request, the patient research partner analysed five included articles to check for coding accuracy and understanding. The number of articles coded by the patient research partner was decided by himself based on his availability and comfort level. The importance of not overwhelming patient research partners has been identified in existing literature (Locock *et al.*, 2019). Identified themes were then synthesised by the researcher using CIS as outlined below.

CIS is an adaptation of meta-ethnography and borrows techniques from Grounded Theory (Glaser, 2017). It was selected as the synthesis methodology for this review due to its ability to integrate both qualitative and quantitative evidence (Flemming, 2010). CIS incorporates conventional systematic review methodology with traditional techniques of qualitative enquiry enabling the generation of new perspectives and theories through the critical interrogation of existing contradictions, flaws and assumptions. Essentially, CIS seeks to problematise existing literature. One of its defining features is its ability to generate synthetic constructs, a third order construct, the result of transforming underlying evidence into new conceptual forms and synthesising argument(s) (Dixon-Woods *et al.*, 2006). As Dixon-Woods explains: "*this argument integrates evidence… into a coherent theoretical framework… to provide more insightful, formalised and generalisable ways of understanding a phenomenon*" (Dixon-Woods *et al.*, 2006). The CIS stages outlined by Flemming were followed for the purposes of this review (Flemming, 2010), with any identified flaws, assumptions and contradictions used to structure the reviews discussion.

3.2.4 Quality assessment

Finally, Buckley et al's criteria (Buckley *et al.*, 2009) were used to quality appraise included peer-reviewed studies by both the patient research partner and research (this was completed during one of our regular meetings). In line with previous research (Tai *et al.*, 2016), studies scoring seven or above were considered to be high quality. Sensitivity analyses, a form of analysis that tests for the effect on conclusions drawn when lower quality studies are excluded, were also conducted by the researcher. Such analyses are considered important in any qualitative synthesis warranting their inclusion (Thomas & Harden, 2008). Consistent with the synthesis method chosen, conceptual relevance took precedence over methodological rigour (Dixon-Woods *et al.*, 2006).

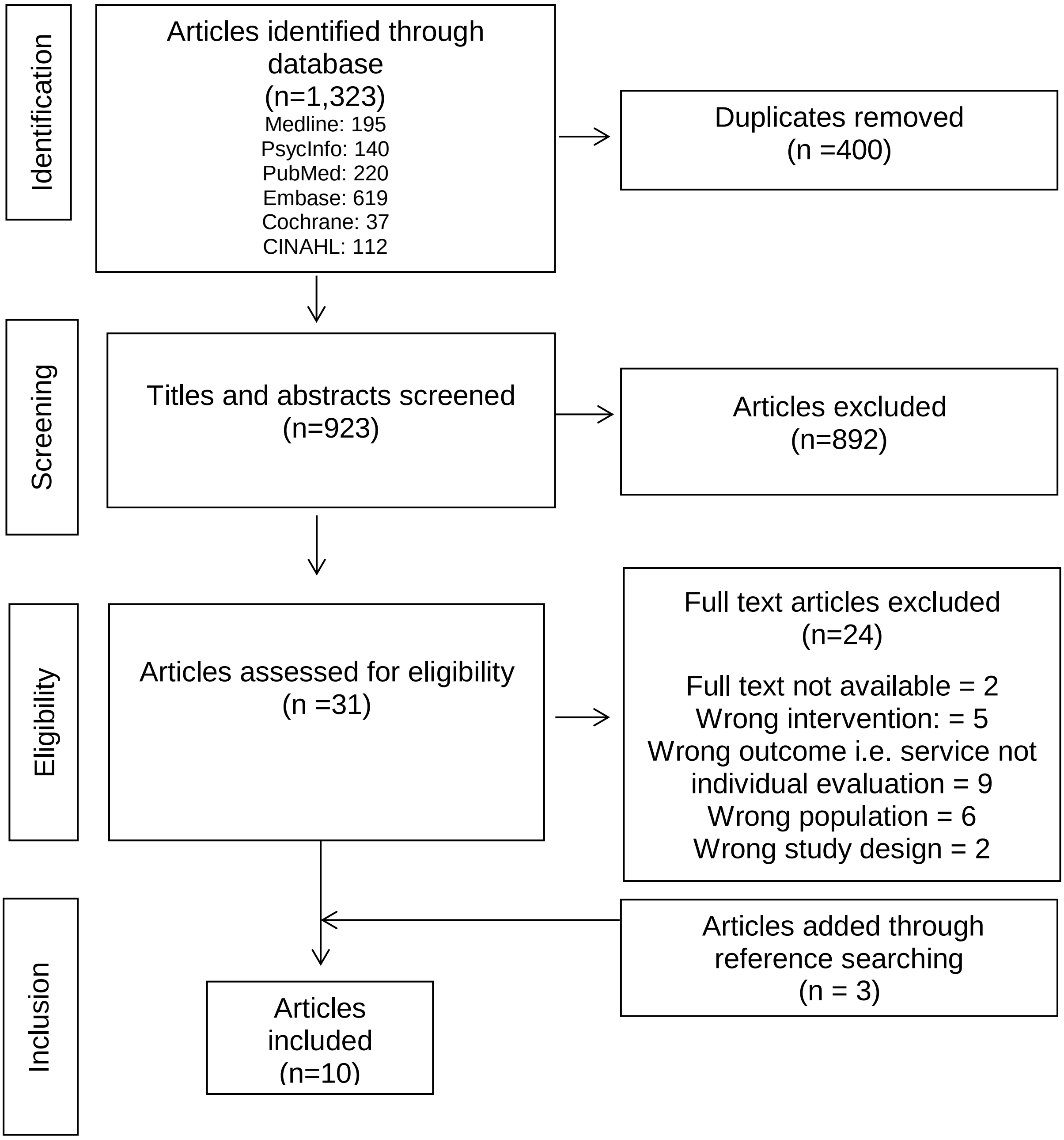


Figure 3 PRISMA peer review inclusion process

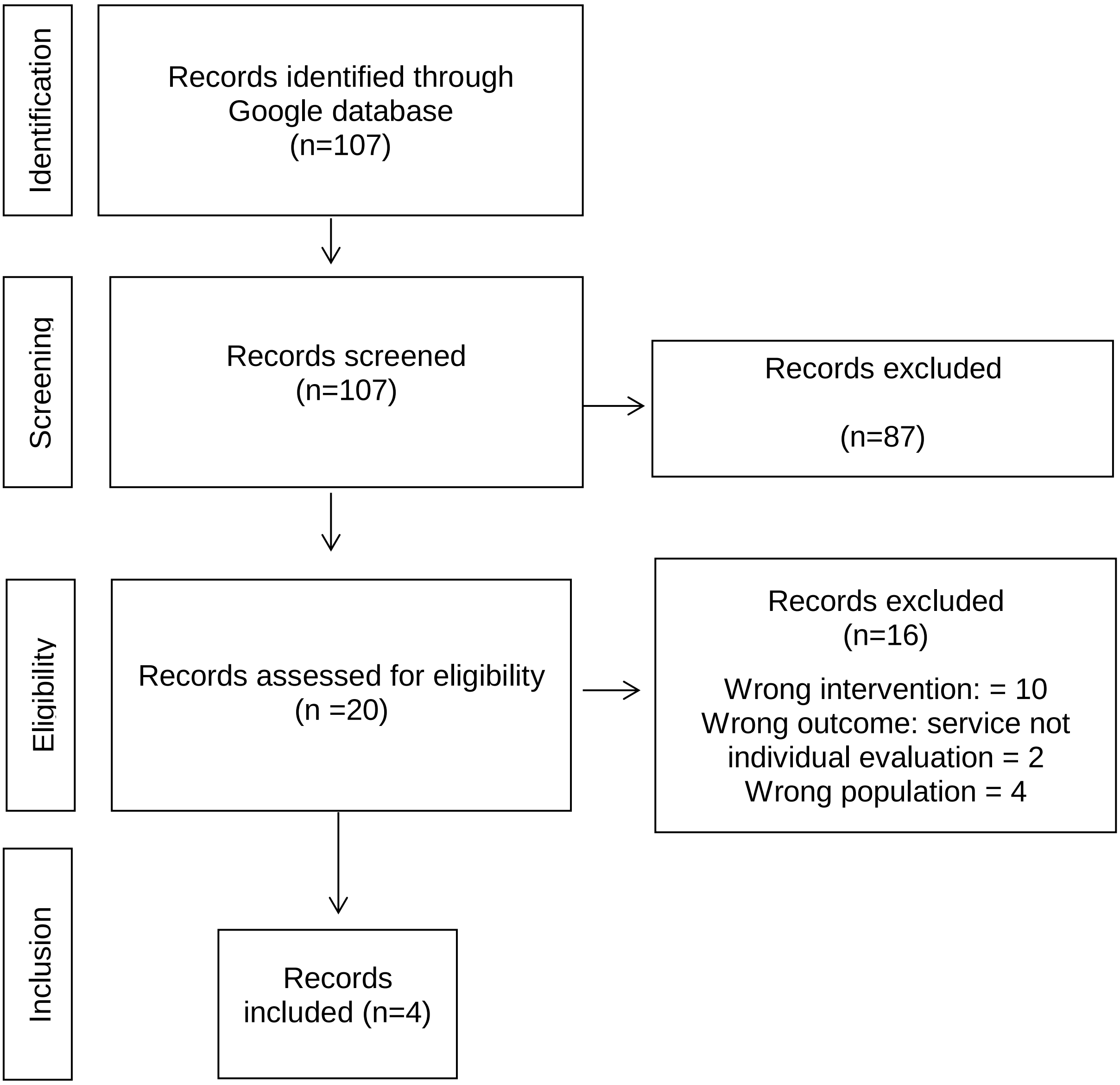


Figure 4 PRISMA grey literature inclusion process

3.3 Results

3.3.1 Study characteristics

Fourteen articles discussing a total of nine patient feedback tools were included. Ten from the peer-reviewed literature (Figure 3) and four from the grey literature (Figure 4). Academic publications were primarily published in the UK (n=5) with articles also published in Canada, Sweden, US, Italy and France. Characteristics of included studies are presented in Table 6.

Study quality

As shown in Table 6, six of the peer-reviewed articles were appraised as high quality. Sensitivity analyses indicated that the exclusion of studies assessed as low quality (i.e. appraisal score of below seven), had no effect on the conclusions drawn. All studies were therefore included to be inclusive of the available literature.

Review findings are presented in the following order: patient involvement in the i) design ii) administration and iii) evaluation of patient feedback tools for practising psychiatrists.

Table 6 Included study characteristics

Author	Study Location	Study population	Intervention	Setting	Design perspective	Assessment areas	No. of items	Scale used	Quality Appraisal* score
Peer-reviewed literature									
Schroder et al. 2007 (Schröder, Wilde Larsson & Ahlström, 2007)	Sweden	116 patients	Quality in psychiatric care (QPC)	In-patient psychiatry	Patient with limited professional involvement – patient interviews	Patient dignity and respect, security, participation, recovery and environment	69	4 item Likert scale (1= totally disagree, 4 = totally agree). Not applicable option.	8
Violato et al. 2008 (Violato, Lockyer & Fidler, 2008b)	Canada	101 psychiatrists, 2,456 patients	CPSA-PAR	Psychiatry	Professional - working group inclusive of psychiatrists and other physician specialists. No patient involvement discussed	Medical knowledge and skills, attitudes and behaviour, professional responsibilities, practice improvement activities, administrative skills and personal health	40	5 point rating scale (1= strongly disagree, 5 = strongly agree). Unable to assess option.	9
Campbell et al. 2008 (Campbell *et al.*, 2008a)	UK	13,754 patients, 380 participant doctors	GMC patient and colleague questionnaire	Doctor performance including psychiatry	Professional - authoritative guidelines	Good Medical Practice	18	5 point Likert scale (1= poor, 5 = very good or 1=strongly disagree, 5 = strongly agree) and two binary responses (yes/no)	6
Lelliot et al. 2008 (Lelliott *et al.*, 2008)	UK	347 consultant psychiatrists, 6657 patients	ACP 360	Psychiatry	Professional – interviews with 24 specialist mental health care workers only	Communication, availability, emotional intelligence, decision making, relationship with patients, relationships with patients' relatives, partners and carers	17	Six point scale, (1=very low, 6 = excellent)	7
Mason et al. 2009 (Mason *et al.*, 2009)	UK	554 consultants with over 16,000 replies	360 degree appraisal	Doctor performance including psychiatry	Professional and existing literature	Respect and consideration, involvement, clarity of communication, carer/family	5	Four point scale (1=poor, 4 = very good). Unable to comment option	5

						involvement, information provision			
Stewart et al. 2010 (Stewart *et al.*, 2010)	US	149 pre-implementation and 137 post implementation surveys	PSQ-18	Psychiatric out-patients	Professional and existing literature	“General satisfaction”, “technical quality”, “interpersonal manner”, “communication”, “time spent with doctor”, “anxiety”, “computer use” and “confidentiality”	23	Five point Likert scale, (1 = strongly agree, 5 = strongly disagree)	8
Campbell et al. 2011 (Campbell *et al.*, 2011)	UK	1065 doctors, 30,333 patients	GMC patient questionnaire	Doctor performance including psychiatrists	Professional - authoritative guidelines	Good Medical Practice	9	Five point Likert scale, (1=poor, 5 = strongly agree). Not applicable or don’t know option available	7
Laughrane & Pant 2012 (Laugharne & Pant, 2012)	UK	7,500+ patient surveys	Care Quality Commission in-patient survey	In-patient satisfaction with psychiatrists	Not discussed	Listening abilities, time, confidence and trust, respect and dignity	4 items of interest	Not discussed	6
Barbato et al. 2014 (Barbato *et al.*, 2014)	Italy	204 people with severe mental disorders	Quality assessment of mental health care by people with severe mental disorders	Public agency providing mental health care in Tuscany	Literature review and patient – review of evaluation tools then discussed and developed by consumer focus groups (n=204)	Relations with the professional (behaviour, accessibility, competence), interventions received, environment and facilities, shared decision making, organization aspects, waiting time on the phone, home visits and help in an emergency	45	5 point Likert scale associated with smiles (1= very positive, 6 – very negative)and yes/no responses	5
Zendjidjian et al. 2015 (Zendjidjian *et al.*, 2015b)	France	270 responders	SATISPSY - 22	Psychiatry	Patient with limited professional involvement – 80 interviews with 80 hospitalized psychiatric patients. Professional steering committee	Staff, quality of care, personal experience, information, activity and food	22	5 point Likert scale (1 = extremely less than expected, 5 = better than expected)	8

Grey Literature									
Royal College of Psychiatrists, 2011 (Royal College of Psychiatrists, 2011)	UK	N/A	ACP 360	Psychiatry	Professional – interviews with 24 specialist mental healthcare workers only	Communication, availability, emotional intelligence, decision making, relationship with patients, relationships with patients' relatives, partners and carers	17	Six point scale, (1=very low, 6 = excellent)	-
Royal College of Psychiatrists, 2014 (Royal College of Psychiatrists, 2014)	UK	N/A	ACP 360/GMC	Psychiatry	Professional	Good Medical Practice	Not discussed	Not discussed	-
Academy of Medical Royal Colleges, (Academy of Medical Royal Colleges)	UK	N/A	Patient feedback	Doctor performance including psychiatry	Professional – authoritative guidelines, Good Medical Practice	Good Medical Practice	Not discussed	Not discussed	-
Royal College of Psychiatrists, 2017 (Royal College of Psychiatrists, 2017b)	UK	N/A	ACP 360	Psychiatry	Professional	Good Medical Practice	15	Six point scale, (1=very low, 6 = very high)	-

* Quality appraisal score out of 11: 7 or above indicates high quality.

3.3.2 Patient and Public Involvement in feedback design

Design perspective

Six of the nine tools reviewed were designed from a professional perspective only (Academy of Medical Royal Colleges; Campbell *et al.*, 2008b; Campbell *et al.*, 2011; Lelliott *et al.*, 2008; Mason *et al.*, 2009; Royal College of Psychiatrists, 2011; Royal College of Psychiatrists, 2014; Royal College of Psychiatrists, 2017a; Stewart *et al.*, 2010; Violato, Lockyer & Fidler, 2008b). For example, the ACP 360, the tool currently used by the Royal College of Psychiatrists to revalidate psychiatrists in the UK advertises itself as *"the only tool designed and validated for psychiatrists, by psychiatrists*" (Royal College of Psychiatrists, 2017a). Professional perspectives were often obtained through professional steering or working groups and pre-defined authoritative guidelines, such as Good Medical Practice (Campbell *et al.*, 2008b). One tool was designed from a combination of patient and professional perspectives (Barbato *et al.*, 2014). Two tools reviewed were designed from the patient perspective with minimal professional input (Table 6) (Schröder, Wilde Larsson & Ahlström, 2007; Zendjidjian *et al.*, 2015b).

Tool content

Where reported, the generation of tool content was dominated by professional input (n=3/5) (Campbell *et al.*, 2008b; Lelliott *et al.*, 2008; Violato, Lockyer & Fidler, 2008b). Authors of one article stated only criteria: "…*the regulatory authority and the physicians themselves believed to be important*" were included (Violato, Lockyer & Fidler, 2008b, p.529).

In most instances, professional opinion and authoritative guidelines were used as a proxy measure for the patient voice.

However, this was not the case in two instances (Schröder, Wilde Larsson & Ahlström, 2007; Zendjidjian *et al.*, 2015b). Following interviews with 20 patients of whom 17 had in-patient psychiatric care experience, five descriptive categories of care quality were developed: patient dignity and respect; a patient's sense of security e.g. trust; patient participation in care; patient recovery, e.g. supportive guidance, opportunities for post-care follow-up and care environment, e.g. personal space and aesthetics (Schröder, Wilde Larsson & Ahlström, 2007). Another study used face-to-face semi-structured interviews with 80 in-patients with various diagnoses including, schizophrenia, bipolar, mental and behavioural disorders due to psychoactive substance use (Zendjidjian *et al.*, 2015b). Patient interview data was then used to determine question design and response scales.

However, while often described as patient generated, the categorisation or analysis of suggested content appeared to be at the professionals' discretion (Lelliott *et al.*, 2008; Zendjidjian *et al.*, 2015b). No articles reported analysis of data in collaboration with patients and/or members of the public. The content of a patient feedback tool therefore appeared to be another area in which professional opinion typically superseded patient contributions.

Finally, the number of domains covered in patient feedback tools varied from four (Laugharne & Pant, 2012) to eight (Zendjidjian *et al.*, 2015b). The number of questions asked to assess these domains also varied (n=5-69). No papers reported patient involvement in discussions around the number of domains or questions asked. No rationale for the variability of included questions and domains was identified.

Question design

Patient involvement in the formatting of proposed questions was mixed. Where drawn upon, patient involvement was favourably described (Barbato *et al.*, 2014). For example, Barbato et al. acknowledged how involving patients prompted the importance of a more direct and friendly style of questioning, e.g. ‘do you get on well with your psychiatrist?’ (Barbato *et al.*, 2014). When not involved, authors reported high ‘unable to rate’ responses (Lelliott *et al.*, 2008) and patient response confusion (Campbell *et al.*, 2008b). For example, despite being tested for “*face validity and feasibility by eight consultants and their colleagues only….”* one of the acknowledged limitations of Lelliot et al.’s tool was the *“substantial number of patients unable to rate some items”* (Lelliott *et al.*, 2008). Campbell et al. also identified one item that caused some patient confusion (Campbell *et al.*, 2008b). When responding to the statement ‘I have no reservation about seeing this doctor again’, 87 respondents altered their initial binary response (yes or no), following a misunderstanding or misreading of the question (Campbell *et al.*, 2008b). This statement (related to reservation) also had a substantially higher proportion of adverse ratings in comparison to other questions asked (Campbell *et al.*, 2008b). Such confusion may be attributed to a lack of patient involvement in the design of feedback questions.

Response scales

Response scales were defined by patients in two cases (Barbato *et al.*, 2014; Zendjidjian *et al.*, 2015b). Following patient suggestions, Barbato et al. used smileys in conjunction with a five point Likert scale (very positive-very negative) (Barbato *et al.*, 2014) and Zendjidjian adopted the language used by patients in preceding interviews as the response scale modalities for a five point Likert scale, i.e. extremely less than expected – better than expected to facilitate patient understanding (Zendjidjian *et al.*, 2015b). No other articles discussed the decision process of response scale agreement in collaboration with patients or members of the public.

3.3.3 *Patient and public involvement in feedback administration*

One article directly involved patients in the administration of a patient feedback tool (Barbato *et al.*, 2014). Barbato et al. employed six patients to administer the questionnaire, offer assistance if required and collect completed tools. Professional involvement in this process was deliberately kept to a minimum to limit possible conformity and social desirability bias (Barbato *et al.*, 2014). The low refusal rate of 12% and enhanced patient representation achieved was directly attributed to patient involvement by the article's authors (Barbato *et al.*, 2014).

3.3.4 *Patient and public involvement in feedback evaluation*

Piloting

In regard to evaluation, four articles reportedly involved patients in the piloting of proposed tools (Mason *et al.*, 2009; Schröder, Wilde Larsson & Ahlström, 2007; Stewart *et al.*, 2010; Zendjidjian *et al.*, 2015b). In one instance, six patients recruited through a local patients' association with experience of psychiatric care were asked to complete the proposed questionnaire at home and then evaluate it using a piloted checklist (Schröder, Wilde Larsson & Ahlström, 2007). Participants were required to assess each tool item in terms of: importance in care quality (1=very important, 5=of little importance); clarity, e.g. clear and easy to understand, acceptable or unclear and hard to understand; general structure, relevance and usefulness (Schröder, Wilde Larsson & Ahlström, 2007). Participant evaluations were then discussed with researchers either face-to-face or by phone, leading to the exclusion of 58 items due to perceived importance (n=10); emotionally charged or overlapping content (n=20) and small levels of perceived importance (n=28). Two other included articles also reported the reduction of question items and re-wording of questions to facilitate understanding, following patient involvement in the piloting stage (Mason *et al.*, 2009; Stewart *et al.*, 2010).

However, in most cases, the piloting of tools was assessed by the profession with *"their patients"* (Lelliott *et al.*, 2008, p.157) as passive recipients. For example, tool appropriateness was assessed by allowing:

> "*Every physician to be assessed to review the questionnaires and provide feedback that was incorporated into the final*" version (Violato, Lockyer & Fidler, 2008b, p.256)

Two reviewed tools reported the use of informal feedback by participating doctors only (Campbell *et al.*, 2008b).

Validation

With the exception of one tool not yet validated (Stewart *et al.*, 2010), the psychometric properties of a patient feedback tool were often used to determine all aspects of validity and acceptability. For example, as stated by Campbell et al.,:

> "*Analysis of psychometric properties showed that both surveys were acceptable to patients and colleagues*" (Campbell *et al.*, 2008b, p.192).

Tool acceptability was also assessed through the examination of patient participation and levels of missing data (n=5/8) (Campbell *et al.*, 2008b; Lelliott *et al.*, 2008; Violato, Lockyer & Fidler, 2008b; Zendjidjian *et al.*, 2015b):

> "*The high rate of return from patients suggests that raters did not find the questionnaire over burdensome*" (Lelliott *et al.*, 2008, p.159)

Patient participation or response omission was therefore used as a default measure for tool acceptability, regardless of the questions ignored or authenticity of responses.

Finally, although large numbers of patients participated in the validation of proposed tools (Campbell *et al.*, 2008b), validation was often passive with limited opportunities to influence change. In some instances, physicians also selected the patients to be involved in the tool's validation introducing possible bias (Lelliott *et al.*, 2008).

3.4 Discussion

This review addressed an identified gap in existing literature by exploring the presence of patient involvement in the design, administration and evaluation of patient feedback tools for practising psychiatrists (Barbato *et al.*, 2014; Bjertnaes, Iversen & Kjollesdal, 2015; Delaney, Johnson & Fogg, 2015). Despite strong policy rhetoric (General Medical Council, 2012), review findings suggest that patients are rarely involved in the design, delivery or evaluation of patient feedback tools for practising psychiatrists. Exploration of more collaborative ways of designing and evaluating patient feedback tools is therefore warranted.

Existing patient feedback tools are predominantly informed by professional opinion alone. Following the five dimensions of involvement identified by Tritter (Tritter, 2009), findings from this review suggest that patients are often passively involved, with limited influence or control over how they are involved, if at all, when they are involved and what happens to their contributions, if anything. However, it is important to note that this is not always the case.

Where patient involvement did occur, it was often favourably described, leading to enhanced patient understanding, representation and lower levels of ‘unable to rate’ responses. Similar outcomes of patient involvement have also been reported in other areas beyond psychiatry (Haywood, Staniszewska & Chapman, 2012; Staniszewska *et al.*, 2014; Staniszewska *et al.*, 2012), providing further support for such conclusions.

3.4.1 Identified flaws

In line with CIS, this discussion considers the potential flaws, assumptions and contradictions that underpin existing patient feedback tools as a result of the limited patient and public involvement identified. Firstly, as reported above, despite a strong policy commitment (Royal College of Psychiatrists, 2014), existing patient feedback tools used to assess the performance of individual psychiatrists as required in revalidation may be undermined by their reliance on professional opinion alone. Such opinions often supersede patient input, with the ability to influence change severely limited. While this may reflect a need for ‘scientific or statistical’ assurances, given previously held assumptions of credible knowledge, the exclusion of patients may also reflect a repeatedly acknowledged power imbalance between patients and the profession and the historic approach to keeping these two communities distinct (Laugharne & Priebe, 2006). By relying on professional opinion alone, existing patient feedback tools may be ignoring domains of care considered to be of most importance from a patient perspective (Eiring *et al.*, 2015; Trujols *et al.*, 2013). Patient understanding also appears to be undermined by a lack of involvement with high rates of confusion and ‘unable to rate responses recorded’. Such findings may challenge the authenticity of feedback provided. Furthermore, a lack of consistent involvement across the different stages of a tool’s development e.g. design, administration and evaluation is concerning, given the previously acknowledged benefits of such involvement (Haywood *et al.*, 2015). Although not always easy to deliver, anticipated difficulties should not be used to deter patient involvement efforts.

3.4.2 Existing assumptions and contradictions

Existing patient feedback tools may also be undermined by three underpinning assumptions. Firstly, some tool developers appear to assume that professional and patient agendas are synonymous. Three articles included in this review demonstrate that this is not the case (Barbato *et al.*, 2014; Boyer *et al.*, 2013; Schröder, Wilde Larsson & Ahlström, 2007). A lack of concordance between patient and psychiatrist desires has been widely reported, as has a lack of commonality between carer, patient and psychiatrist experiences (Barbato *et al.*, 2014). For example, Lelliot et al. acknowledges that colleagues (i.e. professionals) and patients are two independent groups whose perceptions and experiences of consultants are derived from different perspectives (Lelliott *et al.*, 2008). It is therefore imperative, that those responsible for designing existing patient feedback tools do not take the views of one population group to be indicative of the other, i.e. colleague interests to be indicative of patient desires, or vice versa. Secondly, those responsible for evaluating patient feedback tools often assume that psychometric validation, patient participation, or absence of missing data is indicative of patient acceptability. However, some authors conclude that to determine patient acceptability from these measures alone is reductionist and jeopardises tool validity (Schröder, Wilde Larsson & Ahlström, 2007). If patients perceive the content or process of a patient feedback tool to be inappropriate or compromised in anyway, individuals are unlikely to be motivated to complete it, or provide honest results (Gayet-Ageron *et al.*, 2011).

This has important implications for the tools content and response process validity. As stated by Downing et al., (2003) once one validity domain is undermined, so is that tools ability to be used as an equitable form of assessment (Downing, 2003). The current reliance on psychometric validation alone is therefore unfavourable. Alternative measures of acceptability may be required.

Finally, those looking to design and receive completed patient feedback tools sometimes assume that psychiatric patients do not have the capacity or desire to be involved (Goodwin, 1999; Tait & Lester, 2005). This assumption is directly challenged by a number of articles reviewed (Barbato *et al.*, 2014; Boyer *et al.*, 2013; Schröder, Wilde Larsson & Ahlström, 2007; Zendjidjian *et al.*, 2015b). An alternative interpretation to this dominant discourse is that it is the tool and the traditionally exclusive approach to its design, administration and evaluation that lacks the capacity to facilitate meaningful engagement, not the individual patient or healthcare professional. For example, while patients may not have the required capacity at a given point in time, this is unlikely to be true for the entirety of their journey. The opportunity to provide patient feedback should therefore be patient initiated as opposed to policy dicitared or clinician dependent.

3.4.3 Strengths and limitations

Strengths of this review include its rigorous application of accepted guidelines (Khan *et al.*, 2001; Moher *et al.*, 2009), quality appraisal of included studies, inclusion of grey literature and co-production with the patient research partner. However, its limitations must also be acknowledged. Most of the evidence reviewed relied primarily on volunteer samples (Campbell *et al.*, 2008b). Results may not therefore be representative of the wider population. In some cases, doctors also chose the patients to take part in evaluation exercises, introducing possible patient selection and response bias. Furthermore, this review only included articles published in the English language due to previously acknowledged resource limitations. The potential risk of publication bias is therefore also acknowledged. Finally, included articles rarely described the level of patient involvement in sufficient detail. This is an acknowledged limitation of existing literature (Staniszewska & Henderson, 2004). The review and its subsequent conclusions are therefore reliant on the information available at the time of writing.

3.4.4 Implications

With these limitations in mind, the implications for this review are clear. Firstly, it is evident that patients have rarely been involved in the design, administration or evaluation of patient feedback tools for practising psychiatrists, justifying the exploration of more collaborative ways of patient feedback design and evaluation (Berzins *et al.*, 2018; Gunasekara, Patterson & Scott, 2017; Williams, Coyle & Healy, 1998). Secondly, questions must be asked about why patients have been excluded from patient feedback design and evaluation. Is it due to a lack of patient and/or professional willingness? Or uncertainty and lack of familiarity? Thirdly, patient participation, psychometric validation, or absence of missing data should not be used to determine patient acceptability alone. Such processes often provide limited insight into acceptability and value. Finally, in recognition of the absence of patients in the design, administration and evaluation of patient feedback tools for practising psychiatrists, existing patient feedback tools may not include the domains of care considered to be of most importance from a patient perspective. Critical exploration of what constitutes as psychiatric care quality from a patient perspective is therefore required.

3.4.5 Conclusion

In conclusion, while inherently agreed that patient feedback tools should include the patient perspective, existing patient feedback tools largely rely on professional insights only. As a result, existing patient feedback tools may be undermined by a number of identified flaws, assumptions and contradictions, including the belief that professional and patient agendas are synonymous; psychometric validation is indicative of patient acceptability and psychiatric patients do not have the capacity or desire to be involved. Critical exploration of the domains of psychiatric care considered to be of most importance from a patient perspective is required to gain important insight into the relatively unexplored patient perspective (Farrelly & Lester, 2014; Klingaman *et al.*, 2015). The exploration of patient experience reviews forms the central focus of cycle two as outlined below.

4.0 Cycle 2 – What do patients share online about their psychiatric care experiences and how does this compare, if at all, to existing patient feedback tools?

4.1 Introduction

As evidenced above, patients are rarely involved in the design, administration, or evaluation of existing patient feedback tools for practising psychiatrists (Baines *et al.*, 2019b). There is therefore a risk that the domains of care considered to be of most importance from a patient perspective are not included in existing feedback tools (Staniszewska *et al.*, 2012). However, critical exploration of this suggestion and identification of what matters most to patients in a psychiatric interaction is severely limited (Farrelly & Lester, 2014; Klingaman *et al.*, 2015), as is the exploration of professional concerns that patients with a psychiatric condition could leave factually incorrect or malicious comments (Patel *et al.*, 2016).

One way to address these gaps is through the examination of online patient reviews (Emmert & Meier, 2013; Emmert *et al.*, 2014; Patel *et al.*, 2016; Verhoef *et al.*, 2014). Online reviews often enable individuals to construct their healthcare experiences in their own words as opposed to conforming to those already decided for them. By exploring online reviews, a more nuanced understanding of what patients describe and attribute value to in their psychiatric care experiences can be developed, helping to inform the overall aims and research questions of this thesis. If the content of online reviews is found to differ to that used in existing patient feedback tools, further exploration of patient perceptions and experiences may be warranted.

This second research cycle therefore sought to address the following research questions:

1. What do patients share online about their psychiatric care experiences?
2. How does this compare, if at all, to the content used in the two most commonly used patient feedback tools for revalidating psychiatrists?

Findings from this chapter have been published in the *Patient Experience Journal* and can be found here (Baines *et al.*, 2019a).

4.2 Methods

Cycle two used a qualitative observational design to explore the content of psychiatric care reviews on the health and social care review website Care Opinion. Similar to previous research (Griffiths & Leaver, 2018; Locock *et al.*, 2020c), Care Opinion was selected as the database for this research as it is the largest health and social care review website in England. Furthermore, Care Opinion publicly shares all published reviews and can therefore facilitate research of this kind. The focus of a single website such as TripAdvisor, of which Care Opinion shares some similar functions with, has been used in other published research studies (Locock *et al.*, 2020c; Ramsey, Sheard & O'Hara, 2019). However, the researcher acknowledges the limitations of looking at a single, yet extensive database.

To address the second question of this research cycle, the content shared in online reviews was compared with the content used in the two most commonly used patient feedback tools for revalidating psychiatrists - the patient feedback tool provided by the GMC and the ACP 360 tool provided by the Royal College of Psychiatrists.

4.2.1 Search strategy:

All psychiatric care reviews published on the website Care Opinion, from its inception in 2005 to the 12th June 2017, were identified using the following search terms: “mental health” OR “mental illness” OR “mentally ill” OR mental OR psychiatric OR psychiatrist OR psychiatry OR depression OR depressed OR anorexia OR anxiety OR “eating disorder” OR psychosis OR psychotic OR PTSD OR “self-harm” OR bipolar. To ensure relevance, searches were restricted to those tagged by Care Opinion moderators as related to: adult mental illness, addiction services, clinical psychology, eating disorders, forensic psychiatry, old age psychiatry, liaison psychiatry, psychiatric intensive care, primary care mental health, refugee and asylum seeker health, crisis resolution, perinatal psychiatry or psychotherapy. To maximise sensitivity and specificity, search terms were designed in collaboration with the CEO of Care Opinion and volunteer mental health patient research partner as previously described.

4.2.2 Inclusion and exclusion criteria:

Online reviews that discussed psychiatric care delivered in part, or in full, by an individual psychiatrist were included. Reviews that did not refer to an individual psychiatrist were excluded due to the pre-defined focus of this research. While some reviews may have referred to additional healthcare professionals, the environment, or other healthcare services, each review must have included reference to an individual psychiatrist in order to be included. For clarity, only information pertaining to the care or interaction with an individual psychiatrist was analysed.

Reviews about child psychiatric care, Alzheimer’s Disease and Dementia or learning difficulties were excluded as domains of care quality are likely to differ in these contexts that go beyond the remit of this thesis. Examples of exclusion decisions made included being anxious about the removal of a tooth, or hip operation that did not require psychiatric attention.

4.2.3 Data selection:

Reviews were selected for inclusion using a two-stage process. Firstly, the researcher screened all identified reviews using an inclusion criterion form created with the patient research partner to ensure review inclusion/exclusion standardisation. To enhance reliability, 20% (n=32) of identified reviews were also screened by the patient research partner based on his availability and desire to do so. This was achieved by printing off a copy of the reviews for the patient research partner to read through during a six-week period and exclude/include relevant reviews using the inclusion form. Following the initial screening, potentially eligible reviews were then reviewed again for full inclusion with any discrepancies (n=1) between the patient research partner and researcher resolved through discussion until consensus was achieved. Figure 5 shows the inclusion and exclusion decisions made.

4.2.4 Data extraction:

A piloted data extraction form designed by the researcher was used to extract information about: review submission and publication date; author status; name of organisation involved; review content; and other healthcare professionals, services, or environments referred to. Based on their content, reviews were also categorised by the patient researcher partner and researcher as positive, negative or mixed in order to address previously raised concerns that psychiatric patients would leave malicious comments about psychiatrists online (Patel *et al.*, 2015).

4.2.5 Data analysis:

Reviews were analysed using the Framework analysis method (Ritchie & Spencer, 1994). Firstly, the patient research partner and researcher familiarised themselves with fifteen included reviews through repeated readings and discussions during one of their fortnightly meetings. The patient research partner and researcher then generated themes from the data leading to a comprehensive coding framework. This was achieved by individually marking initial thoughts and ideas in the right-hand margin of printed reviews and then transforming these ideas into broader themes. During this process, suggested themes were regularly revised or combined, with new codes created when encountered data did not fit existing codes. The coding framework was then used to individually analyse all included reviews by the researcher. Themes were charted using Nvivo (NVivo 11, 2012) to facilitate retrieval, enabling the researcher to analyse similarities and differences across the data set. To address the second research question, ('how does patient content shared online compare, if at all, to the two most commonly used patient feedback tools in the revalidation of psychiatrists'), the coding framework was mapped and compared against the domains of care and questions asked in the two most widely used patient feedback tools for revalidating psychiatrists as previously described (General Medical Council, 2019; Royal College of Psychiatrists, 2017b). This process was again conducted in co-production with the patient research partner using colour coordinated post-it-notes to denote domains of care identified by reviews and those included in existing patient feedback tools.

4.3 Results

4.3.1 Summary of included reviews

A total of 264 reviews were identified, 152 were included (Figure 5). Based on their content, included reviews were categorised as: 33% positive (n=50/152), 16% mixed (n=25/152), or 51% negative (n=77/152). The majority of review authors self-identified as a patient (n=104/152), with service users (n=18/152), relatives (n=9/152), carers (n=9/152), staff members posting on behalf of a patient (n=5/152), parents/guardians (n=3/152), friends (n=3/152) and a staff member (n=1/152) also represented.

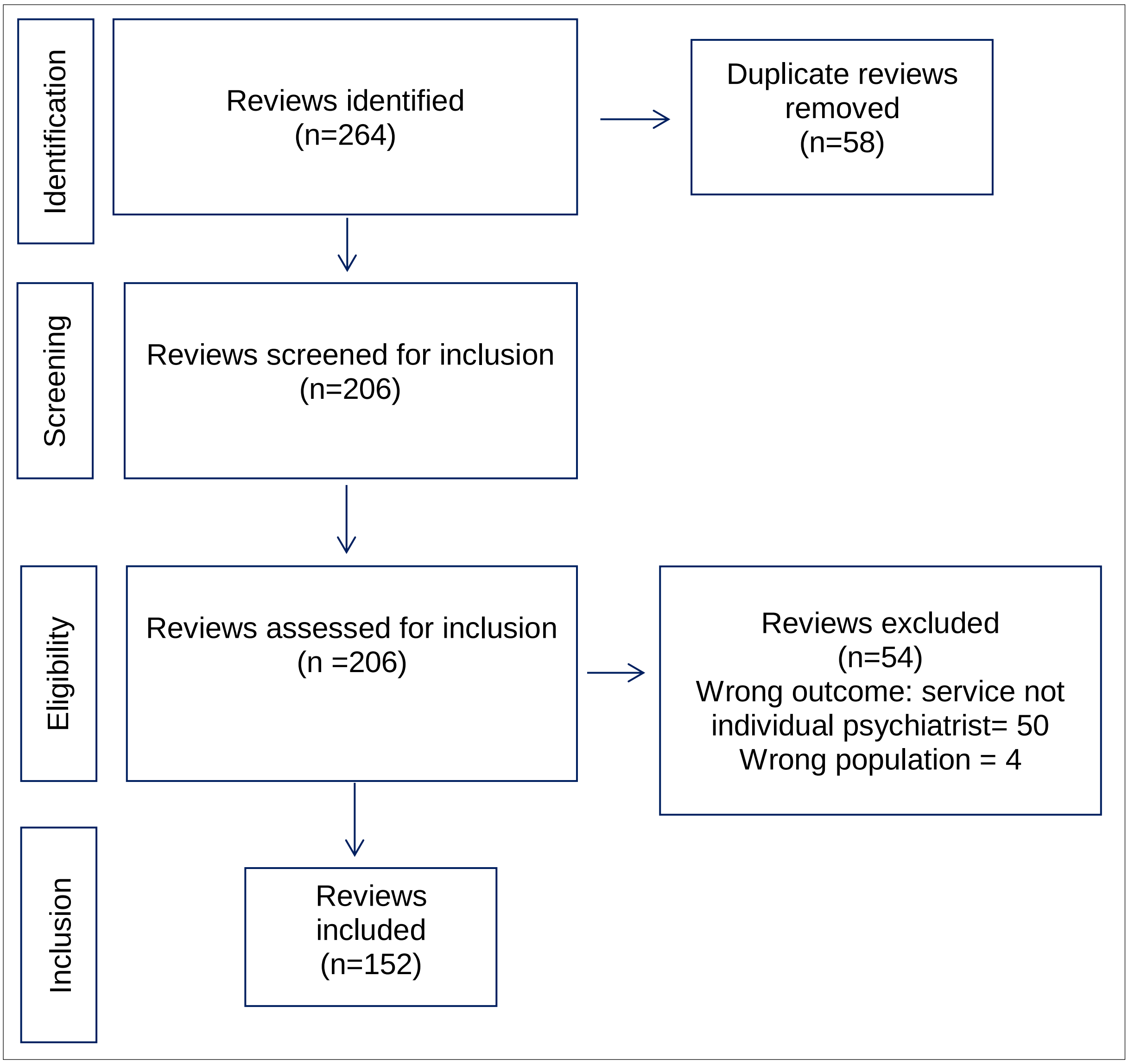


Figure 5 Inclusion and exclusion process of psychiatric care reviews published on Care Opinion.

Self-reported conditions, experiences, or diagnoses disclosed included: schizophrenia, schizoaffective disorder, dissociative identity disorder, multiple personality disorder, psychosis, bi-polar, Attention Deficit Hyperactivity Disorder, depression, post-natal depression, post-traumatic stress disorder, anxiety, self-harm, substance abuse and suicide attempts highlighting the variety of experiences reviewed.

4.3.2 What do patients share about their psychiatric care experiences online?

Beginning with the question of 'what do patients share about their psychiatric care experiences online?' patients described a variety of both positive and critical aspects of psychiatric care quality as outlined below.

Positive aspects of psychiatric care quality

Patients described 49 positive determinants of psychiatric care quality at the individual practitioner level. Table 7 identifies those most frequently described. The words used by patients have been retained wherever possible to maintain authenticity.

Table 7 Positive aspects of psychiatric care at the individual practitioner level

Positive psychiatrist behaviours	No. of reviews
1. Listened to	14
2. Supportive	14
3. Caring	14
4. Understanding	12
5. Treats people with dignity and respect	11
6. Involves (Shared decision making, carer involvement)	10
7. Non-judgemental and accessible	9
8. Kind	9
9. Spends time with patients	7
10. Helpful	7
11. Discusses medication side effects and provides information	7

*75 possible reviews (n=50 positive, n=25 mixed)

Patients often described a number of positive aspects of psychiatric care quality in combination with one another. For example:

> *"I have received brilliant care from the psychiatrist, he really is fantastic, because he listens to me and he gives me options for my treatment, I feel that I'm really involved in my treatment and included in decisions."* (Unique Identifier, referred to as UID hereafter 295923)

> *"I wish to highlight the care from my Consultant Psychiatrist. At no point have I felt out of the loop regarding my care. Her thorough, learned, consistent understanding, compassion, encouragement, gentle and honest method of practice has allowed me to go from strength to*

> *strength. I have always been part of any decisions made both as an inpatient and outpatient. I feel so cared for, understood and supported"* (UID 311614)

More than one in four experiences reviewed (n=45/152) wanted to thank those responsible for their psychiatric care. This was evident from both a patient and family/carer perspective as evidenced below:

> *"I was fortunate to be assigned to a wonderful consultant psychiatrist... she has given me the gift of 'mental-wellness' and the confidence to go forward positively into the future. She herself is a gift to the profession in which she practices and to all the patients who like myself have come under her care. I can never thank her enough."* (UID 171477)

> *"As a family, we'd like to register our profound thanks to all those who were connected in the care of my nephew*." (UID 295558)

Critical aspects of care quality

Conversely, patients also described a number of behaviours considered to be detrimental to psychiatric care quality (Table 8).

Table 8 Unhelpful behaviours considered to be detrimental to psychiatric care quality at the individual practitioner level

Unhelpful behaviours	No. of reviews
1. Lack of shared decision making	17
2. Detrimental attitudes	17
3. Poor communication	14
4. Hears but doesn't listen	14
5. Power imbalance	14
6. Judgemental	11
7. Lack of carer involvement	11
8. Dismissive	11
9. Lack of respect	10
10. Lack of sensitivity	9
11. Lack of understanding	8

*102 possible reviews (n=77 negative, n=25 mixed)

A lack of shared decision making was one of the behaviours most frequently described by patients. This was often aligned with other care domains including a lack of carer involvement as outlined below:

> "*I felt that decisions made about my treatment and care were completely out of my hands. I felt like the psychiatrist had made his mind up about what was going to happen before my family/friends/advocate & I entered*

> *the room and all we were given was the opportunity to ultimately agree*." (UID 298009)

Similar to the positive behaviours described above, patients often described unhelpful domains of psychiatric care simultaneously. For example:

> *"The way the psychiatrist treated me was degrading. It took a lot for me to go there and tell him how I felt and it felt like he was being dismissive, he treated me like a child. I felt worse when I left and ended up going home and attempting suicide… they still treat us as lesser human beings."* (UID 24139)

A cyclical pattern between critical psychiatric care experiences and detrimental behaviours was discussed by a number of patients (n=25). However, 29 reviews also described positive outcomes of recovery and *"life-saving*" care as a result of the care received by individual psychiatrists:

> *"I feel like you have given me another chance at life and that's wonderful!"* (UID 86975)

> *"The miserable depressed me has completely changed and I actually felt better than I ever had in my life! I hardly drink now - I had a period of abstinence that lasted about six years… I've even stopped smoking. I am working and expect that this will continue until retirement... I wonder where I would be now without them? Dead? On the streets? Who knows."* (UID 27812)

> "*With the help and support I have received I now have work as a volunteer, a house and a life."* (UID 206459)

However, given the cyclical pattern identified and distressing experiences reviewed, during our analysis, the patient research partner identified the quality of patient feedback responses as problematic. Oriel expressed concern that unhelpful, or tokenistic responses to online patient feedback could further enforce negative experiences of care, impacting upon patient outcomes and recovery. In line with the iterative and flexible nature of action research, further work was carried out to co-produce a patient feedback response framework to directly address this issue. Findings from this published work can be found here.

Interestingly, patients rarely discussed psychiatric care in relation to the care provided by a single psychiatrist. Patients identified 47 other roles and/or services in addition to psychiatrists, consultant psychiatrists, locum psychiatrists, duty psychiatrists and assistant psychiatrists (Table 9). An example of some of the additional healthcare professionals and/or services identified are underlined in the example below:

> "*I was originally transferred to my local Community Mental Health Team in North Herts from CAMHS services in another area. Initially the support I received was excellent. I was completely involved in my care. I had a skilled and compassionate Social Worker, a great Psychiatrist and a brilliant Support Worker… I also no care co-ordinator (which was promised to me when my last one left)... A new Psychiatrist eventually said I could have a CPN who was my co-ordinator for 2 months…I was getting CBT from the Psychologist there… The mental health helpline have been very rude to me on occasions… The same goes for the Crisis teams… on one occasion the Consultant told me… On discharge from the Community team I was told I could self-refer myself back if I ever needed help, when I tried to do this a few weeks ago this was refused. Even my GP said I could do this*."(UID 57352)

Table 9 Additional healthcare professionals and/or services identified by patients in addition to psychiatrists, consultant psychiatrists, locum psychiatrists, duty psychiatrist and assistant psychiatrist.

GP (n=37)
Community psychiatric nurse (n=27)
Community mental health team (n=19)
Crisis team (n=16)
Nurse (n=15)
Psychologist (n=12)
Secretary (n=10)
Administrator (n=10)
Social worker (n=7)
Support worker (n=5)
Occupational therapist (n=5)
Clinical care co-ordinator (n=4)
Care co-ordinator (n=4)
Complaints manager (n=2)
PALS (n=2)
Psychiatric liaison team (n=2)
Counsellor (n=2)
Student (n=2)
Paramedics (n=2)
Mental health team (n=1)
Community link worker (n=1)
Social inclusion and wellbeing service (n=1)
Peer support worker (n=1)
Service manager (n=1)
Community nurse (n=1)
Sister (n=1)
District nurse (n=1)
IAPT (n=1)
Trainee (n=1)
A&E staff (n=1)
Police (n=1)
111 (n=1)
CRT (n=1)
Neurologist (n=1)
Mental health service management (n=1)
House officer (n=1)
Physiologist (n=1)
Therapist (n=1)
Housekeeper (n=1)
Duty worker (n=1)
EMHU psychologist (n=1)
Referral team (n=1)
Ward manager (n=1)
Home treatment team (n=1)
Health visitor (n=1)
Chaplain (n=1)
Pharmacist (n=1)

4.3.3 How does the content shared online compare, if at all, with the content used in the two most commonly used patient feedback tools for revalidating psychiatrists?

As evidenced in Table 10 and Table 11, some of the most frequently described domains of psychiatric care quality from a patient perspective are not included in the two most commonly used patient feedback tools for revalidation purposes.

Table 10 Comparison of most frequently described domains of psychiatric care from a patient perspective and domains of care used in the two most widely used patient feedback tools for revalidating psychiatrists.

Aspects of quality psychiatric care from a patient perspective	Royal College of Psychiatrist ACP360 Questionnaire	General Medical Council Patient Questionnaire
Listened to	“Listens to what I say”	“Listening to you”
Supportive	“Offers me hope and optimism”	-
Caring	“Shows warmth and is genuine and understanding”	-
Understanding	“Shows warmth and is genuine and understanding”	-
Treated with dignity and respect	“Shows respect for me”	-
Involves (Shared decision making, carer involvement)	“Values my opinions” “Includes my opinions when making decisions with me” “Asks me about my points of view” “Takes into consideration the needs of my family and/or carers” “Asks the opinions of my family and/or carers where appropriate”	“Involving you in decisions about your treatment” -
Non-judgemental and accessible	“Is friendly and easy to approach”	“Making you feel at ease”
Kind	-	-
Spends time with patients	-	-
Helpful	-	-
Discusses medication side effects and provides information	“Provides useful information about my care and treatment when I need it or ask for it” “Makes information easy for me to understand”	-

The GMC questionnaire did not include the majority of psychiatric care domains described by patient participants (n=2/11) (Table 10).

Table 11 Items not discussed in patient reviews but listed in existing patient feedback tools

Royal College of Psychiatrists ACP360 Questionnaire	General Medical Council Patient Questionnaire
“Keeps appointments and is on time”	“Being Polite”
“Remains calm under pressure”	“Assessing your medical condition”
	“Providing or arranging treatment for you”
	“This doctor will keep information about me confidential”
	“This doctor is honest and trustworthy”
	“Doctors ability to provide care”
	“Completely happy to see this doctor again”

Conversely, the specialty specific Royal College of Psychiatrists ACP 360 tool did include the majority of care quality domains from a patient perspective (n=8/11), with the exception of being kind, spending time with patients and being helpful. However, the ACP 360 tool also included two care domains not discussed in online reviews. This included being on time and remaining calm under pressure. Furthermore, the language and categorisation used by patients in their online reviews to describe domains of psychiatric care often differed to that used in existing feedback tools, highlighting a further area of disparity. For example, being caring and understanding were repeatedly discussed as two distinct, yet connected domains of care online. However, in the two existing patient feedback tools reviewed, these were often amalgamated.

4.4 Discussion

This research addresses an identified gap in existing literature by exploring what patients share online about their psychiatric care experiences and how these compare, if at all, to the content used in the two most commonly used patient feedback tools for revalidating psychiatrists. Research findings demonstrate that patients most frequently describe feelings of being listened to, supported and cared for as beneficial domains of psychiatric care. In contrast to the specific focus of patient feedback in revalidation, research findings suggest that patients rarely discuss the care provided by a single psychiatrist in isolation from other healthcare professionals or services. Forty-seven additional healthcare professionals and/or services were described by patients in their online reviews. Furthermore, comparison of the domains of psychiatric care quality most frequently described by patients identified some areas of similarity and disparity with the two most commonly used patient feedback tools for revalidation purposes. While the speciality specific ACP 360 tool appeared to include the majority of domains described from a patient perspective, the generic feedback tool provided by the GMC did not. However, three domains of care most frequently described by patients were not included in the ACP 360. Similarly, two existing domains currently used in the ACP 360 tool were not discussed by patient reviews at all – 'keeps appointments and is on time' and 'remains calm under pressure'. Furthermore, the language and categorisation used to describe psychiatric care domains also differed between online patient reviews and existing feedback tools, identifying a further area of disparity.

4.4.1 Comparison to existing literature

Findings from this research share some similarities with existing literature including the characteristics of "a good psychiatrist" as identified by clinical tutors in the UK (Bhugra *et al.*, 2009). For example, being a good communicator and listener, being empathetic and understanding were all identified as beneficial domains of psychiatric care by clinical tutors (Bhugra *et al.*, 2009). However, in contrast to the findings reported by Bhugra and others, online patient reviews did not describe several domains of care repeatedly identified as beneficial by professionals including clinical competency in diagnosis, investigations and management, ability to make appropriate clinical decisions and appraise staff members (Bhugra *et al.*, 2009). Findings from Taylor &

MacRae report similar disparities between patient and psychiatrist values (Taylor & MacRae, 2011). In 2007, Taylor & MacRae undertook a survey in Scotland to explore the top four attributes of a ‘good psychiatrist’. Psychiatrists ranked clinical knowledge as the most important attribute, followed by communicates clearly, interested in people, honest and trustworthy. Conversely, patients ranked good listener as the most important, followed by approachable, treats patients as equals and non-judgemental (Taylor & MacRae, 2011). Similar results have also been reported in Korea demonstrating international comparisons, with patients valuing relational behaviours more than psychiatrists, concluding that a good psychiatrist can be defined as “*a good communicator and listener with a professional manner, who respects confidentiality and has good doctor-patient relationships”* (Kim et al., 2015, p.632).

4.4.2 Strengths and limitations

Strengths of this research include its application of a rigorous search process; generation of new knowledge that address identified gaps in existing understanding; coproduction of a patient feedback response framework that has been used internationally to change existing practice (Care Opinion Australia, 2020) and co-production with the patient research partner. However, its limitations must also be acknowledged. While extensive in scope, this research used one data source, Care Opinion. Exploration and comparison with other online feedback websites would be useful. Patient and carer perceptions of psychiatric care quality were also amalgamated in this research unless differentiated by author status. Future research exploring any disparity between carer and patient identified domains of psychiatric care quality would also be beneficial.

4.4.3 Implications

With these limitations in mind, the implications for this research are clear. Firstly, research findings suggest that the current revalidation requirement for patients to disaggregate the care provided by an individual psychiatrist from the wider healthcare team, service or environment is difficult to achieve. Interactions external to an individual psychiatrist appear to influence, both positively and negatively, the quality of an individual's experience. Identifying ways that this could be resolved or explained would be beneficial. Secondly, although the speciality specific ACP 360 tool covered the majority of domains, the more generic GMC questionnaire failed to address half of the psychiatric care domains identified as important from a patient perspective. Furthermore, some domains of care currently used in existing patient feedback tools were not described in online patient reviews highlighting a further area of disparity. Such findings further support the concern that existing patient feedback tools used in the revalidation of psychiatrists may not include aspects of care quality considered to be of most importance from a patient perspective as highlighted in cycle one. Thirdly, the language and categorisation of care domains used in online patient reviews often differs to that used in existing patient feedback tools. Such results highlight the importance of tailoring patient feedback tools to the relevant population it seeks to serve. As previously suggested, this may best be achieved through co-production (Berzins *et al.*, 2018; Gunasekara, Patterson & Scott, 2017; Williams, Coyle & Healy, 1998), although limited research has explored this suggestion.

Finally, this research goes some way in exploring the belief that online feedback platforms such as Care Opinion are a channel for disgruntled patients, particularly those with "*psychiatric or personality disorders*" (Patel *et al.*, 2015).

While critical experiences were encountered, findings from this research demonstrate that one in four experiences reviewed wanted to directly thank those involved in delivering psychiatric care. This provides an alternative perspective to the, at times, protective discourse traditionally used to deter online patient feedback engagement and hesitations to accept patient feedback from the mental health community more generally (Patel *et al.*, 2015). However, it is important to consider the potential limitations of patient feedback online.

Patients who share their experiences online are unlikely to be representative of the entire patient population (Greaves *et al.*, 2013; Rozenblum & Bates, 2013; Verhoef *et al.*, 2014). However, the same arguments could be made about the requirements in revalidation to collect a pre-defined number of patient responses (often 20-30 once every five years), with evidence to suggest healthcare practitioners self-select which patients to respond, introducing possible bias (Archer *et al.*, 2018). Furthermore, when viewed in relation to the total number of reviews available on Care Opinion at the time of analysis, reviews about the care of an individual psychiatrist represented less than 1% of all available reviews. While this may reflect the targeted focus of this research, i.e. care provided in part, or in full by an individual psychiatrist, the low number of reviews may also be indicative of a wider cultural need to encourage, promote and accept the sharing of psychiatric care and mental health experiences more broadly. Previous research has acknowledged the therapeutic benefits of providing patient feedback and significant associations between patient care ratings, clinical effectiveness, healthcare outcomes, resource expenditure (Armstrong *et al.*, 2013; Doyle, Lennox & Bell, 2013) and care quality (Bardach *et al.*, 2012; Greaves *et al.*, 2012; Kleintjes, Lund & Swartz, 2012; Thornicroft *et al.*, 2008; Verhoef *et al.*, 2014). Ensuring the most important domains of psychiatric care from a patient perspective are included and identifying ways to maximise the perceived value and acceptability of patient feedback tools from both a patient and professional perspective is therefore imperative.

4.5 Conclusion:

In conclusion, cycle two demonstrates that some of the most frequently described domains of psychiatric care quality from a patient perspective are not included in existing patient feedback tools. The language and categorisation used to describe psychiatric care domains often differs between patients and existing feedback tools, identifying a further area of disparity. Further work is needed to incorporate patient perceptions, desires and aspirations into existing patient feedback tools and identify ways in which the perceived value and acceptability of existing feedback tools could be improved. This forms the focus of cycle three as outlined below.

5.0 Cycle 3 – What are patient perceptions, experiences and aspirations for the design, content and process of existing patient feedback tools?

5.1 Introduction

Building on findings from cycles one and two, cycle three seeks to explore patient perceptions, experiences and aspirations for patient feedback tools in the revalidation of psychiatrists. The rationale for this cycle stems from the acknowledged exclusion of patients in the design, administration and evaluation of existing feedback tools as reported in cycle one, the acknowledged disparity between domains of psychiatric care described by patients in online reviews and those currently used in existing patient feedback tools as evidenced in cycle two and the limited amount of research in this area (Eiring *et al.*, 2015; Trujols *et al.*, 2013), particularly in the context of revalidation. Furthermore, as suggested by Farrelly and Lester, limited research has explored the behaviours, attributes and skills patients consider to be most conducive to the therapeutic relationship (Farrelly & Lester, 2014). Although important in all healthcare settings, the therapeutic relationship (arguably the focus of patient feedback in revalidation) is considered to be crucial in mental health, accentuating the importance of this research (Gunasekara, Patterson & Scott, 2017; Lelliott *et al.*, 2008; Perry *et al.*, 2013). Finally, although one of the most commonly used patient feedback tools for revalidating psychiatrists, the ACP 360 has received limited attention since its inception in 2005. Current perceptions of psychiatric care quality may differ to those that inspired its generation 15 years ago.

This research cycle therefore sought to address the following research questions:

- What, if anything, would patients like to give their feedback on? What behaviours, attributes and skills are considered most conducive to the therapeutic relationship?
- What, if anything, would motivate patients to give their feedback?
- How do patients perceive the two most commonly used patient feedback tools in the revalidation of psychiatrists (GMC questionnaire and Royal College of Psychiatrists ACP 360 tool)?

5.2 Methods

5.2.1 Focus groups, semi-structured interviews and open-ended online survey

This research cycle used focus groups, semi-structured interviews and an open-ended survey. Justification for choosing a qualitative, as opposed to quantitative design stems from the previously acknowledged aims of this thesis, i.e. to explore people's thoughts, perceptions and experiences as opposed to quantify, measure and generalise. Adopting a quantitative design such as a randomised control trial may have resulted in the individual meaning, nuances and experiences of psychiatric care being overlooked, further widening the gap between the existing understanding of healthcare professionals, academic researchers and lived experiences of individual patients.

Justification

Justification for using focus groups and semi-structured interviews include their ability to:

- Elicit opinions and perceptions of relatively unexplored areas (Edwards & Staniszewska, 2000; Gunasekara, Patterson & Scott, 2017; MacDonald, 2012)

- Provide rich insight into social processes to a greater extent than their quantitative counterparts (Edwards & Staniszewska, 2000)
- Include individuals who are unable to read or write (Kitzinger, 1995)
- Explore people’s experience of healthcare services (Kitzinger, 1995)

However, the individual strengths and limitations of focus groups and interviews should also be considered. For example, focus groups can provide unique insight into a range of views, experiences and ideas (Bramesfeld *et al.*, 2007), while also facilitating the discussion of sensitive topics and provision of more critical comments in comparison to interviews as a result of group level support (Kitzinger, 1995). However, some participants in a focus group setting may feel silenced, or ostracised, by more dominant participants. Concerns of confidentiality may also be affected in a focus group setting, particularly for ‘captive’ audiences such as those sectioned under the Mental Health Act (Kitzinger, 1995). As a result, despite their time consuming nature (Brooker & Dinshaw, 1998), semi-structured interviews were also conducted to accommodate individual needs and provide a space for people to share experiences they may not have otherwise shared in a group setting (Hill *et al.*, 2012). As advised by the patient research partner and others (Hill *et al.*, 2012), it was acknowledged that some participants may have felt uncomfortable meeting new people, particularly when discussing experiences of psychiatric care. Interviews were therefore offered either face-to-face or over the phone depending on peoples preference to further facilitate involvement.

However, highlighting the flexible and adaptive nature of action research, some participants also expressed a desire for the topic guide to be made available electronically in the form of an open-ended survey for individuals who felt uncomfortable leaving their homes, or speaking on the phone. This request was actioned by the researcher following a revision (Appendix 2) to the original ethics application and HRA approval (Appendix 3 & 4).

The inclusion of three methods, (focus groups, interviews and online survey) follows Macdonald's recommendation for at least three methods to be used to transcend the limitations of each individual method (MacDonald, 2012). Furthermore, all three methods have also been identified as effective methods of data collection in action research further justifying their inclusion (MacDonald, 2012).

Topic Guide

A topic guide was designed in co-production with the patient research partner (Appendix 5). This was achieved by holding reflective discussions with the patient research partner during our fortnightly meetings following wider reading of the background literature (chapter one), systematic review findings (cycle one) and analysis of online patient reviews (cycle two). Questions used in the topic guide were purposefully open-ended to facilitate in-depth discussions with suggested prompts provided to facilitate further discussion if required. As proposed by Kitzinger, encouraging participants to respond in an open, as opposed to closed, or direct manner, using their own words and communication style may enable a more nuanced understanding of people's knowledge, understanding and attitudes to be developed (Kitzinger, 1995). Importantly, the topic guide used for the focus groups, interviews and electronic survey were the same to ensure participants were treated equally and had the same opportunities to respond regardless of their preferred method. The topic guide broadly covered the following areas:

- The behaviours, attributes and/or skills considered most conducive to the therapeutic relationship in psychiatric care
- Desires and aspirations for patient feedback tools in the revalidation of psychiatrists
- Potential difficulties and suggested solutions in providing patient feedback for revalidation purposes
- Motivations for providing patient feedback for revalidation purposes
- Perceptions of the two most commonly used patient feedback tools in the revalidation of psychiatrists

Print outs, or images if completing the online survey, of the two most commonly used patient feedback tools (GMC patient feedback questionnaire and ACP 360 tool) were presented during the focus groups, interviews and electronic survey. Importantly, existing feedback tools were only presented after the questions that explored patient experiences, aspirations and motivations had been asked to limit potential bias in responses.

5.2.2 Setting and participants

Participants were people with personal or care related experience of psychiatric care in the UK. Similar to previous research, a psychiatric diagnosis was not included as a criterion in this research due to its focus of providing feedback on psychiatric care experiences as opposed to their current diagnosis (Bramesfeld *et al.*, 2007). However, a short demographic questionnaire (Appendix 6) was included to try and ensure a variety of people had been spoken to. Provision of this information was entirely voluntary. The inclusion and exclusion criteria used for this research cycle are outlined below, followed by their justification.

Inclusion criteria

Participants of any gender, ethnicity, or socio-demographic group, aged 18-65, with personal, or care related experience of psychiatric care in the UK (not related to paediatric, learning difficulties, Dementia or Alzheimer's) and an ability to understand and speak the English language were included.

Exclusion criteria

Participants below the age of 18, or above the age of 66, unable to speak or understand the English language, with no personal or care related experience of psychiatric care, or psychiatric care experience related to Dementia, Alzheimer, learning difficulties or paediatrics alone were excluded.

Criteria justification

Justification for this criterion stems from discussions with the patient research partner and psychiatrist colleagues. It was suggested that Alzheimer, Dementia, learning difficulties or paediatric patients (17 years and below) were likely to have different skills, desires and expectations for patient feedback that exceeded the remit of this thesis (Brooker & Dinshaw, 1998). Similar to existing research (Brooker & Dinshaw, 1998; Cooper, 2016; Puschner *et al.*, 2016), psychiatric care experiences in these settings were therefore excluded in order to maintain a relevant research focus. However, the exclusion of such experiences does not mean to suggest that they are irrelevant areas for future research. Similarly, while the researcher wanted to be as inclusive as possible, due to the limited resources available, an accurate and sensitive translation of non-English data could not be provided. The possibility of introducing bias in the research project as a result of this exclusion is therefore acknowledged.

Setting

All focus groups and interviews were arranged at a time and place of the participants' choosing (with the exception of their own home due to University policy). The electronic version of the topic guide was distributed using a web link and could be completed wherever and whenever by participants who had internet access.

Clinical settings were avoided wherever possible due to acknowledged power disparities and inherent biases within such settings, i.e. participants constructing narratives using medical jargon and only raising issues believed to be important in a clinical encounter (Brooker & Dinshaw, 1998; Williams, Coyle & Healy, 1998). However, due to the nature of participant circumstances, one focus group was conducted in an in-patient secure unit. In this instance, the focus group was held in the ward's arts and crafts room with one non-clinical member of staff present as required by security protocols. Although in a clinical setting, the researcher felt it was important to explore in-patient perceptions as evidence suggests inpatients often report undesirable experiences of psychiatric care (Weich 2018). Exploring such perceptions and ensuring in-patient aspirations and desires were included was therefore considered imperative.

Refreshments and homemade cakes were provided by the researcher as an expression of her gratitude and attempt to facilitate an informal and comfortable setting. All focus groups were held in a circle to facilitate eye contact and turn taking wherever possible.

Finally, based on his availability, the patient research partner was present at four of the eight focus groups conducted. The rationale for this decision stems from existing research that suggests the active involvement of someone from the community you hope to work with can help to engage individuals whose voices are not normally heard, including marginalised groups such as psychiatric patients (Gilburt, Rose & Slade, 2008). Research conducted by Gillard et al., (2010) suggests that participants find the involvement of someone they can identify with as a more comfortable and positive experience. For example, some participants reported finding it personally encouraging to see a patient as a team member (Gillard *et al.*, 2010). Similar results have also been reported by Tait (2005) who explored patient involvement in mental health services and highlighted the ability of patient involvement to encourage others to relax, with some researchers suggesting that participant responses are likely to be more ‘honest’ when someone with a lived experience is involved as part of the team (Tait & Lester, 2005). The active involvement of the patient research partner is therefore well supported.

All focus group participants were asked if they were happy for the patient research partner to join prior to any focus groups being conducted. A short paragraph written by the patient research partner about his background as evidenced below was also provided to provide further context/information.

> “*My name is* [real name], *I am a 61 year old male and have extensive experience of psychiatric care. Following a nervous breakdown in 2016, I am currently receiving help and support for a number of diagnoses including schizophrenia, multiple personality disorder, psychosis and acute paranoia. I have been working with Rebecca as an equal member of the research team since 2016. I look forward to meeting you all and hearing about your experiences”* (Oriel, introduction paragraph)

It is important to note that the patient research partner was not present at any of the one-to-one interviews due to afore mentioned reasons, i.e. participants feeling uncomfortable in a group setting or meeting new people.

Focus group and interview settings used in this research included a community centre, spiritual shop, health and wellbeing hub, church hall and University.

5.2.3 Sample size

A sample size of 54-60 participants (six patient focus groups, with six-eight participants in each focus group and 12 interviews) was originally proposed. This was considered to be a practical, realistic and feasible sample size for a self-funded PhD that would allow for sufficient in-depth qualitative research likely to lead to data saturation, defined as the point at which no new generic themes or variations of a given theme emerge (Eliacin *et al.*, 2015; Staniszewska *et al.*, 2014). The proposed sample size was also discussed and agreed with the patient research partner and local service-user/carer support group in acknowledgement of reported challenges in recruiting large numbers of people from the mental health community (Gayet-Ageron *et al.*, 2011).

5.2.4 Recruitment

Participants were recruited using a volunteer, purposeful sampling approach based on the pre-defined inclusion and exclusion criteria outlined above. The definition of purposeful sampling used in this research stems from that provided by Ritchie, Lewis & Elam who define purposeful sampling as a sampling technique that serves an investigative purpose rather than to be statistically representative of a population (Ritchie, Lewis & Elam, 2003). Research invitations (Appendix 7) were sent by the researcher via email to identified gatekeepers at charitable/volunteer organisations known to help community members with psychiatric care experiences including Mind, Healthwatch, Heads Count, CHIL, Hearing Voices, Recovery Devon, Royal College of Psychiatrist Service User Group and Heads Together. The identified gatekeeper then disseminated the invitation to those who met the required inclusion criteria.

Research invitations were also shared by gatekeepers via their social media (Twitter) as this has been shown to be effective in encouraging recruitment from stigmatised groups (Berzins *et al.*, 2018). The involvement of community groups and voluntary sector organisations in the recruitment process was a conscious decision following existing evidence that suggests such involvement can help facilitate engagement with marginalised/disadvantaged groups such as those experiencing mental ill-health (Gillard *et al.*, 2012; Robinson, 2014). Reminder emails were sent to the identified gatekeepers by the researcher two weeks after the initial invite if no response had been received. If no response was received after this reminder email, no further communication was sent.

5.2.5 Data collection

At the beginning of all interviews and focus groups, participants were provided with a verbal summary of the process and overall study. Participants were reminded that their involvement was entirely voluntary and that the content of any information shared would be confidential and made anonymous through the removal of any identifiable information and use of relevant pseudonyms. The verbal summary used in the interviews and focus groups was also contained in the information sheet for the online survey. All audio data was recorded using a Dictaphone and transcribed verbatim by the researcher. A copy of the transcripts was also provided to participants to ensure data accuracy, helping to maintain research rigour as identified below.

5.2.6 Data analysis

Data was analysed in co-production with the patient research partner using inductive thematic analysis (Table 12) as outlined by Braun and Clarke (Braun & Clarke, 2006):

Table 12 Six-step thematic analysis as outlined by Braun and Clarke (2006)

Phase	Description of process
Data familiarisation	Transcribing data, reading and re-reading of transcripts, noting down initial ideas
Generation of initial codes	Coding interesting features of the data, organising data relevant to each code
Searching for themes	Collating codes into potential themes and gathering all relevant data to each theme
Reviewing themes	Checking the themes work in relation to coded extracts and the entire data set
Defining and naming themes	Ongoing analysis to refine specifics of each theme, generation of names for each theme
Producing the report	Final opportunity for analysis, selecting appropriate extracts, discussion of analysis, production of report

Similar to the process outlined in cycle two, inductive thematic analysis with the patient research partner was achieved by providing two copies of anonymised transcripts at a time. This was based on the research partners' request. An informal training session on thematic analysis was provided during one of our regular meetings using a training package the researcher had previously delivered for patient research partners.

Thematic analysis was selected for the purposes of this research cycle as it is advocated as a useful and flexible method to generate a rich, yet detailed and complex account of qualitative data (Braun & Clarke, 2006). Adopting an inductive approach also helped to ensure identified themes arose from the data generated as opposed to predefined concepts and ideas that are often largely informed by professional opinion alone (cycle one).

The decision to include the patient research partner in the analysis process stems from identified limitations of existing research that often fails to include patients in such processes (Jennings *et al.*, 2018; Locock *et al.*, 2019). As identified by Jennings et al. (2018) this often means that a valuable and integral perspective is missing in the interpretation of research findings (Jennings *et al.*, 2018). Patient involvement in the analysis process is also believed to enhance the thoroughness of analysis (Jennings 2018), with such partnerships reportedly providing deeper insight into the complexity, nuances, ambiguity and richness of participant accounts (Jennings *et al.*, 2018). Furthermore, including more than one perspective in the analysis process is believed to increase the depth and breadth of analysis, mitigating potential bias by creating consensus, helping to further validate research findings (Eliacin *et al.*, 2015; Ennis & Wykes, 2013; Lloyd *et al.*, 2013). The involvement of the patient research partner in the analysis stage is therefore well supported. Appendix 8 lists the number of changes made as a result of this co-production process.

5.2.7 Maintaining rigour

Finally, rigour was maintained using the processes outlined in Table 13.

Table 13 Processes taken to ensure qualitative rigour in cycle three

Trustworthiness criteria	Processes taken to ensure qualitative rigour
Credibility	Triangulation - Method triangulation through focus groups, interviews and online survey - Source triangulation through multiple charities contacted and involved - Analyst triangulation through patient research partner Peer debriefing - Review of data collection, analysis and reporting through supervision and patient research partner - Sharing of research findings with Royal College of Psychiatrists Negative case analysis - Identification and sharing of experiences that contrasted against those of the majority during focus groups and interviews Member checks - Copy of transcript sent to participants to ensure accuracy and confirm intended meaning Clarifying questions and probes asked
Transferability	- Dense description of research methods and context as outlined above
Dependability	- Maintaining accurate records of data management and collection - Provision of verbatim extracts
Confirmability	- Acknowledgement of study’s limitation

5.2.8 Ethical considerations

Due to participant requests of an online survey, this research required an ethical amendment to the original ethical approval provided by The Health Research Authority (reference number -17/YH/0353) and Faculty Research Ethics Committee for Health and Human Sciences (reference number- 17/18-846) at the University of Plymouth (Appendix 2, 3 & 4). All participants received an information sheet and gave written informed consent prior to any data collection.

5.3 <u>Results</u>

5.3.1 Participant characteristics

In total, seventy-seven participants took part in the focus groups (n=8, 61 participants), interviews (n=3, all completed by phone), or online survey (n=13). As demonstrated in Table 14, participation was primarily from central and South West England.

Table 14 Self-declared location of focus groups, interviews and online surveys

Location	Focus Group	Interviews	Online surveys	Total
Penzance	1	-	-	1
Plymouth	2	-	-	2
Exeter	2	2	1	5
Bristol	-	-	1	1
Bath	-	-	1	1
Somerset	-	-	2	2
Wiltshire	-	-	1	1
London	3	1	2	6

Table 15 shows the demographic information provided by participants including age, gender and mental health experience/condition. The provision of this information was entirely voluntary, accounting for the lower number of responses.

Table 15 Demographics of patient participants where provided

Category	Response						
Gender (n=41)	Female (n=21)	Male (n=20)					
Age (n=36)	26-33 (n=5)	34-41 (n=6)	42-49 (n=5)	50-57 (n=11)	58-65 (n=9)		
Ethnicity (n=38)	White British (n=38)	Black British (n=1)	Muslim (n=1)				
Perspective (n=41)	Carer and survivor/service-user/user (n=13)	Patient (n=25)	Advocate (n=2)	Group facilitator (n=1)			
Mental health experience/condition (n=26)	Depression (n=8)	Anxiety/generalised anxiety disorder (n=4)	Borderline/ Personality Disorder (n=4)	Bulimia nervosa (n=1)	Post-natal depression (n=1)	Anorexia Nervosa (n=1)	Psychosis (n=4)
	Post-traumatic stress disorder (n=2)	OCD (n=3)	Cognitive impairment (n=2)	Schizophrenia (n=6)	Asperger’s (n=1)	Autism (n=1)	Panic Attacks (n=2)
	Depression and anxiety (n=6)						

Thematic analysis

Inductive thematic analysis of participant responses identified five key themes: i) behaviours, attributes and skills considered most conducive to the therapeutic relationship, ii) motivations for providing patient feedback; iii) perceived problems with existing patient feedback tools; iv) issues of power and existing culture and v) suggested solutions. Each theme and their corresponding sub-themes are discussed in turn below with verbatim extracts provided wherever possible. In recognition of the extensive amount of data collected, tables are used at times to present the data in a more accessible form.

5.3.2 Behaviours, attributes and/or skills considered to be helpful in the therapeutic relationship

Beginning with behaviours, participants described 45 behaviours, attributes and skills they considered to be most conducive to the therapeutic relationship (Table 16). Those most frequently described included:

> Being "*treated like a human being, not another statistic or number on a conveyor belt"* (focus group 1, participant 4)
>
> A "*psychiatrist's willingness to really listen"* (online survey, participant 8)
>
> "*Involving service users"* and their carers/family members *"so not everything is done for you, but with you"* (focus group 3, participant 6), provided this was not at the expense of the individual patient
>
> Being open and feeling "*valued and respected"* (focus group 2, participant 4) - "*it matters that a psychiatrist treats me as an equal"* (online survey, participant 10).

Table 16 Identified behaviours, attributes and skills considered most conducive to the therapeutic relationship from a patient perspective, ordered according to frequency

Identified behaviours	Supporting quotes
1. Treated holistically not just as a condition	“*Treating that person in a holistic way, not just as a condition”* (Focus group 1, participant 6) “*They recognise you as a person first and foremost, not a patient”* (Focus group 1, participant 8) “*It’s about getting to know you as a person, rather than your condition, it’s about recognising you as an individual”* (Focus group 5, participant 10)
2. Actively listens and hears	“Interviewer: what matters most to you in a psychiatrist? *somebody who listens”* (Focus group 5, participant 1) “*A willingness to really listen”* (Focus group 1, participant 3) *“It’s back to this revolutionary idea of listening”* (Focus group 2, participant 4) “*Actually listening and hearing...the hearing bit is the important bit because listening and hearing are two different things, you can listen to a person and not actually hear what they say, so for me it’s important that they hear me, not just listen, but actually hear…”* (Interview,1)
3. Involves family members and carers (but not to the extent of ignoring patients) *Shared decision making*	“*As a carer it was actually to be involved”* (Focus group 7, participant 3) “*I think it’s important that you have a question about involving services users”* (Focus group 3, participant 6) “*When I go to anywhere my husband always comes with me because he’s my carer and it’s like sometimes I might as well not be in the room because they’re talking to him. And quite a few times I’ve said you know ‘I am here’*“ (Focus group 2, participant 10)
4. Open, approachable and adaptable *Non-judgemental* *Open minded* *Welcoming* *Flexible/adaptable*	“*Non-judgemental I think is important as well and also adaptability because every patient is different and in order to be as effective as possible with different patients and even the same patient at different times, they need to be able to adapt their style of talking and body language and all these sorts of things adaptability”* (Focus group 4, participant 5) “*The most important thing for me, is that they come with an open mind… in other words don’t go on every report they’ve read about this person, just for a minute try and start ‘hey this is what I’ve got in front of me’”* (Interview,1)
5. Respectful	“*Treat everyone with respect”* (Focus group 5, participant 12) “*Respect for families”* (Focus group 5, participant 11)

6. Discusses and reviews medication and its side effects	"*There's nothing about medication in this* [existing questionnaire] *it would be helpful if you could have a few questions about medication and about your input in it"* (Focus group 3,pt1) *"It's a simple straight forward one but also rather than just involving you, have you been given enough information, have you been told of the side effects?"* (Focus group 7, participant 1) "*No one has ever had the conversation with me about coming off medication… I don't want to be on medication for the rest of my life but that looks like how it's going to happen*" (Focus group 2, participant 5)
7. Accurate note taking *Ability to see notes*	"*I've had issues where things have been written, quite major things, that then have affected a referral somewhere and that still hasn't been corrected and although I know there will be a lot of resistance from professionals to do that, it's about you and is supposedly have a 'no decision about you without you' but if you don't know what's been written about you, how can you be informed?* … *My GP now that I've had for the past two years has two screens so he has his screen and then he has a screen for the patient so you can see exactly what's been written about you and then you say 'well hang on a minute' why have you put that and I think that's what we should be moving towards in psychiatry"* (Focus group 5, participant 10) "*Well this is the problem because unfortunately the way the whole system is, is most clients do not have any access to what is then written about them or said about them"* (Interview,1)
8. Clear communication *Clear explanation*	"*Good communication is important"* (Focus group 4, participant 6) "*Psychiatrists' should be good communicators… communicating well with people… because they're supposed to be in a caring profession, we make the assumption that they can communicate"* (Focus group 2, participant 2) "*They need to explain clearly…"* (Online survey, participant 10)
9. Works in equal partnership	"*It's about equality, I wouldn't want anyone to go and see the psychiatrist and feel inferior to them"* (Focus group 1, participant 8) "*I think the ideal is a partnership approach, the quality of recovery when you have a connection, a therapeutic connection and working together which is shared responsibility in the part of the psychiatrist as well as the part of the patient and a dialogue that is supported, not to see it as a them and us"* (Focus group 4, participant 6) *"It matters that a psychiatrist treats me as an equal"* (Online survey, participant 10)
10. Empathetic	"*Empathy, someone who empathises with you"* (Focus group 1, participant 1)
11. Understanding	"*Understanding"* (Focus group 3, participant 2)
12. Compassionate	"*There's something about being human and compassion"* (Focus group 2, participant 2)

	“*There’s a human element to it, there’s an element of compassion”* (Focus group 2, participant 8)
13. Reads patient history	“*Make sure they’ve read some of your notes”* (Focus group 2, participant 1)
14. Caring	“*Caring”* (Online survey, participant 6)
15. Trusting and trustworthy *Trusting of patients to know their own experience*	“*Someone who trusts you to know your own experience”* (Online survey, participant 13) “*There has to be openness, honesty and trust”* (Focus group 1, participant 4) “*Being truthful”* (Focus group 7, participant 1)
16. Makes patients feel comfortable *Makes patients feel safe*	“*I’m thinking about my experiences as a carer and what my wife had, she said that she had to feel comfortable with the person because she was going to tell them her most inner, most intimate thoughts… she said there were very few psychiatrist who gave her the confidence to tell them exactly how she felt”* (Focus group 7, participant 3) “*Put you at ease so you can express yourself, I think that’s the most important thing for me…”* (Focus group 1, participant 4)
17. Honest	“*All people generally want is to be honest with them. They might not like what you’re saying but if you’re honest…”* (Focus group 1, participant 8) “*Honesty”* (Focus group 7, participant 1)
18. Has an understanding of systems or services external to psychiatry	“*Have a broader knowledge themselves of what other support and services are available that they can refer to… a lot of psychiatrists’ have no outside understanding of what other services are going on… I’m not saying that they should take responsibility for ensuring that you engage with that service or you get referred to that service but they should know that there is a service”* (Focus group 1, participant 3)
19. Values patient input and experiences	“*Valuing what people have to say”* (Focus group 2, participant 2) “*Listen to me and values my opinion”* (Online survey, participant 10)
20. Supportive and encouraging	“*Is he encouraging you to try and do more? Encouraging you to challenge your abilities”* (Focus group 3, participant 4) “*Supportive”* (Interview,3)
21. Provides feedback on progress *Offers praise*	“*Giving helpful feedback”* (Focus group 4, participant 7) “*Praise for the good things, not just looking at the bad, sort of saying well done, you’re actually doing well. Acknowledge improvement and things”* (Focus group 3, participant 4)
22. Human dress code	“*He had his hair down to his waist and a big wispy moustache and I loved him to bits because he was himself and seeing someone in a straight suit, frightens me to death”* (Focus group 1, participant 1)

	“*I think the way professionals dress needs to be modified and not formal attire… you can identify with them more then generally can’t you”* (Focus group 1, participant 6)
23. Patient	“*Patience is very important I think because a lot of patients will keep going back and it could take a long time for them to get better”* (Focus group 4, participant 6)
24. Offers reassurance	“*Need to be reassuring and hopeful”* (Focus group 7, participant 1)
25. Timely	“*Most important to give feedback on timekeeping”* (Online survey, participant 6)
26. Kind	“*Kind attitude”* (Online survey, participant 3)
27. Dedicated	“Interviewer: what matters most to you in a psychiatrist? Participant 1: *One that’s dedicated”* (Focus group 2, participant 1)
28. Knowledgeable	“*To be knowledgeable in medicine”* (Focus group 6, participant 2) *“To be well versed and knowledgeable in the subject”* (Interview,3)
29. Attentive	“*Someone whose attentive”* (Interview,3)
30. Fair	“*Fair”* (Focus group 3, participant 4)
31. Doesn’t make patients feel rushed	“*Somebody who makes you feel like you’ve got time”* (Focus group 5, participant 6)
32. Offers help	“*Let me help you…”* (Focus group 2, participant 5)
33. Offers hope	“*Needs to be reassuring and hopeful”* (Focus group 7, participant 1)
34. Passionate	“*Be passionate”* (Interview,3)
35. Authentic	“*There’s something about being authentic”* (Focus group 5, participant 3)
36. Enthusiastic	“*Enthusiastic, it’s good that someone has enjoyment about what they talk about, as long as they have passion”* (Interview,3)
37. Gentle	“*Somebody who’s going to listen to them, whose gentle with them”* (Focus group 1, participant 1)
38. Helpful	“*Helpful”* (Interview,1)
39. Modesty	“*Have some modesty”* (Focus group 1, participant 1)
40. Person-centred	“*It’s that compassion, understanding, person-centred”* (Focus group 2, participant 2)
41. Polite	*“Polite”* (Focus group 2, participant 5)
42. Reliable	“*Reliability”* (Online survey, participant 6)
43. Sympathetic	“*What matters most to me in a psychiatrist is sympathy”* (Online survey, participant 6)
44. Tolerant	“*Suppose you have to be quite tolerant as well”* (Interview,3)
45. Warm	“*If they’re warm, they’re more likely to be someone whose relatable sort of thing”* (Interview,1)

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When encountered, participants often positively described the effects of the behaviours, attributes or skills identified. For example, as suggested by participant two:

> "*… compassion, being human, listening and valuing… people would never come back from him* [psychiatrist] *feeling dismissed, or misunderstood or unseen"* (Focus group 2, participant 2)

Conversely, participants who experienced their polarities described less favourable outcomes, often with long last effects as evidenced below:

> "*A psychiatrist has made decisions about my medication without consulting me… and it was a horrendous experience. It made me distrustful of the medical profession for years after and I even remember the name of that psychiatrist as clear as if it were yesterday."* (Focus group 8, participant 1)

Similar to cycle two, desirable behaviours were often described simultaneously. For example, as suggested by participant one in focus group six, "*I think listening, as well as compassion and empathy are key"* (Focus group 6, participant 1)

Only two participants identified *"knowledge"* (Focus group 6, participant 2) as a desirable behaviour, attribute or skill. Most behaviours focused on:

> "*Interpersonal skills, the listening, the communicating, the treating you as an individual, the respecting you,"* (Focus group 1, participant 3)

Such attributes are frequently associated with patient-centred care and the relational as opposed to transactional nature of relationships.

5.3.3 Motivations for providing patient feedback

Following the description of conducive behaviours, participants also described a number of motivations for providing patient feedback as reported in Table 17.

Table 17 Identified motivations for providing patient feedback from a patient perspective, presented in order of frequency

Motivations	Verbatim examples
Knowing feedback had been heard, used and acted upon when required	"*Knowing it was going to be used would be a motivation… knowing it changed something for the better"* (Online survey, participant 5); "*Knowing it's going to have an effect rather than just being another tick box exercise"* (Focus group 7, participant1)
Quality improvement and service failure prevention for others	"*I would give feedback if I thought it would improve mine, or others experiences"* (Online survey, participant 9), "*Knowing it was going to be shared with the health care professionals involved to improve care for everyone"* (Online survey, participant 6)
Professional development	"*I think if it was presented as part of their learning, their professional development then actually that's the motivation, because that's what it is basically. It's not feedback about how the service is running, it's about them as a professional individual"* (Focus group 2, participant 4); "*I think if you had it under the auspices of professional improvement that, it's ok, if you had a bad experience then it's to help them improve"* (Focus group 7, participant 3)
Opportunity to praise	"*It's not just about negative things, it's also about the positives, because there are some psychiatrists that do fantastic work and we want to shout out about it and share that example and I think that should be encouraged because that in itself, could highlight areas of good and bad practice"* (Focus group 6, participant 1)
Patient empowerment and partnership	"*It would also start to bring everything onto an equality basis, because then you're actually giving me advice, you're part and parcel of this process… the journey becomes one they are both involved in and that would bring enormous benefits"* (Focus group 1, participant 9).

Motivations most frequently described by participants included knowing that their feedback had been responded to. Some participants described a desire for "*feedback on the feedback"* (Focus group 3, participant 5), or "*receiving a thoughtful reply"* (Online survey, participant 6), echoing findings from cycle two and the importance of the co-produced response framework previously described.

The presence of a feedback loop was seen as a way of demonstrating that feedback had been listened too, helping to justify "*the time spent filling in questionnaires"* (Focus group 3, participant 6). For example, as suggested by participant seven:

> "*If you've gone through the trouble of providing feedback, it would be nice to hear what's changed, how that's been received and what is being put in place to prevent it from happening again, rather than it goes off into the ether and you never hear anything back."* (Focus group 5, participant 7)

Other motivations that were repeatedly reiterated by participants included the opportunity to praise, facilitate empowerment and partnership working. However, perceptions of a tick box exercise was often described as a deterrent to patient feedback engagement and perceived value as outlined below.

5.3.4 Perceived problems with existing patient feedback tools

While all participants acknowledged the importance and desire to provide patient feedback, many participants identified concerns with the two most commonly used patient feedback tools. Concerns most commonly described by participants related to five key areas: i) design and accessibility, ii) content, iii) processes and systems, iv) perceived purpose and v) frequency of opportunity. Each theme is discussed in turn below with a summary of findings provided in Table 20.

Design

Lack of a feedback loop

As previously alluded to, participants frequently described the lack of a feedback loop as a significant flaw in existing patient feedback design. For example:

> "*People do this and they never hear a thing about it, nothing changes"* (Focus group 3, participant 5)

> "*We give feedback and then what happens? We never hear any more"* (Focus group 1, participant 5)

Some participants also alluded to feedback fatigue as suggested by participant ten below:

> "*Everywhere you go now, before you come out of hospital you'll get somebody come round with about five sheets how did you get treated? What did you think of the staff? What could we do better? I filled in all of that lot… three weeks later nothing had changed, they still brought the same letter around*" (Focus group 2, participant 10)

However, having the opportunity to provide feedback on more mundane aspects of everyday life such as mobile phone, or internet banking experiences but not psychiatric care was challenged by some participants. For example:

> "*Why should food and cars and everything in life be graded but psychiatrists work not?"* (Focus group 4, participant 2).

Tick-box design and feedback classification

Other critiques of the two most commonly used patient feedback tools for revalidation purposes included their intimidating *"tick-box"* design:

> "Participant 1: *It feels intimidating*
> Participant 2*: too formal, too long*
> Participant 3: *feels like your A levels*
> Participant 1: *extremely mechanical"* (Focus group 3)

The dominant view of patient feedback as a tick-box exercise was at times attributed to its association with medical revalidation as opposed to intrinsic, or educational motivations. As suggested by participant eight, this often resulted in some participants questioning the motivations behind patient feedback collection:

> "*You need to go back a step and see why do you need to collect this feedback? Is it because you need to meet the revalidation requirements? When actually it is about improving your practice, your skills, you as a psychiatrist…. when it's feedback you gather because the revalidation requires you to tick a box and they, the GMC, look at it and say 'well you've got your feedback' and they tick a box, it's a fruitless, poisonous tree because it's coming out of revalidation. It should be coming out of you wanting to improve as a clinician."* (Focus group 4, participant 8)

Current definitions of what constitutes as meaningful patient feedback was also repeatedly questioned by participants, with the current design of existing feedback tools considered to be counterintuitive to quality improvement and professional development:

> "*I think the psychiatrist would learn a lot more about the patient if after every question there wasn't four tick boxes, if there was somewhere where you could put a sentence together, in the patient's own words, because I think they'd be able to understand the patient a lot better"* (Focus group 3, participant 4)

Feedback authenticity:

> "*I'd prefer to have something short and large comment boxes so I could freely write about my experiences rather than tick lots of boxes that don't really feel like I can express my feedback"* (Online survey, participant 7)

And response bias:

> "*The tick box thing, that's used for everything, I think it just encourages people to smack something off really quick and not care about it"* (Focus group 3, participant 5)

Importantly, narrative comments or "*anecdotal feedback"* was considered to be "*a powerful thing".* As stated by one participant, *"it gives us a voice"* (Focus group 1, participant 1)

Positioning, number and size of free text comments

The positioning, number and size of free text comments used in existing feedback tools was also identified as particularly problematic by participants. For example:

> "*It's* [free text box] *quite small and at the back, by the time you get there you've switched off"* (Focus group 3, participant 3)
>
> "*It's on a scale of 1-5, tick, tick, tick, tiny little text box…"* (Focus group 1, participant 5)

Content

Question relevance, value and accessibility

Participants also repeatedly quizzed the relevance, accessibility and value of existing questions *"that don't ever change"* (Focus group 2, participant 1). As questioned by participants five and one:

> "Participant 5: *Are they,* [existing questionnaires] *measuring the issues that we feel are important?*
> Participant 1: *exactly*
> Participant 5*: As opposed to ones that somebody has already decided?"*
> (Focus group 6)

Other participants questioned why they couldn't "*just put down what you feel, rather than having to comply with what they want?"* (Focus group 1, participant 7). Concerns of content value, accessibility and acceptability appeared to be exacerbated by unclear wording and unhelpful phrasing. For example:

> "Participant 2: *I keep seeing the word doctor but I thought this was for psychiatrists?*
> Participant 5: *Yes and that's confusing right from the start*
> Participant 2*: If it had the word psychiatrists that would be easier*
> Participant 5: *Or even the name of your psychiatrist*
> Participant 2: *That would be better*
> Participant 6: *Provides useful information about my care and treatment when I need or ask for it?*
> Participant 5: *When I need and ask for it? Don't you always need it?*
> Participant 6: *Perhaps you don't need that second part of the question…"*
> (Focus group 3)

Questions that were described as particularly irrelevant by the majority of participants included questions about a doctor's ability to remain calm under pressure, the provision of information when a patient 'needs or asks for it', the importance of patients' health and wellbeing for attending their appointment (GMC tool only) and assessment accuracy (GMC tool only).

Processes and systems

Many participants also expressed concern at existing patient feedback processes and systems, particularly a fear of repercussions as identified below.

“A fear of repercussions”

“*A fear of negative repercussions*” (Focus group 1, participant 8) or “*fear of it* [honest patient feedback] *adversely influencing treatment”* (Online survey, participant 6) was described as a significant barrier to patient feedback engagement or authenticity. As demonstrated in Table 18 below this issue was repeatedly discussed by participants at length.

Table 18 Fear of repercussions and verbatim examples

Theme	Verbatim examples
Fear of repercussions	“*There’s one word that keeps coming up and it’s fear, people fear making the report”* (Focus group 5, participant 7) “*If it is bad, are you essentially being labelled as a bad, or difficult patient?...you have to comply because if not, you’re not going to get out, you’re not going to see your kids”* (Focus group 4, participant 9) *“It would leave a doubt in my mind, if he’s not allowing me out again, is it because I said something against him, I couldn’t help feeling that”* (Focus group 3, participant 3) “*People are really worried about using it* [feedback tool] *because people think it will have an impact on their care”* (Focus group 3, participant 5) “*You are putting yourself out there, there is a risk of if I say this, will I get worse treatment?*” (Focus group 6, participant 6) “*It’s very difficult because whether you’re the patient or the carer, whose in a unit, or under a psychiatrist, there are sometimes when you feel it would be unsafe to give negative feedback. I have been in that situation… I really wasn’t happy to give negative feedback, when my child was left alone 250 miles away from home with those staff members for long periods of time”* (Focus group 6, participant 7)

As a result, participants often suggested that they would falsify their feedback to avoid such repercussions. For example:

> "*I would actually tell white lies, I would have to"* (Focus group 7, participant 3)

> "*Positively altering what I say, that would be better than negatively feeding back to worsen my treatment"* (Interview 2)

A fear of repercussions for psychiatrists due to a litigious and regulatory culture was also identified by participants:

> *"There's a fear of this blame culture isn't there, where people are too worried about saying sorry because you know, litigation, taken to court and so we've lost that…doctors, medical students can't actually say sorry this has happened to you without that suddenly becoming a major legal problem. I think for that to happen there needs to be trust and acceptance on both sides, because we're too much into this litigious culture which is restricting how we feel and think"* (Focus group 8, participant 6)

As a result, one participant described this phenomena as a circle of fear:

> "*We've missed the point… psychiatrists are equally fearful of what patients would say in their feedback and they are almost looking for reassurance that the feedback they give isn't going to cause them to lose their licence. There's a circle of fear there really isn't there? But again, maybe this is where it needs to go back to real grass roots and maybe this whole criteria needs to be relooked."* (Focus group 1, participant 5)

Challenges to the value and credibility of patient feedback

Building on the fear of repercussions described above, some participants questioned a perceived bias in patient feedback tool design:

> "*This one is designed to get reasonable results*" (Focus group 7, participant 3)

Biased patient feedback responses:

> "*It would affect my honesty… I would be very wary, very careful about what I say"* (Focus group 8, participant 1)

And the 'pathologisation' or rejection of patient feedback due to assumed vulnerabilities following a psychiatric diagnosis:

> "Participant 4: *are they going to excuse that* [patient feedback] *by saying, 'oh well the patient is particularly paranoid'?*

> Participant 5: *yes, you become your diagnosis then don't you? That's their illness, so of course they're going to say that"* (Focus group 1)

The pathologisation of patient feedback was repeatedly discussed by participants as outlined below by participants thirteen, five, four and ten:

> "*As a patient it is too often the case that any negative feedback is taken as a symptom of illness. Feedback that is thrown back at you on a regular basis makes giving feedback in the future seem at best pointless and more often, a damaging and dangerous thing to do"* (Online survey, participant 13)

> "*I think that's another concern. Will it be taken seriously? Will our illness affect the way people respond to that feedback?"* (Focus group 4, participant 5)

Similarly:

> "*They're only looking to confirm what they already think because that's what the person with this diagnosis is likely to do …. Doctor knows best this is what I think and discredit the person and actually pathologise, it's only because of your mental health problem that you're speaking like that and you're thinking like that"* (Focus group 5, participant 4)

> "*I think quite easily sometimes, normal behaviour can be pathologised can't it?"* (Focus group 5, participant 10)

Furthermore, participants perceived an opportunity for health care professionals to "*game*" existing patient feedback tools through biased patient selection. For example, as suggested by participant six:

> "*I'll choose this one and this one because they always come to their appointments on time, they listen to what I say, they take the right medication, they behave themselves, so they're going to give me good feedback… it's outrageous"* (Focus group 8, participant 6)

Furthermore, echoing findings from cycle two, participants also described a number of factors that were often external to the individual psychiatrist yet highly influential in their experiences of psychiatric care. A list of the external factors described by participants is provided below in Table 19.

Table 19 Factors identified as influential to psychiatric care experiences but external to the psychiatrist

External factors considered influential in psychiatric care experience	Verbatim example
Funding and its subsequent impact on access	"*The treatment you get is tempered by economics and funding, it's a postcode lottery… it depends on where you are"* (Focus group 8, participant 1); "*I was waiting seven months by which time I'd fully internalised my issues"* (Online survey, participant 12)*; "you can't get help in your ten minutes"* (Focus group 3, participant 5)
Psychiatrist workloads	"*You can't separate the feedback to the psychiatrists as opposed to feedback to the system in which the psychiatrist operates… so if the psychiatrist isn't giving you enough time, it's maybe because his, or her workload is too great."* (Focus group 6, participant 5)
A perceived drive to "*discharge"*	"*Sometimes it feels like they want to do is discharge you as soon as possible so they can hit all of their relevant targets"* (Focus group 1, participant 5)
Political and geographical influences	"*An issue I've found more since the Tories have been in power… they just want to get rid of you now"* (Focus group 1, participant 2);
Lack of continuity	"*Every time you see a different one, it's like opening the wounds again and again and again"* (Focus group 1, participant 5)
The environment	"*I think one other important things as well is environment, its scary going to an office or somewhere like that, somewhere quiet, formal, clinical, cold. Turn it into a lounge, put an armchair in… you're going to feel so much more at ease… I was in a chair with three psychiatrists in front of me like I was on a board for an interview… and I honestly just felt so intimated, totally intimidated… I felt like I was under the microscope, all the problems one has just gets worse and worse"* (Focus group 1, participant 5). This contrasted against a positive description of a non-clinical environment where one focus group was being held: "*The first time you come here where do you go? You go into that little room. There's no desk, you're not sat there like this* [mirrors gap between two people with legs crossed] *you sit together on the sofa, there's no people taking notes, no cameras up in the corners…"* (Focus group 2, participant 6)
Psychiatrist variability	"*It's a really random thing which psychiatrist you get and which way they do it"* (Focus group 1, participant 11); "*What disturbs me is how much depends on the personality of the psychiatrist you're seeing, because I've had both extremes. I've had horrendous experiences and wonderful experiences, even within the space of a number of months"* (Focus group 8, participant 1)

Restrictive diagnoses and subsequent access to care pathways	"*The problem is, is that diagnosis actually determines your care pathway through the Trust, the actual process. If there was a pathway that CBT may do someone really good, but there's not the pathway there because you've got the wrong diagnosis"* (Focus group 7, participant 3)
Lack of joined up working between services	"*There's a lack of joined up working, if they're not talking to each other, how on earth can that decision be in the patient's best interest?"* (Focus group 1, participant 10); "*Why aren't they communicating with each other? And giving an overall service instead of giving you that bit, him that bit, him that bit, you can have the drugs, I find it very disjointed"* (Focus group 2, participant 5)

Perceived purpose

In addition to the concerns outlined above, participants identified a lack of understanding regarding the intended purpose and use of patient feedback tools for revalidation purposes. Specifically:

> "*What do they do with that feedback? What happens to that feedback?"* (Focus group 2, participant 5)

> "*We don't have enough information here to help us understand"* (Focus group 6, participant 6)

Participants also frequently expressed scepticism about the desire of psychiatrists to change and learn following patient feedback activities. As questioned by participant four:

> *"Is it an exercise where they're actually wanting to learn? They're wanting to improve care, wanting to improve practice? Or is it just a tick box exercise to impress the CQC or whoever?"* (Focus group 5, participant 4)

A perceived resistance to feedback acceptance from psychiatrists was at times attributed to age and a challenge to traditional psychiatric practices by participants. For example:

> "*We've* [patients] *never actually had a professional wanting feedback on their professional conduct, I think I might have had it once in my life."* (Focus group 2, participant 4)

Frequency of opportunity

Following this, participants expressed concern and disappointment at the lack of opportunity to provide patient feedback for revalidation purposes. As suggested by participants three and seven:

> "Interviewer: *currently doctors are required to collect a set amount of questionnaires at a minimum of once every five years*
> Participant 3: *Well there's an obvious issue there?*
> Participant 7: *That's not reflective of their practice, that's rubbish"* (Focus group 1)

Similarly:

> "*I'd love to give feedback, but I've never been asked for it"* (Focus group 6, participant 1)

A lack of opportunity appeared to have important implications for the perceived value and credibility of patient feedback tools with current requirements described as "*laughable",* (Focus group 5, participant 4) and "*frankly unsatisfactory"* (Interview,1). In one instance, revalidation was described as "*invalidating"* (Focus group 5, participant 5) of the patient experience and voice.

Given the extensive data reviewed, a summary of concerns with existing patient feedback tools described by participants is provided below in Table 20.

Table 20 Summary of problems with existing patient feedback tools as described by patient participants

Identified concern	Sub theme	Verbatim examples
Design	Lack of a feedback loop	"*People do this and they never hear a thing about it, nothing changes"* (Focus group 3, participant 5); "*People get fed up because, they say nothing ever changes and often it's a really valid point"* (Focus group 2, participant 2); "*some of these issues impacting patient care go back decades and haven't changed. You end up thinking 'what's the point in saying anything?' Nothing is going to change*" (Online survey, participant 12).
	Tick box design	"*It's very much a tick box exercise"* (Focus group 4, participant 8) "*It's as if the human being only falls within a certain range and only has a certain number of parameters and this is what I don't like about questionnaires"* (Focus group 8, participant 8)
	Positioning, number and length of free text comments	"*It's* [free text box] *quite small and at the back, by the time you get there you've switched off"* (Focus group 3, participant 3) "*It's on a scale of 1-5, tick, tick, tick, tiny little text box…"* (Focus group 1, participant 5)
Content	Relevance, value and accessibility of questions	"Participant 1: *Remains calm under pressure? Random and not really relevant* Participant 6: *not relevant no"* (Focus group 3) "*I mean assessing your medical condition? Well if you go to him or her without knowing your medical condition and he comes up with a medical condition is that a true statement that he's assessed it?* [Laughs] *If you didn't know in the first place? So it's assuming that you know what your medical condition is in the first place…"*(Focus group 7, participant 3)
	Forced compliance with existing content	"*Why can't you just put down what you feel, rather than having to comply with what they want?"* (Focus group 1, participant 7)
	Unclear wording and unhelpful phrasing	"*Please base your answers on the consultation you've had today, the wordings dodgy, like I said you don't see the psychiatrist on a daily basis, so that's a bit confusing, just change it to the last time you met, that would be a bit easier"* (Focus group 7, participant 1) "*I don't know what it means, how important is your health and wellbeing? I don't know it just doesn't make any sense to me, I can't make any sense of that"* (Focus group 3, participant 1)

Processes and systems	A fear of repercussions for both patients and psychiatrists	“*If it is bad, are you essentially being labelled as a bad, or difficult patient?...you have to comply because if not, you’re not going to get out, you’re not going to see your kids”* (Focus group 4, participant 9) “*It’s very difficult because whether you’re the patient or the carer, whose in a unit, or under a psychiatrist, there are sometimes when you feel it would be unsafe to give negative feedback. I have been in that situation… I really wasn’t happy to give negative feedback, when my child was left alone 250 miles away from home with those staff members for long periods of time”* (Focus group 6, participant 7) “*I would actually tell white lies, I would have to”* (Focus group 7, participant 3)
	Challenges to the value and credibility of patient feedback	Bias in patient feedback design - “*this one is designed to get reasonable results*” (Focus group 7, participant 3) Bias in patient feedback responses - “*it would affect my honesty… I would be very wary, very careful about what I say”* (Focus group 8, participant 1) Feedback pathologisation - “*As a patient it is too often the case that any negative feedback is taken as a symptom of illness. Feedback that is thrown back at you on a regular basis makes giving feedback in the future seem at best pointless and more often, a damaging and dangerous thing to do”* (Online survey, participant 13) “*That’s the whole point, some might disregard feedback completely and make an assumption that people are too poorly”* (Focus group 8, participant 1)
	Biased patient selection	“*If he’s got two patients who he finds difficult and then he’s got two that like him and he knows that, then he’s going to choose them isn’t he. It’s like self-censorship isn’t it?”* (Focus group 3, participant 1)
Perceived purpose	Lack of clarity and understanding	“*What do they do with that feedback? What happens to that feedback?”* (Focus group 2, participant 5)
Frequency of opportunity	Lack of opportunity	“*I’d love to give feedback but I’ve never been asked for it”* (Focus group 6, participant 1) “*I’ve been doing this role* [advocate] *for eight years and not once have I seen that form come out, not once, so are they picking and choosing who they ask?”* (Focus group 1, participant 9)

	Lack of frequency and perceived value	“*What would make patient feedback useful or meaningful to you? The ability to feedback would be a good start wouldn’t it?* (Focus group 4, participant 2) “*It’s laughable once every five years, it’s laughable”* (Focus group 5, participant 4)

5.3.5 Patient feedback and its relationship to power, culture and language

Underpinning many of the concerns raised by participants were notions of power, culture and language. Participants frequently described a perceived power imbalance between the social and cultural positioning of patients and psychiatrists as outlined by interviewee one below:

> *“They have a hell of a lot of power, they have more power than the Police, I mean if you think about it they can actually come into your house, you have no right to a solicitor or social worker present and they’ll say, ‘oh you’re not very well, we’re going to lock you up’ and they can just do it. You haven’t got a trial like you have if you were a criminal in prison. If you’re a person who’s been sectioned under the mental health act, they can lock you up, no questions asked…”* (Interview 1)

Power appeared to be a particular area of importance in participant discussions as outlined in Table 21.

Table 21 Verbatim examples of power discussions

“*I don’t think they quite understand the power they have over you… the power is tremendous really, they’re too elitist sitting on top of the pile, the amount of power they wield, it’s scary”* (Focus group 8, participant 1)
“It’s frightening how much power they’ve got. It seriously is” (Interview 1)
“They don’t want to work in partnerships with other professions” (Focus group 2, participant 4)
“He said, ‘my dear, they are guidelines, they are not policy, if I don’t choose to follow them, then I don’t choose to follow them’” (Focus group 1, participant 4)
“*It comes back to how psychiatrists, or some psychiatrists view their role, they think they’re too high and mighty I think”* (Focus group 1, participant 7)
“The psychiatrist is always known as the responsible clinician, so therefore he takes the final responsibility, but when you talk in terms of multidisciplinary team meetings and decisions, that’s what it should mean, it should mean a multidisciplinary team decision and agreement but I have known again in my own personal situation where there have been team meetings and maybe a few people have challenged the psychiatrist’s decision but the psychiatrist overrules and makes that decision” (Focus group 1, participant 4)
“*In hospitals you see them, the psychiatrist walks into the room and everyone sort of suddenly bows down and all these staff start running around…. Their behaviour changes around psychiatrists…. unfortunately even the staff are intimidated by psychiatrists…. the minute the psychiatrist is in the room, everything changes, it’s just unreal”* (Interview 1)
“*I think the reality is, is that there’s a bit of culture on the wards where the psychiatrist is kind of above everyone else”* (Focus group 4, participant 1)

In one instance, a participant directly warned the researcher about anticipated power struggles she was likely to face:

> "*You're up against a very powerful, a very powerful institution, very powerful. If you think about the power these people have… You don't get to go to court like a criminal does, they have a lot of power believe you me…"* (Interview 1)

Participants repeatedly described a perceived *"level of dominance"* (Focus group 4, participant 3) by psychiatrists, causing the majority of participants to view their role as passive and confined by an inability to challenge or influence change.

Language

Notions of passivity were also reflected in the language used by participants. In all focus groups, participants described being "*under"* a psychiatrist (underlining added by the researcher for demonstration purposes):

> "*The psychiatrist that my son has been under and is still under"* (Focus group 1, participant 5)

> "*All my life I've been underneath a psychiatrist"* (Focus group 1, participant 3)

> "*Thankfully I haven't been under him since I was first admitted"* (Focus group 3, participant 3)

> "*It's very difficult whether you're the patient, or the carer of the patient, who's under a psychiatrist"* (Focus group 6, participant 7).

When asked why participants used the word under, one participant replied:

> "*Because he's on the professional side, he's the top, you're under, he can make decisions about your life, about your stay here, where you go, where you move on, how fast you progress, so you are under him really"* (Focus group 3, participant 4)

Language was also often discussed in conjunction with perceived inequality, accessibility and exclusion. For example, as stated by participant four:

> "*For me they need to ask more questions because you present yourself knowing there is something, but you haven't got the language to explain what's going on… from my experience as soon as I've learnt the right*

> *language* [that used by psychiatrists] *I can tell them"* (Focus group 2, participant 4).

For one participant, the need to learn the 'right' language, i.e. that used by psychiatrists, as opposed to using a language that was accessible to all appeared particularly odd:

> "*So this is something* [participant X] *and* [participant Y] *is saying as well, you just said that since you've learnt to speak the language things have been different and it strikes me if we're asking about what would be good, what do you want from a psychiatrist? Would it be something about them speaking your language? Not you speaking theirs?"* (Focus group 2, participant 2)

5.3.6 Solutions

Finally, participants described a number of potential solutions (Table 22) that often related to improving existing patient feedback design, content, processes and information provision.

Having a mixture of qualitative and quantitative questions that focused on both critique and praise was considered to be important, as quantitative questions on their own were described by participants as "*essentially meaningless"* (Focus group 1, participant 7). The size and positioning of free text comments underneath the majority of quantitative questions was also seen as a way to disrupt habitual ticking. Other suggested solutions included a repeated focus on increasing the frequency of feedback opportunities, helping to ensure the provision of patient feedback was patient initiated as opposed to psychiatrist, or policy dependent.

The information and message portrayed in patient feedback tools was also considered to be of paramount importance, with a particular emphasis on empowerment. For example, as suggested by participant four:

> *"If it was presented as we're* [patients] *doing them* [psychiatrists] *a favour, it is more to do with, 'we need your help' not the other way round."* (Focus group 2, participant4)

Providing assurances of anonymity to alleviate an acknowledged “*fear of negative repercussions”* (Focus group 1, participant 4) was also seen as integral, as was providing information on how “*to give feedback that is specific”* (Online survey, participant 11) or “*constructive, give ideas/ways of improving”* (Online survey, participant 9). Finally, participants also acknowledged a desire for future patient feedback tools to be “*be designed in co-production”* (Online survey, participant 9) with both patients and psychiatrists.

Table 22 Suggested solutions to improve the value and acceptability of existing patient feedback tools

Solution theme	Specific suggestion	Verbatim examples and description
Design & content	Be designed in co-production	“*Be designed with co-production”* (Online survey, participant 9); “*Have they involved people actually in their work rather than just by survey”* (Online survey, participant 8)
	Make things easy to understand	“*Simple, easy to read and understand”* (Focus group 1, participant 4)
	Use the word psychiatrist	Use the word “*psychiatrist or even the name of the psychiatrist”* (Focus group 3, participant 2)
	Provide “*flexibility*” (Focus group 7,pt1) and “*choice*” (Focus group 3,pt3) in “*how people do it*” (Focus group 1,pt1)*Please see Appendix 9 for a list of all identified feedback methods, their strengths and limitations from a patient perspective	“*I think it should be open to the individual, some people might want to fill in a form, some people might want a conversation, someone might want to send a text, just ask the person how would you like to give it? And have everything in place*” (Focus group 7, participant 3)
	Have “*a mixture of both”* (Interview,2) qualitative and quantitative measures while remaining sensitive to length	“*The use of multiple choice questions alongside a couple of open ended ones is more appealing and likely to get more responses”* (Online survey, participant 10)
	Provide sufficient space for free text comments	“*I’d prefer to have something short and a large comments box so I could freely write about my experiences rather than tick lots of boxes that don’t really feel like I can express by feedback”* (Online survey, participant 7)
	Place multiple choice questions “*underneath”* (Focus group 1,pt7) free text comments to disrupt habitual ticking	“*Underneath”* (Focus group 1, participant 7)
	Ensure understanding of any scales used	“*What’s poor, what’s less than satisfactory?*” (Focus group 3, participant 6)
	Provide space for both critique and praise	“*Encourage to give balanced feedback”* (Online survey, participant 11)
	Make it “*colourful”* (Focus group 8,pt1)	“*Make the actual thing interesting”* (Focus group 7, participant 1)
	Make space for carer and family member input	“*It would be good to be all in one* (Focus group 1, participant 6)

	Incorporate pictures where possible to aid understanding	“*Some more pictures, I keep going on about this Makaton it’s a way of using words and pictures”* (Focus group 3, participant 2)
	Keep it “*reasonably short”* (Focus group 1,pt6)	“*Reasonably short”* (Focus group 1, participant 6)
Process	Build in a “*feedback loop*” (Interview 1)	*“I think the most important thing, is feedback back to the people who gave their comments, I’ve given up my time to give feedback, what are you going to give back?”* (Focus group 1, participant 5); “*Simple you said we did approach”* (Online survey, pt2)
	Provide “*reassurance of anonymised”* (online survey, pt10) and *“confidential”* (Focus group 4,pt3) feedback processes	“*Reassurance of anonymised”* (Online survey, participant 10); *“confidential”* (Focus group 4, participant 3)
	Offer help to complete feedback questionnaire	“*Maybe something could be put in there, after are you filling in this questionnaire for yourself, child, spouse or other relative? right at the beginning, do you need help filling in this questionnaire”* (Focus group 3, participant 3)
	Provide an anonymised return system or process	“*Maybe a free post envelop”* (Focus group 1, participant 5) or “*box in the waiting room”* (Focus group 1, participant 4)
Frequency of opportunity	Enable feedback to be patient initiated	“*Patient initiated”* (Focus group 5, participant 2) not psychiatrist dependent so patients have the opportunity to provide feedback “*at any time”,* (Online survey, participant 11); “*consistent requests”* (Online survey,pt2)
Definitions	Reconsider what constitutes as ‘valid’ patient feedback	
Information provision	Improve information provision about:	- It being a “*choice”* (Interview 1) to complete - Assurances that “*your treatment won’t be compromised in anyway because of whatever you said”* (Focus group 7, participant 3) - What timeframes or interactions patients should base their feedback on, “*I always assume it’s about the last time I spoke to the psychiatrist but that’s not made clear enough”* (Focus group 3,p participant) - What it’s going to be used for, “*because then you’ve got a bit of an idea about what you’re contributing to, people will be more likely to fill it in because they can see it’s going to be used”* (Focus group 3, participant 1)- “*How this feedback is going to be used”* (Focus group

Information provision (continued)	Improve information provision about: (continued)	3, participant 6); “*What do they do with that feedback? What happens to that feedback”* (Focus group 2, participant 5) - “*Who is going to have this information”* (Focus group 3, participant 2) and where it will appear, “*I would like to know whether it’s going to appear on my case notes”* (Focus group 8, participant 1) - The benefits and importance of patient feedback for both patients and psychiatrists, “*It’s got be communicated to the patient that their feedback is important, you know there are benefits to you for filling this form in”* (Focus group 1, participant 9);*“ If a psychiatrist actually was giving the message it’s really, really beneficial for both me and you that you fill this in because then if I’m not getting it right, I can look at how I can get it right”* (Focus group 1, participant 4) - Advice or information about how to make patient feedback effective, “*We ultimately want to give feedback because we want something to change and actually, providing feedback is really, really important, this is how you can best ensure that your feedback is effective as possible”* (Focus group 6, participant 6)

Participant suggestions were developed into a co-designed patient feedback checklist with the patient research partner. Figure 6 outlines the checklist created as a result of the solutions suggested by participants.

Participant suggestions	**Checklist**	**Yes/No**
Content		
Use the word "*psychiatrists or better yet the name of the psychiatrist"*	Does the tool use the word psychiatrist or name of the psychiatrist?	Yes/No
Provide space for praise and critique "*encouraged to give balanced feedback"*	Does the tool ask for balanced or positive and critical feedback?	Yes/No
Provide reassurance of anonymity and confidentiality	Does the tool provide reassurances about feedback being anonymous and confidential?	Yes/No
Use scales that are easy to understand	Are the scales used for the multiple-choice questions easy to understand? Are they clear/purposeful?	Yes/No
Provide space for carer and family member input** - either, are you filling this in as a patient or family member/carer **or** if you have/are a carer or family member and would like to provide some feedback, please use the space provided below.	Does the tool allow for carer/family member input?	Yes/No
Provide information that it is a "*choice"* to complete	Is it clear that it is a choice to complete the tool?	Yes/No
Provide assurance "*that your treatment won't be compromised in anyway because of what you say"; "there won't be any repercussions"*	Does the tool provide assurance that peoples care will **not** be affected by the content of their feedback?	Yes/No
Provide information about timeframes or what interactions patients should base their feedback on: "*I always assume it's about the last time I spoke to the psychiatrist but that's not made clear enough"*	Is the timeframe patients should be basing their feedback on, (i.e. their last interaction, the last six months, their first interaction etc.) made clear?	Yes/No
Provide information about what it is going to be used for: "*How will this feedback be used? What do they do with it? What happens to it?"; "case notes?"*	Is information provided about how the feedback will be used? Is this explanation clear?	Yes/No Yes/No
Provide information about the importance of patient feedback for both patients and psychiatrists "*it's got to be communicated that their feedback is important, you know there are benefits to you filling this form in"; "if a psychiatrist actually gave the*	Is the importance of patient feedback for both patient care and psychiatrists explained? Is this explanation clear and meaningful?	Yes/No Yes/No

message it’s really, really beneficial for both me and you that you fill this in because…”		
Provide information or advice on how to make patient feedback effective “*encourage feedback that is specific”; “constructive, give ideas/ways of improving”*	Does the tool make it clear about how to give effective feedback?	Yes/No
Layout		
Have “*a mixture of both”* word and number questions as “*the use of multiple choice questions alongside a couple of open ended ones is more appealing and likely to get more responses”*	Does the feedback tool have a mixture of both free text and multiple-choice questions?	Yes/No
Provide sufficient space for free text comments so “*patents can use their own words”; “I’d prefer to have something short and a large comments box so I could freely write about my experiences rather than tick lots of boxes that don’t really feel like I can express my feedback”*	Does the feedback tool provide sufficient space for free text comments?	Yes/No
Place multiple choice questions “*underneath”* free text comments to disrupt habitual ticking	Are the multiple choice questions underneath the free text comments?	Yes/No
Make it colourful – “*make the actual thing interesting”*	Is the patient feedback tool colourful?	Yes/No
Incorporate pictures where possible	If possible, does the patient feedback tool include pictures?	Yes/No
Process		
Provide flexibility and choice about how and when people do it	Do patients have a choice about how and when they complete the feedback?	Yes/No
Being able to submit the feedback in an anonymised way “*free post envelope, box in the waiting room”*	Can patients freepost their questionnaire/leave it in a waiting room or designated area?	Yes/No
Allow feedback to be “*patient initiated”* not psychiatrist dependent – “*feedback at any time”;* “multiple opportunities”	Is the patient feedback tool available to patients at all times? Can they complete it independently of a feedback invitation?	Yes/No
Sense checking at the end		
Make things “*simple, easy to read and understand”*	Is it simple, easy to read and understand?	Yes/No
Keep it “*reasonably short”*	Is the patient feedback tool short?	Yes/No
Build in a “*feedback loop”*	Is there a feedback loop?	Yes/No

Figure 6 Co-designed patient feedback checklist incorporating patient suggestions and aspirations

5.4 Discussion

This research sought to explore patient perceptions, desires and aspirations for patient feedback tools in the revalidation of psychiatrists. Research findings identified a number of motivations for providing patient feedback including knowing feedback had been heard and would lead to change, quality improvement or service failure prevention for others, patient empowerment and the opportunity to praise. Participants also described a number of behaviours, attributes and skills they considered to be most conducive to the therapeutic relationship. Behaviours identified by participants often focused on the interpersonal skills of a psychiatrist and importance of being treated as an equal.

However, while participants repeatedly acknowledged the value and importance in giving patient feedback, participants identified a number of concerns with existing feedback tools. Concerns most frequently described by participants often related to feedback design, content, processes and perceived purpose. Participants repeatedly questioned the relevance, value and suitability of the two most commonly used patient feedback tools reviewed, regularly questioning whether the content of existing feedback tools measured the domains of care patients felt were of most importance, or the domains of care that had already been decided for them. Such findings echo the concerns raised in cycles one and two.

Participants also expressed dissatisfaction at the absence of a feedback loop, limited opportunities to praise, the positioning, size and infrequency of free text comments that allowed patients to construct their own narratives and the intimidating appearance of the feedback tools reviewed. Furthermore, participants viewed the mandatory requirement of patient feedback to be completed only once every five years as a tokenistic, tick box exercise that invalidated the patient experience. Such perceptions appeared to be enforced by a perceived focus on adhering to mandatory regulatory agendas, as opposed to intrinsic or educational motivations.

Finally, a fear of repercussions and perceived circle of fear for both patients and psychiatrists underpinned many of the concerns described by participants. Participants repeatedly acknowledged a risk of biased patient selection and responses as an unintended consequence of current patient feedback tools and processes. For example, some participants stated that they would, and have in some cases, falsify their feedback responses in order to minimise anticipated repercussions. Concerns of patient feedback being dismissed or pathologised as a result of psychiatric diagnoses and assumed vulnerabilities were also repeatedly raised by participants. Such concerns have been widely reported in mental health care more broadly (Berzins *et al.*, 2018). Concerns of feedback rejection or exclusion were often related to power, language and culture, with participants repeatedly acknowledging a disparity between the social positioning of patients and psychiatrists and the use of inaccessible language to sustain these differences. The practise of patients ‘learning’ the language of more dominant discourses in order to survive (Smith *et al.*, 2010) or be involved has been acknowledged in existing literature (Taylor & Sakamoto, 2009).

5.4.1 Comparison to existing literature

Some of the findings from this research mirror those in existing literature. For example, recent research suggests that the intended purpose of revalidation is unclear (Archer *et al.*, 2015; Tazzyman *et al.*, 2017), with some healthcare professionals dismissing revalidation as a bureaucratic, hoop jumping exercise that fails to deliver on assured promises of enhanced patient care and care quality (Archer *et al.*, 2016; Sir Keith Pearson, 2017; Tazzyman *et al.*, 2017). Although existing literature has typically focused on professional perspectives, as demonstrated in this research, perceptions of a tokenistic, tick box exercise are also evident among patient populations. Concerns of healthcare professionals being creative, or ‘gaming’ the system to provide more favourable patient feedback has also been reported by professionals (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020). Again, while previously focused on the professional perspective, such concerns appear to be strongly mirrored by patient perceptions as demonstrated in this research. Furthermore, although not new (Heneghan & Chaplin, 2016; Stickley, 2006; Szasz, 1994), the repeated discussion of power, existing cultures and language suggests such issues are still influential and experienced by participants. Some participants described a desire for a new language to be created that could be understood and accessed by both patients and psychiatrists.

While some participants acknowledged a desirable shift in patient empowerment through the provision of patient feedback, such feedback opportunities were often felt to be experienced too infrequently, if at all by participants. The requirement to collect patient feedback as part of the revalidation process was acknowledged as a challenge to existing power dynamics by participants and may help to explain a perceived lack of acceptance by psychiatrists. Reports of professional resistance and cynicism following such shifts in power and autonomy have been widely reported in existing literature as a result of mandating patient feedback collection (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017). Such findings accentuate the intricate interaction of professional, cultural and historical contexts in psychiatric care as previously described (Davies, 2001).

5.4.2 Contribution to new knowledge

However, while this research supports existing literature, it also contributes new knowledge in the following ways. Firstly, this research identified several motivations for providing patient feedback in psychiatric care for revalidation purposes that are not currently reported in existing literature. The opportunity and desire to praise psychiatrists appears particularly underreported in existing literature and contrasts against the more dominant discourse of psychiatric patients using patient feedback to leave factually incorrect or malicious comments as previously reported by Patel et al., (Patel *et al.*, 2015). Secondly, this research explored the domains of psychiatric care considered most conducive to the therapeutic relationship from a patient perspective, helping to address identified gaps in existing knowledge and understanding (Eiring *et al.*, 2015; Trujols *et al.*, 2013). Many of the behaviours, attributes or skills described by participants focused on the interpersonal skills of the psychiatrist and relational nature of relationships. For example, being listened to, treated as an equal and with respect. Clinical knowledge was only identified as important by two of the 77 participants involved. Patients have also attributed similarly low levels of meaning to clinical knowledge in other research studies (Taylor & MacRae, 2011). Knowledge was also not discussed in the examination of online reviews in cycle two providing further support for this conclusion. Thirdly, this research uniquely identifies factors that support and inhibit the perceived value and acceptability of the two most commonly used patient feedback tools in the revalidation of psychiatrists. Such findings are considered to be of importance (Gayet-Ageron *et al.*, 2011; Hill *et al.*, 2012), given the increasing use of patient feedback tools in regulatory decisions (Salmon & Pugsley, 2017). Finally, this research generated a co-designed checklist of patient aspirations for future patient feedback tools in the revalidation process (Figure 6). This checklist could be used to help ensure future patient feedback tools meet patient aspirations and desires identified in this research, helping to potentially enhance the value and meaning of patient feedback tools from a patient perspective. However, the impact of incorporating patient desires on the perceived value and acceptability of patient feedback tools needs to be explored and compared with professional aspirations and desires to identify any areas of commonality. This forms the focus of cycles four, five and six as later described.

5.4.3 Strengths and limitations

Strengths of this research include: the exploration of patient perceptions and desires using qualitative methods helping to address identified methodological limitations with existing research (Boardman, 2018; Crawford *et al.*, 2011; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a); inclusion of people with a range of psychiatric care experiences including psychosis, schizophrenia and bipolar disorder; exploration of in-patient experiences (Gill *et al.*, 2015); higher than anticipated sample size and confidence that data saturation had been achieved as previously defined (Eliacin *et al.*, 2015; Staniszewska *et al.*, 2014). Other strengths of this research include its co-production with a patient research partner. Informal feedback from participants suggests participants found the presence of the patient research partner to be positive and beneficial in addressing traditional power hierarchies of the researcher and 'researched'. Finally, this research includes three research methods (survey, interviews and focus groups), including one specifically requested by participants reflecting the adaptive and reflective nature of action research.

However, the limitations of this research must also be acknowledged. Firstly, despite using social media and email invitations, based on the demographic information voluntarily provided, the majority of participants identified themselves as white British, from South West or central England. Future research that explores and compares research findings with other ethnicities, and localities would be beneficial. Secondly, this research excluded people who could not understand or speak the English language due to resource limitations. The possibility of introducing response bias is therefore acknowledged as a limitation of this research. Thirdly, this research relies on a volunteer sample. Participants who took part in this research may not therefore be representative of the patient population. Finally, this research explores patient perceptions, aspirations and desires of patient feedback tools alone. Exploration of professional perceptions is also required to provide a holistic understanding (cycle four).

5.4.4 Implications

With these limitations in mind, the implications of this research are outlined below. Firstly, participants identified a number of issues with existing patients feedback tools used in the revalidation of psychiatrists, suggesting a clear need for improvement. Identifying ways to resolve these issues is imperative, as the continued use of ineffective tools has been shown to be detrimental to patient safety and quality of care (Thornicroft *et al.*, 2008). Secondly, many participants challenged the authenticity and subsequent value of existing patient feedback tools due to a fear of repercussions, bias patient responses and bias patient selections. As suggested in cycle one, the reliance on psychometric properties as an indicative measure of validity may therefore be unhelpful, with a broader definition of validity required (Downing, 2003). Thirdly, the intended focus, purpose and use of patient feedback in the revalidation of psychiatrists appears to be unclear from a patient perspective. Why is patient feedback being collected? What does it hope to achieve? And why is it collected so infrequently? The infrequency of collection, i.e. once every five years was described as ‘laughable’ by some participants, sending the perceived message, whether intentional or not, that patient feedback from a handful of patients was only worth exploring once every five years. Finally, efforts must be made to incorporate participant suggested solutions wherever possible and to examine whether the incorporation of such suggestions enhances the perceived value and acceptability of existing patient feedback tools.

5.5 Conclusion

In conclusion, participants identified a number of motivations and desires for providing patient feedback including quality improvement, patient empowerment and opportunity to praise. However, participants also identified a number of issues with the two most commonly used patient feedback tools for revalidating psychiatrists, identifying a clear need for change and development. Issues identified by participants often related to patient feedback design, content and processes, with a number of alternative suggestions provided. While it is vital to explore and understand the patient perspective, it is also important to understand the perspectives and experiences of psychiatrists. Failure to do so would mean we are at risk of perpetuating current practice that suggests one perspective is indicative of the other, helping to either sustain current hierarchical practises, or create a new hierarchy leading to additional causes for concern. Cycle four (chapter six) therefore seeks to explore the experiences, perceptions and aspirations of existing patient feedback tools from a psychiatrist’s perspective, with areas of commonality and divergence between patients and psychiatrists identified and compared in cycle five (chapter seven).

6.0 Cycle 4 - What are psychiatrist perceptions, attitudes and aspirations towards the two most commonly used patient feedback tools in the revalidation of psychiatrists?

6.1 Introduction

Building on the exploration of patient involvement in feedback design (cycle one), comparison of online reviews (cycle two) and patient experiences (cycle three), this research cycles seeks to explore psychiatrist experiences, perceptions and aspirations of patient feedback tools for revalidation purposes. While some research has explored psychiatrist perceptions (Baines *et al.*, 2019c; Heneghan & Chaplin, 2016), this has often been done using surveys or quantitative methods where opportunities for psychiatrists to freely express their experiences and suggestions have been severely limited. Furthermore, most of the limited research conducted in this area was undertaken in the first few years after revalidation implementation (Archer *et al.*, 2018). Given the requirement for patient feedback to be collected once every five years, at the time of Archer et al's., research, it is possible that many psychiatrists had not yet submitted, or engaged with patient feedback for revalidation purposes. Revisiting psychiatrist experiences and aspirations using more qualitative methods may therefore be beneficial, as the first revalidation cycle (typically five years) should now have been completed by the majority of psychiatrists.

This fourth research cycle therefore sought to address the following research questions:

- What, if anything, would psychiatrists find most helpful to receive patient feedback on for revalidation purposes?
- What, if anything, could make patient feedback more meaningful for psychiatrists for revalidation purposes?

- How do psychiatrists perceive and experience the two most commonly used patient feedback tools for revalidating psychiatrists (GMC patient questionnaire and ACP 360)?

The similarities between these research questions and those asked in cycle three (chapter five) are intentional. The next cycle, cycle five (chapter seven) seeks to compare and contrast patient and psychiatrist responses to identify areas of commonality and disparity.

6.2 Methods

To address the research questions outlined above, this research used focus groups and interviews in response to identified limitations of existing research, including an overreliance on quantitative measures (Edwards & Staniszewska, 2000). Further justification for the use of qualitative methods is provided in cycle three to avoid repetition.

A topic guide was designed in co-production with the patient research partner and psychiatrist colleagues (Appendix 10), building on the research findings of this thesis to date. Open-ended questions and prompts were again used to facilitate in-depth discussions.

Similar to cycle three, the topic guide for the focus groups and interviews was the same to ensure participants were treated equally and had the same opportunities regardless of their preferred method. The topic guide broadly covered the following areas:

- Psychiatrist desires and aspirations for patient feedback tools in revalidation
- Motivations for using and receiving patient feedback for revalidation purposes

- Barriers and enablers to using patient feedback for revalidation purposes
- Psychiatrist perceptions and experiences of existing patient feedback tools for revalidation purposes

6.2.1 Participants

Inclusion criteria

Participants were GMC registered psychiatrists with a licence to practise in the UK, of any age, gender, ethnicity or socio-demographic group who primarily worked with adult patients (aged 18-65 years), not related to the delivery of learning difficulties, Dementia or Alzheimer care with an ability to understand and speak the English language.

Exclusion criteria

Psychiatrists who were not licensed; or registered with the GMC; who primarily worked with patients under the age of 18 or above the age of 65, or who worked with learning difficulties, Dementia or Alzheimer's patients alone were excluded.

Criteria justification

Justification for these criteria stems from the pre-defined focus of this research. As previously acknowledged, it has been suggested that learning difficulties, Alzheimer, Dementia, or paediatric patients (17 years and below) are likely to have different skills, desires and expectations for patient feedback that go beyond the remit of this thesis (Brooker & Dinshaw, 1998). Psychiatrists who primarily work within these areas were therefore excluded in order to maintain a manageable and relevant research focus. However, exploring the use and acceptability of patient feedback tools among these communities could be a valuable area for future research.

6.2.2 Sample size

A sample size of 28-36 participants was originally proposed (n=3 focus groups, n=6-8 participants in each, n=12 interviews). This was considered to be a realistic and sufficient sample size based on similar studies exploring attitudes/perceptions towards patient feedback, the work load of psychiatrists, their competing work schedules and inability to buy out clinical time. Despite lower numbers, it was anticipated that data saturation as previously defined would still be achieved.

6.2.3 Recruitment

Participants were recruited voluntarily using an opportunistic and purposeful sampling technique. Beginning with opportunistic sampling, the researcher was invited by the Lead for Revalidation for the Royal College of Psychiatrists to host a focus group with psychiatrists attending a continuing professional development (CPD) day (27th April, 2018). The researcher was allocated a 45 minute slot to conduct the focus groups at the event that was held in a hotel in South West England. Participation in these focus groups was entirely voluntary. This was made clear in all the correspondence provided by the event coordinator prior to the event, pre-circulated information sheet and verbally reiterated by the Lead for Revalidation on the day. An invitation (Appendix 11) was also distributed via email by the Royal College of Psychiatrists to all their current members at the time.

6.2.4 Setting

Focus groups were held in a conference room in the hotel located in the South West of England. Copies of the two most commonly used patient feedback tools also reviewed in cycle three (GMC questionnaire and ACP 360) were provided once participants had been asked about their aspirations for patient feedback tools so participants could familiarise themselves with the existing tools and reduce the potential for bias responses. Participants recruited through the Royal College membership list were invited to either take part in a focus group or interview depending on their preferred method. All participants (n=2) recruited through this process selected interviews as their preferred method. All interviews were held at the private offices of participating psychiatrists at a time and date of their choosing to minimise potential disruptions. Similar to cycle three, all focus groups were held in a circle to facilitate eye contact and turn taking wherever possible.

6.2.5 Data collection

Data was collected using a Dictaphone and transcribed verbatim by the researcher. Participants were provided with a verbal summary of the process and overall study prior to the start of any data collection. Participants were reminded that their involvement was entirely voluntary and any information shared would be confidential. Participants were also reminded that content shared would be made anonymous through the removal of any identifiable information and use of relevant pseudonyms.

6.2.6 Data analysis

Similar to cycle three, data was analysed in co-production with the patient research partner using inductive thematic analysis as outlined by Braun and Clarke (Braun & Clarke, 2006). The process of co-producing the analysis was the same as that outlined in cycles two and three (page 67 & 90). Appendix 12 lists the number of changes made as a result of this process. For clarity, the patient research partner was not present at any of the focus groups or interviews at his request. Such involvement may also have affected the openness and honesty of psychiatrist responses as suggested by the patient research partner.

6.2.7 Maintaining rigour

Rigour was maintained using the same processes outlined in Table 13.

6.2.8 Ethical considerations

Participants provided both verbal and written consent prior to the start of any data collection.

6.3 Results

6.3.1 Participant characteristics

29 psychiatrists took part in the focus groups (n=3, 27 participants) or interviews (n=2). No socio-demographic information was provided by psychiatrists despite being asked. Similar to cycle three (patient perceptions), the provision of socio-demographic information was entirely voluntary.

Inductive thematic analysis identified three key themes: i) perceived problems with existing patient feedback tools; ii) suggested solutions for improvement and iii) concerns of power and control. Each theme and their corresponding subthemes are discussed in turn below supported by verbatim examples.

6.3.2 Perceived problems with existing patient feedback tools

Beginning with perceived problems, psychiatrists described a number of concerns with existing patient feedback tools. Issues most frequently described by psychiatrists included the questioning of patient feedback validity, existing processes, a fear of reprisals, lack of clarity regarding the intended purpose of patient feedback, restrictive tool design and administration difficulties.

6.3.3 Challenges to the validity and credibility of patient feedback

The validity of patient feedback appeared to be a particularly divisive topic between psychiatrists. For example, when asked “*what makes patient feedback valid?”* the majority of psychiatrists responded with psychometric testing. For example:

> “*The validity which is done through studies”* (Interviewee 2).

Similarly:

> “*I think the ACP 360 has been validated with consultants”* (Focus group 2, participant 4)

However, assurances of validity provided by psychometric testing were later questioned and undermined as a result of acknowledged bias patient selection as stated by interviewee two:

> “*I’m a psychiatrist and narrative is what I do, so yes, if they wrote a narrative of what happened then I think that’s actually very valid…if they’re* [patients] *not able to talk, or complete the form, that invalidates the whole thing…the selecting of patients invalidates the whole process…it defeats the purpose … it’s completely useless actually”* (Interviewee 2).

<u>Bias in patient selection</u>

Following these concerns, psychiatrists frequently discussed the ability to game or “*play”* (Focus group 2, participant 5) existing patient feedback tools. For example, despite acknowledging that “*there is some evidence that self-selected feedback is not so effective for obvious reasons”* (Focus group 2, participant 4), the majority of psychiatrists described a number of ways to achieve more positive, not necessarily authentic, or representative feedback responses. For example:

> “*Let’s just check on my Monday clinic which is when you do your slightly anxious patients and then let’s not do my PD* [personality disorder] *clinic* [group laughter], *all those ones that love me”* (Focus group 2, Participants 6 & 5)

> "*You're going to send the questionnaires to* [patients] *you know who will respond and you know like you… I feel one does need to select who you send these things too"* (Focus group 2, participant 4)

Similarly:

> "Participant 2: *People can be selective, they can game play it*
> Participant 4: *This is the issue, you do pick people don't you,*
> Participant 2: *It's not really right to at all but you can*
> Participant 1: *It's not at all appropriate*
> Participant 5: *You can game play it*
> Participant 1*: Oh yeah*
> Participant 5: *There's no checking the process"* (Focus group 1)

However, although often a minority, some psychiatrists viewed the gamification of feedback processes as detrimental and "*invalidating of the whole process"* (Interviewee 2). As a result, some psychiatrists viewed the collection of patient feedback as currently practised a "*completely useless"* (Interviewee 2) or *"tick box exercise"* (Interviewee 1). During an interview, one psychiatrist described the wide spread prevalence of "*cherry picking"* patients for revalidation purposes:

> "*I know that there are many colleagues that are cherry picking… many professionals when it comes down to collecting feedback from patients are cherry picking. If they cherry pick, what is the use?"* (Interviewee 1)

Biased patient responses

In addition to concerns of bias patient selection, bias patient responses were also identified as problematic by psychiatrists. For example, as suggested by interviewee one:

> "*If they're not able to talk openly, that invalidates the whole thing"* (Interviewee 1)

Such issues led one psychiatrist to conclude:

> "*My perceptions are that I learn very little from feedback because it didn't seem credible"* (Focus group 1, participant 4)

A patient's diagnosis and detainment was also referred to as an influential factor in bias patient responses and subsequent feedback acceptance. Such issues were often described as a unique issue faced in psychiatric care. For example:

> "*I think the difficulty is for other doctors, it's much more linear. Your patient comes in with a dodgy knee, they go out with a good knee. They come in with a cataract, they go out without a cataract. It's easy to measure, whereas we are often making a diagnosis nobody wants from people who don't want to come to us in the first place…"* (Focus group 2, participant 9)

Similarly:

> "*In psychiatry, unlike other disciplines, we are dealing with patients who may detest us…"* (Focus group 1, participant 4)

However, such perceptions were not unanimous:

> "*I think that we have an advantage compared with other specialties…"* (Interviewee 1)

While some psychiatrists expressed a view that:

> "*You have to be very careful about how the feedback is interpreted in light of the diagnosis"* (Focus group 2, participant 1)

Or:

> "*It* [feedback] *has to be taken with a pinch of salt"* (Focus group 2, participant 9)

Others strongly opposed such suggestions as demonstrated below:

> "Interviewer*: Questions about validity and reliability come up, particularly if someone is experiencing severe mental illness]*
> Participant*: no I disagree with this]*
> Interviewer*: [And I wondered what your opinion was?*
> Participant*: I disagree with this, I disagree with this, of course. OK, it is not ethical I think for example, we cannot get feedback at the time when a patient is conveyed to hospital by ambulance and when they get down from the ambulance to go to the A and E department, you cannot ask patients to give feedback at that time, this is unethical OK. Because people have to have the mental capacity to be able to give this kind of feedback, at least this is what I think, ok, so you cannot give feedback all the time and I strongly believe that mental health patients can give feedback, it is just the stigma around mental disorders that affects our view of whether people with mental illness are capable of giving feedback…I cannot see why they couldn't give feedback… and why this*

> *feedback can be discredited and devalued, I cannot see why"* (Interviewee 1)

Mirroring concerns of stigma alluded to in the above quotation, interviewee two suggested that "*people hide behind capacity and confidentiality a lot, a lot actually…"* (Interviewee 2). When asked why, the participant replied:

> "*Confidentiality, people hide behind that to avoid unpleasant conversations and the same about capacity, uncomfortable decisions…"* (Interviewee 2)

There was often a clear distinction between psychiatrists who used notions of capacity and diagnosis as justification for feedback exclusion and those who used the same notions as justification for inclusion.

6.3.3.1 Process

Perceptions of the two most commonly used patient feedback tools included process and procedural concerns. As demonstrated in Table 23, such concerns often related to perceptions of a system led, (as opposed to patient led) process and the subsequent infrequency of opportunity. Some psychiatrists acknowledged an inability to act on, or improve their practise in a timely manner due to the five year timeframe. One psychiatrist referred to the collection of patient feedback "*once every five years"* as *"artificial"* (Focus group 3, participant 4). Others referred to such requirements as "*mechanistic",* emphasising the clear relationship between the infrequency of feedback opportunity and its perceived value and meaning among psychiatrist participants.

Table 23 Procedural and process concerns identified by psychiatrist participants

Procedural & process concerns identified by participants	Verbatim examples
Frequency of opportunity	“*Despite the fact that it is mandatory for us to do it once every five years, I tend to do it once every two or three years…I think that five years it’s too much, I’d rather know sooner if I do make a mistake, I wouldn’t like waiting five years to improve my practice”* (Interview 1); “*I agree with you, doing it once every five years… there is something mechanistic about that…it’s not live enough”* (Focus group 1, participant 6)
An unbalanced focus on negativity and complaints	“*I think one of the difficulties is that the system, just the way it works, focuses in on the negatives, you know its complaints that are recorded, investigated and followed through…if plaudits were given as much emphasis as complaints…”* (Focus group 3, participant 4); “*The Royal College* [website] *I can’t find the information I’m looking for but on the front page I can find the information for how to make a complaint”* (Interviewee 2); “*It isn’t just about complaints though is it, I mean people sometimes want to feedback positive things as well, they want that person to know, to talk to someone, to tell them things have gone well and we haven’t really always got a way of doing that”* (Focus group 3, participant 3)
Concerns of anonymisation	“*I think people often find it really difficult to be handed those things, they feel that it’s not going to be anonymised”* (Focus group 1, participant 4); *“I can know the patient because the situation she described was very unique”* (Focus group 3, participant 6)
System led as opposed to patient led	“*I think it would be more useful if patients could have the feedback at the time they want to give it. Because I think sometimes you get the patient feedback for our appraisals, that’s nothing to do with when they want to give it. More of an opportunity for them to sort of say it”* (Focus group 3, participant 5)
Feedback fatigue	“*There’s feedback fatigue, I keep being rung up by banks, online shopping…”* (Focus group 1, participant 7); “*There seems to be feedback on everything like if you phone a bank or something”* (Focus group 2, participant 4)
Low response rates and subsequent concerns of representation	“*There seem to be very few people who respond and I wonder how representative it really is?”* (Focus group 1, participant 1); “*I think the 360 the Royal College one is just a cross sectional one, it just looks at your current case load and random case selection* [group agreement] *but it fails to look at patients who have been discharged with good outcomes, it misses a whole lot of patients so they might just catch patients who are chronically stuck, or not getting better, so we’re only taking a skewed sample”* (Focus group 1, participant 8)
Difficulties disaggregating the individual from the system	“*I mean, I had a patient that I had a bit of a disastrous interaction with, so I got a complaint letter and most of it was justified, it was one of those days where everything went wrong and I had ten minutes for a new patient assessment, I was fed up because other people had been late and so I was stressed and it just didn’t go well…”* (Focus group 3, participant 2); *“I’ve had a very similar experience actually, I’ve had very difficult family, who are forever putting their view forward, we met with them and I said, well I’m trying to do the best I can but we can’t do everything, we’ve got these issues that make it very difficult and they said ‘Oh well thank you, we didn’t understand, we just thought that you weren’t trying’…”* (Focus group 3, participant 4)

Others procedural or process related concerns described by psychiatrists included acknowledged difficulties of disaggregating the system from the individual and a perceived imbalance towards complaints. For example, one psychiatrist acknowledged that there isn't "*really a way"* of feeding back *"positive things, to tell them* [psychiatrists]*"* (Focus group 3, participant 3). However, ways to make a complaint were felt to be clearly visible on the Royal College website, leading to the perception of an unbalanced focus of negativity and criticality by organisations and regulatory bodies (Table 23).

Fear of reprisals

Similar to cycle three, psychiatrists also described a fear of reprisals for both themselves and patients. For example, some psychiatrists discussed the difficulty of patients being critical due to anticipated impacts:

> "*They're worried about criticising their doctor"* (Focus group 1, participant 4)

> "*Even though its anonymised, when you're asked to do it, it's bloody awkward and a bit painful writing something detailed down, especially if it's slightly critical and it's very easy to avoid doing that"* (Focus group 2, participant 6).

Conversely, one psychiatrist felt "*five to ten percent"* of critical responses indicated that patients were not afraid of giving critical feedback, providing an alternative perception:

> "Participant 5: *it was just a tick box thing*
> Participant 8: *but were they worried about being negative on that?*
> Participant 5: *Well clearly not, between five and ten percent were negative"* (Focus group 3)

Concerns of repercussions for psychiatrists were also discussed, with some participants suggesting that the intentional practice of bias patient selection was often a protective solution to mitigate such fears. For example, when asked why they think colleagues 'cherry pick' patient respondents, interviewee one replied:

> *"Because they're afraid of what people live with. They want their revalidation process and their appraisal process and we've seen for example the recent case with* [Bawa Garba] *and all these discussions… People are afraid I think. They're trying to cover their backs. I don't think they have bad intentions, I don't think they do it to lie, or to cover their deficiencies as professionals…"* (Interviewee 1).

Some psychiatrists also discussed the possibility of changing their practice as a result of mandatory patient feedback collection and subsequent fears. For example:

> *"I wonder if you might have raised your game subconsciously* [group laughter] *until you thought you had enough numbers*?" (Focus group 2, participant 4)

Similarly:

> "*People will get more defensive, they will feel that they have to do things for the sake of feedback"* (Interviewee 2)

Such comments reflected later discussions around the emotional impacts of receiving patient feedback as evidenced below:

> "*I was left not feeling very nice after that"* (Focus group 3, participant 6)

> "*You mustn't get too wounded by these things I think must you?"* (Focus group 2, participant 5)

> "*I'm terrified of opening it and that's why I haven't contacted them* [ACP 360] *to release it.* Interviewer: *Why are you terrified?* Participant: *Because I look back at the forty people and I can sort of guess what is on the feedback"* (Interview 2)

6.3.3.2 Perceived purpose

Linked to concerns of process, psychiatrists also repeatedly questioned the perceived purpose of patient feedback with many participants viewing it as a "*tick box exercise"* (Interviewee 1). As a result, the majority of psychiatrists attributed the purpose of patient feedback to fulfilling mandatory requirements. For example, when asked why they collect patient feedback, interviewee two replied:

> "*The honest answer? Because I'm meant to do it"* (Interview 2)

Similarly:

> "*I needed to do it for my appraisal, it didn't change anything, it looked OK for the appraisal"* (Focus group 2, participant 9)

> "*You've got to do it for your appraisal"* (Focus group 2, participant 4)

However, fulfilling mandatory requirements was not the primary motivation for a minority of psychiatrists. As stated by interviewee one:

> "*I collect patient feedback because I think that I'm here for these people. I'm here for patients, so it doesn't make any sense for me to plan interventions, to plan services without asking what they appreciate as important, what they would like. And of course, this does not mean that we will do it, but at least we will have an open discussion of what we're able to offer and then, there is the chance that we can find together alternatives, ourselves with patients. So this is the reason that I collect feedback in order to improve the quality of care we deliver"* (Interviewee 1)

However, such views were a minority in comparison to conforming to existing regulatory requirements.

Patient understanding

Despite these disparities, all psychiatrists agreed that there was a lack of patient information, understanding and awareness. One participant attributed a perceived lack of understanding to poor communication and a need to be more "*open and transparent"* (Interviewee 1) with both patients and psychiatrists about the process and intended purpose of patient feedback for revalidation purposes.

Patient motivations

Other areas of disparity expressed by psychiatrists included assumed patient motivations for engaging in patient feedback opportunities. For example as suggested by interviewee two:

> "*I think the majority of the patients are happy to give feedback… at the end of the day our patients are rational people, like all of us"* (Interviewee 2)

Conversely:

> "*I think some people just can't be bothered basically"* (Focus group 2, participant 4)

Underlying assumptions about patient motivations were often based on participants' own views and beliefs, believing patient desires, expectations and behaviours would be synonymous with their own:

> "*Patients wouldn't like it, I mean I wouldn't like it"* (Focus group 1, participant 4)

However, the danger on relying on such assumptions was challenged by participant eight:

> "*We assume that that* [ACP 360 and GMC questionnaire] *is what they want to feedback on. So the question is what do they want to feedback on?"* (Focus group 3, participant 8)

The relevance of existing feedback tools for patients was repeatedly raised by some psychiatrists, although not all.

6.3.3.3 Design

In regard to design, concerns raised by psychiatrists often centred around five key areas: i) lack of a feedback loop, ii) length, iii) limited patient involvement, iv) "*weak"* questions and v) unhelpful scoring (Table 24). As acknowledged by participants eight and two, asking patients about what they would like was seen as desirable by some participants:

> "*It would be good if as part of our service development we could have a focus group with our patients or their parents and actually ask them, 'what would you like?' I think that will be helpful for us, having the patient, service-user carer involvement would be really good… we don't know what's meaningful for them… There might be things that they think that we haven't even thought about"* (Focus group 1, participants 8 & 2)

Such involvement was described as a way to potentially improve the low quality of existing tool content and questions:

> "*I think some of them* [existing questions] *are weak and weak questions give weak answers"* (Interviewee 2)

Table 24 Design concerns related to existing patient feedback tools as described by psychiatrist participants

Lack of feedback loop	"*You never see the data"* (Focus group 1, participant 6) "*From the patient perspective, if they give you feedback, they want something back again don't they?"* (Focus group 3, participant 2)
Length	"*I think it's* [ACP 360] *too long, if I were asked to give feedback, I might do the first sort of few carefully and then start to lose interest, it's too long"* (Interviewee 2)
Limited patient involvement	"*We assume that that* [ACP 360 and GMC tool] *is what they* [patients] *want to feedback on. So the question is what do they want to feedback on?"* (Focus group 3, participant 8)
"*Weak questions"*	"*I think some of them* [existing questions] *are weak and weak questions give weak answers"* (Interviewee 2)
Unhelpful scoring and desire for narrative comments	"*Do you find the scores helpful? I don't… I would prefer the paragraphs because from my point of view that is actually a lot more useful than 4.6 out of five doesn't really tell me that much… and I guess my sort of thing as a psychiatrist is that it's a lot about the context"* (Interviewee 2)

6.3.3.4 Administration

Moving on to administration, some psychiatrists questioned the administration of patient feedback tools for revalidation purposes. Specifically, their time consuming nature and level of sensitivity required. For one, participant existing tools were felt to "*trigger psychosis"* (Focus group 1, participant 5), thus warranting self, or purposeful selection of patient respondents as previously described. For example, as suggested by participant four:

> "*It's sometimes difficult to send out those questionnaires to patients in a random fashion because in my experience some of the patients have found it highly upsetting to receive these things and become quite paranoid and in one case set off a psychosis that she had to be admitted* [group laughter] *because she misinterpreted so you know, it's quite difficult, so I feel one does need to select who you send these things too…"* (Focus group 1, participant 4)

Others focused on the difficulty of obtaining patient feedback once discharged, particularly when working in a crisis team:

> "*I'm a bit unlucky in my work because as a crisis team consultant, most of the times when I see people, they are at an acute stage of their disorder so at that time it is a bit difficult for me to ask them for feedback. And also it is a bit challenging for me to get feedback after some time*

> *because we usually keep people on our case load for a very short time, so once they start improving, we refer them further on, so I'm losing track of them"* (Interviewee 1)

The cost of patient feedback activities was also acknowledged by participants, "*it's not cheap to do though is it?"* (Focus group 2, participant 1).

6.3.4 Solutions

Despite the concerns raised above, psychiatrists suggested a number of solutions to improve the perceived value of existing patient feedback tools. These often related to existing feedback processes (Table 25), design (Table 26) and content (Table 27).

6.3.4.1 Process

In regard to process, psychiatrists suggested a greater focus on quality of reflection as opposed to quantity of collection, increased frequency of opportunity that facilitates more 'real time' feedback and patient choice on when and how to complete feedback tools as current requirements have "*nothing to do with when they* [patients] *want to give it"* (Focus group 3, participant 5). Enabling patients the opportunity to "*give it* [feedback] *when they want to give it"* was considered to be *"much more useful to you* [psychiatrists] *and the patient"* (Focus group 3, participants 2 &3) as suggested in Table 25 below.

Table 25 Process related solutions as described by psychiatrist participants

Enhanced opportunity	"*It should be an ongoing thing… I would like to receive patient feedback from the patient that I see every two three months I would like to be able to make adaptations in our practice, I would like to be flexible, I would say two, three months would be enough"* (Interviewee 1)
Focus on quality of reflection as opposed to quantity of collection	"*Revalidation I guess it's performing a function, but if we're interested in what our patients experience in appointments with us, we probably need to go beyond an ACP 360 and think about what we actually want to learn from this?* *And also it's the action that you take after that's more important than the feedback itself isn't it? Because if you can't demonstrate reflection and change then…* *Then it's just blind anyway"* (Focus group 2, participants 8, 2 & 5)
Real time	"*We talked about how useful it could be to actually get it* [feedback] *at the time* *and certainly more often* *You want to know every time you see a patient, what they're feeling about the service that they're getting and how they're feeling don't you, every time you see them"* (Focus group 3, Participants 4,3 & 8) "*Immediate patient feedback is more useful"* (Focus group 2, participant 4)
Opportunity to do it face to face	"*So sort of anonymous and non-anonymous, it doesn't all have to be anonymous because you could still do it in human interaction"* (Focus group 2, participant 3)
Benchmark – (although not unanimous)	"*I think if you get a huge number of people saying 'that sucked' that's when the quantifiable element and knowing whether you are an outlier is more useful isn't it, because there may only be one person whose bothered to write a sentence saying he really never shuts up and he never listens but if you notice that actually, when you're bench marked your scores are that little bit more significantly low or high, helps you think, so having the numerical element too"* (Focus group 2, participant 5)
Patient choice on when to complete	"*I think it would be more useful if patients could have the feedback at the time they want to give it. Because I think there have to be processes but sometimes you get patient feedback for our appraisals, that's nothing to do with when they want to give it"* (Focus group 3, participant 5)
Different interpretation	"*I think our feedback has to be interpreted differently"* (Focus group 2, participant 9)
Follow up with patients	"*If a person is discharged from your case load then I am unable to make contact with them in order to get more information because they are not under my care, so legally I'm not allowed…there should be something in general because I think that we need to have some continuity in the follow up of our patients"* (Interviewee 1)
Comparison over time	*"I would like to have some feedback so that I'm able to compare it in the future as well….this is important for us"* (Interviewee 1)
Random selection	"*I think that the choice of who will be given the feedback should be somehow built into our governance system and it should be by chance… so somehow the system should have the ability to choose 1,2,3 of these patients without me being asked, I think this would be a little bit more reliable"* (Interviewee 2)
A more informal approach	"In which format, formalised or informal do you find most helpful if any? *Informal"* (Interviewee 2)

Some psychiatrists also described a desire for patient feedback responses to be "*interpreted differently"* (Focus group 2, participant 9) due to the unique challenge faced in psychiatric care. This view however, was not unanimous. A call for strengthening the process of patient selection including random patient selection was identified by a number of psychiatrists following acknowledged bias patient selection and feedback gamification as previously described.

6.3.4.2 Design

Psychiatrists repeatedly emphasised the need to tailor patient feedback tools to the specific context of psychiatric care, include the name of the psychiatrist and ask specific feedback questions. Question examples provided by psychiatrists included 'did you feel heard', 'did you feel listened too?' (Table 26). The use of specific and tailored questions was also seen as imperative to making feedback "*useful", "otherwise it just won't be valuable at all"* (Focus group 2, participant 6).

A desire to include a mixture of both open and closed questions was repeatedly described by psychiatrists, as narrative comments could help provide contextual information that could facilitate professional development and change. For example, as stated by interviewee one:

> "*Give some space for them to make their own comments. I think this would be helpful, sometimes if we ask people specific questions, it's as if we're guiding them and if we leave them to speak on their own, then we may find things come up that we may not have even thought about…In terms of learning, I find most helpful the open comments, the open comments are more helpful for me…Because people are free to speak about whatever they want… so I would say the open text is important for quality improvement"* (Interviewee 1)

Other suggested solutions included the incorporation of a feedback loop mirroring findings from cycles two and three, with some psychiatrists suggesting further work is required to help facilitate the reporting of patient feedback to both patients and front line clinicians in a helpful, timely and accessible manner (Table 26).

As outlined in Table 26, a desire to incorporate more opportunities to share positive experiences of care was also acknowledged by psychiatrists, as was the exploration of turning “*co-creation”* into “*a reality”* (Interviewee 1).

Table 26 Design related solutions suggested by psychiatrist participants

Design solution	Verbatim example
Specific, tailored or personalised questions	“*It* [feedback] *has to be individualised…to be useful you need it to be personalised to us* [group agreement] *saying I’ve just seen Dr whoever it is and it’s focused on your appointment”* (Focus group 1, participant 6) “*It’s about tailoring the feedback isn’t it, it’s got to be different to other mental health specialties the questions, because otherwise it just won’t be valuable at all. So ‘did you feel heard?’ ‘Did you feel listened to?’ ‘Did I answer your questions?’ Stuff like that rather than sort of really broad questions about whether you like that doctor or not”* (Focus group 2, participant 6)
Presence of a feedback loop	“*I think the most important thing for giving feedback is the loop isn’t it, so you give feedback and you know how that’s being taken seriously, or it’s being considered and I think that would be helpful for patients to have that you know that it has been looked at, it has been considered and sort of actions taken or not taken”* (Interviewee 2) “*There is something about the way that all the evidence these organisations collect, how they are disseminated to front line clinicians I think it is a big issue”* (Interviewee 1) *“If you’re given a monthly spreadsheet of what your feedback is currently, you’re going to start making use of it”* (Focus group 1, participant 10)
Inclusion of narrative comments	“*It’s good when you get more narrative responses* [group agreement] *because it helps you take on board the nature of the criticism”* (Focus group 1, participant 1)
Development of a positive feedback mechanism	“*People sometimes want to feedback positive things as well and we haven’t really always got a way of doing that”* (Focus group 3, participant 3)
Shorter	“*Could be more streamlined”* (Focus group 2, participant 4)
Simplified	“*If you were to redesign the patient feedback tool, is there anything you would change? A lot more simplified, I would simplify the questions”* (Interviewee 2)
More patient involvement	“*This co-creation as a reality ok, it’s gaining more and more fans, a lot of people see the rationale behind all these theories, so at the moment, I don’t think it’s happening as much as it should be happening but I am optimistic…”* (Interviewee 1)
Mix of open and closed questions	“*Open text is important for quality improvement, on the other hand closed questions are also important too, because you can get focused feedback on some issues, this free text can give you universal feedback”* (Interviewee 1)
Carer feedback inclusion	“*What about the relatives of patients because sometimes they have a view don’t they that’s just as important in evaluating effectiveness isn’t it?”* (Focus group 2, participant 6)
Accessibility	“*Easy read forms”* (Focus group 2, participant 8)

6.3.4.3 Desired feedback content

Psychiatrists suggested a range of solutions to improve the content of existing feedback tools. The behaviours, attributes and skills participants considered to be of most importance to receive feedback on included communication, clarity of explanation and medication (Table 27). Other aspirations included the incorporation of suggested improvements, something that was considered to be lacking in existing feedback tools and the provision of more detailed information.

Table 27 Content related solutions as described by psychiatrist participants

Suggested content to included	Verbatim examples
Communication	“*Did I answer your questions?”* (Focus group 2, participant 6) “*Did I explain it well?”* (Focus group 2, participant 4)
Suggested improvements	*“You want to know what the patient wants because sometimes they’re not really able to explicitly tell you what they want unless it’s done in a feedback session like that and say ‘actually I think this might have been better if I had information about medication, or more information about the range of options that I could have’”* (Focus group 1, participant 7) “*I would like to comment on things that could have been a bit better because we don’t have that option do we”* (Focus group 3, participant 5)
Medication	“*We know there’s quite a high non-compliance with medication and that, they’re given advice when prescribed and then they don’t take it, it’d be interesting to know whether that was a measure of how well we’d sort of explained or convinced them that it was a good intervention”* (Focus group 1, participant 9)
When to base feedback on	“*I’ve just seen Dr whoever it is and it’s focused on your appointment”* (Focus group 1, participant 6)
Flexibility to ask questions (although concerns of validity and procedural influences)	*“Having that flexibility to ask… I think sometimes you’re trying something different in consultations and actually if you’re trying something new it would be good to get some formal feedback”* (Focus group 1, participant 3) “Would it be helpful to set your own questions or if you’d made a change and you could get feedback on that? *Yes, that would be very helpful, very helpful”* (Interviewee 1) “*I think individually that would be great, I don’t know how practical that is going to be and certainly the validity”* (Interviewee 2)
Outcome measures	“*Maybe we should look at discharge rates and outcome measures?”* (Focus group 1, participant 8)
Appearance	*“Because I’m quite scruffy, I wear blue jeans we’re not allowed to wear in the Trust, so I ask patients you know…so it’s getting that you think you’ve got an approach that you think suits and actually when patients say ‘yeah I don’t like seeing doctors in suits and ties, because it puts me off, that’s positive feedback because it reinforces that”* (Focus group 2, participant 1)

6.3.5 Power and control

Similar to cycle three (patient perceptions) many of the issues and suggested solutions raised by psychiatrists related to power and control. While the majority of psychiatrists identified a desire to control patient feedback selection as stated by participant four:

> "*I think it's very difficult to get proper feedback in psychiatry unless you pick who you're going to send the questionnaires too, people who you know will respond and you know like you"* (Focus group 1, participant 4)

Others expressed a desire towards "*co-creation"* and "*empowerment"* with participant three acknowledging a potential 'levelling' of power disparities through the inclusion of patient feedback engagement:

> "*I mean it's quite empowering isn't it if you're a patient, because generally you're powerless, so the idea of feedback is you stop being a patient actually, now you're an equal expressing your view about your care and that should be quite a positive thing… you know as your equal, because I am your equal, I would like to comment on things that could have been a bit better"* (Focus group 3, participant 3).

However, positive attitudes towards the inclusion of patient feedback were not common and were typically expressed by a minority of psychiatrists. Despite this, many psychiatrists acknowledged a lack of personal power and control over the regulatory and practical requirements of their job. For example:

> "*I feel constrained by the nature of the job"* (Focus group 2, participant 4)

Similarly:

> "*You're kind of being forced to send out lots of questionnaires as a standard process"* (Focus group 1, participant 10)

As a result, discussions of disempowerment were also discussed in relation to psychiatrist job roles and responsibility.

6.4 Discussion

This research sought to address an identified gap in existing knowledge by exploring psychiatrist perceptions, experiences and aspirations for patient feedback tools currently used in the revalidation process. Research findings indicate that there are a number of limitations with existing patient feedback tools often related to their design, content and ability to gamify the system. While there were some areas of commonality between participants including an acknowledged fear of repercussions, other perceptions and aspirations appeared to be divided. For example, some participants justified the purposeful selection of patients due to a fear of anticipated responses or patient diagnoses. Others criticised such methods, suggesting bias patient selection invalidates the entire process.

Other areas of disparity identified in this research included the perceived purpose of patient feedback. The majority of participants viewed patient feedback as a tokenistic exercise that needed to be completed as a result of mandatory requirements. Conversely, a minority of participants considered patient feedback as an opportunity to improve patient safety and quality of care. Following this, a number of participants identified several unintended outcomes of mandating patient feedback including bias patient selection, altering practise when aware of feedback being collected and a potential increase in defensive practise.

Similar to cycle three (patient perceptions), many of the concerns raised by participants were grounded in perceived issues of power and existing culture, including a divided view on the potential ‘levelling’ of traditional power hierarchies through the inclusion of patient feedback.

As a result, the majority of participants identified a need to improve the two most commonly used patient feedback tools for revalidating psychiatrists. Suggested improvements included allowing patients to complete patient feedback forms more frequently and at their own disposal, including more narrative comments to provide contextual information and greater focus on quality of reflection, as opposed to quantity of collection. Pertinent to the context of this research, some psychiatrists also identified a desire for “*co-creation to become a reality”* to ensure the relevance of feedback tools reflected both patient and psychiatrist desires.

6.4.1 Comparison with existing literature

Findings from this research mirror those of existing literature in the following ways. Firstly, many participants viewed the purpose of patient feedback and revalidation more broadly as a tokenistic exercise (Archer *et al.*, 2015; Tazzyman *et al.*, 2018). This was at times attributed to the infrequency of patient feedback collection and primary focus on quantity of feedback forms as opposed to their quality, or quality of reflective practise. Concerns of bias patient responses and selection have also been acknowledged following the results from a national survey of over 26,171 doctors (Baines *et al.*, 2019c). However, although frequently implied by participants in this research, suggestions of patients being detained affecting patient ratings has been shown to have little effect, even when using the ACP 360 tool (Heneghan & Chaplin, 2018). Such concerns may therefore be unsupported and reflect a further protective discourse used by some psychiatrists to justify patient feedback exclusion or rejection.

The emotional impact of receiving patient feedback, particularly when linked to regulatory outcomes, was also discussed by participants at length. This appears to be an emerging theme in recent literature requiring further exploration and support (Jones *et al.*, 2020; Locock *et al.*, 2020c).It is important to note that during data collection, a national investigation was taking place where a doctor’s personal reflections had been used as part of a criminal trial. This caused significant concern amongst the medical profession more broadly and was identified by participants as a potential barrier to patient feedback use and reflection. Finally, a further area of commonality with existing research includes an evident dichotomy between psychiatrists in support of ‘levelling’ traditional power hierarchies through patient feedback inclusion and those against it (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020).

6.4.2 Strengths and limitations

Strengths of this research include its use of qualitative methods, helping to address identified limitations of existing literature (Edwards & Staniszewska, 2000).This research also provides an updated account of psychiatrist experiences following the completion of the first revalidation cycle. Other strengths of this research include its co-production with a patient research partner. However, its limitations must also be acknowledged. Firstly, this research relied on volunteer participants. Issues inherent with this recruitment methodology are therefore acknowledged. Similarly, many participants were from the South West of England due the location of the CPD event. Furthermore, despite being asked, no participants provided any demographic information. Results may not therefore be representative of psychiatrists more broadly. However, some assurances can be provided in that similar themes from this research have been identified in other research (Baines *et al.*, 2019c).

6.4.3 Implications

With these limitations in mind, the implications for this research are clear. Firstly, psychiatrist responses identify a need to improve existing patient feedback tools, particularly their process, design and content. Secondly, research findings indicate a desire to clarify the perceived purpose and intention of patient feedback for revalidation purposes. Thirdly, research findings further challenge previously accepted assurances of validity and reliability (Violato, Lockyer & Fidler, 2008a). Many participants acknowledged the practice or undertaking of bias patient selection due to anticipated reprisals. Previously held definitions of validity and reliability may therefore be inadequate. The acknowledged practice of using capacity or stigma to justify patient feedback exclusion also needs to be addressed. Identifying ways to develop a supportive culture and environment where healthcare professionals feel safe and supported in reflecting on patient feedback is also imperative (Jones *et al.*, 2020; Locock *et al.*, 2020c). As reported in this research and others (Brooker & Dinshaw, 1998), psychiatrists can also feel disempowered in their own roles and responsibilities. Finally, existing patient feedback tools should strive to incorporate suggested solutions to help improve their perceived value and acceptability.

6.5 Conclusion

In conclusion, this research explored the experiences, perceptions and aspirations of current patient feedback tools for practising psychiatrists. Results indicate a need to improve existing tools, paying particular attention to their design, content and processes. Cycle five seeks to compare and contrast patient (cycle three) and psychiatrist (cycle four) findings to identify areas of commonality and divergence, this may help to inform more collaborative ways of working going forward.

7.0 Cycle 5 - How do patient and psychiatrist perceptions, experiences and aspirations of patient feedback tools for revalidating purposes differ, if at all?

7.1 Introduction

As demonstrated in cycles three (patient perceptions) and four (psychiatrist perceptions), patients and psychiatrists discussed a number of concerns related to the two most commonly used patient feedback tools for revalidating psychiatrists. However, there has been little critical examination of how patient and psychiatrist experiences differ, if at all (Gayet-Ageron *et al.*, 2011; Hill *et al.*, 2012). This research cycle therefore sought to compare patient (cycle three) and psychiatrist perceptions (cycle four). By doing so, a more nuanced understanding of patient and psychiatrist desires can be developed, with identified areas of commonality used to facilitate future co-production efforts. The research question that cycle five seeks to address is therefore as follows:

- How do patient and psychiatrist perceptions, experiences and aspirations of patient feedback tools for revalidation purposes differ, if at all?

7.2 Methods

7.2.1 Data analysis

To address the proposed research question, framework analysis was applied to the qualitative data collected in cycles three (patient perceptions) and four (psychiatrist perceptions) (Ritchie & Spencer, 1994). Acknowledged as a valuable method for analysing textual data, particularly interview transcripts where the comparison of themes across many cases is important (Gale *et al.*, 2013), the five steps of framework analysis outlined by Ritchie and Spencer were applied (Ritchie & Spencer, 1994). Some of these steps were already completed in cycles three and four as outlined below:

i) Familiarisation - achieved by re-reading the interview and focus group transcripts from cycles three and four
ii) Identifying a thematic framework – achieved by amalgamating the inductive thematic frameworks produced in cycles three and four
iii) Indexing – achieved in this research cycle by reviewing the themes and corresponding data from cycles three and four
iv) Charting – achieved in this research cycle by arranging the previously indexed data into charts of themes
v) Mapping and interpretation - achieved in this research cycle by result write up and tabular representation of charted themes

Justification for selecting framework analysis stems from its focus on participants' own words and expressions; its ability to compare and contrast data across many cases while retaining the connection to individual accounts and its ability to acknowledge the complexity of real life and presence of multiple, and at times, competing perspectives (Gale *et al.*, 2013). Framework analysis also lends itself to strong patient and public involvement as recognised by Gale et al., (Gale *et al.*, 2013).

Similar to previous cycles, the patient research partner was involved in data analysis using the same process outlined on pages 67 & 90. Justification for his inclusion stems from recommendations of at least two researchers independently coding the first few transcripts to enhance the credibility of reported findings (Gale *et al.*, 2013). Patient involvement in the analysis stage can also provide alternative viewpoints, helping to ensure one perspective does not dominate the analysis process at the exclusion of others (Gale *et al.*, 2013).

Finally, although well suited to the purpose of this research, the limitations of framework analysis should also be acknowledged. Similar to all qualitative analysis methods, framework analysis is time consuming and resource-intensive (Queirós, Faria & Almeida, 2017). When involving additional stakeholders in the analysis and interpretation of data, the time required is also extended. While acknowledging these limitations, framework analysis was considered to be well suited to the aims and question of this research cycle.

7.2.2 Participants, sample size & recruitment

Details about recruitment and data collection methods are provided on pages 112-113 (cycle three, patient perceptions) and 158-159 (cycle four, psychiatrist perceptions) to avoid repetition. No additional participants were recruited for this cycle.

7.2.3 Maintaining rigour

Rigour was maintained using the same processes outlined in Table 13.

7.3 Results

Results are presented in the following order: comparison of perceived problems with existing patient feedback tools and suggested solutions.

7.3.1 Perceived problems with existing patient feedback tools

7.3.1.1 Design

As shown in Table 28, both patients and psychiatrists questioned the absence of a feedback loop, relevance of existing questions including a predominant focus on critical comments and limited space for narrative comments. Other identified areas of commonality between patients and psychiatrists included concerns around the suitability of existing response scales and their ability to facilitate psychiatrist reflection or patient understanding.

Table 28 Comparison of patient and psychiatrist responses to patient feedback design

Identified area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Lack of a feedback loop	“*People do this and they never hear a thing about it… We give feedback and then what happens? We never hear anymore”* (Focus group 1, participant 5)*”* (Focus group 3, participant 5)	“*We seem not to get any updates about what is happening…”* (Interviewee 1)
Focus on critical comments	“*At the minute, there’s no room for praising, it’s on a scale of 1-5, tick, tick, tick, tiny little text box there isn’t really anything to say actually you did a good job”* (Focus group 1, participant 5)	*“It isn’t just about complaints though is it, sometimes people want to feedback positive things as well, they want to tell them things have gone well and we haven’t really always got a way of doing that”* (Focus group 3, participant 3)
Length	“*By the time you’ve got there you’ve switched off…”* (Focus group 3, participant 3)	“*I think it’s too long, If I were asked to give feedback, I might do the first sort of few and then start to lose interest”* (Interviewee 2)
Relevance, accessibility and value of existing questions	*“Remains calm under pressure? Random and not really relevant”* (Focus group 3, participant 6); “*Provides useful information about my care and treatment when I need to ask for it? When I need and ask for it? Don’t you always need it?”* (Focus group 3, participants 6&5)	“*I think some of them* [existing questions] *are weak and weak questions give weak answers”* (Interviewee 2)
Unhelpful scoring	“*I tend to tick two boxes because I’m not quite sure exactly which one it fits, or I tick in-between them”* (Focus group 3, participant 3)	“*Do you find the scores helpful? I don’t… I would prefer the paragraphs because from my point of view that is actually a lot more useful than 4.6 out of five, doesn’t really tell me that much…”* (Interviewee 2)
Question inflexibility	“*Questions don’t ever change”* (Focus group 2, participant 1) “*I filled in all of that lot…three weeks later nothing had changed, they still brought the same letter around”* (Focus group 2, participant 10)	*“Having that flexibility to ask… I think sometimes you’re trying something different in consultations and actually if you’re trying something new it would be good to get some formal feedback”* (Focus group 1, participant 3)
Limited space for free text comments	“*Tiny little text box”* (Focus group 1, participant 5); “*Why can’t you just put down what you feel rather than having to comply with what they want?”* (Focus group 1, participant 7)	*“I would prefer the paragraphs because from my point of view that is actually a lot more useful than 4.6 out of five, doesn’t really tell me that much…”* (Interviewee 2)
Not designed with patients	“*Are they* [existing questionnaires] *measuring the issues that we feel are important…as opposed to ones that somebody else has already decided?”* (Focus group 6, participant 5).	“*We assume that that* [existing questions] *is what they* [patients] *want to feedback on.”* (Focus group 3, participant 8); “*we don’t know what’s meaningful for them…There might be things that they think that we haven’t even thought about”* (Focus group 1, participant 8 & 2)

Furthermore, pertinent to the context of this research, both patients and psychiatrists questioned the level of patient involvement in the design and evaluation of existing patient feedback tools. For example, as stated by patient participant five:

> "*Are they* [existing questionnaires] *measuring the issues that we feel are important…as opposed to ones that somebody else has already decided?"* (Focus group 6, patient participant 5)

Similarly:

> "*We assume that that* [ACP 360 and GMC questionnaire] *is what they* [patients] *want to feedback on. So the question is what do they want feedback on?"* (Focus group 3, psychiatrist participant 8)

7.3.1.2 Process

Patients and psychiatrists acknowledged a fear of repercussions for one another (Table 29). For example, patients repeatedly expressed concerns that psychiatrists would purposefully select patients more likely to give favourable, not necessarily authentic, feedback. This behaviour was confirmed by a number of psychiatrists, although not all. As a result, both patients and psychiatrists questioned the validity and acceptability of patient feedback as reported in Table 30.

Table 29 Comparison of patient and psychiatrist responses regarding a fear of repercussion

Shared area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Fear of repercussions for patients	“*Fear of it* [patient feedback] *adversely influencing treatment”* (online survey, participant 6); *“people fear making the report”* (Focus group 6, participant 7); *people are really worried about using it* [feedback process] *because people think it will have an impact on their care”* (Focus group 3, participant 5); “*I would actually tell white lies, I would have to”* (Focus group 7, participant 3)	“*They’re worried about criticising their doctor”* (Focus group 1, participant 4); “*I think people often find it really difficult to be handed those things, they feel that it’s not going to be anonymised”* (Focus group 1, participant 5); “*I can know the patient because the situation she described was very sort of unique”* (Focus group 2, participant 6)
Fear of repercussions for psychiatrists	“*There’s fear for them, you know, we’ve missed the point… psychiatrists are equally fearful of what patients would say in their feedback and they are almost looking for reassurance that the feedback they give isn’t going to cause them to lose their licence? There’s a circle of fear there really isn’t there? But again, I mean, maybe this, is where it needs to go back to real grass roots and maybe this whole criteria needs to be relooked”* (Focus group 1,pt5) “*There’s a fear of this blame culture isn’t there, where people are too worried about saying sorry because you know, a litigation taken to court and so we’ve lost that.. doctors, medical students can’t actually say sorry this has happened to you without that suddenly becoming a major legal problem, I think for that to happen there needs to be trust and acceptance on both sides, because we’re too much into this litigious culture which is restricting how we feel and think”* (Focus group 8,pt16)	“*I’m terrified of opening it and that’s why I haven’t contact them* [ACP 360] *to release it”* (Interview 2);“Interviewer: *Why do your colleagues cherry pick?* Participant: *Because they’re afraid of what people live with, they want their revalidation process and their appraisal process…people are afraid I think, they’re trying to cover their backs I think…”* (Interview 1); “*In a way we’re not bold enough to sort of say that because we’re scared if anything happens it will come back to bite us on the bum… we’re scared of being honest sometimes”* (Focus group 3, participant 2)

Table 30 Comparison of patient and psychiatrist responses regarding the validity of patient feedback

Shared area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Biased patient responses	“*Positively altering what I say, that would be better than giving negative feedback back to worsen my treatment”* (Interviewee 2); “*It would affect my honesty…I would be very wary, very careful about what I say”* (Focus group 8, participant 1)	“*If they’re not able to talk openly, that invalidates the whole thing”* (Interviewee 1) “*They’re worried about criticising their doctor”* (Focus group 1, participant 4); “*I think the feedback that is left, it’s more likely to leave feedback if you’re angry with it”* (Interviewee 2)
Biased patient selection	“*I’ll choose this one and this one because they come to their appointments on time, they listen to what I say, they take the right medication… so they’re going to give me good feedback…it’s outrageous”* (Focus group 8, participant 6)	“*Let’s just check on my Monday clinic which is when you do your slightly anxious patients and then let’s not do my PD clinic* [group laughter] *all those ones that love me”* (Focus group 2, participants 6 & 5); “*I think it’s very difficult to get proper feedback in psychiatry unless you pick who you’re going to send the questionnaires to, people who you know will respond and know like you. I feel one does need to select who you send these thing to”* (Focus group 2, participant 4)*”*
Opportunity to gamify the system	“*People will play the game to get high scores, that’s fundamentally wrong, who’s that helping? It’s not helping anybody is it?* (Focus group1, participant 4) “*If he’s got two patients who he finds difficult and then he’s got two that like him and he knows that, then he’s going to choose them isn’t he?”* (Focus group 3, participant 1)	“*People can be selective, they can game play it* *This is the issue, you do pick people don’t you,* *It’s not really right to do at all but you can* *It’s not at all appropriate* *You can game play it* *Oh yeah* *There’s no checking the process* *It’s down to your own personal processes* (Focus group 2, participants 2,4,5 & 1); “*It’s the selecting of patients, it defeats the purpose…it’s completely useless…it invalidates the whole process”* (Interviewee 2)
Frequency of opportunity	“*I’d love to give feedback but I’ve never been asked for it”* (Focus group 6, participant 1) “*I’ve never had a feedback form*” (Focus group 8, participant 1)	“*Doing it once every five years…there is something mechanistic about that…it’s not live enough”* (Focus group 1, participant 6) “*Doing it once every five years is a bit artificial isn’t it?”* (Focus group 3, participant 4); “*I think*

	"*I've been doing this role for eight years and not once have I seen that form come out, not once"* (Focus group 1, participant 9) "*It's laughable once every five years, it's laughable"* (Focus group 5, participant 4) "*Revalidation is so invalidating"* (Focus group 5, participant 5)	*that five years is too much, I'd rather know sooner if I do make a mistake, I wouldn't want to wait give years to improve my practice"* (Interviewee 1)
Social desirability	**-**	"*I wonder if you might have raised your game subconsciously* [group laughter] *until you thought you had enough numbers?"* (Focus group 2, participant 4)
Defensive practice	-	"*Defensive practice…People will get more defensive, they will feel that they have to do things for the sake of feedback"* (Interviewee 2)
Disaggregating the individual from the system	"*You can't separate the feedback to the psychiatrists as opposed to feedback to the system in which the psychiatrist operates…and one of the things I've found is a lot of the external things, are all the staff members saying I completely agree with you and the point you're making, but we're fighting that point ourselves within the system so you know if the psychiatrist isn't giving you enough time, it's maybe because his, or her workload is too great"* (Focus group 6, participant 5)	"*I've had a very difficult family who are forever putting their view forward, we met with them and I said, 'well I'm trying to do the best I can but we can't do everything, we've got these issues that make it very difficult' and they said, 'Oh well thank you, we didn't understand, we just thought that you weren't trying…'"* (Focus group 3, participant 4)
Feedback fatigue	"*Everywhere you go now…"* (Focus group 2, participant 10)* *Participant was referring to life in general as opposed to psychiatric care	"*There seems to be feedback on everything, if you phone a bank or something"* (Focus group 2, participant 4)
Response rates	-	"*There seem to be very few people who respond and I wonder how representative it really is"* (Focus group 1, participant 1); "*It* [ACP 360] *fails to look at patients who have been discharged with good outcomes, it misses a whole lot of patients, so we're only taking a skewed sample"* (Focus group 1, participant 8)

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As evidenced by Table 30 above, some psychiatrists identified additional concerns that were not discussed by patient participants. These additional areas of concern included response rates, representation, the altering of behaviours when aware of feedback being collected and a rise in defensive practice. Despite these differences, both patients and psychiatrists repeatedly expressed concerns at the infrequency of feedback opportunities and the message this sent, whether intentional or not, about the perceived purpose and value attributed to patient feedback.

7.3.1.3 Purpose

Furthermore, as demonstrated in Table 31, both patients and psychiatrists appeared to share the view that the purpose and intention of existing feedback tools is unclear. Participants often viewed the collection of patient feedback as a tick box exercise, driven by regulatory requirements as opposed to intrinsic, or quality improvement motivations (Table 31). However, although motivations for providing patient feedback were fairly similar from a patient perspective, a disparity between psychiatrist motivations was often evident. Some psychiatrists reported completing patient feedback activities with the sole intention of meeting appraisal requirements. Others, although often a minority, described motivations of quality improvement. However, fulfilling mandatory requirements appeared to be the overriding driving force for the majority of psychiatrists, supporting patient concerns that patient feedback for revalidation purposes is often viewed as a tokenistic exercise that typically receives limited attention or reflection beyond its collection.

Table 31 Comparison of patient and psychiatrist responses to the perceived purpose and motivation of patient feedback

Shared area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Unclear purpose	“*What do they do with that feedback? What happens to that feedback?”* (Focus group 2, participant 5); *“We don’t have enough information here to help us understand”* (Focus group 6, participant 6)	“*I’ve had patients say, ‘what is that?’ And they think they’re going to court, they don’t open it because they’re anticipating something worse”* (Focus group 1, participant 5)
Tick box exercise	“*It’s very much a tick box exercise”* (Focus group 4, participant 8)	*“You’ve got to do it for your appraisal”* (Focus group 2, participant 4)
Motivations for providing/receiving patient feedback	Evidence of change - “*knowing it was going to be used would be motivation…knowing it changed something for the better”* (Online survey, participant 5) Quality improvement and service failure prevention for others, *“I would give feedback if I thought it would improve my, or others experiences”* (Online survey, participant 9) Professional development, “*If you had it presented as part of their learning, their professional development then that’s the motivation”* (Focus group 2, participant 4) The opportunity to praise – “*I would give feedback if it offered a way to praise positives”* (Online survey, participant 9) Patient empowerment and partnership - “*It would also start to bring everything onto an equality basis as well, because then you’re actually giving me* [psychiatrist] *advice, you’re part and parcel of this process…the journey becomes one they are both involved in and that would bring enormous benefits”* (Focus group 1,participant 9)	Fulfilling mandatory requirements *“Why do you collect patient feedback? The honest answer? Because I’m meant to do it”* (Interviewee 2); “*I needed to do it for my appraisal, it didn’t change anything”* (Focus group 2, participant 9) Opposing (minority) view *“I collect feedback in order to improve the quality of care we deliver”* (Interviewee 1) “*I mean it’s quite empowering isn’t it if you’re a patient, because generally you’re powerless, so the idea of feedback is you stop being a patient, now you’re an equal expressing your view about your care and that should be quite a positive thing…”* (Focus group 3, participant 3)
Message sent by frequency of opportunity	“Interviewer: *what would make patient feedback more meaningful to you?* Participant: *The ability to feedback would be a good start wouldn’t it?”* (Focus group 4, participant 2); “*If we’ve come down to the only form of giving feedback for the most important person whose got your life in their hands for the period that you are being detained getting feedback from twenty people in the space of five years, you know, I think that’s frankly unsatisfactory”* (Interviewee 1)	“Interviewer: *what message do you think that it sends to patients that it’s once every five years?* Participant: *That it’s a tick box exercise, that’s it”* (Interviewee 1)

Linked to concerns of feedback engagement and reflection were concerns of feedback pathologisation, i.e. treated as abnormal or untrue, due to psychiatric diagnosis or assumed issues of capacity. Some psychiatrist responses appeared to confirm such practice as demonstrated in Table 32 below.

Table 32 Comparison of patient and psychiatrist responses to feedback pathologisation

Shared area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Feedback pathologisation and/or rejection due to assumed vulnerabilities or issues of capacity	"Participant 4: *are they going to excuse that* [patient feedback] *by saying 'oh, well the patient is particularly paranoid?* Participant 5: *yes, you become your diagnosis then don't you? That's their illness, so of course they're going to say that"* (Focus group 1) "*As a patient it is too often the case that any negative feedback is taken as a symptom of illness."* (Online survey, participant 13) "*Doctors know best this is what I think and discredit the person and actually pathologise, it's only because of your mental health problem that you're speaking like that…"* (Focus group 5, participant 4) "*That's the whole point, some might disregard patient feedback completely and make an assumption that people are too poorly"* (Focus group 8, participant 1) *"I think quite easily sometimes, normal behaviour can be pathologised can't it?"* (Focus group 5, participant 10)	"*You have to be very careful about how the feedback is interpreted really in light of the diagnosis"* (Focus group 2, participant 1) "*I think our feedback has to be interpreted differently… it has to be interpreted with a pinch of salt"* (Focus group 2, participant 9)

However, the pathologisation or rejection of patient feedback due to assumed vulnerabilities was not accepted by all psychiatrist participants. For example, as stated by interviewee one:

> "*I strongly believe that mental health patients can give feedback, it is just the stigma around mental disorders that affects our view of whether people with mental illness are capable of giving feedback…I cannot see*

> *why they couldn't give feedback… and why these feedback can be discredited and devalued, I cannot see why"* (Psychiatrist interviewee 1)

However, this view was not unanimous.

7.3.1.4 Content

Finally, in regard to content, patients and psychiatrists agreed on a number of topics as outlined in Table 33. Collectively, patients and psychiatrists shared eight core areas: communication skills, understanding, being actively listened to and heard, valuing an open and approachable relationship, discussing medication, helpfulness and appearance.

Table 33 Shared areas of importance by both patients and psychiatrists

Shared areas of importance	Patient verbatim examples	Psychiatrist verbatim examples
“Actively listens and hears” “Open and approachable”	*“Active listening”* (Focus group 2, participant 6) “*A willingness to really listen”* (Focus group 1, participant 3) “*Put you at ease so you can express yourself, I think that’s the most important thing for me…”* (Focus group 8, participant 4) *“Made me feel at comfort or at ease”* (Focus group 2, participant 6)	“*Did you feel heard? Did you feel listened to?”* (Focus group 2, participant 6) *“Is that person feeling comfortable to have a conversation with me? I think that is the most important feedback that I think is helpful?”* (Interviewee 2)
“Discusses medication”	“*There’s nothing about medication in this* [existing questionnaire] *it would be helpful if you could have a few questions about medication and about your input in it”* (Focus group 3, participant 1)	“*We know there’s quite a high non-compliance with medication and that, they’re given advice when prescribed and then they don’t take it, it’d be interesting to know whether that was a measure of how well we’d sort of explained or convinced them that it was a good intervention”* (Focus group 1, participant 9)
Communication	“*Good communication is important”* (Focus group 4, participant 6)	“*Did I explain it well?* (Focus group 2, participant 4); “*Did I answer your questions?”* (Focus group 2, participant 6)
Understanding	“*Understanding”* (Focus group 3, participant 2)	*“The one thing that is really important I think is that they’ve understood the information because we get a lot of misinterpretation, if patients have understood what was discussed that would be really valuable”* (Focus group 1, participant 8)
Appearance	“*He had his hair down to his waist and a big wispy moustache and I loved him to bits because he was himself and seeing someone in a straight suit, frightens me to death”* (Focus group 8, participant 1) “*I think the way professionals dress needs to be modified and not formal attire… you can identify with them more then generally can’t you”* (Focus group 8, participant 6)	*“Because I’m quite scruffy, I wear blue jeans we’re not allowed to wear in the Trust, so I ask patients you know… and actually when patients say ‘yeah I don’t like seeing doctors in suits and ties, because it puts me off, that’s positive feedback because it reinforces that”* (Focus group 2, participant 1)
Helpful	*“Helpful*” (Interviewee1)	*“Was I helpful? And if I wasn’t helpful ‘what can I do to get to the next stage?’ ‘Was I helpful enough?’”* (Focus group 2, participant 4)

However, patients also described thirty-four additional behaviours, attributes and skills that were not identified by psychiatrist participants. Echoing findings from cycle two, behaviours identified by patient participants alone were often those considered to be most conducive to the therapeutic relationship including, being treated holistically not as condition, feeling involved through shared decision making and respected. Table 34 shows the areas discussed by patient participants alone.

Table 34 Behaviours, attributes and skills described by patient participants alone

- Treated holistically not just the condition (treated as an individual, treated like a human being)
- Respectful
- Works in equal partnership
- Compassion
- Caring
- Honest
- Supportive and encouraging
- Offers reassurance
- Kind
- Knowledgeable
- Fair
- Offers hope
- Authentic
- Gentle
- Person centred
- Reliable
- Tolerant
- Involves – family members and carers, shared decision making
- Accurate note taking
- Empathetic
- Reads patient history
- Trusting and trustworthy
- Has an understanding of systems and services outside of psychiatry
- Patient
- Timely
- Dedicated
- Attentive
- Doesn’t make patients feel rushed
- Passionate
- Enthusiastic
- Modest
- Polite
- Sympathetic
- Warm

7.3.2 Suggested solutions

Despite these disparities, patients and psychiatrists described a number of shared solutions regarding the design (Table 35), process (Table 36) and information (Table 37) of patient feedback tools for revalidation purposes.

7.3.2.1 Design and accessibility

Both patients and some psychiatrists expressed a desire for patient feedback tools to be co-designed, simplified and contain a combination of both free text and closed questions (Table 35). While patient participants discussed the positioning of multiple choice questions underneath free text comments to disrupt habitual ticking, the inclusion of more narrative comments appeared desirable to both patients and psychiatrists.

Patients also expressed a desire for existing patient feedback tools to be made more colourful and less formal, while psychiatrist participants discussed a desire to change existing questions if they had made a change to their practise. However, concerns of how this would practically work and its perceived impact on ‘validity’ were also raised.

Table 35 Comparison of patient and psychiatrist responses to suggested design and accessibility solutions

Shared suggested solutions	Patient verbatim examples	Psychiatrist verbatim examples
Patient involvement/co-production	“*Be designed with co-production”* (Online survey, participant 9)	“*This co-creation as a reality ok…”* (Interviewee 1)
Simplified	“*Simple, easy to read and understand”* (Focus group1, participant 4)	“*There needs to be a simplicity to it”* (Focus group 2, participant 5)
Specific, tailored or personalised questions	Use the word “*psychiatrist or even the name of the psychiatrist”* (Focus group 3, participant 2); “*encourage people to give feedback that is specific”* (Online survey, participant 11)	“*I think it has to be individualised to be useful…you would need it to be personalised saying I’ve just seen Dr whoever it is and it’s focused on your appointment”* (Focus group 1, participant 6); “*specific feedback that’s a bit more relevant”* (Focus group 2, participant 4)
Mixture of both open (narrative) and closed questions	“*Have a mixture of both”* (Interviewee 2); “*The use of multiple choice questions alongside a couple of open ended ones is more appealing and likely to get more responses”* (Online survey, participant 10)	“*Open text is important for quality improvement, on the other hand closed questions are also important too, because you can get focused feedback on some issues”* (Interviewee 1)
Sufficient space for free text/narrative responses	“*I’d prefer to have something short and a large comments box so I could freely write about my experiences rather than tick lots of boxes that don’t really feel like I can express my feedback”* (Online survey, participant 7)	“*Give some space for them to make their own comments somehow, if we leave them to speak on their own…People are free to speak about whatever they want…things come up that we may not have e thought about”* (Interviewee 1)
Space to give both praise and criticism	“*Encouraged to give balanced feedback”* (Online survey, participant11)	“*People sometimes want to feedback positive things as well and we haven’t really always got a way of doing that”* (Focus group 3, participant 3)
Carer/family inclusion	“*It would be good to be all in one* [carer/family feedback]” (Focus group 1, participant 6)	“*What about the relatives of patients because sometimes they have a view don’t they that’s just as important in*

		evaluating effectiveness isn't it?" (Focus group 2, participant 6)
Length	"*Reasonably short"* (Focus group 1, participant 6)	"*A4 size single sheet"* (Interviewee 2)
Question flexibility	-	*"Would it be helpful to set your own questions or if you'd made a change and you could get feedback on that? Yes, that would be very helpful, very helpful, but I think the whole context of this process needs to change"* (Interviewee 1)
Multiple choice question location	Place multiple choice questions "*underneath"* (Focus group 1, participant 7) free text comments to disrupt habitual ticking	-
Colour	"*Colourful…bit happier, less formalised"* (Focus group 8, participant 1); "*Make the actual thing interesting"* (Focus group7, participant 1)	-

7.3.2.2 Process

Process related solutions suggested by participants included increasing the frequency of opportunity and incorporating a feedback loop for both patients and psychiatrists (Table 36). As one patient stated, a feedback loop does not need to be complex, but must acknowledge what has been done as a result of the feedback provided. Unique to psychiatrist responses, psychiatrist participants also reported a desire for more real time feedback with a greater focus on reflection as opposed to quantity of feedback collection as previously described (Table 36).

Table 36 Comparison of patient and psychiatrist responses to suggested process solutions

Shared suggested solution	Patient verbatim examples	Psychiatrist verbatim examples
Build in a feedback loop	“*Feedback loop”* (Interviewee 1); “*simple you said we did approach”* (Online survey, participant 2)	“*Most important thing for giving feedback is the loop isn’t it…”* (Interviewee 2)
Frequency of opportunity (flexibility and choice on when and how to complete)	“*Patient initiated”* (Focus group 5, participant 2); “*multiple opportunities”* (Online survey, participant 10); “*I think it should be open to the individual, some people might want to fill in a form, some might want a conversation, someone might want to send a text, just ask the person how would you like to give it?”* (Focus group 7, participant 3)	“*I think it would be more useful if patients could have the feedback at the time they want to give it… you get patient feedback for our appraisals, that’s nothing to do with when they want to give it”* (Focus group 3, participant 5); *“They give it when they want to give it, much more useful to you and the patient”*“(Focus group 3, participant 2)
Real time	-	“*Useful it could be to actually get it at the time”* (Focus group 3, participant 4); “*Immediate feedback”* (Focus group 1, participant 7)
Focus on reflection	-	“*It’s more of the reflection isn’t it*” (Interviewee 2); “*You could argue that it would truly work if there would be something, your appraiser would be able to go on a scale of one to ten, does this person respond to feedback? No reflection at all to appraisee achieves change, that’s more important*” (Focus group 2, participant 2)

7.3.2.3 Information

One final solution suggested by both patients and psychiatrists included the provision of relevant information. While some areas of commonality were clearly evident including providing information on who and when to base feedback on, patient participants also identified a number of additional areas where further information was required. Patient suggestions for information often focused on including why completing a patient feedback form may be beneficial from a patient perspective, assurances of anonymity and clear explanations that the provision of patient feedback would have no adverse impacts on future healthcare delivery (Table 37). These last two suggestions were discussed at length by patient participants accentuating their perceived importance.

Table 37 Comparison of patient and psychiatrist solutions to information provision

Suggested solutions:	Patient examples	Psychiatrist examples
Information on why it might be beneficial to complete	"*It's got to be communicated that their feedback is important, you know there are benefits to you for filling this form in"* (Focus group 1, participant 9)	-
When feedback refers to	"*I always assume it's about the last time I spoke to the psychiatrist but that's not made clear enough"* (Focus group 3, participant 3)	"*I've just seen Dr whoever it is and it's focused on your appointment"* (Focus group 1, participant 6)
Assurance of anonymity	"*Reassurance of anonymised"* (Online survey, participant 10)	-
Assurance that it won't affect care	Assurance that "*your treatment won't be compromised in anyway because of whatever you said"* (Focus group7, participant 3); "*There won't be any repercussions"* (Focus group 1, participant 2)	-
Advice on how to give effective patient feedback	"*We ultimately want to give feedback because we want something to change and actually, providing feedback is really, really important, this is how you can best ensure that your feedback is effective as possible"* (Focus group 6, participant 6)	-
Information on where the feedback will go, who will see it and where it will be stored	"*How this feedback is going to be used?"* (Focus group 3,participant 6); *"What happens to that feedback"* (Focus group2, participant 5) "*Who is going to have this information"* (Focus group 3, participant 2)	-
Voluntary basis	It being a "*choice"* (Interviewee 1) to complete	-
Include suggested improvements	"*Encourage people to give feedback that is specific"* (Online survey, participant 11); "*Constructive, give ideas/ways of improving"* (Online survey, participant 9)	"*Maybe they could tell us what helped them and what didn't help them?"* (Focus group 1, participant 8); "*I would like a comment on things that could have been a bit better because we don't have that option do we?"* (Focus group 3, participant 5)

Finally, other solutions suggested by participants included a need to explore and evaluate suggested changes, helping to address perceived patient and psychiatrist disempowerment as reported in Table 38 below.

Table 38 Comparison of patient and psychiatrist responses to patient and psychiatrist disempowerment

Shared area of concern	Patient verbatim examples	Psychiatrist verbatim examples
Patient disempowerment	"*Are we really equal to psychiatrists as a patient? No, No of course not.*" (Focus group 6, participants 2 & 3); "*They have a hell of a lot of power*" (Interviewee 1)	"*There are not as many people as in other medical specialties where this power gradient between professionals and patients is there…*" (Interviewee 1); "*generally you're* [patient] *powerless*" (Focus group 3, participant 3)
Psychiatrist disempowerment	-	"*I feel constrained by the nature of the job*" (Focus group 2, participant 4) "*you're being forced to send out lots of questionnaires as a standard process*" (Focus group 1, participant 1)
A desire for a shared understanding of language	"*You said that since you've learnt to speak the language, things have been different and it strikes me if we're asking about what would be good? Would it be something about them speaking your language? Not you speaking theirs?*" (Focus group 2, participant 2) "*For me, they need to ask more questions because you present yourself knowing there is something, but you haven't got the language to explain what's going on… as soon as I've learnt the language* [language used by psychiatrists] *I can tell them*" (Focus group 2,participant 4)	-
A desire for patient empowerment		"*You've got to empower them* [patients] *in the first place haven't you*" (Focus group 2, participant 5).

7.4 Discussion

This research addressed a gap in existing literature by comparing patient and psychiatrist perceptions of patient feedback tools for revalidation purposes (Eiring *et al.*, 2015; Trujols *et al.*, 2013). Research findings indicate that both patients and psychiatrists share a number of concerns regarding the design, process, purpose and content of existing feedback tools. Both patients and psychiatrists express concern at the absence of a feedback loop, the relevance, value and acceptability of existing questions, response scales and limited number of narrative comments currently included. Furthermore, both patients and psychiatrists repeatedly questioned the validity of existing patient feedback tools. Participants reported a number of unintended consequences following the mandatory collection of patient feedback including ‘gamifying’ the system and falsifying feedback responses in order to avoid anticipated repercussions. Such practices appeared to be confirmed by some, but not all patient and psychiatrist responses.

One area of divergence between patients and psychiatrists included discussions of response rates and representation by psychiatrists alone. Such terminology is reflective of traditional positivist research discourses as opposed to patient-centred care, or experience. This may reflect an acknowledged disparity between the perceived purpose and intention of patient feedback and entrenched notions of what constitutes as ‘valid’ knowledge from a patient and psychiatrist perspective.

Other acknowledged areas of disparity between patient and psychiatrists included desirable content. Although patients and psychiatrists shared eight core areas including being actively listened to and heard, valuing an open and approachable relationship, discussing medication and communication skills, patients described an additional 34 areas of importance considered to be beneficial to the therapeutic relationship. Similar to cycle two, behaviours not identified by psychiatrists included some of the behaviours, attributes and skills most frequently described by patients including being treated holistically, not just as a condition and being involved in shared decision making processes. The level of disparity between domains of care discussed by patients and psychiatrists may reflect previously exclusive approaches to patient feedback design as acknowledged in cycle one, helping to accentuate the importance of including patient insight in patient feedback design and content generation (Miller *et al.*, 2015).

Interestingly, the provision of information appeared to show the greatest level of disparity between patients and psychiatrists, suggesting an evident gap in existing understanding. While patients and psychiatrists agreed on a need to provide information on who and what to base feedback on, patients also repeatedly expressed a desire to provide information on why completing a feedback form would be beneficial from a patient perspective, assurances of anonymity and clear statement that the provision of patient feedback would have no adverse effects on care delivery. This disparity further highlights the importance of involving both patients and psychiatrists to ensure all needs and desires are considered.

7.4.1 Comparison with existing literature

This research shares many similarities with existing literature including an acknowledged desire for patients to use patient feedback opportunities as a way to praise healthcare staff and services (Powell *et al.*, 2019), an acknowledged fear of reprisals for both patients and psychiatrists (Baines *et al.*, 2019c; Berzins *et al.*, 2018; Brooker & Dinshaw, 1998) and concerns around the infrequency of feedback opportunities (Sir Keith Pearson, 2017). Following previous discussions around the emergence of patient centred care in chapter one, there appears to be a divide between psychiatrists who have embraced such a transition and those who remain reliant on the historical biomedical model. Indeed, some form of ‘abuse’ (Stickley, 2006) still appears to take place in the form of feedback pathologisation and bias patient selection due to anticipated responses as reported by Asprey et al., and others (Asprey *et al.*, 2013; Baldie *et al.*, 2018; Carter *et al.*, 2016; Gayet-Ageron *et al.*, 2011). The purposeful selection and exclusion of patients arguably helps to ensure that patients remain passive as opposed to active and involved (Beattie *et al.*, 2014; Snyder & Engström, 2016). The lack of certainty regarding the purpose of patient feedback has also been widely reported in existing literature (Archer *et al.*, 2018), as has uncertainty regarding the perceived purpose of revalidation more broadly (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017).

7.4.2 Contribution to new knowledge

Unique contributions of this research include its comparison of both patient and psychiatrist responses helping to generate new knowledge and understanding. As identified by Boardman and others, most of the existing literature has explored such perspectives in isolation of one another (Boardman, 2018; Crawford *et al.*, 2011; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a). This research also helps to provide novel insight into the methods used by both patients and psychiatrists to ‘game’ patient feedback for revalidation purposes.

7.4.2 Strengths and limitations

Strengths of this research include its application of an accepted analysis method (Srivastava & Thomson, 2009) and co-production with a patient research partner. However, as reported in cycles three and four, this research relies on a volunteer sample. The findings should therefore be interpreted with caution. Further discussion of the limitations of each data set are provided in cycles three and four to avoid duplication.

7.4.3 Implications

Implications of this research include the acknowledgement that patients and psychiatrists agree, more than they disagree, on areas of concern and ways to improve existing patient feedback tools. Secondly, the areas of divergence identified in this research highlights the detrimental outcomes of exclusive approaches to patient feedback design and content generation. Areas of divergence may be overcome by adopting a more inclusive approach such as co-production, although further exploration of this approach is required. Thirdly, the previously accepted validity of patient feedback continues to be challenged by both patients and psychiatrists, highlighting an underpinning theme throughout cycles one to five. Both patients and psychiatrists reported falsifying feedback scores, pathologising feedback due to anticipated vulnerabilities and purposefully selecting patients more likely to give favourable, not necessarily authentic, feedback responses due to a fear of repercussions. The processes that give rise to such behaviours should be addressed. Finally, both patients and psychiatrists acknowledged a need to evaluate suggested solutions.

7.5 Conclusion

In conclusion, patients and psychiatrists share more areas of commonality than divergence when reviewing existing patient feedback tools. Exploration of suggested solutions and their potential impacts should be undertaken. This forms the focus of cycles six (chapter eight) and seven (chapter nine) as outlined below.

8.0 Cycle 6 - Co-production of patient feedback tool for revalidation purposes with both patients and psychiatrists

8.1 Introduction

This cycle brings together research findings from cycles one-five by co-producing a patient feedback tool with patients and psychiatrists for revalidation purposes. Justification for this research cycle stems from practical and methodological needs identified in previous research cycles and existing literature more broadly (Boardman, 2018; Crawford *et al.*, 2011; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a). Furthermore, evidence suggests that working with both patients and psychiatrists can help to achieve a greater sense of ownership over patient feedback tools, perceived usefulness (Riiskjær *et al.*, 2010), trust and engagement (Carter *et al.*, 2016). However, critical exploration of co-producing a patient feedback tool is limited, highlighting a further gap in existing knowledge and understanding that this research seeks to address. Finally, the continued use of ineffective feedback tools has been shown to be detrimental to the overall quality of care received (Thornicroft *et al.*, 2008). Identifying ways to improve existing feedback tools is therefore imperative. This penultimate research cycle therefore sought to address the following research questions:

- What do patients and psychiatrists co-produce when creating a patient feedback tool for revalidation purposes?
- How, if at all, does this compare to the current ACP 360 tool?

Justification for comparing the co-produced feedback tool with the ACP 360 tool stems from its specific focus on psychiatric care and acknowledged exclusion of patients and the public in its design and evaluation as reported in cycle one (chapter three). The acknowledged exclusion of patient involvement in the ACP 360 tool enables comparative opportunities while remaining sensitive to the unique context of psychiatric care. The final research question of what impact, if any, does co-production have on the perceived value and acceptability of a patient feedback tool is addressed in the final research cycle, cycle seven (chapter nine).

8.2 Methods

To address the research questions outlined above, two workshops were held: a co-production workshop with both patients and psychiatrists and a refinement workshop. Although the refinement workshop was intended to include both patients and psychiatrists, no expression of interests was received by psychiatrists as later described.

An overview of each workshop is presented below, followed by details of their recruitment, setting, data collection and analysis.

Co-production workshop

The first two-hour workshop sought to co-produce a patient feedback tool with both patients and psychiatrists. This was achieved by:

- Identifying and agreeing:
    - An appropriate *number* of behaviours, attributes and skills to be included
    - The *specific* behaviours, attributes and skills identified in cycles two-five to be included
- Creating and agreeing:
    - Question content, wording and phrasing
    - Scale content and design
    - Feedback design and layout
    - Information design and content presented alongside the newly created patient feedback tool

Questions that were co-produced by both patients and psychiatrists were also compared with the ACP 360 tool given its extensive use in revalidation practise and acknowledged exclusion of patients and the public in its design and evaluation (cycle one, chapter three).

For purposes of transparency, the process of this co-production workshop began with informal introductions, establishment of ‘ground rules’ by participants to facilitate a mutual and respectful session, informal explanation of the research study by the patient research partner and researcher and generation of goals the group hoped to achieve by the end of the session. The remainder of the session focused on achieving these goals with a lunch break provided in between. The co-production workshop was facilitated by the patient research partner and researcher in regards to time keeping, clarifying any information shared and adhering to the goals set out by the group.

To facilitate familiarity with the information shared, an information pack (Appendix 13) was circulated to participants two weeks prior to the co-production workshop date. Information contained within this pack included a summary of research findings to date, response scale examples, a cut and stick exercise containing the most frequently suggested solutions from cycles three-five and a list of all behaviours, attributes and skills identified by participants in cycles two-five arranged alphabetically.

Unlike the proceeding cycles, a copy of the two most commonly used patient feedback tools was purposefully not included in the information pack to avoid any undue influence or perceived limitations as to what could be created. Justification for including response scale examples stems from a request made by the patient research partner who suggested such examples may be helpful to include as some people may be unfamiliar with response or Likert scales. Similar to all other research information, the information pack was put together with the patient research partner at one of our regular meetings to ensure ease of understanding and relevance.

Refinement workshop

The second two-hour workshop sought to refine the patient feedback tool co-produced in workshop one by:

- Examining the accessibility, understanding, content, design and layout of the co-produced patient feedback tool beyond the influence of the Royal College of Psychiatrists or previous research involvement as explained below and further refining or adapting the co-produced tool where required.

The resulting tool was checked against the co-designed feedback checklist produced in cycle three (chapter five). Details of the workshops recruitment, setting and data collection are presented below.

8.2.1 Participants (workshop 1)

Inclusion & exclusion criteria

Due to its co-productive nature, both patients and psychiatrists were invited to take part in workshop one. Table 39 outlines the inclusion and exclusion criteria applied.

Justification for this criteria is provided on pages 109 & 157 to avoid duplication. It is important to reiterate that the exclusion of certain participants from this research does not mean to suggest that their experiences and interests are unworthy areas of future research.

Table 39 Patient and psychiatrist inclusion and exclusion criteria

Participant group	Inclusion criteria	Exclusion criteria
Patients	- Any gender or ethnicity - Aged 18-65 years - Personal or care related experience of psychiatric care not solely related to learning difficulties, paediatric Alzheimer or Dementia care - An ability to speak and understand the English language	- Below the age of 18, or above the age of 65 - Personal or care related experience of psychiatric care related to learning difficulties, paediatric, Alzheimer or Dementia care only - Inability to speak or understand the English language
Psychiatrists	- Any gender or ethnicity - GMC registered psychiatrist with a current licence to practise - Experience of delivering adult psychiatric care not solely related to Alzheimer or Dementia care - An ability to speak and understand the English language	- Not registered with the GMC or does not hold a current licence to practise - Experience of delivering child, Alzheimer or Dementia related psychiatric care only - Inability to speak and understand the English language

8.2.2 Recruitment (workshop 1)

Patients

Patient participants were recruited through the Royal College of Psychiatrists service-user network and contacts made during the previous research cycles using a volunteer, purposeful sampling approach. A research invitation co-designed by the patient research partner and researcher was circulated via email by the Royal College of Psychiatrists to all members of their service-user network (Appendix 14). Patients who had been involved in the previous research cycles and had given their consent to be contacted for future research opportunities were also sent the same invitation for consistency. Previous participants or members of the Royal College service-user network who expressed an interest (n=12) were then invited by the researcher to take part in the co-production workshop.

Psychiatrists

Psychiatrist participants were also recruited using a volunteer, purposeful sampling approach from contacts made during the previous research cycles and the Royal College of Psychiatrists to ensure they had a licence to practise. Participants who had previously taken part in this research and had agreed that they could be contacted for further research opportunities (n=6) were invited by the researcher via email to take part in the co-production workshop. Members of the Royal College were also contacted using the same email invitation distributed by the Royal College. Despite this, no expressions of interest from the Royal College were received.

ACP 360 representative

At the request of the College, a representative from the ACP 360 team was invited to observe the co-production workshop and provide information about the existing patient feedback tool and processes if required. This request was as a result of the workshop setting as detailed below.

8.2.3 Setting (workshop 1)

Workshop one was held at the Royal College of Psychiatrists (14th June 2019). The Royal College had been made aware of the research being undertaken through their Lead for Revalidation at the time. As a result, the patient research partner and researcher were invited to hold a co-production workshop at their venue. For clarity, the Royal College did not commission this research in anyway.

Although a more mutual setting would have been preferable, the Royal College provided a space near central London, lunch and reimbursed patient participants for their time and travel. This would have been unachievable if relying on the researcher alone due to the self-funded nature of the PhD and subsequent financial limitations. However, the potential bias caused as a result of this setting is acknowledged as a limitation of this research, providing justification for the second refinement workshop outlined below.

8.2.4 Participants (workshop 2)

Inclusion and exclusion criteria

With the exception of being a member of the Royal College service-user network and/or previous research involvement, the same inclusion and exclusion criteria listed in Table 39 was applied to the refinement workshop. Justification for this approach stems from a desire to further refine and test the co-produced feedback tool created in workshop one beyond the potential influence of the Royal College of Psychiatrists or previous research involvement.

8.2.5 Recruitment (workshop 2)

Patients

Patient participants were recruited through a local mental health support group. An email invitation was sent by the group’s coordinator to all members to avoid any undue influence by the researcher. The initial invite was followed up by an email reminder sent two weeks later. Individuals who expressed an interest were then invited by the researcher to attend a co-production workshop (17th of October 2019).

Psychiatrists

The Revalidation Lead at the Royal College of Psychiatrists circulated an email invitation to practising psychiatrists. However, similar to workshop one, no expressions of interest were received through this route.

8.2.6 Setting (workshop 2)

The second workshop was held in the conference room of a local health and wellbeing hub. The charity often hold their support group meetings at this venue, helping to ensure accessibility and familiarity for participants.

8.2.7 Data collection (workshops 1 & 2)

Both workshops were audio-recorded using a Dictaphone and transcribed verbatim by the researcher. Participants were provided with a verbal summary of the process and overall study prior to the start of the workshop session. This was delivered by the patient research partner and researcher.

In both workshops participants were reminded that their involvement was entirely voluntary and that the content of any information shared would be confidential and made anonymous through the removal of any identifiable information and use of relevant pseudonyms.

8.2.8 Data analysis

Data from both workshops were analysed using an inductive thematic approach as outlined by Braun and Clarke (Braun & Clarke, 2006). Similar to previous research cycles, data analysis was conducted in co-production with the patient research partner for the aforementioned reasons. Data from workshop one was analysed before the planning and undertaking of workshop two.

8.2.9 Maintaining rigour

Rigour was maintained using the same processes outlined in Table 13.

8.2.10 Ethical considerations

Ethical approval was provided by The Health Research Authority (reference number -17/YH/0353) and Faculty Research Ethics Committee for Health and Human Sciences (reference number- 17/18-846) at the University of Plymouth (Appendix 2, 3 & 4). All participants provided written informed consent prior to any data collection or research participation.

8.3 Results

8.3.1 Workshop one

A total of 12 participants took part in workshop one (11 patients and one psychiatrist). Findings are presented in the following order of themes: co-production of content, design, provision of information and processes.

8.3.1.1 Co-production and agreement of content

The content of the patient feedback tool was created in three stages.

Stage 1:

Firstly, using the alphabetised list of behaviours identified in cycles two-five, all participants independently identified a maximum of ten behaviours, attributes or skills they considered to be most conducive to the therapeutic relationship. Once chosen, participants shared their selections with the wider team. Ten behaviours, attributes or skills were chosen as an appropriate number by participants as it "*felt like a good number*" that would prevent "*habitual ticking*" (patient participant 6) while avoiding overwhelming potential respondents or diluting the meaning of patient experience.

While participants acknowledged that their choice of behaviours often overlapped with one another, participants suggested that some behaviours could be amalgamated, or further refined. The second stage of this co-production process therefore explored whether any of the behaviours, attributes or skills selected could be meaningfully amalgamated, if at all.

Stage 2:

All behaviours selected by participants in stage one (n=27/52) were listed in order of frequency by the research partner on a white board. Participants then discussed what behaviours could be meaningfully amalgamated, if at all. Decisions made as a result of these collective discussions are outlined in Table 40 for purposes of transparency.

Table 40 Decisions and justification for including certain behaviours, attributes and/or skills in newly co-produced patient feedback tool

Decision made	Justification
Keeping ‘trust’ and ‘listening’ distinct	*“Trust feels like a separate quality. You can be looking like you’re listening to someone, but you might not be trusting what they’re saying”* (participant 2)
Combining ‘involves’ and ‘patient centred care’ with ‘equal partnership’	“Participant 6: *I wonder if we can combine equal partnership and involves?* Psychiatrist: *yes, that’s what I was thinking as well because if you involve the person]* Participant 6: *I chose equal partnership rather than involves because they were kind of similar* [group agreement] Participant 6: *But involve kind of feels like the psychiatrist is the gatekeeper to involving whereas equal partnership is everyone is in it together if that makes sense* Participant 7: *you could add patient centred care to that as well”*
Incorporating ‘discusses medication and its side effects’ with communication	“Psychiatrist: *The other thing that I think we can combine as well is clear communication with discusses medication because here in the list it says clear explanation, so discusses medication and provides explanation about why, what the person should expect as side effects* Facilitator: *so maybe something about including the discussion of medication and its side effects* [group agreement] Participant 1: *yes and formulation, diagnosis, you know all those* Psychiatrist: *yes, this all falls under communication to me as well”*
Keeping ‘listening’ and ‘communication’ as distinct entities	“Participant 1: *in a way listening also falls under communication* Participant 2: *hmm* Participant 1: *if you’re not listening, you’re not communicating* [group agreement]”
Keeping ‘help’ and ‘hope’ distinct	“Psychiatrist: *I would also say that offering help and hope is in that attribute of a compassionate person* Participant 1: *although I would for me, just in terms of offering hope, I see hope as a distinct concept in itself*

Keeping ‘help’ and ‘hope’ distinct continued	Participant 7: *I guess it’s different to offer someone hope in general then it is to suggest specific solutions which might help, because you can suggest solutions without actually being very hopeful about it if that makes sense?* Participant 1: *yeah* Facilitator: *ok so keep help and hope distinct?* Participant 6: *Hope isn't a promise, it's separate to. I'm given hope but with the caveat that in the future things will be different* Facilitator: *and is that important to have that hope now?* Participant 6: *now yeah, that's why we challenge the use of the word suffering and things like that because it takes away that hope when you get the diagnosis]* Participant 1: *I also think they* [psychiatrists] *have to offer hope, I think they’re probably in the strongest position of any mental health profession to offer that hope”*
Keeping ‘clear communication’ and ‘reads history’ as distinct entities	“Participant 6: *would reads history go into clear communication?* Psychiatrist: *I think most service users feel that doctors don't read the history, because reading the history and taking the history is the foundation of medicine, so if people feel that doctors should be doing this more, it means that we don't do it,* Participant 6: *It's very frustrating to go into see a professional and have to try and remember what's gone on in the past* Psychiatrist*: yeah,* Participant 6: *whereas it's there in the notes in front of them*”

Many of the decisions outlined in Table 40 were discussed at length by participants including the importance of hope. As participant one suggested:

> "*I think they* [psychiatrists] *have to offer hope. I think they're* [psychiatrists] *probably in the strongest position of any mental health profession to offer that hope"* (participant 1).

Similar to cycles three and four of this research, underpinning many of the decisions made were concerns of language, power and inactivity. For example, participants often described the difficulty of getting inaccurate patient records changed and challenged dominant discourses of suffering and/or sufferers. As a result, many of the behaviours selected by participants related to partnership working, patient-centred care and the relational nature of psychiatric care (Table 41).

During this second stage, consensus of the ten behaviours considered most conducive to the therapeutic relationship from both a patient and psychiatrist perspective was achieved (Table 41).

Table 41 Ten behaviours, attributes and/or qualities considered most conducive to the therapeutic relationship

Equal partnership
Clear communication
Actively listens
Non-judgemental
Treated holistically
Honest
Reads patient history
Understanding of external systems and services
Compassionate
Gives hope

Table 42 outlines the selection process that led to the top ten behaviours made by participants for purposes of transparency.

Table 42 Selection process of top 10 behaviours, attributes and/or skills considered most conducive to the therapeutic relationship

Original scoring		*Decision to combine equal partnership and involve*		*Decision to combine patient-centred with equal partnership*		*Decision to combine discusses medication with communication*	
Behaviour, attributes and/or skills	*Frequency*	*Behaviour, attributes and/or skills*	*Frequency*	*Behaviour, attributes and/or skills*	*Frequency*	*Behaviour, attributes and/or skills*	*Frequency*
Non-judgemental	12	Equal partnership (and involve)	13	Equal partnership (involve, patient-centred)	21	Equal partnership (involve, patient-centred)	21
Actively listens	12	Non-judgemental	12	Non-judgemental	12	Clear communication (discusses medication)	17
Treated holistically	11	Actively listens	12	Actively listens	12	Non-judgemental	12
Clear communication	10	Treated holistically	11	Treated holistically	11	Actively listens	12
Involves	9	Clear communication	10	Clear communication	10	Treated holistically	11
Patient centred	8	Patient centred	8	Reads patient history	8	Reads patient history	8
Reads patient history	8	Reads patient history	8	Understanding of systems or services external	8	Understanding of systems or services external	8
Understanding of systems or services external	8	Understanding of systems or services external	8	Compassionate	7	Compassionate	7
Compassionate	7	Compassionate	7	Discusses medication	7	Honest	7
Discusses medication	7	Discusses medication	7	Honest	7	Offers hope	7
Honest	7	Honest	7	Offers hope	7	Empathetic	6
Offers hope	7	Offers hope	7	Empathetic	6	Willingness to really listen	5
Empathetic	6	Empathetic	6	Willingness to really listen	5	Not feeling rushed	4
Willingness to really listen	5	Willingness to really listen	5	Not feeling rushed	4	Authentic	3
Equal partnership	4	Not feeling rushed	4	Authentic	3	Feeling safe	3
Not feeling rushed	4	Authentic	3	Feeling safe	3	Feeling valued	3
Authentic	3	Feeling safe	3	Feeling valued	3	Offers help	3
Feeling safe	3	Feeling valued	3	Offers help	3	Open	3
Feeling valued	3	Offers help	3	Open	3	Trust	3
Offers help	3	Open	3	Trust	3	Accurate note taking	2
Open	3	Trust	3	Accurate note taking	2	Approachable	2
Trust	3	Accurate note taking	2	Approachable	2	Caring	2

Accurate note taking	2	Approachable	2	Caring	2	Helpful	2
Approachable	2	Caring	2	Helpful	2	Kind	2
Caring	2	Helpful	2	Kind	2	Knowledgeable	2
Helpful	2	Kind	2	Knowledgeable	2	Offers reassurance	2
Kind	2	Knowledgeable	2	Offers reassurance	2	Patient	2
Knowledgeable	2	Offers reassurance	2	Patient	2	Provides feedback on progress	2
Offers reassurance	2	Patient	2	Provides feedback on progress	2	Respect	2
Patient	2	Provides feedback on progress	2	Respect	2	Understanding	2
Provides feedback on progress	2	Respect	2	Understanding	2	Warm	2
Respect	2	Understanding	2	Warm	2	Welcoming	2
Understanding	2	Warm	2	Welcoming	2	Attentive	1
Warm	2	Welcoming	2	Attentive	1	Encouraging	1
Welcoming	2	Attentive	1	Encouraging	1	Inspires confidence	1
Attentive	1	Encouraging	1	Inspires confidence	1	Reliable	1
Encouraging	1	Inspires confidence	1	Reliable	1	Sympathetic	1
Inspires confidence	1	Reliable	1	Sympathetic	1	Tolerant	1
Reliable	1	Sympathetic	1	Tolerant	1	Comfortable	0
Sympathetic	1	Tolerant	1	Comfortable	0	Confident in abilities	0
Tolerant	1	Comfortable	0	Confident in abilities	0	Dedicated	0
Comfortable	0	Confident in abilities	0	Dedicated	0	Enthusiastic	0
Confident in abilities	0	Dedicated	0	Enthusiastic	0	Fair	0
Dedicated	0	Enthusiastic	0	Fair	0	Gentle	0
Enthusiastic	0	Fair	0	Gentle	0	Human dress code	0
Fair	0	Gentle	0	Human dress code	0	Modesty	0
Gentle	0	Human dress code	0	Modesty	0	Passionate	0
Human dress code	0	Modesty	0	Passionate	0	Polite	0
Modesty	0	Passionate	0	Polite	0	Supportive	0
Passionate	0	Polite	0	Supportive	0	Timely	0
Polite	0	Supportive	0	Timely	0		
Supportive	0	Timely	0				
Timely	0						

Once consensus was achieved amongst the group, the top ten behaviours were turned into statements by participants as outlined below in Table 43. All statements were purposefully phrased by participants in a positive manner and used I/me statements to encourage greater ownership and empowerment. For example, as suggested by participant one:

> "*I would like the statement, my psychiatrist treats me as a person not as a condition"* (participant 1)

Statements were considered easier to understand than questions. Justification for positively phrasing the statements included the belief that identified behaviours "*should always be present in psychiatric care*" (participant 11).

Table 43 Co-produced and agreed question statements

My psychiatrist/ Dr [XXX]…
Respects me as an equal partner in my care
Communicates in a way that is easy to understand
Actively listens
Is non-judgmental
Treats me as a person, not as a condition
Is open and honest in their approach
Reads my history
Has a good understanding of systems and processes that may affect me and my family
Is compassionate
Gives me hope

Stage 3:

Finally, the behaviours and related statements created in the co-produced tool were compared with the 15 questions asked in the existing ACP 360 tool (Table 44).

Table 44 Comparison of ACP 360 content with the behaviours used in the co-produced feedback tool

Existing question currently asked in ACP360	Behaviour, attributes and/or qualities selected by participants	Verbatim example/justification
1. Is friendly and easy to approach	Compassion and equal partnership	"*Friendly, that's certainly compassion, I think it's also about equal partnerships"* (participant 1)
2. Listens well to what I say	Communication	"Participant 2: *That's communication* Participant 3: *communication* [general group agreement] *"*
3. Provides useful information about my treatment when I need or ask for it	Communication	*"Communication"* (participant 3)
4. Speaks clearly so that I can understand	Communication with the addition of in a way that is easy to understand	"Participant 1: *I don't like the wording of it because it makes me feel a bit like* [slow speech] *'speaks clearly so that I can understand"'* Participant 6: *its patronising isn't it?* Participant 1: *and also, 'so that I can understand', that's putting the burden on me to understand, does that make sense?* Facilitator: *absolutely* Participant 4: *makes information understandable makes it more impersonal* Facilitator: *So if we had a question of clearly communicates in a way that makes sense, or in a way that is easy to understand so that you take the 'me' part out following* [name] *point?* [general group agreement]"
5. Keeps appointments and is on time	Not discussed by participants in cycles two-five but believed to be covered by clear communication, honesty and equal partnership	"Participant 1: *for me it comes into clear communication because I don't mind if someone is late, but I like to know, 'oh sorry I'm late I was with another patient'* Participant 3: *it's polite* Participant 1: *exactly, it falls under clear communication and equal partnership as well* Participant 8: *and honesty as well, 'sorry I'm late, something happened'* "Participant 3: *and also the big thing, I've never found my psychiatrist sitting around, just thinking about other things and not interested in actually seeing me, I've never ever noticed that at all* Participant 4: *it's hard to be on time anyway because if you're listening to somebody and it takes longer then you're late for the next person*

		Psychiatrist: *and nobody in healthcare is on time* [group laughter]”
6. Shows warmth and is genuine and understanding	Compassion	“*Compassion”* (participant 3)
7. Offers me hope and optimism	Hope	“Participant 1: *I would separate hope from optimism, hope and optimism are two distinct things for me* Facilitator: *do we prefer hope and optimism as two separate questions or hope and help that came up?* Psychiatrist: *just hope, not optimism, I think hope is stronger,* Participant 5: *optimism can be more of a false hope”*
8. Shows respect for me	Equal partnership & non-judgemental	“*Equal partnership”* (participant 4) “Participant 6: *non-judgemental as well* Psychiatrist: *non-judgemental as well”*
9. Always values my opinions	Equal partnership	“*Equal partnership, I think it does the umbrella”* (participant 2)
10. Includes my opinions when making decisions with me	Equal partnership	“Participant 6*: So I think 9, 10, 13 and 15, they're all, a bit weak* Psychiatrist*: and 11 as well I think* Participant 5*: Number 10 I have an issue with opinions in that context because I have choices* Participant 1: *a very good point* Participant 5:*I have choices* Participant 6:*: They can listen to your opinions, doesn't mean they have to do anything about it, it needs to be a bit stronger than that* Participant 4: *I think 9 10 and 11 are the same* Psychiatrist*: yeah that's how it seems to me as well* Participant 5: *I think choices should be used instead of opinions”*
11. Asks me about my points of view	Equal partnership	- Please see above -
12. Makes information easy for me to understand	Communication	“*There’s three about making information and communicating information so there’s three, four and twelve all about communication”* (participant 1)
13. Takes into consideration the needs of my family and/or carers	Systems and processes that may affect me and/or my family. May be resolved through feedback design and future research (this topic	“Facilitator: *Takes into consideration the needs of my family and/or carers. Do we feel we've captured that element?* Psychiatrist*: not only the needs but also the views, also needs to be taken into account”* “Participant 1*: this is and I apologise if I offend anyone, but this is from my own personal experience, it drove me mad, when professionals took*

generated a wealth of discussion as outlined in the verbatim extract)	*into account my family's views and I hated it when they liaised with my family. Now I know particularly carers really value that involvement, that discussion, but where's the middle ground in that? If that makes sense?* Participant 2*: and you mentioned the doctor would talk to your wife not you* Participant 1: *Is there a separate one of these for carers?* Facilitator*: no, not currently* Participant 1: *I think sometimes carers might need something different from their psychiatrist or want different things* [from patient questionnaire] *like I might value a sense of humour, whereas my mum might have valued the professionalism and the fact that my psychiatrist was wearing a suit and tie and able to regurgitate the BMF. That's, is the BMF?* Participant 5: *I think it's really important to have a separate questionnaire for patients and one for the families and that the patients should be given the option to fill it out themselves, or for a professional to help them out, not a family member* Participant 3: *I think you do the stuff for carers because sometimes if you're sectioned and told you don't have capacity, then decisions are made about you, without you and your family might not even know about* Participant 6: *Yeah, so I think sometimes it's really important for carers to have more involvement then they currently do, but in other situations, it can go completely the other way, so I think you need it to be open* Psychiatrists: *I think that both times, the network of social relationships is important, because if you see things through systems thinking, to an extent, families are also part of the creation of the situation, but also part of the solution as well, inevitably, so it is difficult. Many times I come across in my work when person with some issues tell me 'I don't want to tell my parents about this' while I know that they live with their parent, they spend all the day with their parent, it is very difficult then to work, to meaningfully work. That is why I am a little bit sceptical about this.* Participant 3: *There might be issues as well, things are affecting you I was in hospital for a year under section and I've got three children and my children might have needed help, you know me not being there for a year* Participant 6: *yeah carers might need support as well*

		Psychiatrist*: exactly* Participant 3*: and my younger child was probably too young but my older two probably knew and were very scared* Facilitator*: so maybe if we return to this issue when we are going through the design of the patient feel tool, maybe we can see if we can get a bit of a middle ground at the moment and then there's probably a whole other research project looking at carer feedback* Participant 1*: sorry we were doing so well* [group laughter]”
14. Remains calm under pressure	Not considered relevant by participants	“Participant 1: *where did that come from out of interest? Like what was the rationale for that?* Facilitator: *I'm going to direct that to the ACP 360 team* ACP team: *well the tool was originally developed in 2005 a long time before I was involved, to be honest I’m not entirely sure,* Participant 1: *I don't want to lose what the original intention was but I don't understand what the original intent was* Participant 2: *I mean calm under pressure is something that maybe a psychiatrists colleagues might be evaluating, you know in an A and E situation, or in another situation you might be evaluating that. But, as a patient, no* Facilitator: *and psychiatrists do have to collect colleague feedback so maybe that is something that would get picked up there?* Participant 8: *it's maybe also about the professionalism of the psychiatrist as well which is captured in the other elements”*
15. Asks the opinions of my family and/or carers where appropriate	Respects my choices as part of equal partnership	“*Respecting my choices”* (participant 2)

As demonstrated above, the comparison exercise revealed that the majority of care domains used in the ACP 360 tool were encompassed by the newly selected behaviours with the exception of ‘remains calm under pressure’, ‘keeps appointments’ and ‘is on time’. Similar to cycles two-five, these attributes were no longer considered relevant by participants involved in the co-production workshop. Although the content of the ACP 360 tool was frequently attributed to communication and equal partnership by participants, the newly selected behaviours also identified new areas of importance including being treated as a person not as a condition, having a good understanding of a patients history and understanding the systems and processes that may affect patients and their family.

Furthermore, the comparison exercise demonstrated that the language used in the newly co-produced patient feedback tool differed to that used in the existing ACP 360 tool. For example, when reviewing the existing question of ‘speaks clearly so that I can understand’, participants stated that such phrasing was patronising and placed the burden on patients, as opposed to the communication skills and ability of psychiatrists. The wording of ‘*in a way that is easy to understand’* was suggested as a more desirable and equitable alternative. Other distinctions of language highlighted by participants included hope and optimism with both patients and the psychiatrist agreeing that hope was stronger than optimism, concluding that optimism offers undesirable “*false hope”* (participant 5).

An important differentiation between opinions and choices was also discussed by participants as outlined below:

> “Participant 5: *I have an issue with opinion because I have choices*
> Participant 1: *a very good point*

> Participant 5: *I have choices… choices should be used instead of opinions"*

When asked if participants felt the behaviours, attributes or skills they had selected contained all the necessary information, participants identified a need to expand the question focusing on an accurate understanding of wider systems as outlined below:

> "Facilitator: *In terms of going through these 15* [existing questions] *and these 10* [agreed behaviours, attributes or skills]*, do we feel like we've covered everything?*
> Participant 1: *I feel like we need more on accurate understanding of the system. Because I think the ones that we've got are really good, but I don't think there is anything that is asked in here that gives us the ability to measure that.*
> Facilitator: *OK*
> Participant 6: *I think there is something about that understanding of systems and services in line with being treated holistically as well because even if you take the family and carer situation out of it, you need to understand more than what is happening in that consultation room right there to treat a person, rather than a diagnosis if that makes sense*
> [General group agreement]
> Facilitator: *maybe something about understanding of systems and processes that will help me?*
> Participant 1: *because if I'm feeling that I'm being treated as a person, the psychiatrist must have an understanding because he's treating me like a person, so I think asking something directly around that*
> Participant 4*: yeah because if I'm go into hospital and I go in to see a psychiatrist and I'm worried that my children aren't getting the support, then I'm not going to be feeling good as well*
> Facilitator: *ok so maybe understanding of systems and processes that will help me and/or my family? Would that capture it?*
> Participant 7: *yes, that's great"*

The psychiatrist did however acknowledge the potential difficulty of this task, particularly in light of the rapidly changing landscape of healthcare systems and services. For example:

> "*May I play devil's advocate a little bit? First of all, we are talking about systems that are becoming more and more complex, they don't seem to be getting simpler…I am not saying anything of course that the psychiatrists shouldn't have an understanding to an extent of what is happening in general with the benefits system, with the social work, with the mental capacity act. However, I am sceptical of how did the knowledge and experience question alone could have, this is the only thing that I am thinking"* (psychiatrist, participant 9).

8.3.1.2 Co-production and agreement of question scales

Following the identification of agreed behaviours, attributes or skills, participants designed a response scale that could help facilitate patient understanding and psychiatrist reflection. Some example scales were provided in the pre-circulated information pack to help facilitate idea generation (Appendix 13) and familiarity at the patient research partners' request. Decisions related to the scale design are outlined in Table 45 below.

Many of the decisions made about the wording and response scale content related to ease of understanding and enhanced accessibility. For example, using a combination of both smiley faces and text was identified as the most effective way to facilitate patient understanding. Language was again identified as particularly significant, reiterating its central role in facilitating ownership and acceptability. For example, "*neutral is better than neither… it implies that you've got an opinion"* (participant 7).

Table 45 Decisions made and justification for response scale design

Decision made	Justification
Inclusion of both smiley faces and words to facilitate ease of understanding and accessibility	*“You've got to use them both because you can't just use smiley faces because some people can't process what those smiley faces mean* [general group agreement]*”* (participant 4); “*Smiley faces are good because I can read them and understand them, the text at the minute, but in the future, I won’t be able to”* (participant 1) “*So maybe you need the two, the faces and the numbers* [general group agreement] *and then you've got both there haven't you”* (participant 2)
Use of seven scales as this balanced detailed feedback with undesirable complexity	“Psychiatrist: *I think having four of them is too little* Participant 4: *yeah, you need a bit more* Psychiatrist: *you need a bit more if you want to get detailed feedback”* (psychiatrist and participant 4)
Agreement that smiley faces needed to be on colour	“*As white font on black moves, it’s all moving about”* (participant 2) “Participant 3: *yellow faces black font* Psychiatrist: *with the colours* [traffic light system] *people cannot see the colours as well, there are people who cannot differentiate between the colours* Participant 3: *colour blindness* Psychiatrist: *absolutely”* (psychiatrist, participants 3 & 4)
Agreement to use ‘strongly agree - strongly disagree’, as opposed to satisfaction, always true, or high/low.	“Participant 4: *I always find it easier when there is a statement that I can either strongly disagree with, or agree with* Facilitator: *ok* Patient 1: *treated me with respect, strongly agree or strongly disagree* Facilitator: *do you feel that’s accessible?* Patient 6: *Yes, it’s better than low and high* [general group agreement] *you have to think quite hard about low and high, agree is more encompassing* Facilitator*: do you prefer satisfy or agree strongly disagree?* Participant 5: *I think the agree one* Participant 4: *agree* Participant 6: *agree* Participant 1: *do we agree or strongly agree?* [group laughter] Participant 2: *agree”*
Have a neutral option in the middle of the seven scale options	“*I think neutral is better wording than neither agree or disagree because it implies that you've got an opinion*” (participant 7) “*Neutral in the middle again makes it a bit easier to understand”* (participant 3)

8.3.1.3 Co-production and agreement of layout/design

Following the identified behaviours and scale content, participants sought to independently design the layout of the patient feedback tool. This was facilitated through a cut and stick exercise, where the most frequently suggested solutions identified in cycles three-five e.g. free text comments, multiple choice questions, provision of sufficient information and balanced opportunities to provide praise and critique were presented as individual cut out squares. The cut and stick worksheet was again included in the pre-circulated information pack (Appendix 13) to facilitate refection and familiarity. Initial reactions to the content of the cut and stick document included "*I really like it"* (participant 1).

Once completed, participants shared their designs and layout with the wider team and voted for the one they considered to be most appealing, accessible and likely to encourage patient feedback engagement and psychiatrist reflection.

There was unanimous agreement that information should go first, "*that was quite easy wasn't it?"* (participant 1), followed by what the psychiatrist did well and what they could do to improve:

> "*I would see this* [what could be improved] *as coming after* [things that were helpful] *because a lot of people find that easier to complete and that comes back to your earlier suggestion of putting the easier things first"* (Patient participant 3)

Participants also expressed a desire for the critical and positive questions to be identical in design:

> "Participant 3: *I think the negative question should have the choice of words as well, identical layout of the positive*
> Participant 6: *yeah that seems a good way of evening it out, not prompting someone to do more of either then"*

The placement of the multiple choice question, (i.e. the 10 behaviours selected using the seven point response scale designed) was considered to be most effective before the final free text comment of ‘Please share anything else about your experiences with Dr…/your psychiatrist that you feel hasn’t been covered*’* to allow respondents a final opportunity to put things into their own words. For example:

> “Participant 6: *because we’ve got those first two free text ones, could we then have the multiple choice and then the last free text because people might have thought of things in the process of the multiple choice*
> Participant 2*: that’s how I think as well*
> Participant 4: *it would also be more logical*
> Participant 5: *because if you have the green one under the grey one, it’s asking about your whole experience, not just the negatives, it’s the whole thing and that sort of rounds it all up*
> Participant 2: *and as you said, sometimes the multiple choice questions prompts a bit of thought and you suddenly think of something you wouldn’t have*
> [General group agreement]”

This layout decision was also seen as a helpful way to break up the free text comments and potentially daunting appearance:

> “Participant 2: *sometimes when I’m faced with too many free text boxes in a questionnaire]*
> Participant 1: *I don’t bother]*
> Participant 2: *I switch off a bit, so it’s nice to break it up a bit*
> [General group agreement]”

Interestingly, the placement of who the feedback tool was being completed by i.e. a patient or carer, appeared particularly divisive as outlined below. Reasons for its final location (at the end of the feedback tool) often related to patient voice, choice and opportunity:

> “Participant 1: *what was the reason why people put it* [who the feedback was being completed by] *last?*
> Participant 4*: it was actually after the discussion that we had at the table I slowly started to realise that carer family member input was something that might be required as a separate thing that we could have a whole session on*
> [General group agreement]
> Participant 1: *do you think by having it at the front it might cloud people’s judgement, is that's what you're saying?*
> Participant 3: *yeah*
> Participant 1: *OK*
> Participant 5: *I put it at the end because I felt the patient view was more important*

> Participant 4: *totally, I agree with you*
> Participant 5: *That's why I put it at the end*
> Participant 4: *by having it at the beginning it becomes a leading question*
> Psychiatrist: *no, no,*
> Participant 1: *how so*?
> Participant 5: *because if you tick it as a carer then you might be the one who goes 'oh, I'll fill the rest of the form in', whereas if you put it as the bottom, do you want any input on the form, then that's your bit at the bottom, if you've got it first, 'are you the carer?' 'Yes', tick that, then you'll carry on and go through the rest of it*
> Participant 3: *by putting it at the beginning, some carers might take that choice away from you and automatically choose to fill the form out*
> Participant 2: *yeah I agree with that*
> Participant 1: *I'd get rid of it now, I've completely U-turned it's gone*
> [Group laughter]
> Participant 3: *well it's got to be on the form for now hasn't it because you've only got the one form, but when there's two forms, it doesn't need to be on there?*
> Psychiatrist: *yeah*
> Participant 1: *when there's two forms, it absolutely doesn't need to be on there*
> Psychiatrist*: yeah definitely"*

The repeated request for a separate carer feedback form highlights its perceived importance from a patient and psychiatrist perspective.

Other important aspects of design considered by participants included the desire for colour and issues of accessibility:

> "Participant 3: *having colours, coloured boxes makes it better, it could just be two colours alternate, but it needs colour because the grid is moving, it's moving about*
> Participant 1: *and also perhaps have, if it's online to have an option for colour blind and stuff like that because some people process colours differently*
> Psychiatrist: *red and green so anything like this,*
> Participant 1: *just to make sure it ticks all of those boxes,*
> Participant 3: *perhaps online having an audio version for accessibility"*

8.3.1.4 Process

Although not the direct focus of the workshop, the process of patient feedback was also repeatedly discussed by participants, particularly ways in which to assure anonymity and confidentiality. As participant one states:

> "*I always find that it's not what the wording is, but how it's administered. So, [name] you've got to do this form and return it to me, it's not really anonymous, doesn't give me confidence… you could have the best*

> *worded confidentiality statement on the planet, but if the process is not giving me confidence, it doesn't matter what you say"* (participant 1)

A reported desire to send feedback responses directly to the Royal College was related to the disparity between assurances of anonymity and perceived, or experienced feedback practices. For example:

> "*Participant 1: I don't think anything you say is going to give reassurance of that* [feedback not affecting future healthcare delivery], *I know that that sounds pessimistic but, again I think it's the way and the process in which it* [feedback tool] *is administered that gives that reassurance as opposed to the wording that we use. You can say it won't affect their treatment and that almost puts the thought in your head. It's more about guidelines and strengthening the guidelines about how it should be administered and processed.*
> ACP representative: *would it be rigorous enough to have the option so if the psychiatrist was offering you this process returning to their office, or, essentially we could direct it back to the Royal College, would you be satisfied with that?*
> Participant 1: *I think an option would be really, really good*
> Participant 6: *yeah that would be good*
> [General group agreement]"

However, the ACP representative acknowledged that the decision of where respondents could send their feedback responses was often at the psychiatrists' discretion.

8.3.1.5 Co-production and agreement of information

Following these concerns, participants co-produced an information sheet that sought to explain the process, purpose, focus and impact of patient feedback. This was achieved by considering the questions participants felt were most important to address and then creating relevant responses to these questions. Some of the questions identified by participants included: why patients had been invited to give feedback; who had been invited to give feedback; whether the feedback is anonymous; how the feedback will be used and who will see the feedback shared. During these conversations, the ACP representative acknowledged on several occasions that:

> *“We* [ACP 360] *give guidance to the psychiatrist but not to the people that might be receiving these emails…there’s something in the text in the email they receive, but they couldn’t necessarily very easily find anything on-line if they went on the website about is what this is, how it works, the typical experience… we have that* [feedback related information] *for psychiatrists but there is nothing for patients” (ACP 360 representative)*

Furthermore, a participant who had previously received the ACP 360 tool and called the GMC due to a lack of understanding and awareness replied that “*that* [patient focused information] *is the thing I would have found most helpful”* (participant 2). When asked if the newly co-produced information would have prevented her from phoning the GMC, the participant replied “*yes, absolutely”* (participant 2), highlighting the necessity and value of such information.

Other aspects of information that were considered important to portray included the doctors name, the word psychiatrist and option to include a picture of the psychiatrist for the following reasons:

> Participant 1*: I think if you have the doctor’s name on it, that helps, because if you're seeing lots of different psychiatrists or whatever, the department gives you this, you're like well what one? I've seen three in the last couple of weeks*
> [General group agreement]
> Facilitator: *that was also a suggestion from patients to include a photo*
> Participant 1: *yes, such a good idea, that's a really good idea*
> [General group agreement]
> ACP representative: *and also if a psychiatrist has a really long surname, they will often reduce it and be called say call me Dr O or something and then you get a really long one on the questionnaire and you think well who this is?*
> [Group laughter]
> Participant 1: *I think the photo is more important than the name*
> Facilitator: *so maybe adaptability where Dr XXX is, the doctor could put the name that they think patients will recognise most and maybe having the option for including a snapshot?”*

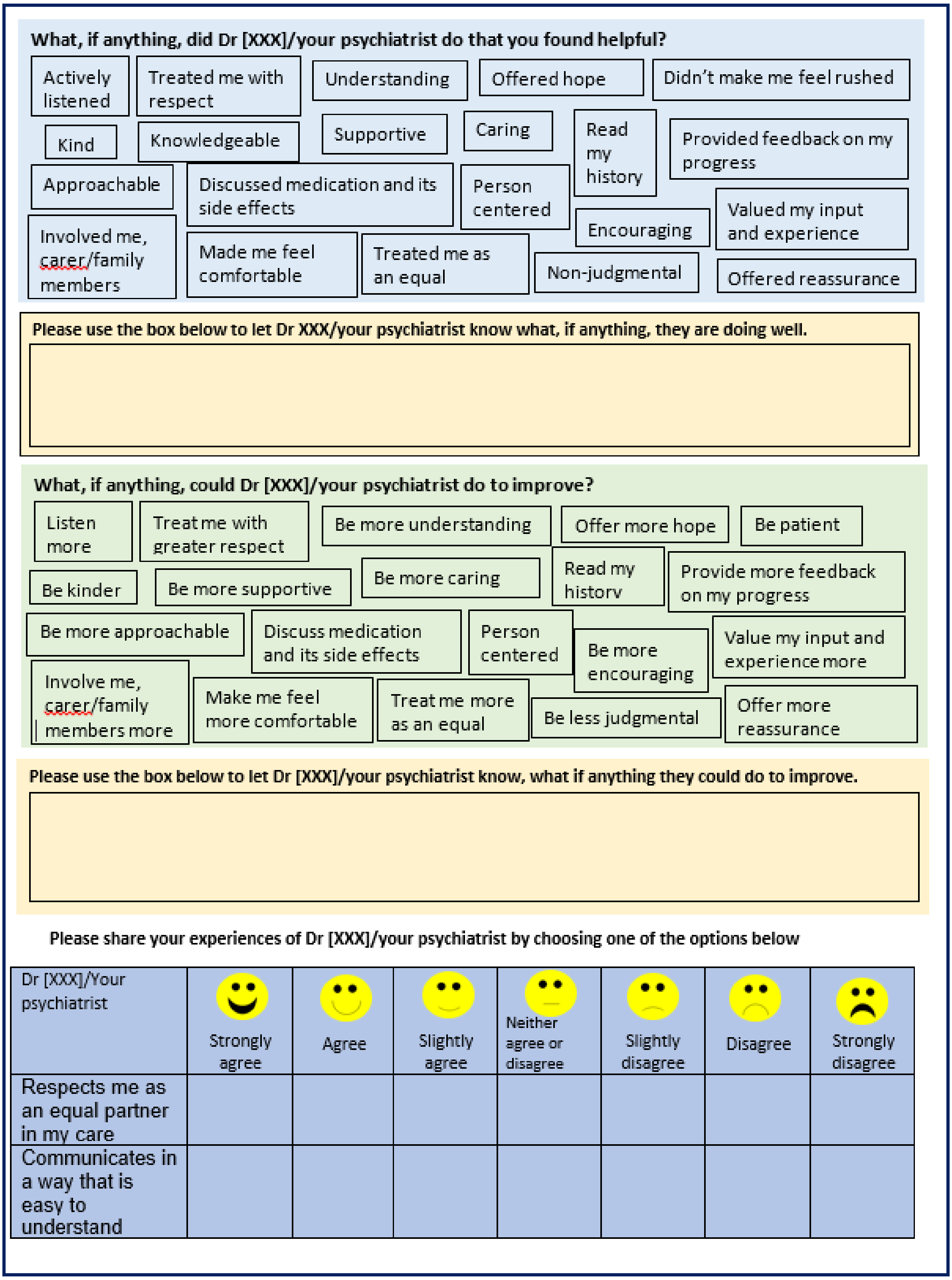
However, the ACP 360 representative acknowledged the potential difficulties in achieving this as it was not common practice. Participants went on to highlight why a picture was so important, particularly in psychiatric care as demonstrated below:

> “Participant 1: *I think a photo is so important though, in terms of identifying, just because I know that when I've been an inpatient, I haven't necessarily been in the right frame of mind to remember names and I would love to give some feedback on my in-patient doctors both good and bad, but I can't even remember the name, but seeing their face*
> Participant 6: *yeah*
> Participant 2: *and you don't necessarily remember the different roles people play]*
> Participant 1: *and some of them don't even introduce their names”*

8.3.1.6 Co-produced patient feedback tool and information

The initial patient feedback tool and information sheet co-produced by patients and psychiatrists is presented below in Figure 7 and Figure 8.

At the request of participants, variations of the newly designed feedback tool and information sheet were created by the patient research partner and researcher following changes to their colour, font and size only. Variations of the co-produced tool and newly designed information sheet were then tested and refined in the second workshop as outlined below.



What, if anything, did Dr [XXX]/your psychiatrist do that you found helpful?

Actively listened
Treated me with respect
Understanding
Offered hope
Didn’t make me feel rushed
Kind
Knowledgeable
Supportive
Caring
Read my history
Provided feedback on my progress
Approachable
Discussed medication and its side effects
Person centered
Encouraging
Valued my input and experience
Involved me, carer/family members
Made me feel comfortable
Treated me as an equal
Non-judgmental
Offered reassurance

Please use the box below to let Dr XXX/your psychiatrist know what, if anything, they are doing well.

What, if anything, could Dr [XXX]/your psychiatrist do to improve?

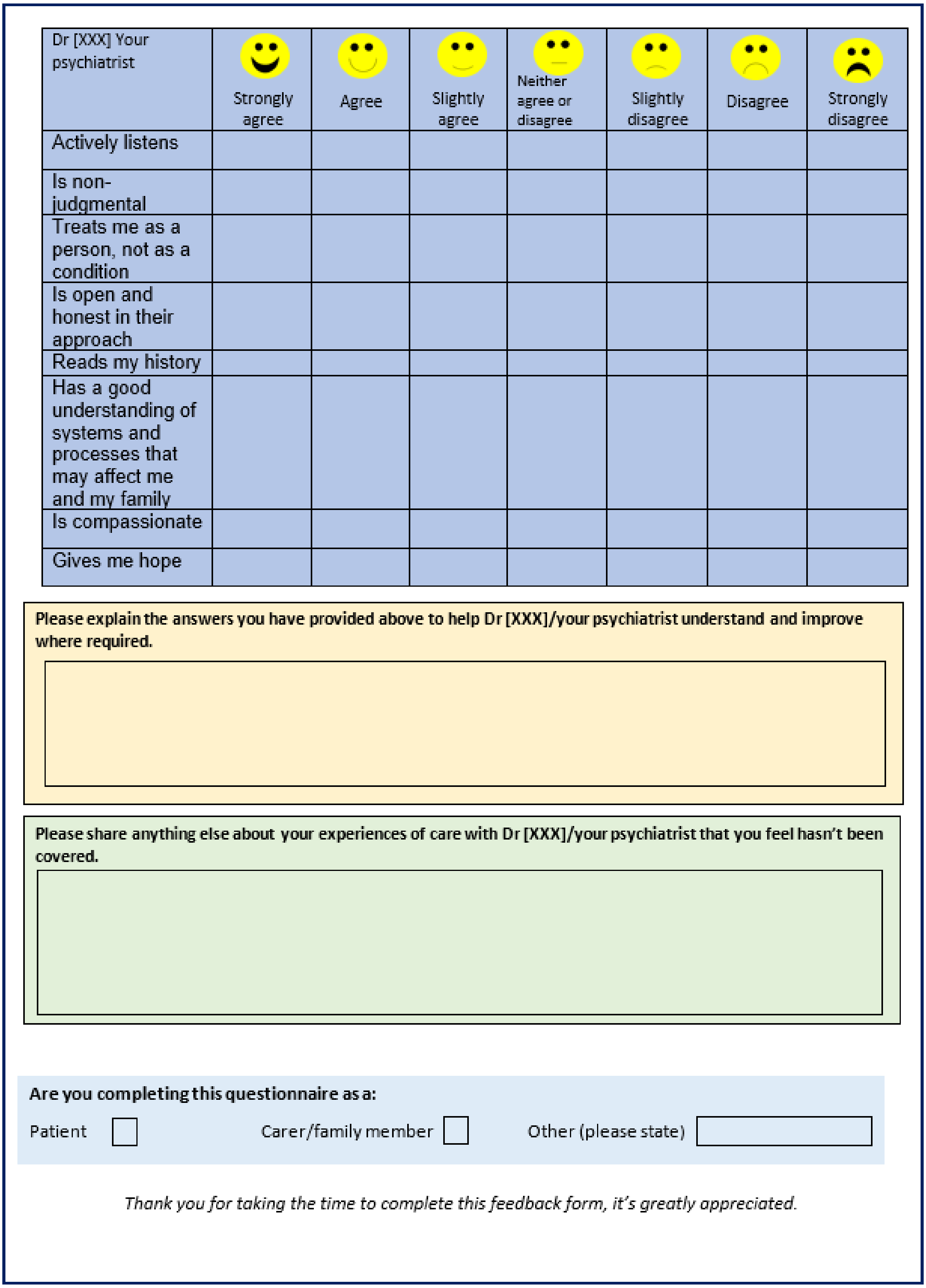
Listen more
Treat me with greater respect
Be more understanding
Offer more hope
Be patient
Be kinder
Be more supportive
Be more caring
Read my history
Provide more feedback on my progress
Be more approachable
Discuss medication and its side effects
Person centered
Be more encouraging
Value my input and experience more
Involve me, carer/family members more
Make me feel more comfortable
Treat me more as an equal
Be less judgmental
Offer more reassurance

Please use the box below to let Dr [XXX]/your psychiatrist know, what if anything they could do to improve.

Please share your experiences of Dr [XXX]/your psychiatrist by choosing one of the options below

Dr [XXX]/Your psychiatrist	Strongly agree	Agree	Slightly agree	Neither agree or disagree	Slightly disagree	Disagree	Strongly disagree
Respects me as an equal partner in my care							
Communicates in a way that is easy to understand							

Figure 7 First version of the co-produced patient feedback tool



Dr [XXX] Your psychiatrist	Strongly agree	Agree	Slightly agree	Neither agree or disagree	Slightly disagree	Disagree	Strongly disagree
Actively listens							
Is non-judgmental							
Treats me as a person, not as a condition							
Is open and honest in their approach							
Reads my history							
Has a good understanding of systems and processes that may affect me and my family							
Is compassionate							
Gives me hope							

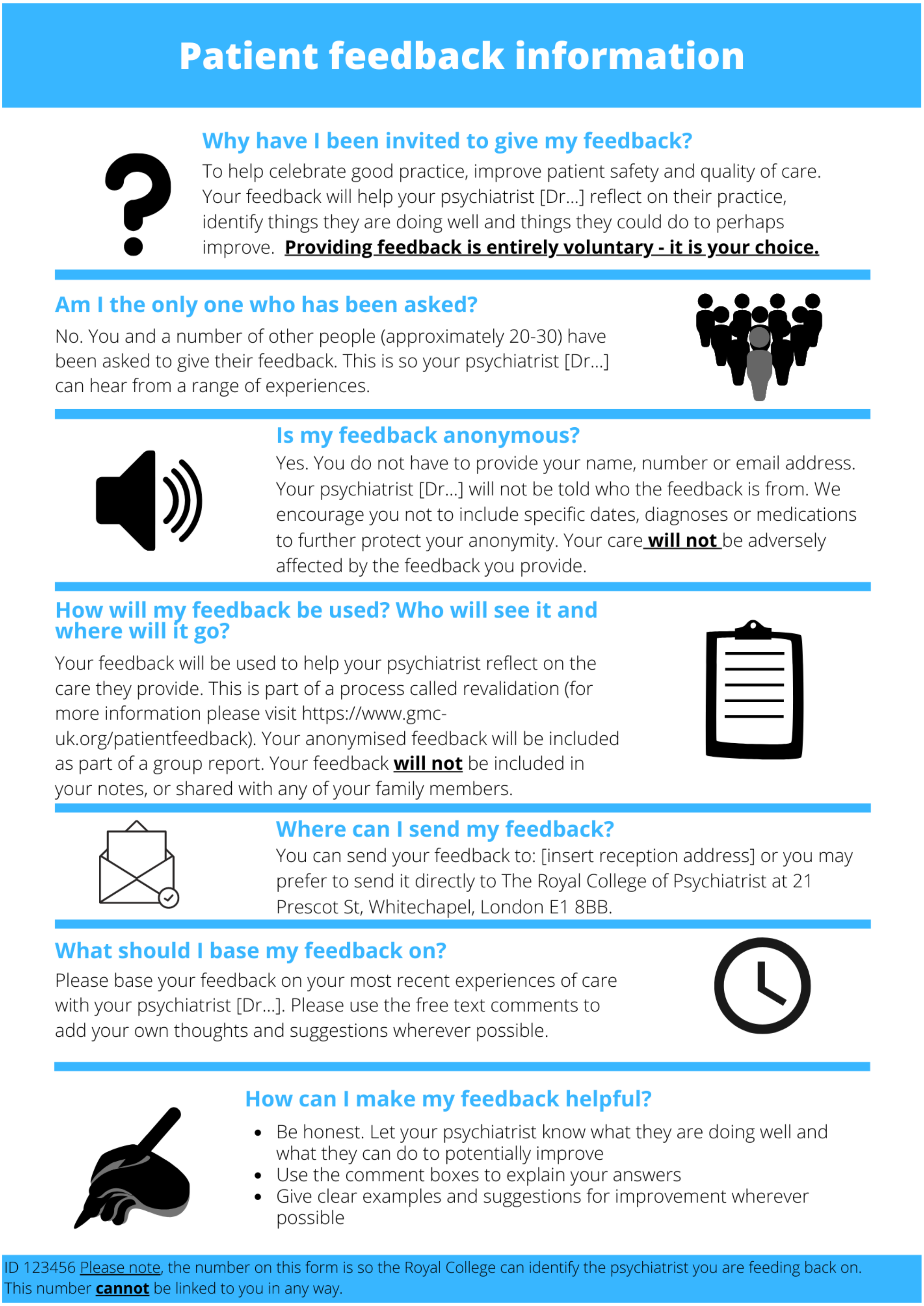
Please explain the answers you have provided above to help Dr [XXX]/your psychiatrist understand and improve where required.

Please share anything else about your experiences of care with Dr [XXX]/your psychiatrist that you feel hasn't been covered.

Are you completing this questionnaire as a:

Patient ☐ Carer/family member ☐ Other (please state) ☐

Thank you for taking the time to complete this feedback form, it's greatly appreciated.



Patient feedback information

Why have I been invited to give my feedback?

To help celebrate good practice, improve patient safety and quality of care. Your feedback will help your psychiatrist [Dr...] reflect on their practice, identify things they are doing well and things they could do to perhaps improve. **Providing feedback is entirely voluntary - it is your choice.**

Am I the only one who has been asked?

No. You and a number of other people (approximately 20-30) have been asked to give their feedback. This is so your psychiatrist [Dr...] can hear from a range of experiences.

Is my feedback anonymous?

Yes. You do not have to provide your name, number or email address. Your psychiatrist [Dr...] will not be told who the feedback is from. We encourage you not to include specific dates, diagnoses or medications to further protect your anonymity. Your care **will not** be adversely affected by the feedback you provide.

How will my feedback be used? Who will see it and where will it go?

Your feedback will be used to help your psychiatrist reflect on the care they provide. This is part of a process called revalidation (for more information please visit https://www.gmc-uk.org/patientfeedback). Your anonymised feedback will be included as part of a group report. Your feedback **will not** be included in your notes, or shared with any of your family members.

Where can I send my feedback?

You can send your feedback to: [insert reception address] or you may prefer to send it directly to The Royal College of Psychiatrist at 21 Prescot St, Whitechapel, London E1 8BB.

What should I base my feedback on?

Please base your feedback on your most recent experiences of care with your psychiatrist [Dr...]. Please use the free text comments to add your own thoughts and suggestions wherever possible.

How can I make my feedback helpful?

- Be honest. Let your psychiatrist know what they are doing well and what they can do to potentially improve
- Use the comment boxes to explain your answers
- Give clear examples and suggestions for improvement wherever possible

ID 123456 Please note, the number on this form is so the Royal College can identify the psychiatrist you are feeding back on. This number **cannot** be linked to you in any way.

Figure 8 First version of the co-produced information sheet

8.3.2 Workshop two: refinement and consolidation

16 participants with no prior research involvement or links with the Royal College of Psychiatrists took part in the second, refinement workshop. As previously described, this workshop was intended to be with both patients and psychiatrists. However no interest from psychiatrists was received. Despite this, the aim of the second workshop remained unchanged: to explore the understanding and acceptability of the newly co-produced patient feedback tool and information sheet beyond the potential influence of the Royal College of Psychiatrists or previous research involvement.

Participants reviewed ten variations of the newly co-produced tool (colour, size and font only) developed in workshop one followed by the existing ACP 360 patient feedback tool. Participants were not informed which tools had been co-produced in order to avoid any potential bias. Research findings are presented in a similar order to workshop one: content, design, provision of information and process.

8.3.2.1 Content

Beginning with content, participants appeared to value the word choice element of the newly co-produced tool. For example, as stated by participant four:

> "*It definitely does help when asked how you feel about that, how do I phrase that, how do I say it? How do I say it so it makes sense? It's good"* (participant 4)

Similarly:

> "*Yeah it's really helpful"* (participant 12).

When reviewing the wording and language of the co-produced tool, participants unanimously agreed that it was easy to understand, plain and simple.

Participants were also asked if they felt any behaviours, attributes or skills were missing from the questions or word choice options. Participants were unanimous in their response, with no alternative behaviours, attributes or skills suggested. The number of behaviors, attributes and skills in the word and multiple choice questions was also considered to be informative but not overwhelming, supporting the decisions made in workshop one. For example, as suggested by participant seven:

> "*I think it* [patient experience] *would get lost if you removed any"* (Participant 3).

Similarly:

> "*Your eyes just wonders over them and then you come to a point where you settle on one quite naturally and it's quite a natural and organic thing*" (Participant 7)

8.3.2.2 Design

The boxed design of the word search option was also favourably described by participants. However, participants acknowledged a desire for the boxes to be made more uniform and the free text boxes to be enlarged.

Participants did not like the use of dark colours (one of the variations provided), preferring pastel colours as they were considered to be "*more inviting"* (participant 10) or *"user friendly"* (participant 3). Participants preferred black as opposed to coloured fonts (another variation provided), citing potential difficulties "*for people who are colour blind and people with learning disabilities"* (participant 8). Other reasons for excluding coloured fonts included the possibility of bias. For example, as suggested by participant nine:

> "*I thought, hold on a minute, I'm going to be put off the words in red and I'm going to be encouraged or motivated by the words in green and I thought that could be a problem"* (participant 9)

A participant who had worked with adults with learning disabilities also suggested using Arial size 12 font as a minimum size to help facilitate accessibility.

The use of emojis/smiley faces in the response scale was considered helpful in facilitating understanding, "*emoji's are good"* (participant 4). Finally, once informed at the end of the workshop that the patient feedback tool had been co-produced, participants requested that an acknowledgment of this process was added to the feedback tool as this was seen as highly desirable and empowering.

8.3.2.3 Provision of information

With regards to information, participants requested that the word "*invited"* be used as opposed to "*asked"*; the patient feedback form be titled "*patient experience"* as "*patients are used to seeing that as general hospital terminology as well"* (participant 14) and the information sheet be titled "*your voice matters"* (participant 14) to highlight the importance of a persons voice, its value and subsequent acknowledgement in psychiatric care.

When reviewing the information sheet, participants commented that they liked the "*key bits"* (participant 3) of information around no adverse effects being bold and underlined. Reactions to this co-produced design included:

> "Participant 4: *that's good*
> Participant 3: *really good"*

Other responses to the co-produced information included "*brilliant"* (participant 4), *"really like it" (*participant 3).

Comparison with existing tool

When compared with the existing ACP 360 tool, participant responses included:

> “*The one* [ACP 360] *definitely needed tightening up”* (participant 9)
>
> *“The other one* [ACP 360] *is far too tick boxy and formal”* (participant 4)
>
> *“I know its* [ACP 360] *not, but to me it looks like a form for the local police, it’s very off putting”* (participant 10)
>
> *“It* [ACP360] *looks quite bullish, it’s intimidating”* (participant 1)

Similarly:

> “Participant 7: *It makes it look more for you,* [newly co-produced tool] *whereas the other one* [ACP 360] *looks more clinical and that you’re doing it to benefit somebody else*
> Participant 3: *yeah I agree with that”*
> Participant 1: *it’s* [newly co-produced tool] *just a whole site more user friendly…it’s very inviting and it also makes it look more simple to complete*
> Participant 7: *it doesn’t look so dense*
> Participant 1: *looking at the first one* [ACP 360] *although it only takes up one page, but actually it looks far too official*
> Participant 2: *yeah, it’s a lot”*

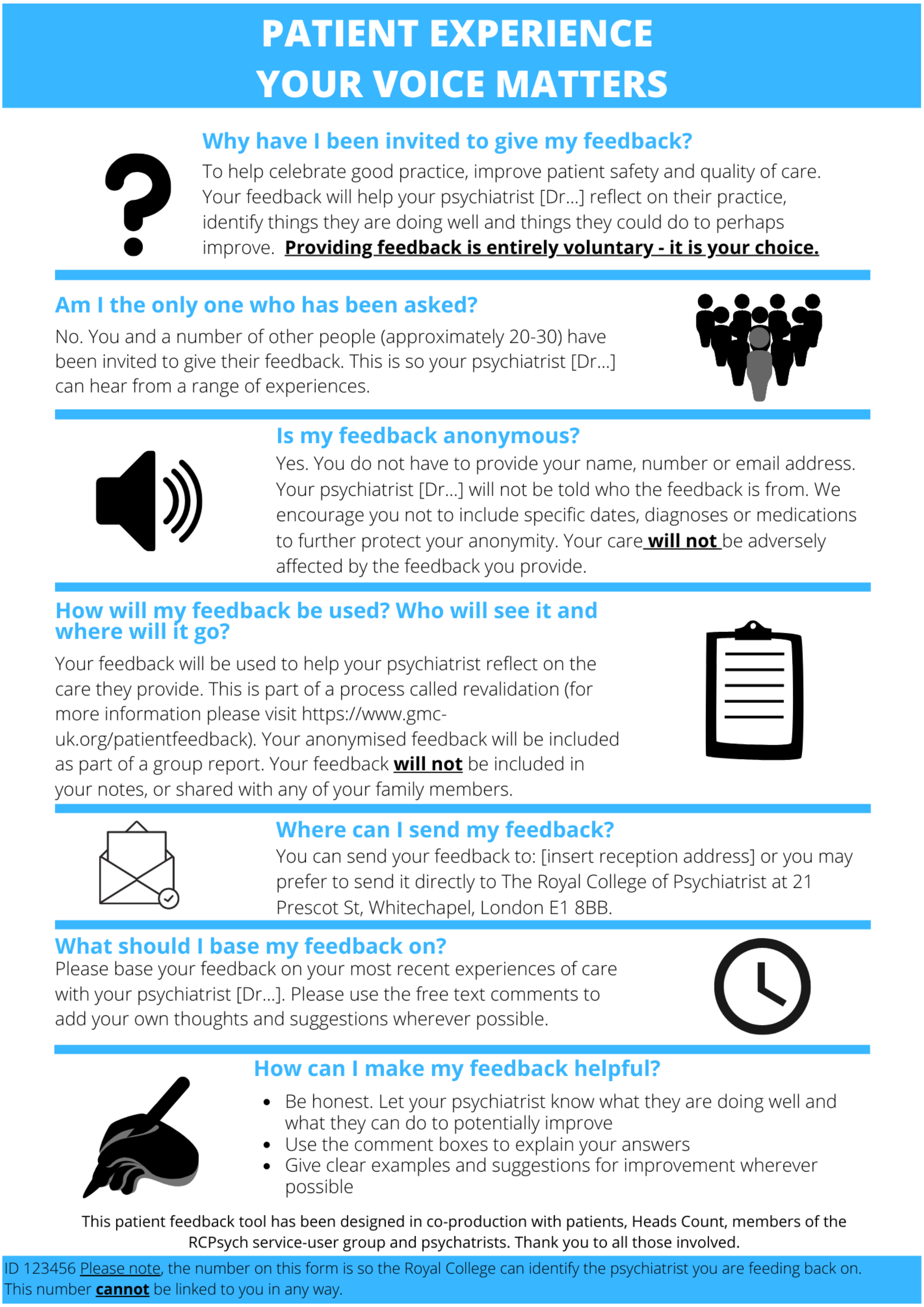
As stated by participant four:

> “*You have no choice there* [ACP 360], *whereas here* [newly co-produced feedback tool] *you’re making the choice for yourself”* (participant 4)

This was identified as a central *“and important point”* (participant 7) by all participants.

8.3.2.4 Final version

Finally, all of the suggestions and requests outlined above were incorporated into a refined version of the information sheet (Figure 9) and patient feedback tool presented below (Figure 10).



PATIENT EXPERIENCE
YOUR VOICE MATTERS

Why have I been invited to give my feedback?

To help celebrate good practice, improve patient safety and quality of care. Your feedback will help your psychiatrist [Dr...] reflect on their practice, identify things they are doing well and things they could do to perhaps improve. **Providing feedback is entirely voluntary - it is your choice.**

Am I the only one who has been asked?

No. You and a number of other people (approximately 20-30) have been invited to give their feedback. This is so your psychiatrist [Dr...] can hear from a range of experiences.

Is my feedback anonymous?

Yes. You do not have to provide your name, number or email address. Your psychiatrist [Dr...] will not be told who the feedback is from. We encourage you not to include specific dates, diagnoses or medications to further protect your anonymity. Your care **will not** be adversely affected by the feedback you provide.

How will my feedback be used? Who will see it and where will it go?

Your feedback will be used to help your psychiatrist reflect on the care they provide. This is part of a process called revalidation (for more information please visit https://www.gmc-uk.org/patientfeedback). Your anonymised feedback will be included as part of a group report. Your feedback **will not** be included in your notes, or shared with any of your family members.

Where can I send my feedback?

You can send your feedback to: [insert reception address] or you may prefer to send it directly to The Royal College of Psychiatrist at 21 Prescot St, Whitechapel, London E1 8BB.

What should I base my feedback on?

Please base your feedback on your most recent experiences of care with your psychiatrist [Dr...]. Please use the free text comments to add your own thoughts and suggestions wherever possible.

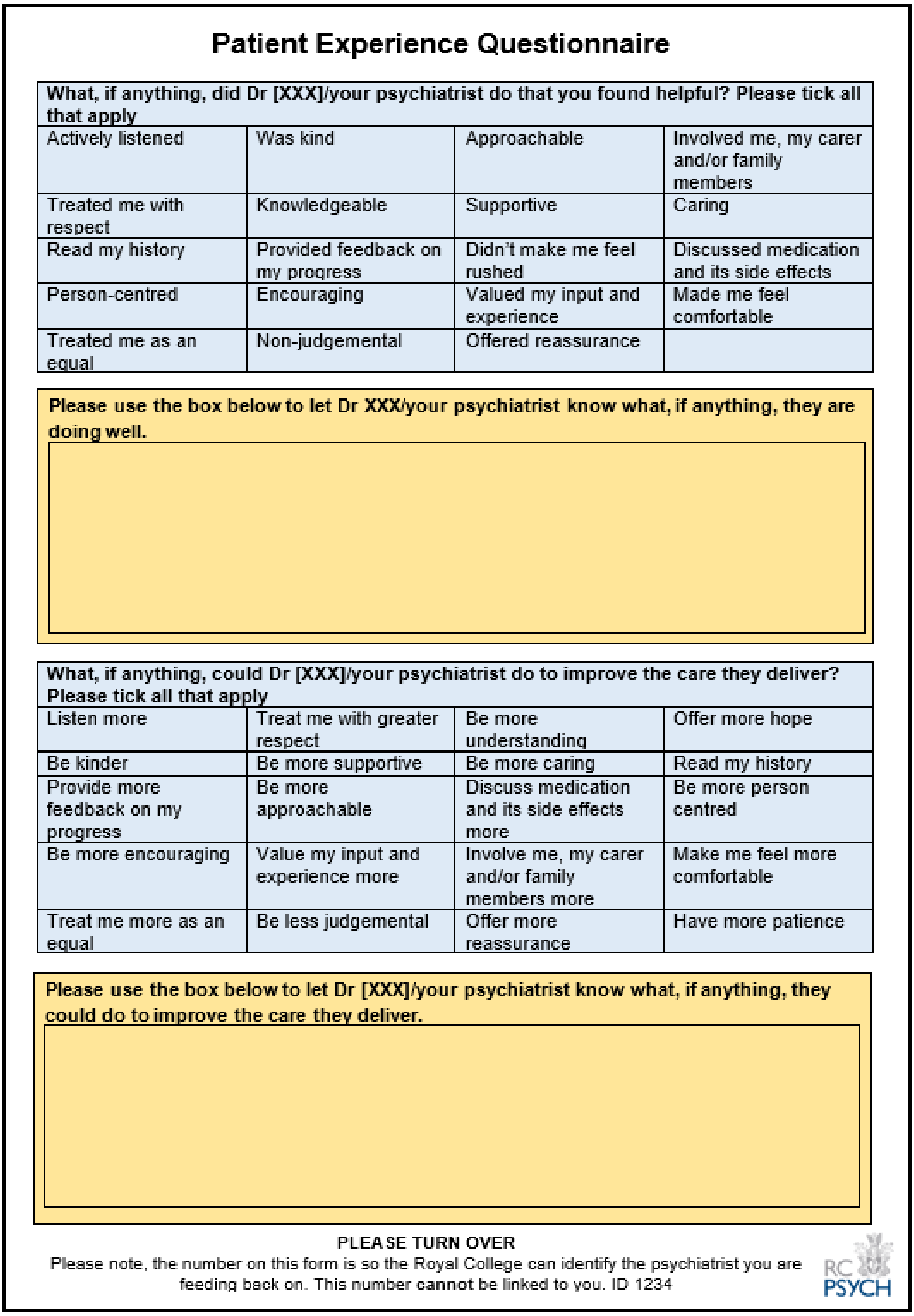
How can I make my feedback helpful?

- Be honest. Let your psychiatrist know what they are doing well and what they can do to potentially improve
- Use the comment boxes to explain your answers
- Give clear examples and suggestions for improvement wherever possible

This patient feedback tool has been designed in co-production with patients, Heads Count, members of the RCPsych service-user group and psychatrists. Thank you to all those involved.

ID 123456 Please note, the number on this form is so the Royal College can identify the psychiatrist you are feding back on. This number **cannot** be linked to you in any way.

Figure 9 Refined information sheet



Patient Experience Questionnaire

What, if anything, did Dr [XXX]/your psychiatrist do that you found helpful? Please tick all that apply

Actively listened	Was kind	Approachable	Involved me, my carer and/or family members
Treated me with respect	Knowledgeable	Supportive	Caring
Read my history	Provided feedback on my progress	Didn't make me feel rushed	Discussed medication and its side effects
Person-centred	Encouraging	Valued my input and experience	Made me feel comfortable
Treated me as an equal	Non-judgemental	Offered reassurance	

Please use the box below to let Dr XXX/your psychiatrist know what, if anything, they are doing well.

What, if anything, could Dr [XXX]/your psychiatrist do to improve the care they deliver? Please tick all that apply

Listen more	Treat me with greater respect	Be more understanding	Offer more hope
Be kinder	Be more supportive	Be more caring	Read my history
Provide more feedback on my progress	Be more approachable	Discuss medication and its side effects more	Be more person centred
Be more encouraging	Value my input and experience more	Involve me, my carer and/or family members more	Make me feel more comfortable
Treat me more as an equal	Be less judgemental	Offer more reassurance	Have more patience

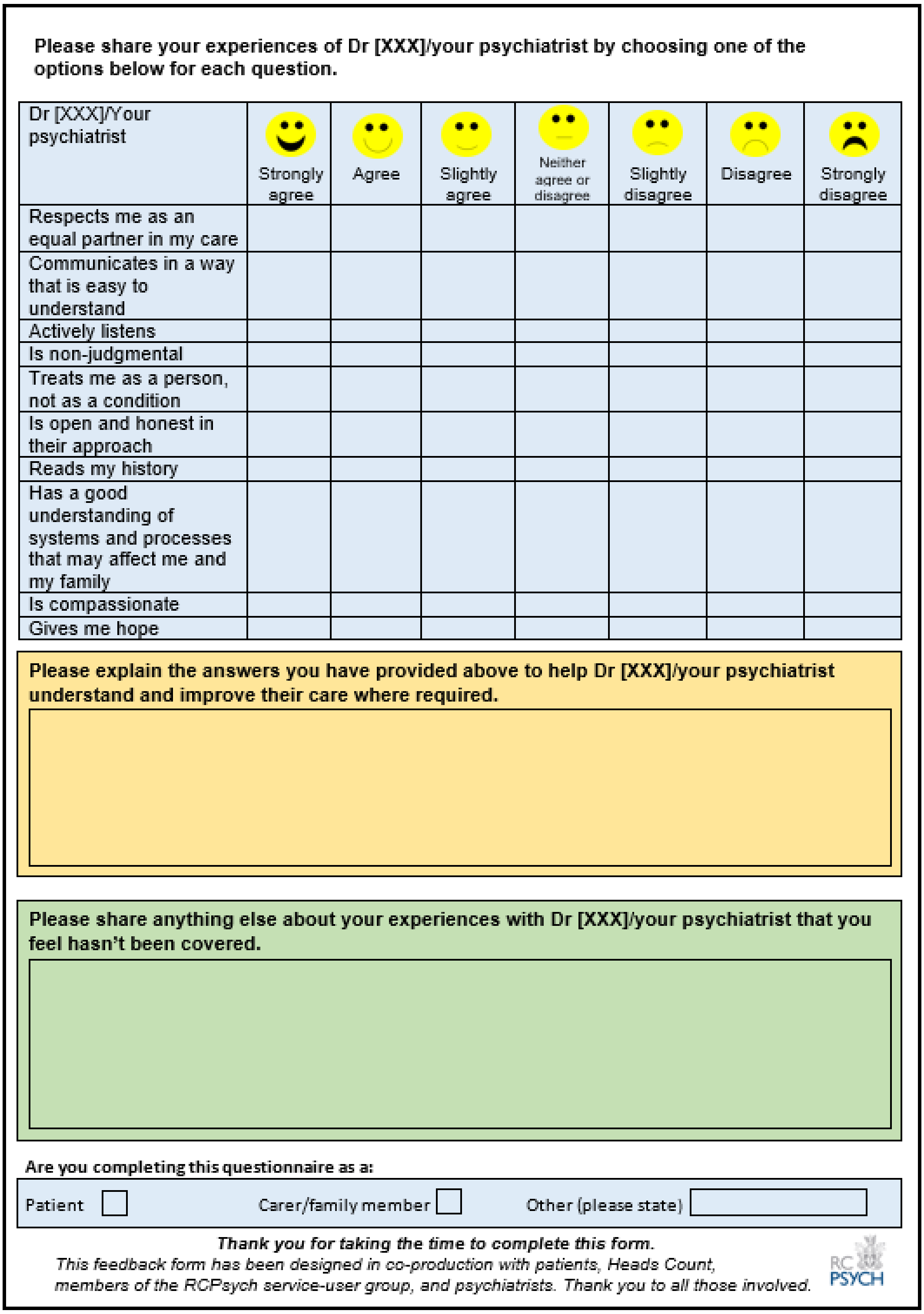
Please use the box below to let Dr [XXX]/your psychiatrist know what, if anything, they could do to improve the care they deliver.

PLEASE TURN OVER

Please note, the number on this form is so the Royal College can identify the psychiatrist you are feeding back on. This number **cannot** be linked to you. ID 1234

RC PSYCH

Figure 10 Refined patient feedback tool



Please share your experiences of Dr [XXX]/your psychiatrist by choosing one of the options below for each question.

Dr [XXX]/Your psychiatrist	Strongly agree	Agree	Slightly agree	Neither agree or disagree	Slightly disagree	Disagree	Strongly disagree
Respects me as an equal partner in my care							
Communicates in a way that is easy to understand							
Actively listens							
Is non-judgmental							
Treats me as a person, not as a condition							
Is open and honest in their approach							
Reads my history							
Has a good understanding of systems and processes that may affect me and my family							
Is compassionate							
Gives me hope							

Please explain the answers you have provided above to help Dr [XXX]/your psychiatrist understand and improve their care where required.

Please share anything else about your experiences with Dr [XXX]/your psychiatrist that you feel hasn't been covered.

Are you completing this questionnaire as a:

Patient ☐ Carer/family member ☐ Other (please state) ☐

Thank you for taking the time to complete this form.

This feedback form has been designed in co-production with patients, Heads Count, members of the RCPsych service-user group, and psychiatrists. Thank you to all those involved.

Figure 10 Refined patient feedback tool page 2

Comparison of how the refined feedback tool and information sheet compared to the checklist created in cycle three is provided in Appendix 15. As indicated by participants, the only aspects not achieved were the inclusion of pictures in the feedback tool. However, the addition of emoji's was felt to be a suitable compromise. Other aspects that were marked as ‘unclear’ by participants when reviewing the checklist included choice about how and when patients could complete the feedback tool, availability of the feedback tool to patients at all times and presence of a feedback loop. These were process or implementation issues that extended beyond the remit and influence of ourselves as researchers and this co-production process.

8.4 Discussion

This research addressed an identified gap in existing literature by exploring what patients and psychiatrists co-produce when creating a patient feedback tool for revalidation purposes (Boardman, 2018; Crawford *et al.*, 2011; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a). Previous approaches to patient feedback design have typically kept patients and healthcare professionals distinct with patient behaviours, voices and narratives historically marginalised, demonised, or removed altogether (Davies, 2001). The co-productive nature of this research therefore provides an alternative method to the dominant approach used in extant literature (Brooks *et al.*, 2017; Mead & Bower, 2000; Snyder & Engström, 2016).

Patients and psychiatrists selected the number and types of care domains considered most conducive to the therapeutic relationship based on findings from cycles two-five, co-created response scales considered most helpful in facilitating patient understanding and reflective practice, generated positively worded statements to encourage greater ownership and empowerment by using I/me statements and designed the layout of the co-produced patient feedback tool to facilitate ease of understanding without overwhelming potential respondents or diluting the patient experience. The intentional wording, phrasing and content of the co-produced tool often centred on patient voice, choice and opportunities as a desirable and alternative language. For example, "*your voice matters", "I have a choice", "I have an opinion".* The refinement process identified some areas for improvement including the visible acknowledgement of the co-produced process, selection of pastel colours for the feedback tool and renaming the information sheet to '*patient experience - your voice matters*'.

8.4.1 Comparison with existing literature

Findings from this research indicate that the interpersonal, or relational components of the interaction between patients and psychiatrists is what appears to matter most to both patients and psychiatrists (Jagosh *et al.*, 2011). The importance of such behaviours has been widely reported in existing literature (Chambers *et al.*, 2017; Gunasekara, Patterson & Scott, 2017; Lelliott *et al.*, 2008; Perry *et al.*, 2013), as has a desired holistic approach that explores not only the biological, but also the psychological and social dimensions of health and illness (Engel, 1962). Similarly, as acknowledged in previous research cycles, both patients and psychiatrists expressed a desire for large narrative, or free text comments. Recent research has highlighted the value of such comments and their ability to provide contextual information that encourages reflective practice and quality improvement (Jones *et al.*, 2020; Lockyer *et al.*, 2018) to a greater extent than that achieved in quantitative measures alone (Marsh *et al.*, 2019). As suggested by Marsh et al., more narrative comments are felt to elicit greater insight into the relational aspects of patient experience, e.g. how were you treated, as opposed to the more transactional components of care e.g. was the service on time, often favoured in quantitative measures (Marsh *et al.*, 2019). Narrative comments are also felt to act as a catalyst for change that serve a different purpose to quantitative measures by disrupting assumptions as opposed to counting occurrences (Marsh *et al.*, 2019). Other areas of convergence with existing literature includes participant desires to positively phrase questions and incorporate I/me statements to facilitate ownership and empowerment (Chambers *et al.*, 2017).

8.4.2 Contributions to new knowledge

Despite these similarities, some of the research findings reported above appear to be unique. For example, no research to the researcher's knowledge has yet explored the content of a co-produced patient feedback tool for revalidation purposes. As acknowledged by one participant, "*you have no choice there* [existing patient feedback tool] *whereas here* [co-produced feedback tool] *you're making the choice for yourself"* (Participant 4). Although not the focus of the workshops, the inclusion or removal of carer input also appeared to be a particularly divisive issue, warranting further examination (Olasoji, Maude & McCauley, 2017). Finally, participants often spoke about hope in psychiatric care and the important role psychiatrists play in providing such hope. This appears to be an underreported focus of psychiatric care in existing knowledge and understanding (Işık & Ergün, 2019).

8.4.3 Strengths and limitations

Strengths of this research include its use of two workshops in two distinct geographies (London and South West England) to explore any undue influence by the Royal College of Psychiatrists or previous research involvement. Informal feedback shared at the end of the workshops suggested a good level of rapport had also been developed, e.g. "*It was well facilitated, people got to have their say"* (participant 1). Participants also indicated that the sharing of information prior to the start of workshop one was helpful - "*it was helpful to have some of the reading beforehand to get thinking about it, but actually what we did in the* *meeting was the most productive”* (participant 2). The psychiatrist involved also acknowledged “*that this* [co-production] *is something we should be doing much better, involving people”* (psychiatrist), indicating a possible appetite for future co-productive efforts going forward. Other strengths of this research include its contribution to new knowledge by exploring patient feedback tools from both a patient and professional perspective (Eiring *et al.*, 2015; Trujols *et al.*, 2013), co-producing a patient feedback tool with both patients and psychiatrists (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a), exploration of the behaviors, attitudes and skills considered must conducive to the therapeutic relationship in psychiatric care (Farrelly & Lester, 2014) and examination of factors that support and inhibit the perceived value and acceptability of patient feedback tools for revalidating psychiatrists (Gayet-Ageron *et al.*, 2011; Hill *et al.*, 2012).

However, its limitations must also be acknowledged. Firstly, both samples rely on volunteer purposeful sampling with an ability to speak and understand the English language. The introduction of possible bias as a result of this criterion and sampling method is therefore acknowledged. Secondly, despite several recruitment routes, only one psychiatrist took part in the co-production workshop. No psychiatrists took part in the refinement workshop. Although the recruitment of healthcare professionals is known to be difficult (Parkinson *et al.*, 2015), particularly in unfunded research, this low level of participation is acknowledged as a limitation of this research. Finally, initial responses to the co-production workshop may be have been biased due to the workshops location, i.e. the Royal College. However, steps were taken to mitigate this wherever possible including the clear indication that the Royal College was not funding this research in any way and inclusion of a second refinement workshop in a different location with different participants that sought to explore tool relevance and acceptability.

8.4.4 Implications

The implications of this research include the acknowledgement that patients and psychiatrists can co-produce a patient feedback tool, with each community bringing unique insights and suggestions. The historical reliance on a ‘doctor/researcher knows best’ approach may therefore be redundant and no longer justifiable (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a). Secondly, language appears to be an integral component in facilitating the acceptability, usability and perceived ownership of patient feedback tools (Barbato *et al.*, 2014). While often seemingly minor, the impacts and meaning of words chosen are often central to either challenging, or perpetuating existing power hierarchies and archaic roles of passivity and inactivity typically assigned to patients (Dabby, Tranulis & Kirmayer, 2015; Ma, 2017; Vigo, 2016). Creating a language that is acceptable and empowering to all communities involved is therefore essential. This can arguably only be achieved if all communities are involved in its creation. Thirdly, research findings give credit to the acknowledged risk of relying on historical data to establish theories of care quality from a patient perspective (Beattie *et al.*, 2014; Biringer *et al.*, 2017). As reported in cycles two-six, a number of domains included in the original ACP 360 tool are no longer considered relevant, or of value, to both patients and psychiatrists (remains calm under pressure, keeps appointments and is on time). Furthermore, despite best intentions, assurances of anonymity and confidentiality appear to be provided by the processes of patient feedback collection as opposed to confidentiality or privacy statements. Ensuring the reality of patient feedback collection reflects the content of confidentiality statements is therefore essential in facilitating trust and engagement. In addition, the need to provide accurate patient information has again been highlighted as essential in this research. As acknowledged by the ACP 360 representative, services often provide healthcare professionals with information about the purpose, intention and process of patient feedback activities but often fail to provide this information to patients, the ultimate end-users. The potential for misunderstanding is therefore high. Finally, although initial responses from participants seem encouraging, the impact of co-production on the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists is yet to be fully explored. It is this latter implication that the final research cycle, cycle seven, seeks to address.

8.5 Conclusion

In conclusion, this research suggests that patients and psychiatrists can co-produce a patient feedback tool that incorporates the views, aspirations and desires of both communities. However, the impact of co-production on the perceived value and acceptability of a patient feedback tool is yet to be examined. It is this last and final point that cycle seven seeks to explore.

9.0 Cycle 7 - What difference if at all, does co-production have on the perceived value and acceptability of a patient feedback tool?

9.1 Introduction

This final research cycle sought to explore the thoughts and perceptions of both patients and psychiatrists when reviewing three patient feedback tools and information sheets. Each tool and information sheet have been designed with varying levels of patient involvement as outlined below:

i) The patient feedback tool and information sheet co-produced by patients and psychiatrists in cycle six
ii) The current ACP 360 tool originally designed in 2005 with no patient or public involvement as acknowledged in cycle one
iii) A hybrid feedback tool and information sheet that combines elements of the co-produced feedback tool created in cycle six and changes made by the ACP 360 team alone with no patient involvement or consultation*

*Please see Appendices 16-18 for each of the three information sheets and feedback tools and a list of changes made to the co-produced feedback tool by the ACP 360 team with no patient involvement or consultation in Appendix 19.

Through the exploration of patient and psychiatrist perceptions, this research sought to explore the potential impact of co-production on the perceived value and acceptability of patient feedback tools. For the purposes of this research, value was defined as the importance, or usefulness, an individual attributed to the tool. Acceptability was defined as the suitability of the feedback tool from a participants perspective drawing on the definition provided by van der Vleuten (van der Vleuten, 1996b).

Justification for this research cycle stems from the repeated criticism of traditional approaches to patient feedback design and evaluation (Boardman, 2018; Crawford *et al.*, 2011; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a) and subsequent need to explore alternative methodologies (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a). For example, as stated by Boardman:

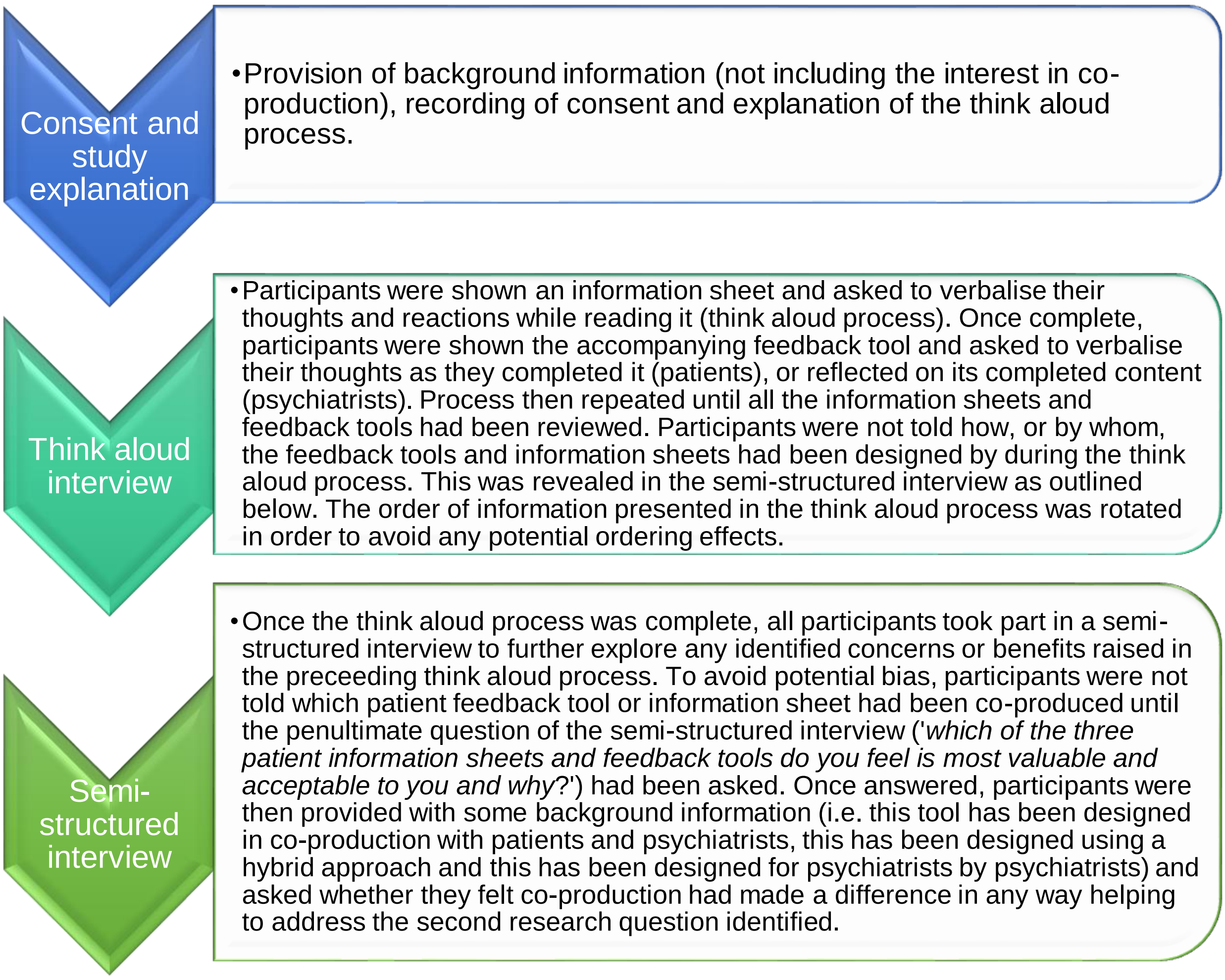
> "*Mental health has, as yet, not focused sufficiently on the patient perspective. To improve this situation, service users and carers need to be involved in the entire process of developing, testing and measuring outcomes. This means listening effectively to the patient voice by developing a co-productive approach…"* (Boardman, 2018, p.5)

This final research cycle therefore sought to address the following research questions:

- How do patients and psychiatrists perceive, understand and experience three patient feedback tools and their accompanying information sheets?
- What impact, if any, does co-production have on the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists?

9.2 Methods

To address the above research questions, think aloud interviews (Van Someren, Barnard & Sandberg, 1994; Willis, 2004) were conducted on a one-to-one basis with patients and psychiatrists followed by a semi-structured interview as shown in Figure 11. Justification for this approach is provided below. For clarity, participants experienced this as a 'single' interview ranging from 30-75 minutes.



Consent and study explanation

- Provision of background information (not including the interest in co-production), recording of consent and explanation of the think aloud process.

Think aloud interview

- Participants were shown an information sheet and asked to verbalise their thoughts and reactions while reading it (think aloud process). Once complete, participants were shown the accompanying feedback tool and asked to verbalise their thoughts as they completed it (patients), or reflected on its completed content (psychiatrists). Process then repeated until all the information sheets and feedback tools had been reviewed. Participants were not told how, or by whom, the feedback tools and information sheets had been designed by during the think aloud process. This was revealed in the semi-structured interview as outlined below. The order of information presented in the think aloud process was rotated in order to avoid any potential ordering effects.

Semi-structured interview

- Once the think aloud process was complete, all participants took part in a semi-structured interview to further explore any identified concerns or benefits raised in the preceeding think aloud process. To avoid potential bias, participants were not told which patient feedback tool or information sheet had been co-produced until the penultimate question of the semi-structured interview ('*which of the three patient information sheets and feedback tools do you feel is most valuable and acceptable to you and why*?') had been asked. Once answered, participants were then provided with some background information (i.e. this tool has been designed in co-production with patients and psychiatrists, this has been designed using a hybrid approach and this has been designed for psychiatrists by psychiatrists) and asked whether they felt co-production had made a difference in any way helping to address the second research question identified.

Figure 11 Process of think aloud and semi-structured interviews used

Justification for exploring the three information sheets and feedback tools identified include the opportunity to explore varying levels of patient involvement i.e. none (current ACP 360), some (adapted co-production tool by the ACP 360 team) and all (co-produced feedback tool produced in cycle six). Each feedback tool is also specifically designed for revalidation purposes in the context of psychiatry. The comparison of these three information sheets and feedback tools is therefore well supported given their shared psychiatric context, revalidation focus and varying levels of patient involvement.

Think aloud and semi-structured interviews

Think aloud (a research method where participants are asked to verbalise their thoughts and feelings when completing an activity or task (Charters, 2003; Giles *et al.*, 2013; Mitchell *et al.*, 2020)) and semi-structured interviews were selected for the purposes of this research due to their:

- Frequent pairing in existing literature (Charters, 2003; Taylor *et al.*, 2019) including in the examination of patient-reported outcome measures (Mitchell *et al.*, 2020) and healthcare innovations (Richardson *et al.*, 2017)
- Ability to identify errors or struggles as they occur in near real time, including levels of understanding, acceptability and response or completion difficulties helping to provide more realistic and authentic accounts of problems encountered by individuals when completing feedback tasks (Mitchell *et al.*, 2020)
- Potential reduction in researcher bias due to limited levels of interjection by the researcher (Mitchell *et al.*, 2020)

Furthermore, as suggested by Willis, think aloud interviews "*explicitly focus on the cognitive processes that respondents use to answer survey questions. Therefore, covert processes that are normally hidden, as well as overt observable ones, are studied*" (Willis, 2004, p.1). Think aloud interviews can therefore provide additional insight into participant understanding and reactions that may otherwise remain unknown if relying on more direct, or quantitative, methods alone (Willis, 2004).

The opportunity for patients and psychiatrists to verbalise their thoughts and opinions was also seen as an important methodological and political decision given the historical exclusion of the patient voice previously acknowledged and feelings of disempowerment reportedly experienced by some psychiatrists (Brooker & Dinshaw, 1998). Finally, similar to existing research (Bailey *et al.*, 2016; Hernan *et al.*, 2016; Mitchell *et al.*, 2020; Taylor *et al.*, 2019), justification for the inclusion of semi-structured interviews includes their ability to gain further insight and clarification into the thoughts, perceptions and reactions participants share during their think aloud interviews.

Although well suited to the aims of this research, the limitations of the think aloud method should also be acknowledged. For example, verbalising internal thoughts and reactions is not common practice. Think aloud interviews can therefore be unfamiliar for participating individuals. As suggested by Willis, participants were therefore encouraged to take part in a ‘warm up’ activity (Willis, 2004). In this instance participants were asked to describe the number of windows in their house or where the interview was taking place to become familiar with the verbalising process. At the request of the patient research partner, regular assurances of there being no right or wrong answers were also provided in an attempt to address the lack of familiarity with the think aloud process.

Despite these potential limitations, think aloud and semi-structured interviews were considered to strongly align with the aims and questions of this final research cycle.

Topic guide

As is common practice in think aloud processes (Willis, 2004), no topic guide was developed for the think aloud interview. At the beginning of each think aloud interview, participants were asked to “*think aloud while reviewing the* *information sheets and completing or/reflecting on the patient feedback tool in front of them*". Participants were also asked to "*talk as much as possible*" about their thoughts and feelings and reassured that there were "*no right or wrong answers*". Importantly, as suggested by Van Someren, Barnard & Sandberg (1994), once this information had been provided, any other form of researcher interjections were kept to a minimum to reduce potential disruptions unless participants had stayed silent for 15 seconds or more where they were encouraged to keep thinking aloud wherever possible (Van Someren, Barnard & Sandberg, 1994).

Based on the previous research findings (cycles one-six) and existing literature reviewed, a topic guide for the semi-structured interviews was designed in co-production with the patient research partner and psychiatrist colleague (Appendix 20). Open-ended questions and prompts were used to facilitate in-depth discussions. The topic guide broadly covered the following areas:

- Overall perceptions and experiences of the information and feedback tools reviewed
- Exploration of any difficulties, areas of interest, or concern raised during the think aloud process
- Perceived value and acceptability of the three information sheets and feedback tools
- Any suggested improvements for the information reviewed

9.2.1 Participants

Both patients and psychiatrists were invited to take part in this final research cycle as they both form an integral part of the revalidation process. It was therefore imperative that the views and opinions of both patients and psychiatrists were included (Crawford *et al.*, 2011).

Inclusion criteria

The inclusion criteria used in this research cycle was similar to that outlined in Table 39 with the exception of no prior research involvement. Justification for the criterion has been previously provided on pages 109 & 157 to avoid repetition. If participants were involved in the co-production of the patient feedback tool they may be more inclined to report more positive feelings towards it. The recruitment of participants with specific characteristics or experiences, in this instance no prior research involvement, is typical of think aloud activities, further justifying this approach (Willis, 2004).

9.2.2 Sample size

A sample size of 12 participants (n=6 patients, n=6 psychiatrists) was originally proposed. This decision was made following the sample size in similar research studies (Al-Jabr *et al.*, 2019; Berry, Lobban & Bucci, 2019) and difficulties imposed as a result of COVID-19. Other factors related to this decision included the work load of psychiatrists and inability to buy out clinical time as previously reported. Despite these limitations, the proposed sample size was considered to be feasible for a PhD thesis and capable of achieving data saturation as previously defined (page 113).

9.2.3 Recruitment

Patients

Patients were recruited using a volunteer, purposeful sampling approach based on the pre-defined inclusion and exclusion criteria outlined in Table 39. Research invitations (Appendix 21) were sent via email to identified gatekeepers at three mental health charitable/volunteer organisations (two local and one national) known to support people with mental health experiences. The charity/volunteer organisations had not previously been involved in this research. Identified gatekeepers at each organisation then disseminated the research invitation to individuals who met the pre-defined inclusion criteria. Justification for involving community and voluntary sector organisations has been previously provided on page 114 to avoid duplication. If no response had been received by the organisation, a reminder email was sent two weeks later. If no response was received after this reminder email, no further communication was sent. Participants who expressed an interest (n=10) and had given their consent to be contacted by the researcher were then invited to take part in an interview at a time of their choosing.

Psychiatrists

Psychiatrists were also recruited using a volunteer, purposeful sampling approach. Following an invitation by a senior psychiatrist colleague, a research invitation was distributed to a network of practising psychiatrists in the South West of England (n=12). The informal network had been established through a previous research project. Psychiatrists who expressed an interest (n=6) were invited to take part in an interview at a time of their choosing.

9.2.4 Setting

Due to the pandemic, all interviews were conducted online via Zoom or over the phone with the exception of two interviews held in accordance with all social distancing requirements once lockdown restrictions had been eased. All participants were given the opportunity for patient feedback tools to be posted to a relevant address prior to the interview date, with the understanding that participants would not open the package until the interview started in order to best replicate the process of receiving a patient feedback tool through the post as frequently practised in revalidation, or seeing the feedback tool for the first time helping to achieve a more authentic experience.

9.2.5 Data collection

During the think aloud interview, participants were shown the three feedback information sheets and blank/or completed tools in a sequential order that changed on a rotating basis, i.e. participant 1 reviewed information sheet and feedback tool A (co-produced), B (hybrid) then C (original), participant 2 reviewed information sheet and feedback tool B, C then A, participant 3 reviewed information sheet and feedback tool C, A then B etc. The order in which the information sheet and tools were presented was intentionally rotated to reduce any bias caused as a result of the order in which information was presented. While patient participants reviewed and completed a blank feedback tool, psychiatrists were also shown a completed, but anonymised, example of each feedback tool to help explore the level of reflection achieved as a result of the feedback shared. This was considered to be an important element to include, as the ability of a patient feedback tool to facilitate reflective practice has been identified as vitally important in previous research cycles and existing literature more broadly (Edwards *et al.*, 2011; Jones *et al.*, 2020). For clarity, completed feedback tools were only shared with psychiatrists if participants had given their consent to do so.

Furthermore, in order to avoid potential bias, participants were not told about how the information reviewed was designed until the penultimate question of the semi-structured interview had been asked (‘which of the three patient information sheets and feedback tools do you feel is most valuable and acceptable to you? Why?’). Once answered, participants were provided with some background information (i.e. this tool was designed in co-production with patients and psychiatrists, this one was designed using a hybrid approach and this one was designed by psychiatrists for psychiatrists) and asked whether they felt co-production had made a difference, if at all. Importantly, any information relating to the co-productive nature of the information reviewed was removed prior to any of the interviews taking place.

Due to the coronavirus restrictions and inaccessibility to the relevant technology, all interviews were conducted by the researcher alone. However, as evidenced below the research partner was still involved in the analysis process.

All data was recorded using a Dictaphone and transcribed verbatim by the researcher.

9.2.6 Data analysis

Data was analysed in co-production with the patient research partner using inductive thematic analysis (Braun & Clarke, 2006) as previously described. The process of co-producing the analysis was the same as that outlined in cycles two and three (pages 67 & 90) with the exception of posting transcripts to the research partner due to the Corona virus pandemic.

9.2.7 Maintaining rigour

Rigour was maintained using the same processes as outlined in Table 13.

9.2.8 Ethical considerations

Due to the pandemic, an ethical amendment to allow interviews to take place online and/or over the phone (Reference number 19/20-1286) was submitted (Appendix 22). Due to the Corona virus pandemic, participants provided written consent by returning completed consent forms in the post using a pre-paid envelop to facilitate accessibility and inclusivity, or gave verbal consent at the beginning of the interviews depending on participant preferences.

9.3 Results

Sixteen participants (10 patients, 6 psychiatrists) took part in this research. Inductive thematic analysis identified four key themes: overall perceptions of information sheets, patient feedback tools, perceived impact of co-production and areas for future research. Each core theme and their related sub themes are discussed in turn below, beginning with perceptions of information sheets. Similar to all previous research cycles, verbatim examples are provided and tabulated in some cases to facilitate ease of understanding and comparisons. Patient and psychiatrist responses are differentiated, e.g. ‘patient, participant 1’, ‘psychiatrist, participant 10’ for reporting purposes.

9.3.1 Overall perceptions, understanding and experiences of information sheets reviewed

Positive perceptions, understanding and experiences

With the exception of one psychiatrist who valued the reduced emphasis on anonymity in the hybrid information sheet, participants unanimously identified the co-produced information sheet as the most engaging and acceptable version. Such preferences were often attributed to its design, content and layout as identified in Table 46 below.

Table 46 Perceived benefits of the original ACP 360, hybrid and co-produced information sheet identified during the think aloud and semi-structured interviews

Perceived benefits	Original ACP 360 information	Hybrid information sheet	Co-produced hybrid sheet
Design			
Layout	“*It’s on the same piece of paper”* (patient, participant 5)	**-**	“*I think it’s nicely laid out, its fairly clear, these would be like your FAQs* [frequently asked questions] *in terms of why you asked me to do it, where does it go, what is the purpose of it”* (patient, participant 7) “*This is more clearly laid out, user-friendly I would say”* (patient, participant 5) “*The design of having the lines in between different topics instead of here you’re just sort of reading straight through”* (patient, participant 12) “*I think that this is better to read, I like it better, it has this why, why [blue lines] that’s why”* (psychiatrist, participant 13)
Colour	**-**	**-**	“*I like the colour, colour is nice”* (patient participant 4) “*Yeah just colour and simple”* (patient, participant 6)
Icon use	**-**	“*I like the pictures on it”* (patient, participant 3) “*I like the idea of having the thing* [megaphone] *there doing that, that’s good because is my feedback going to be anonymous or is it going to be heard by everyone in the town centre?”* (patient, participant 5)	“*These things here* [icons] *are excellent, that especially* [crowd icon], *I want to be part of a group, it’s so obviously right, the envelope thing* [icon] *is excellent”* (patient, participant 5) “*The icons are good as well, I like the icons, they’re pretty simple, simple is always good”* (patient, participant 7) “*The graphics are better on this one”* (patient, participant 12) “*It has these visuals, it’s easy for people*” (psychiatrist, participant 13)
Font size	**-**	**-**	“*This has bigger letters than the other one”* (psychiatrist, participant 13)
Bold and underlined	**-**	**-**	“*You’ve got in bold and underline, ‘providing feedback is entirely your choice’, this is the best one so far, you’ve got at the bottom it ‘cannot be linked to you’”* (patient, participant 1)

Content			
Assurances of anonymity	-	-	“*So I like this next one* [co-produced] *about explaining how, how many and why, and how it’s going to be anonymous, I think that’s really useful*. *I mean, is my feedback anonymous? It’s clear and then how will it be used, yeah that’s really good. Yeah, I like all of that. I like all of it”* (psychiatrist, participant 9) “*It feels a bit more anonymised this one, and feels like you’re not going to get in trouble*” (patient, participant 3) “*Yeah so this one encourages you not to include specific dates so covers you really, so again makes you feel at ease…As well your feedback isn’t included in your notes so you can give a more honest review then”* (patient, participant 2)
Advice on how to provide constructive feedback	-	“*It explains how to give feedback”* (patient, participant 4)	“*Oh that’s good, it gives some guidance on how to make it helpful”* (patient, participant 4) *“Suggestions of how to make feedback helpful, great*” (psychiatrist, participant 9)
Detail of how data will be destroyed	*“What’s in the notes,* [reads notes] *‘questionnaire and envelop will be destroyed once results are analysed’, I quite like that, because there’s a lot of mistrust around records and documents being kept, particularly where benefits etc. are concerned, so I think there’s a lot of thoughts that anything that is written or documented can go against people so I think that that is helpful to put in there to say you know it will be destroyed*	-	-

	or incinerated or whatever the technique is. Carbon friendly let’s hope!” “ (patient, participant 7)		
Information on where to send feedback	-	-	“*I think that it’s clear you can send your feedback directly, you have more confidence in it not being read by your doctor”* (patient, participant 12) “*Excellent, I think this is excellent, I like the format as well, excellent where you can send feedback. I think it is great”* (psychiatrist, participant 13)
Language	-	-	“*It’s more in plain English”* (patient, participant 5) “*This just straight away feels better to read, easier to read… it’s not intimidating”* (patient, participant 3) “*This feels more friendly, the language in this one seems kinder, it’s less concerning than that one* [original ACP 360] *it’s easier to read and take in”* (patient, participant 1)
Less repetitive	-	“*I thought that was less repetitive it felt more direct and brief”* (psychiatrist, participant 10)*	-

*Psychiatrist respondent who preferred the hybrid information sheet

The layout, content and design of the co-produced information sheet appeared to be key in facilitating engagement and ease of understanding for both patients and psychiatrists (Table 46). For example, as suggested by participant one:

> "*I'm just more drawn to it* [co-produced information] *than the others. This feels a bit more on my level in terms of the way it's laid out, the way it looks. It does make a big difference. I think it's more simple whereas this one* [hybrid], *probably has much of the same information in it, but seems a bit more formal"* (patient, participant 1)

Similarly:

> "*It's just really nicely laid out and I think it's a significant improvement* [on the original ACP 360] *in terms of layout and appeal. The visual appeal is just* greater*. I think it would be more encouraging if you were wondering whether to fill it in or not. I think it's clear what is going to happen to it. So everything about it makes it a totally better product"* (psychiatrist, participant 9)

Participants repeatedly described a more empowering message when reviewing the co-produced information sheet often as a result of its language, content and use of underlined text (all suggestions made in cycles three-six of this research). For example, as suggested by participant four:

> "*I like the colour. The top bit is empowering about 'your voice matters'"* (patient, participant 4)

Similarly:

> "*They've underlined 'your care will not be adversely affected', 'it cannot be linked to you', 'entirely voluntary', so I look at the colours and then the bold bits and underlined because that's what I tend to do. 'It cannot', 'will not', isn't included in your notes… you'd be more honest and you could give them a more honest review. It* [co-produced] *reassures you, definitely that one first"* (patient, participant 2)

In contrast, one psychiatrist commented on the unhelpful size of information provided in the original ACP 360 tool (Appendix 16) and subsequent message this portrayed:

> *"This one* [original ACP 360]*, the size doesn't reflect the importance of patient feedback and as compared to this* [co-produced information]*, I think that this is better to read, I like it better. I don't think that anyone would be able to realise how important this is* [original ACP 360]*, while you give 'your voice matters', this they cannot miss"* (psychiatrist, participant 13)

Other elements identified as beneficial by participants included the use of icons, suggestions on how to provide constructive feedback and presence of information on how to send feedback responses to the Royal College directly (Table 46). These were all suggestions made in cycles three-six of this research.

The repeated assurances of anonymity were also often favourably described by both patients and psychiatrists. For example:

> "*So I like this next one* [co-produced] *about explaining how, how many and why, and how it's going to be anonymous, I think that's really useful*. *I mean, is my feedback anonymous? It's clear and then how will it be used, yeah that's really good. Yeah, I like all of that. I like all of it"* (psychiatrist, participant 9)

Similarly:

> "Interviewer: *OK, so of the three in front of you, which, if any of them, do you feel is most valuable to you?*
>
> Participant: *this one* [co-produced]
>
> Interviewer: *can I ask why?*
>
> Participant: *just everything really, it seems more anonymous, and seems like they've taken more care in doing this one as opposed to that one* [original ACP 360] *that just feels like someone's just typed it up and not really read through it"* (patient, participant 4)

The level of detail provided in the co-produced information sheet (Appendix 18) appeared to be acceptable, with many participants reportedly feeling more trusting and at ease with the information shared. For example, as suggested by participant three:

> "*It feels more anonymised this one* [co-produced]*, you're not going to get in trouble"* (patient, participant 3)

Similarly:

> "*I'm already trusting this* [co-produced information] *whereas I'm not trusting that* [hybrid] *so my responses are going to be ones where I'm feeling very, very scratchy about it, whereas here I'm feeling much more supported.* '*Be honest, let your psychiatrist know what they are doing well.' I think be honest is really, really cool. This be honest is a real thing because it's only by that, that they're able to get proper feedback"* (patient, participant 5)

Interestingly, as evidenced in Table 46, providing information on one page (a trait shared by all information sheets reviewed) and details of how data will be destroyed were the only positive aspects of design or content described by participants when reviewing the original ACP 360 information.

Critical perceptions, understanding and experiences

In regard to concerns, the addition of two safeguarding sentences in the hybrid information sheet (Appendix 17) appeared particularly problematic (Table 47). The safeguarding sentences presented below were created by the ACP 360 team alone with no patient involvement or consultation. Justification for their inclusion by the Royal College included “*the College has a duty of care and safeguarding policy requiring appropriate action to protect the safety of a vulnerable person if we receive information of concern”* (Appendix 19).

The safeguarding sentences were placed directly below the ‘is my feedback anonymous?’ section:

> *“**Please note:** If there is something included in your feedback that makes us concerned about your welfare, or the welfare of others, then we will need to share this information with others as we have a duty of care. The details you provide in your feedback may mean it could be possible to identify you e.g. if you decide to include your name, diagnosis etc.”*

The inclusion of these sentences often formed a central point of disruption and frustration during the think aloud interviews. The sentences also had important implications for feedback engagement and authenticity as identified below:

> “[Reading safeguarding sentences]… *Oh forget it* [completing the feedback tool], *it’s got to go, you’re basically breaching confidentiality and it’s a fundamental breach of confidentiality right at the beginning. You’re saying ‘oh, no, no, no, no we won’t share, we won’t do this, be honest’, well how can you be honest if your honesty is then going to be used against you? So no I wouldn’t fill in this form at all … it’s going to be used against the person and I think that’s critical. I bet you that* [safeguarding sentence] *knocks off hundreds of people who otherwise want to give feedback. I for one would turn around and say you must be joking”* (patient, participant five)

Similarly:

> *“…* [reads safeguarding sentences] *Ok, that makes me not want to complete it anymore or be honest, considering you’re asking me to give feedback about the person who is delivering my psychiatric care. So yes the layout is good, the fact that it is badged up is good, but that sentence would stop me giving honest feedback”* (patient, participant four)

Table 47 Perceived limitations with the hybrid information sheet as identified by participants

Perceived limitations with the hybrid information sheet		Verbatim example
Design		
	Layout	“*That’s way too busy, I am now in that middle age where I can’t read past a page of A4, nobody is going to sit and read that”* (psychiatrist, participant 14)
	Formal and corporate appearance	“*It feels quite wordy, my initial looking at it, there’s a lot of information to look at and take in, this feels quite formal”* (patient, participant 5) “*It’s quite corporate”* (patient, participant 1)
	Similarity with diagnostic mental health tools	“*I wouldn’t be true or honest because I feel it’s a diagnostic tool and it’s going to be used against me rather than with me”* (patient, participant 8)
	Boarder	“*This is not necessary for example* [the boarder]” (psychiatrist, participant 13) “*It seems to me that someone has put all this flash stuff around the edges for no rhyme or reason”* (patient, participant 5)
	Font size	“*The text is still quite small”* (patient, participant 4)
	Colour	“*I’d make the font bigger”* (patient, participant 11) “*This very dark purple/blue, it’s quite corporate”* (patient, participant 1)
Content		
	Safeguarding sentence	“*Again, this one has got the issue with the disclaimer… it’s about is my feedback anonymous isn’t it? That’s key”* (patient, participant 8) “*I’m not going to complete that form, it’s not happening*” (patient, participant 5) “*So again, you’re not going to tell the whole truth in case you’re going, you’re going to worry about what you say and how you say it*” (patient, participant 12) “*I think there’s lots of things here that make it ambiguous about how anonymous the feedback is and how it might affect them, because I don’t think I know of any service user who hasn’t faced trouble accessing care, and if then asked to read this and give feedback and be honest, that wouldn’t then worry”* (patient, participant 11)

Although some participants understood the need to include such information from a legal and safeguarding perspective only, e.g. "*that will be based on some kind of legal advice, or medical advice that they've received won't it"* (patient, participant 7), this often contradicted the perceived purpose of patient feedback activities and assurances of anonymity shared in the preceding information. For example, as suggested by participant seven:

> "*It's conflicting isn't it? It's either anonymous or it isn't. Depending on what you're asking people for, depicts whether you need to put that in there"* (patient, participant 7)

After reading the safeguarding sentences, many participants stated that they would no longer fill in the patient feedback tool regardless of its quality or be dishonest in their feedback response. For example:

> "*You're not going to tell the whole truth, you're going to worry about what you say and how you say it"* (patient, participant 12)

> "*I wouldn't be true or honest because I feel it's a diagnostic tool and it's going to be used against me rather than with me"* (patient, participant 8)

Similarly:

> "*When they talk about 'your feedback may mean it could be possible to identify you', that straight away makes me feel like I don't want to answer it. That instantly puts me off, I don't want to read it now, I wouldn't answer the rest, it would have gone straight in the bin…"* (patient, participant 3)

When reviewing the hybrid patient feedback tool (Appendix 17), the same participant expressed disappointment at missing out on a feedback opportunity as a result of the included sentences and his subsequent actions:

> "*The questions are better on this one* [in comparison to the original ACP 360], *'treats me with respect, treats me as an equal partner…' This one just shows that they care more, but again, I wouldn't have got that far from the first bit* [accompanying information sheet] *which is annoying really because I would have missed out. I would have preferred to answer this one* [hybrid in comparison to original ACP 360]*"* (patient, participant 3)

Similar concerns about the inclusion of the safeguarding sentences were also raised by psychiatrist participants as identified below in Table 48.

Table 48 Verbatim examples of comments made about safeguarding sentences by psychiatrists when reviewing the hybrid information sheet

Verbatim examples
"'*Details that you provide in your feedback may mean that you could possibly…', I don't know, I think I would personally take that out because it's obvious that it's not anonymous isn't it? I mean it's not anonymous, if they can identify you to protect yourself or others, then it's not anonymous, and I think to a certain extent we're always covering our back, you know, it's a feedback questionnaire. It's not a mental health assessment. I don't think you have a particular duty of care because you're not, if someone is saying I'm suicidal, they need to go somewhere else and tell people they're suicidal not tell you through this. This is quite honest as a feedback questionnaire, we're always trying to protect everybody, and in a way it over complicates things, so my own view would be to take it out and make it anonymous. Why shouldn't it be anonymous*?" (psychiatrist, participant 10)
"*I think it raises more issues than it answers, and I'm not sure that that paragraph serves quite the right purpose"* (psychiatrist, participant 9)
"*But how you are going to find that* [patients name]? *It would be helpful to go back to people if there was something concerning but you will not be able to find them even if you are concerned. So either this will be omitted because no matter what happens, if people have concerns we cannot get hold of you, or if you want to share your contact details then this is something different. This you can take it if my feedback is anonymous you would say that given it is about mental health and the risk of suicide and all this stuff then we are afraid that your feedback isn't going to be anonymous, but these two don't connect with each other*" (psychiatrist, participant 14)

Issues of anonymity were also raised by psychiatrists in relation to organisational interference with patient feedback collected for revalidation purposes. For example, as suggested by participant 14:

> *"The feedback is something personal to me, that patient gives it to me in order to improve my practice. OK? I don't think the patient gives any feedback because they want to do harm to them, if they wanted to do harm they would take them straight to the GMC straight away, so I think that this should be for the doctor rather than the GMC because the GMC has other means of picking up all these concerns about a doctors practice. If you want to have this tool to help us improve ourselves, if we want to use this tool as another Big Brothers eye upon us then it is deemed to fail I think. People will not engage with the process and that is why I believe they should take off the anonymous stuff, ok? They have to make up their minds at the Royal College, is this going to be anonymous or non-anonymous? It it's going to be anonymous, then by default you cannot find who gave this feedback so no matter if you are concerned about the fact that someone says I am going to kill myself, you cannot*

> *find who is this person that will kill themselves, it is clear to me."* (psychiatrist, participant 14)

There often appeared to be confusion as to who the feedback was being collected for, organisations or the individual healthcare professionals?

A suggested compromise or improvement for the safeguarding sentences included a need to respect the potentially upsetting process of providing patient feedback and including relevant contact details for care co-ordinators or the Samaritans. For example, as suggested by participant seven:

> "*People may get triggered by this so I think anything that sort of indicates that 'we recognise', 'we understand that this may be difficult for you' would be good"* (patient, participant 7)

Similar suggestions were also made by psychiatrists as evidenced below:

> "*I might want to say something like, 'if you're concerned about your current care or safety please call the person at your mental health service'*" (psychiatrist, participant 9)

Although signposted information was included in the hybrid information sheet reviewed (Appendix 17), its terminology and phrasing was considered to be in need of refinement by participants.

Finally, although often described by participants as more favourable in comparison to the hybrid information sheet due to the included safeguarding sentences, participants also identified a number of concerns with the original ACP 360 information sheet (Appendix 16) as evidenced below in Table 49.

Table 49 Identified concerns related to the original ACP 360 information sheet

Issue	Verbatim example
<u>Design</u>	
Layout	*“It’s fairly busy isn’t it, you know just the visual impact”* (psychiatrist, participant 9)
Formal and uninviting	“*I wouldn’t do it. It’s too formal. It’s too wordy*” (patient, participant 1)
Illogical order	“*It doesn’t necessarily follow a logical order. So please try to be as honest as you can at the top, and then the envelope in which you’re putting it would make more sense to be at the bottom. You could see it as something that might follow through the process a little bit better”* (psychiatrist, participant 9)
<u>Content</u>	
Lack of assurances about anonymity	“*I don’t think this one uses the word anonymous, that I think should be in there somewhere considering the thing that you are doing and why you are doing it. It says that my name isn’t required, but that doesn’t tell me not to put my name on it”* (patient, participant 4)
Limited information	“*Is that all there is, literally just here? That bit here? It doesn’t really say apart from saying that it can improve and develop the quality of care, it doesn’t really say a lot more about how else it’s going to be used”* (patient, participant 1) “*It doesn’t specify who the questionnaire is going to, it says it’s going to an analysis team, it doesn’t actually say your doctor or whoever may be part of that analysis team”* (patient, participant 12)
Not reassuring	“*Doesn’t seem reassuring, just reading it doesn’t make me feel better or anything”* (patient, participant 3) *“As someone who is a service user this would make me worry* [original ACP 360 information]. *It opens up lots of ways that you could worry. This raises a lot of what ifs, honestly or dishonestly, I wouldn’t do it at all, no”* (patient, participant 11)
Not personally addressed	“*It’s not personally addressed to me, so it’s obviously just a mass produced thing. I appreciate that might be difficult to do, it might cost a bit more, but it doesn’t really feel like they’re that interested in my personal reviews. It just feels like a mass, ‘here’s a bunch of leaflets’ see how many you get back kind of thing”* (patient, participant 1)
Terminology	“*I suppose there’s the life-long question of patient, service-user, client and I know that the College centrally did adopt patients as its preferred term a little while back but that’s obviously not filtered through to this particular department”* (psychiatrist, participant 9)
Readability	“*It’s a bit confusing really, I don’t really understand it”* (patient, participant 2)

Similar to the hybrid version, some participants revealed that they would no longer complete the original ACP 360 form due to the limited amount of information provided. Two participants appeared to be particularly concerned by the limited level of information shared:

> *"'So he or she can improve the care he or she provides', I don't know, there's some trick going on. I'm not getting this, but something is wrong here. My gut reaction to reading this is that I wouldn't fill it out. It doesn't appear to be completely honest. I've just got this feeling that they're hiding something and I'm not sure what it is* [continues reading]. *Well there you go, once results have been analysed, so it's pointless destroying it, it's already analysed. You've already used it for whatever purpose you're going to use it for and what purpose is that? I don't know what the purpose is? What is the purpose? That's really freaky actually, I don't like that at all"* (patient, participant 5)

Similarly:

> "*I don't like that one at all* [original ACP 360], *that one made me really worried"* (patient, participant 8)

No reports of not completing the feedback tool as a result of the information shared were made by participants when reviewing the co-produced information sheet. Such comments were only made when reviewing the hybrid and original ACP 360 version, highlighting the importance and influential nature of patient information in encouraging patient feedback engagement and authenticity.

Suggestions

Some suggestions for improving the co-produced and hybrid information sheet were provided by participants including altering the wording of 'celebrate good practice' to *"identify good practice"* (patient, participant 12) to respect those who may not have had a positive experience; adding "*unless you wish to"* after advice on not to include specific medications, diagnoses or dates as "*some people are very open and want to share it"* (patient, participant 12) and including "*frequently asked questions"* in the information sheet title "*because it's a familiar term that people know and also makes* *them feel like they're not the only one asking questions and having concerns"* (patient, participant 12).

One psychiatrist participant also suggested the transformation of included information "*into an animation which can help to explain what is needed…the written jargon could be put into a 30 second film which would be much easier and people would watch it"* (psychiatrist, participant 14).

Despite these suggestions, with the exception of one psychiatrist participant who valued the reduced emphasis on anonymity in the hybrid version, participants unanimously identified the co-produced information sheet as the most engaging and acceptable version for the aforementioned reasons.

9.3.2 Overall perceptions, understanding and experiences of patient feedback tools

Positive perceptions, understanding and experiences

With the exception of one comment made about its length, participants shared no positive descriptions or experiences of the original ACP 360 feedback tool (Table 51). The overwhelming majority of positive perceptions described by participants were attributed to the co-produced elements (following findings from cycles three-six) listed in Table 50 below.

Table 50 Co-produced elements of the patient feedback tools

Co-produced elements of the hybrid and co-produced patient feedback tool
Layout (including font size and colour)
Use of positive (what are they doing well) and critical (could improve) word search design questions
Increased number and size of free text comments
Strongly agree – strongly disagree response scale in conjunction with smiley faces
Question content including terminology
Number of included questions
Inclusion of ‘anything that hasn’t been asked’ question
Inclusion of ‘who has this feedback form been completed by’ question and response options

When asked which patient feedback tool participants considered to be most valuable and acceptable, all but two participants (one psychiatrist, one patient) who preferred the hybrid tool due to its brevity selected the co-produced feedback tool. No participants selected the original ACP 360 tool as the most valued or acceptable tool.

Table 51 Perceived benefits of the original ACP 360, hybrid and co-produced patient feedback tool as identified by participants

Perceived benefits	Original ACP 360 tool	Hybrid feedback tool	Co-produced feedback tool
Design			
Layout	-	-	“*This one in this size is the clearest and I like how it’s laid out”* (patient, participant 11) “*Just in terms of layout and use of colour and so on, it just makes it”* (patient, participant 6)
Colour	-	-	“*It’s a more relaxed colour* [in comparison to the purple used in the hybrid] *the very dark purple or blue, it’s quite corporate”* (patient, participant 1) “*I like the colours by the way, really counts”* (patient, participant 5)
Font size	-	-	“*This one in this size is the clearest, you would have more chance of being able to access this for a broader range of people, it’s a bigger font, its clearer”* (patient, participant 11) “*I prefer the size of font”* (patient, participant 5)
Content			
Relevance of questions asked	-	“*Ah there is one about honesty here, ‘is open and honest in their approach’, that’s good. Developed a good knowledge of my history, yeah OK …. there is one on honesty which is good. Is there one about listens there, listens well? Yeah, listens well to what I say, that’s important*” (psychiatrist, participant 10) “*To be fair, the questions are better on this one* [in comparison to original ACP 360] *but I wouldn’t of got that far from the first bit* [information sheet just reviewed]” (patient, participant 3)	“*I like it’s asking the right questions, treats me as a person not as a condition, that’s great, that’s what people want”* (patient, participant 7) “*Nice questions generally… simpler and more relevant and the last question of anything else about your experience of care that hasn’t been covered, yeah that’s a good one”* (psychiatrist, participant 9) “*There’s some good stuff in here, kind, read my history, offered hope… and then a separate box for something that’s not on there as well, so that’s quite good”* (patient, participant 1) “*I like the questions…they’re all good statements”* (patient, participant 6)

Relevance of questions asked cont.		“*I think it’s good that it’s got addresses all me needs including medical social and physical that’s one of the big arguments”* (patient, participant 6)	
Constructive/ balanced feedback (identical in hybrid and co-produced version)	-	*“I quite like this because I think we should always capture what people felt is going well, because sometimes we might not know that we are doing it well, and I like the word improve because no one comes to working thinking that they’re going to do a bad job so I think improve is always a thing, we should always look to improve”* (psychiatrist, participant 13)	*“I like the idea of prompting constructive feedback, it turns it into a more constructive process and it probably helps the psychiatrist but it also probably helps the patient be more effective in the feedback actually because they can still leave it blank can’t they? It just makes it really easy for them to do”* (psychiatrist, participant 9)
Word search design	-	-	*“I quite like that, the idea of actually giving people some more specifics for doing to improve, because I think narrative comments on feedback, they’re sort of the discretionary effort on questionnaires that people may not always feel like doing, whereas something that gives you a bit more direction, would maybe get a bit more granularity. I like the idea of prompting the constructive feedback, it actually turns into a more constructive process and it probably helps the psychiatrist, but it also probably helps the patient be more effective in the feedback actually because they can still leave it blank can’t they? They’re not obliged to complete it, it just makes it really, really easy for them to do it”* (psychiatrist, participant 9) “*I like the concept of people choosing the buzz words, it helps them choosing, it brings consistency”* (psychiatrist, participant 13) “*You haven’t got to think in your head, what words you’re trying to think of, how to improve, it’s just yeah I want them to do this more, because it’s easy to say*

			what they're good about, but if it's there you can just tick away…I like this format" (patient, participant 12)
Response scale (identical in hybrid and co-produced tool)	**-**	"*Oh this one is better than the original, I think just adding the smiley faces it just immediately makes it more engaging, and making the questions you know, just a bit simpler and more relevant I think*" (psychiatrist, participant 9) "*The agree and strongly disagree is better than the low, moderately low, moderately high, it sounds better and there's a neutral button, well there is a don't know or N/A but having a middle ground is good. Yeah, an improvement on the last one* [original] " (patient, participant 1) "*I like the pictures on here compared to the face arrow that looks really cheap and poorly designed* [original ACP 360]" (patient, participant 5)	"*I like the agree scales I must say, you've got that ability to agree or disagree so yeah I like it better"* (psychiatrist, participant 9) "*I like the strongly agree, disagree, that's much more personal it's a bit clinical when you say high, very high, low, it's to clinical"* (patient, participant 8) "*Again I like the smiley faces"* (patient, participant 1) "*I like the wording it gives me an option not to agree"* (patient, participant 12)
Length/ number of questions asked	"*It's on the same piece of paper"* (patient, participant 5)	"*I think I prefer this one to the other one* [co-produced feedback tool] *because it's simplified"* (patient, participant 8) "*Slightly less questions"* (psychiatrist, participant 13)	"*I think, because the original has got what 15 questions? Some of which I said were duplicates but they've been taken out here*" (psychiatrist, participant 9)
Size and number of free text comments	**-**	"*You've got two big boxes down below that you can actually put writing in, and normal sized writing as opposed to having to write in hieroglyphics like you'd have to with that one* [original ACP 360]" (patient, participant 1) "*I like how the boxes let you write things underneath it there"* (patient, participant 3)	"*It allows the patient to have a narrative"* (patient, participant 5) "*Good to have the open boxes"* (psychiatrist, participant 10) "*Yeah this is much better so you can actually write some useful stuff about what they are doing well"* (patient, participant 4)

Participants often reported that they felt they had more opportunities to express their experiences in their own words as a result of the design and format of the co-produced tool. For example:

> "*Ok I'm looking at this* [co-produced tool] *and I'm much happier,* [having just reviewed ACP 360 and hybrid version]. *I'm looking at things here and I'm allowed to choose, not being told. I'm allowed to actually put my input into it and I love the idea that there's then a text box to let them know what they're doing well, if anything… I'm allowed to actually discuss, have my own input, actually verse the sentence. This sentence is written for me* [ACP 360] *whereas here, I'm making up the sentence, the paragraph, the narrative. It's so, so important that this is the case. This is so much better… I actually feel as though I am writing the feedback"* (patient, participant 5)

While recognising a shift from patient passivity to activity, participant nine suggested:

> "*I like this one* [coproduced tool] *because I like the way that people can make specific feedback as long as those questions are things that patients have told you that they want to feedback on. I would respect that and think that because it's actually prompting people to think in a constructive - this is how you could improve, that may be quite challenging for patients who are used to being quite passive to be thinking in that way but it recognises an important shift*" (psychiatrist, participant 9)

Similarly:

> "*Yeah tick all of these ones that apply, this is very good. Ok, will improve the care they deliver, excellent and here are these things that we were saying* [that mattered in a therapeutic relationship]*, very well done, communicate, please explain the answers you have provided. Excellent, this is excellent, this is excellent, this is excellent… the feedback form has more boxes for them* [patients] *to give feedback on their own rather than what we prescribe*" (psychiatrist, participant 14)

The inclusion of the word search design and free text question that asked if 'anything had not been covered' (two co-produced elements, Table 50) appeared to be of particular value. For example, as suggested by participant 14:

> *"It's easy for people and then by using these* [word search options], *they can build upon these choices and write more things here* [free text comment] *and also they can add something that may not be here* [free text comment asking to share anything that may have been missed or not covered] *as well so I wouldn't definitely look to use this one"* (psychiatrist, participant 14)

Both the word search design and free text question were removed by the ACP 360 team and therefore not included in the hybrid version (Appendix 19). Reasons for their exclusion provided by the ACP 360 team often related to existing reporting functionality. For example,

> "*Addition of this functionality* [word search question] *is a challenge for system development. Reduction from 3 pages to 2 pages reduces risk of lost/separated pages of printed questionnaires"*

Similarly:

> "[removal of free text box] *To create a more concise questionnaire, the option to add an explanation of scores has been combined with the free text box on what's been done well/could be improved. The other feedback box was removed for similar reasons"*

However, although a favourable design, two participants suggested removing the first word search option in the co-produced tool as it was considered to provide limited detail in comparison to the multiple choice question that focused on similar behaviours, attributes or skills. This was however not a unanimous suggestion. The majority of participants appeared to value the level of detail provided by the word search design. For example, "*this one gives more details, and the more details, the better the feedback"* (psychiatrist, participant 14)

Other aspects of design that was favourably described by participants included the content and terminology of the co-produced response scale applied to both the co-produced and hybrid feedback tool (Table 51). Many participants suggested that the response scale used encouraged greater understanding, ownership and choice in comparison to the original ACP 360 tool. For example:

> *"You've got the ability to agree or disagree so I like it better"* (psychiatrist, participant 9)

> "*I like the strongly agree, disagree because that's much more personal, it brings it back to me"* (patient, participant 8)

> "*I like the wording of this* [co-produced response scale]*, it gives me the option not to agree"* (patient, participant 11)

Similarly:

> "*I like the smiley faces, it helps"* (patient, participant 2)

> "*I really, really like that a lot* [co-produced response scale] *because it explains itself with agree, strongly agree. It's got faces with emotions and so on and so forth which are good"* (patient, participant 5)

> "*I like the pictures on here* [hybrid] *compared to the face arrow that looks really cheap and poorly designed* [ACP 360]*"* (patient, participant 4)

Participants repeatedly identified the increased size and number of free text questions as beneficial in both the hybrid and co-produced tool:

> "*It's better than the last one* [ACP 360] *because you've got two big boxes down below that you can actually put writing in and normal sized writing as opposed to having to write in hieroglyphics like you'd have to with that one"* (patient, participant 1)

> "*Good to have the open boxes, it's really important to have that"* (psychiatrist, participant 10)

However, following perceived power imbalances, some participants identified a need to "*give permission"* to continue on a separate page when filling out a free text box. For example, as suggested by participant six:

> "*You need to include something like 'continue on a separate sheet if necessary' because there are people who feel they've got to fit everything in and will write minutely. I think you need to give people permission almost because there are some people that won't, particularly in the clinical context. Psychiatrists are so powerful, and if you're at the hard end of being unwell, they can be part of the process of depriving you of your liberty, so you feel quite circumspect about doing things that are not immediately, obviously permissible"* (patient, participant 6)

Linked to permission, participants also frequently identified the indication of who the feedback tool was being completed by as a beneficial and important aspect, often preferring the approach used in the co-production tool with the acknowledged caveat that feedback tools should be completed by patients themselves wherever possible. For example:

> "*This one* [co-produced] *says are you completing this feedback form as a patient, or a carer, or other. That's more specific* [in comparison to the hybrid tool] *but again I don't think people should answer it on behalf of patients without asking them because you're not getting a true reading, it should come*

> *from the patient, even if it's bad, you shouldn't get a family member to answer it because they don't properly know what you think"* (patient participant 2)

Similarly:

> "*That's much, much better, patient, carer, family that is how you should do it"* (patient, participant 5)

As demonstrated in Appendix 19, the ACP 360 team removed the:

> "*Multiple options on who is completing the questionnaire to reduce inconsistency/simplify reporting. Just one option remains to confirm if the form is completed on behalf of a patient"* (Appendix 19)

In regard to content, participants repeatedly described a greater level of perceived relevance when reviewing the co-produced content. For example, as suggested by participant nine:

> "*Nice questions generally* [co-produced tool]*, the last question at the end of anything else about your experience of care that hasn't been covered, yeah that's good, I like that. The questions are simpler and more relevant I think, because that one* [original ACP 360] *has got 15 questions, some of which are duplicated and there's something about respecting peoples time isn't there, if you're asking the same question three times, you're not really respecting peoples time"* (psychiatrist, participant 9)

Similarly:

> "*It's asking all the right questions* [co-produced tool]*, treats me as a person not as a condition, that's great and that's what people want. They want to be treated as an equal, not looked down upon. It's all the key things, equal partner, treated as a person"* (patient, participant 7)

When reviewing the original ACP 360 form, one participant stated "*I would also include another question, 'treats me as a person not as a condition'"* (patient, participant 12). This was the exact phrasing used in the co-produced patient feedback tool following suggestions made in cycles two-six. A similar experience was also encountered by a psychiatrist who expressed a desire to include a question around honesty when reviewing the original ACP 360 tool. A question on honesty was included in the co-produced and hybrid feedback tool at the request of both patients and psychiatrists due to its perceived relevance and importance in cycles three-six. When encountered, the psychiatrist stated "*ah there is one about honesty here, 'is open and honest in their approach', that's good*" (psychiatrist, participant 10), reiterating its perceived importance.

Interestingly, when reviewing a completed version of the three patient feedback tools by the same patient, one psychiatrist acknowledged:

> "*Also, do you notice the ratings tend to change? See everything is strongly agree* [participant responses on co-production tool] *because it* [tool] *gives details. While here* [original ACP 360] *it is still high, no comments at all here* [original ACP 360] *because this kind of form makes people not want to give any feedback because it's very small, they don't see it* [free text box]. *This one* [hybrid] *is kind of an improvement compared with this one* [original] *but then when they got to write more information on their own, it comes back as better"* (psychiatrist, participant 14)

The psychiatrist suggested that the feedback responses could have been more positive as a result of the patient feeling more empowered and respected when using the co-produced tool. For example, when drawing a comparison with the original ACP 360 tool, the psychiatrist suggested:

> "*This is more of an admin task that you give to people we say 'don't worry it'll just take one minute to fill it in, just tick the boxes'"* (psychiatrist, participant 14)

Further examination of any differences in perceived tool value and subsequent feedback responses may be an interesting area for future research.

Critical perceptions, understanding and experiences of patient feedback tools reviewed

However, participants also described a range of factors that inhibited the perceived value and acceptability of the patient feedback tools reviewed, as outlined in Table 52 below. Similar to the information sheets reviewed, criticisms often related the design and content of the original ACP 360 and hybrid tool. For example:

> "*I shy away from this* [hybrid tool]*, everything about it suggests that it's too professional, and by being too professional someone hasn't looked at what is worthwhile for the patient in terms of appearance and design"* (patient, participant 5)

Table 52 Perceived problems with patient feedback tools reviewed as identified by participants

Perceived problem	Original ACP 360 tool	Hybrid tool	Co-produced tool
Design			
Font size	"*I have issues about its small font"* (patient, participant 12) "*I find that really small print"* (patient, participant 2)	-	-
Layout	"*The layout isn't user friendly"* (patient, participant 8) "*The layout is very boxy, very matter of fact…very formal"* (patient, participant 1) "*That one is just nothing, I would totally switch off with that I could finish in about ten seconds and it wouldn't mean anything"* (patient, participant 4)	"*I shy away from this* [hybrid tool]*, everything about it suggests that it's too professional, and by being too professional someone hasn't looked at what is worthwhile for the patient in terms of appearance and design"* (patient, participant 5)	"*It's too busy for me"* (patient, participant 8)
Lack of colours	"*I would have colours"* (patient, participant 3)	-	-
Uneven number of questions	"*Finishes on an odd number as well, some people don't like that"* (patient, participant 2)	-	-
Disengaging appearance	"*I would imagine very few people do that one* [ACP 360] *after discharge"* (patient, participant 11) "*It's not very friendly"* (patient, participant 2)	"*It's quite formal again apart from the smiley faces a little bit more friendly but still quite formal"* (patient, participant 1)	-
Logo/banners	"*I don't like the logos, that means nothing to me, ACP 360 it looks like I should be grading some kind of corporate event or something"* (patient, participant 1)	-	-
Content			
Perceived relevance, placing or appropriateness of questions	"*Remains calm under pressure' I don't know why I don't like that it insinuates they should be flapping if it starts to become a bit hard, I don't want that at all"* (patient, participant 7) *"I don't know why I would want to be asked questions about why my psychiatrist is friendly and easy to approach when I I would just assume that*	"*I also think 11 that's going beyond the scope of the service, like the NHS is very clear that it has a set amount that it can do for each person…"* (patient, participant 11)	"*I like the one about hope I just think it's a bit dismissive having it there at the bottom, I'd like it at the top"* (patient, participant 7)

Perceived relevance, placing or appropriateness of questions continued	*that was a given anyway. And listens to what I say should be a given, and speaks clearly so that I can understand should be a given. Also, I’m thinking there, are they just thinking that I can’t understand what a psychiatrist has got to say, do they need to put it in stupid terms, when I’m not stupid”* (patient, participant 1) “*… not really in-depth, ‘keeps appointment on time’, just questions that don’t really mean anything to me… they’re just a bit robotic*” (patient, participant 3)	*“‘Communicates in way that I understand’, it’s important but does it still give the same message as last time?”* (patient, participant 1)	*“Could you put gives me hope about my future, actively listens to me?”* (patient, participant 2)
Number of questions	“*There’s too many questions in there””* (patient, participant 1)	-	-
Lack of ‘permission’	-	-	“*Wonder whether it’s worth saying continue on a separate sheet if necessary… I think you do need to give people permission almost”* (patient, participant 6)
Text box size and frequency	“*I didn’t see it”* (patient, participant 2) “*It’s so small”* (psychiatrist, participant 10) “*It’s very small, it’s another tick box, ‘oh we better put that in just in case”* (patient, participant 8) “*The box isn’t big enough to write anything of any use”* (patient, participant 5)	-	-
Repetitive questions	“*13 and 15 look quite similar, 10 and 11 have got similarities, 9, 10 and 11 have got similarities”* (psychiatrist, participant 9) “*Number four and twelve are the same questions”* (patient, participant 1)	-	-
Scale content and design	“*The sad face to the arrow, I don’t like that”* (patient, participant 7) “*The language at the top doesn’t work, ‘listens well to what I say’, ‘low’, ‘very low’, ‘moderately low’,*	-	-

	doesn’t make sense. The scale doesn’t make sense and the smiley faces are a bit weird” (patient, participant 1)		
Lack of clarity	-	“*Please tick the box if you are completing this questionnaire on behalf of a patient, what if I am a patient, do I tick it because I’m doing it on behalf of myself? That doesn’t make sense, it should just be are you a patient, carer or other I think*” (patient, participant 4) “*They’ve put down here what they could do to improve, they haven’t put to improve care, just to improve in what sense? There’s no clarity… this doesn’t match up* [free text comment underneath Likert scale questions*, Say I had a bad experience and I put everything as strongly disagree all the way down the line then its ‘please tell them what they are doing well?’ Well nothing is being done well here, but it’s not suggesting that you can put that in, its suggesting that you can only put that in there, so they are telling you that they are basically presuming that you are going to actually have wonderful commentaries about your psychiatrist, they’re presuming the case”* (patient, participant 5)	-

A lack of understanding and awareness of who ACP 360 were was also seen as confusing and frustrating by participants. For example, as suggested by participant one:

> “*It’s got this ACP 360 plastered all over it, I don’t know what that is, the ACP 360 seems like a company as opposed to providing feedback on someone that’s dealing with me for my mental health… it looks like I should be grading some kind of corporate event”* (patient, participant 1)

A lack of perceived relevance and clarity in the first free text comment box of the hybrid tool (another alteration by the ACP 360 team, Appendix 19) was also identified as problematic by participants as evidenced below:

> “*You’re asking people* [hybrid] *to explain their scores but only by writing something that they’re doing well? So how can I give a negative score but only explain my positive ticks? That doesn’t make sense whereas this one* [co-produced tool]*, if I gave positive I can give reasons for positive and if I gave negative, I can give reasons for negative”* (patient, participant 5)

Furthermore, in contrast to the scale used in the hybrid and co-produced tool previously described, the content and design of the response scale in the original ACP 360 feedback tool appeared challenging and difficult to understand. For example, as suggested by participant one:

> *“The language at the top doesn’t work, grammatically, ‘listens well to what I say’, ‘low’, ‘very low’, it doesn’t make sense. The scale doesn’t make sense and the smiley faces are a bit weird”* (patient, participant 1)

In one instance, the response scale prevented a participant from engaging with the patient feedback tool entirely:

> “*Right I already have a problem, a big problem, because the responses don’t match the question, so is ‘friendly and easy to approach’, ‘very low’, ‘moderate’ and already I’m stuck. ‘Listens well to what I say’, ‘very low’, ‘low’, no. Yeah I wouldn’t be able to fill this in so that’s that one”* (patient, participant 11)

As suggested in Table 52, many participants stated that they missed the free text comment in the original ACP 360 tool due to its size and location:

> "*I didn't notice it* [free text comment], *it's very small, doesn't give much scope for actually putting down what my thoughts are. There's not enough space to put anything meaningful in there, it's kind of out of the way as well isn't it. It's not big enough, if I had genuine feedback, good or bad, I'd have to have teeny tiny writing to fit it into there"* (patient, participant 1)

As a result, one participant concluded that the ACP 360 tool and its designers "*don't seem like they care"* (patient, participant 3). Others suggested "*it's just a tick box thing, they're not going to use it"* (patient, participant 8); "*it's a conveyor belt"* (patient, participant 2).

Psychiatrists also expressed dissatisfaction at the size and location of the free text box in the original ACP 360 tool, echoing research findings from cycles three-six:

> "*Not got a great deal of space for further comments. Oh I see 'overleaf if required', yeah doesn't feel like its inviting much in the way of narrative either which is actually usually the most useful stuff in terms of reflection*" (psychiatrist, participant 9)

> "*What is this box here to fill in here for comments, do they have to fill it in with an electronic microscope?"* (psychiatrist, participant 14)

> "*Oh so you have got an open box but it's so small that you can't put anything in it, it's got an open box but it's so small people will forget to use it"* (psychiatrist, participant 10)

The potential reduction in levels of reflective practice achieved as a result of this perceived inadequacy was also raised by patient participants:

> "*There's two boxes, one for good and bad* [hybrid], *whereas the other one* [ACP 360] *was a tiny box. I think this one* [ACP 360] *is less informative for the psychiatrists professional development than that one, it tells you less, gives you less to reflect on*" (patient, participant 4)

Finally, some participants questioned the number, relevance and perceived duplication of included questions during their think aloud interviews, particularly in relation to the ACP 360 tool as evidenced below:

> *"'Remains calm under pressure'* [question in original ACP 360 tool]*… oh I don't like that, I don't want it in at all"* (patient, participant 8)

> "*Questions 13 and 15 look quite similar, 10 and 11 have got similarities, nine, 10 and 11 have got similarities* [original ACP 360]*"* (psychiatrist, participant 9)

> “*This box is too much really, too many questions, too many of them are similar, number four and twelve are the same* [original ACP 360]*”* (patient, participant 1)

Similarly:

> “*Keeps appointment on time, just questions that don’t really mean anything to me… they’re robotic questions, they’re not in-depth”* (patient, participant 3)

One psychiatrist expressed concern about the lack of questions examining clinical competency as evidenced below:

> “*I think it’s pretty good, the only thing that isn’t there is competence, you know, it’s all the human side of things but actually one of the most basic aspects of being a good doctor is being competent. Do they think I’m competent? Because they might think I’m a right so and so, but I’m good at my job. So I’d like to know whether my patients think I’m competent or not, I think that’s a fairly important question”* (psychiatrist, participant 10)

However, concerns of clinical competence were not identified by any other participant, reflecting its seemingly low priority.

Similarly, in addition to concerns raised in cycles three and six, two patients questioned the patronising nature of a question included in the original ACP 360 tool:

> “‘*Speaks clearly so that I can understand’… are they just thinking that I can’t understand what a psychiatrist has got to say, do they need to put it in stupid terms? I’m not stupid”* (patient, participant 1)

The same participant also expressed concern at the slight rewording in the hybrid tool reviewed:

> *“‘Communicates in way that I understand’, it’s important but does it still give the same message as last time?”* (patient, participant 1)

Similarly:

> “‘*Speaks clearly so that I can understand’, if I’m going to see the psychiatrist, I am just as intelligent as that person is, and I don’t want to be spoken down to”* (patient, participant 12)

For clarity, the revised wording used in the hybrid tool was not the co-produced content created in workshop six (Appendix 19). During the co-production workshop, participants purposefully ensured the responsibility of the question lay on the skills of the psychiatrist as opposed to the skills and capacity of individual patients. As a result, some participants described the original ACP 360 questions as patronising, "*simple"* (patient, participant 3) and "*basic"* (patient, participant 2), contrasting against the largely positive descriptions provided when reviewing the co-produced tool content.

Suggested improvements

Some suggestions for improvement were made by participants including: moving 'gives me hope' to nearer the top of the multiple choice questions in both the hybrid and co-produced tool due to its perceived importance; removing 'all' from 'all my health needs' to reflect service capacity issues and expanding some of the multiple choice questions, including "*'gives me hope about my future'* and *'actively listens to me'"* in the co-produced feedback tool (patient, participant 3). One psychiatrist also suggested that some of the multiple choice questions should be negatively phrased to disrupt habitual ticking, "*my personal view is that you need some negative questions there otherwise people just tick, tick, tick"* (psychiatrist, participant 13). Such suggestions contrasted against the intentional decision made by participants in cycle six to positively frame all statements on the grounds that identified behaviours, attitudes or skills should be present in all psychiatric care interactions.

Despite these suggestions, with the exception of two participants (one patient, one psychiatrist) who preferred the hybrid feedback tool due to its brevity, participants repeatedly attributed the greatest value and acceptability to the co-produced feedback tool for the aforementioned reasons.

9.3.3 Perceived impact of co-production

After reviewing all of the information shared, participants were asked to order the reviewed information according to their perceived value and acceptability. As previously mentioned, all but one psychiatrist selected the co-produced information sheet as their most valued and accepted version followed by the original ACP 360 tool and hybrid information sheet as a result of the included safeguarding sentences. Similarly, all but two participants who selected the hybrid version due to its brevity selected the co-produced feedback tool, followed by the hybrid and original ACP 360 version. Once the background information had been provided (e.g. this one is co-produced, this one uses a hybrid approach and this one was designed by psychiatrists, for psychiatrists), participants were asked if they felt co-production had made a difference in any way. Responses to this question are outlined in Table 53 below.

As stated by one psychiatrist:

> "*I really believe that these are the important things* [co-production] *that we should be doing. We should start moving away if we want to save the NHS because if we carry on in the same way, I think that the NHS is going to become private. We have to be open with people and have a good partnership with people, up until now we don't seem to have*" (psychiatrist, participant 14)

Many participants expressed dissatisfaction at the lack of patient involvement in the ACP 360 tool when the background information was revealed. For example:

> "*You see they say they wanted to do a patient thing and then they changed the one that patients decided"* (psychiatrist, participant 14)

> "*Not one part of me is surprised by that, this is very clearly not written by a service-user"* (patient, participant 11)

Table 53 Perceived impact of co-production by both patients and psychiatrists

Patient participants	Psychiatrist participants
"*It's* [co-produced] *definitely an improvement because it allows the patient to have a narrative"* (patient, participant 5) "*This* [co-produced feedback tool] *is from the patient as opposed to the psychiatrist. They don't understand what it's like to answer those questions from their point of view, it's easy for them* [psychiatrists] *to read through and answer, but for someone whose on the other side of it, it's quite hard"* (patient participant 3) "*It definitely makes a difference because no matter how hard you try, you don't know what other people who have been embedded in the service are thinking and feeling, there's just so much people take for granted"* (patient participant 6) *"For me it* [co-production] *makes it more personal, person-centred. They've listened, it feels like they've listened, it feels more person centred and not too clinical in its approach"* (patient, participant 8)	"*The involvement of patients has undoubtedly, undoubtedly made improvements. It's genuinely interesting to see, it's great, really good."* (psychiatrist, participant 9) "*Oh yeah, I preferred it to number one* [original ACP 360] *didn't I? So yeah. I mean the thing is if the patient prefers number three, use number three, because they're your client group aren't they, not psychiatrists. The patient should have the say of what the best design is. I suppose the recipient is the psychiatrist so they have to make sense of it, but you can make sense of that*" (psychiatrist, participant 10) "*I think it is excellent, this is excellent… this gives information* [hybrid tool] *but this gives more information* [co-produced tool]. *I would definitely go for this one* [co-produced]*, it has these visuals, it's easy for people and then by using these* [suggested word search question]*, they can build upon these choices and write more things here* [free text comments] *and also they can add something that may not be here* [free text comment about things that may not have been covered] *as well so I would definitely look for this one"* (psychiatrist, participant 14)

Both the hybrid and co-produced tool were considered to be an improvement on the original ACP 360 tool. However, frustrations were also expressed at the hybrid's failure to include patients in the entirety of the process:

> "*Absolutely, it does make a difference* [co-production] *but obviously what needs to happen is that the people who are dealing with the questionnaires need to take on board more of the information that has come from patients and the various communities. In other words you can't co-produce and then go 'oh we'll just pick and choose'. The process is nearly back to square one. People can't give up their time and expertise and then the College make final additions and changes without any patient involvement, they're at a half-way house"* (patient, participant 5)

Similarly:

> "*They've definitely made progress, just not all the way"* (patient, participant 11)

Some participants acknowledged a change in attitudes towards patient involvement and approaches to mental health, care and delivery more broadly. For example:

> *"It covers what is going to happen to the actual paper, but it doesn't necessarily say what's going to happen in response to the feedback* [original ACP 360]*. I know people really want more feedback about how their feedback has been used and I think that reflects the sort of era in which this was designed, it was far more thinking about getting the feedback, getting it in, and administratively dealing with it, rather than the process of reflection, development, change and improvement I guess"* (patient, psychiatrist participant 9)

Similarly:

> "…*it becomes apparent later on that they've somehow interpreted it and its come back differently. And I remember years ago, understanding and reading my notes because you weren't allowed to read them in those days and realising that a lot of stuff had been misinterpreted and then of course not being in any position to do anything about it whereas of course now I would*. *You can ask to see your notes anyway… I think psychiatry is getting better at acknowledging the complex quilt of health, housing, economic, jobs, it all knits together but we've got a long way to go*" (patient, participant 6)

9.3.4 Areas for future research and considerations going forward

Finally, in recognition of the increasing delivery of healthcare online as a result of Covid-19 participants expressed a desire to explore how the co-produced feedback form may "*relate to video consultations…"* (patient, participant 7). The rapid digitisation of healthcare services in response to Covid-19 also resulted in some participants questioning whether the feedback tools and information sheets would be made available online and offline, following an enhanced focus on digital inclusion. Participants also suggested providing "*further information about revalidation"* (patient, participant 7) in a paper based leaflet as people aren't always able to get online. Other areas of future research identified by a psychiatrist participant included examination of whether the perceived value and acceptability of a feedback tool affects the quality and positive ratings of feedback responses.

Despite these suggestions, participants repeatedly acknowledged that "*the joint approach is the best… working together makes a difference"* (patient, participant 11).

9.4 Discussion

This research sought to address an identified gap in existing literature by exploring how, if at all, the co-production of a patient feedback tool and information sheet affects its perceived value and acceptability among patients and psychiatrists (Berzins *et al.*, 2018; Gunasekara, Patterson & Scott, 2017; Williams, Coyle & Healy, 1998). Responding to criticisms of existing methods (Boardman, 2018; Crawford *et al.*, 2011; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a) and limited research into this area (Berzins *et al.*, 2018; Bramesfeld *et al.*, 2007), this research used think-aloud and semi-structured interviews to explore the thoughts, perceptions and reactions of both patients and psychiatrists.

Research findings indicate that all participants, with the exception of one psychiatrist who preferred the hybrid version due to its reduced assurances of anonymity, identified the co-produced information sheet as the most valued and acceptable version. Reasons for this selection were often attributed to the decisions made in the co-produced workshop (cycle six) informed by research findings from cycles two-five. For example, participants repeatedly acknowledged the importance of colour, overall design, ‘friendly’ language, level of accessible information, inclusion of helpful pictures/icons, repeated reassurances of anonymity and suggestions of how to provide constructive feedback.

Although similar in design and layout, the inclusion of two safeguarding sentences in the hybrid information sheet by the ACP 360 team with no patient involvement caused significant disruption and frustration for both patients and psychiatrists. As a result, many participants stated that they would no longer complete the feedback tool or be dishonest in their response. Similarly, the information provided in the original ACP 360 tool was described by participants as unclear and limited, with some participants expressing severe doubt and worry about completing the feedback tool, if at all. No participants identified any positive attributes of the ACP 360 information sheet with the exception of it being on one page and letting participants know how data will be destroyed. Such findings highlight the importance and influential nature of information in encouraging feedback engagement and authenticity.

Similar findings were also found when reviewing patient feedback tools. With the exception of two participants who valued the brevity of the hybrid tool, participants unanimously identified the co-produced feedback tool as the most valued and acceptable tool. Again, responses provided by participants were often attributed to the co-produced elements informed by cycles two-six. For example, participants felt that the co-produced tool enabled greater choice, ownership and generation of patient narratives as a result of the word search design, greater number of included free text comment boxes, enhanced relevance of questions asked and accessible response scale. Although some suggestions for improvement were identified by participants, the co-produced feedback tool was repeatedly identified as the most valued and acceptable tool in comparison to the hybrid and original ACP 360 tool. In all cases, the hybrid and co-produced tool were believed to be an improvement on the original ACP 360 tool. Such findings provide strong support for the added value of co-production given the greater value consistently attributed to it by participants.

9.4.1 Comparison with existing literature

Findings from this research support existing literature in multiple ways. Firstly, this research cycle supports the importance of interpersonal skills in facilitating a meaningful and effective therapeutic relationship as widely reported (Chambers *et al.*, 2017; Gunasekara, Patterson & Scott, 2017; Lelliott *et al.*, 2008; Perry *et al.*, 2013). Secondly, the inclusion of more narrative comments appears to be desirable given their ability to provide contextual information (Jones *et al.*, 2020; Lockyer *et al.*, 2018), but also a sense of empowerment in participants being able to construct their narratives in their own way, using their own language. Thirdly, similar to the findings reported in cycle one, the inclusion of emoji's or smiley faces in response scales appears to be beneficial in facilitating patient understanding and acceptability (Barbato *et al.*, 2014). Furthermore, there were repeated references to a perceived power imbalance in psychiatric care throughout this research cycle, although this was seen to be improving by some participants, with some way still yet to go (Rahimi, 2014).

Similar to cycles two-six, findings from this research cycle also provides support for the suggestion that relying on historical data to establish theories of care quality is a risk (Beattie *et al.*, 2014; Biringer *et al.*, 2017). As recognised by Beattie et al., what constitutes care quality from a patient perspective is likely to change over time (Beattie *et al.*, 2014; Biringer *et al.*, 2017). As evidenced in this research, some of the questions asked in the original ACP 360 tool now hold little importance or value for participating patients and psychiatrists. In some cases, the questions included in the original ACP 360 tool were considered to be patronising and irrelevant, providing further support for the conclusion that patient feedback tools lose their effectiveness over time (Riiskjær *et al.*, 2010). However, similar to the findings reported by Barbato et al., the active involvement of patients in feedback design and evaluation can help to create more 'friendly' and patient-centred use of language (Barbato *et al.*, 2014).

9.4.2 Contribution to new knowledge

Although supportive of existing literature, findings from this research also provide some unique insights into the potential value of co-producing a patient feedback tool for revalidation purposes, something that has not yet been done to the researchers' knowledge. Furthermore, findings from the think aloud interviews emphasise the influential nature of patient information in encouraging feedback engagement and authenticity. The importance of feedback information appears to be an overlooked component of patient feedback design in existing literature (Gayet-Ageron *et al.*, 2011). Finally, this research provides valuable insights and reactions to the inclusion of safeguarding sentences in ‘anonymised’ feedback tools. As identified by several participants, if patient feedback tools are truly anonymous, then the ability to identify individuals based on their feedback content should not be possible or permissible. Such findings echo the concerns raised in cycle six of anonymity statements holding little value on their own; it is the actions and processes that truly provide assurances of anonymity. Furthermore, as highlighted by both patients and psychiatrists, if the purpose of patient feedback in revalidation is to provide anonymous feedback, then a safeguarding sentence about identifying individual respondents may be detrimental and unhelpful. As suggested by one participant, this may reflect a lack of clarity regarding the intended purpose of patient feedback in revalidation and the process of revalidation more broadly (Archer *et al.*, 2015; Tazzyman *et al.*, 2017)

9.4.3 Strengths and limitations

Strengths of this research include its application of research methods frequently applied in similar research studies (Charters, 2003; Taylor *et al.*, 2019), examination of three patient feedback tools specifically designed for revalidation purposes in a psychiatric setting with varying levels of patient involvement, co-production with a patient research partner and exploration of both patient and psychiatrist perceptions beyond the potential influence of previous research involvement or restrictions imposed by quantitative measures (Willis, 2004). Other recognised strengths of this research include its use of research methods that generate in-depth insights into the experiences, thoughts and perceptions of both patients and psychiatrists (the ultimate end users of the information shared), helping to address the reported silencing and marginalisation of patients (Davies, 2001) and disempowerment of psychiatrists as sometimes reported.

Furthermore, the process applied in this research responds to a number of limitations reported in cycle one (Baines *et al.*, 2019b). For example, this research tool was actively led by patients and psychiatrists in regards to the number of feedback domains and questions to include; psychiatrists did not select which patients got to take part in this evaluation stage as is often the case (Lelliott *et al.*, 2008), reducing possible bias. The generation of the co-produced tool content was also done in co-production with both patients and psychiatrists as opposed to relying on professional opinion alone. This approach may help to explain the absence of any ‘unable to answer’ responses made by participants when reviewing the co-produced tool, (although negative comments and failure to engage with the ACP 360 and hybrid tool were frequently made), and absence of repeated requests to remove any feedback items due to perceived irrelevance, lack of importance or ‘emotionally charged’ content as reported in other patient feedback tools reviewed in cycle one (Schröder, Wilde Larsson & Ahlström, 2007).

Despite this, the limitations of this research must also be acknowledged. Firstly, although comparable to other research studies (Al-Jabr *et al.*, 2019; Berry, Lobban & Bucci, 2019), the sample size in this research may have been hampered as a result of the Covid-19 pandemic and greater reliance on digital technologies such as Zoom and telephones. The use of online platforms may also have affected the flow of interviews although this is often hard to measure (Salmons, 2014). Furthermore, similar to previous research cycles, this sample relies on a volunteer sample.

Potential biases as a result of this sampling method including concerns of representation are therefore also acknowledged. However, some assurances of the conclusions drawn can be provided as research findings reached data saturation as previously defined (page 113).

9.4.4 Implications

With these limitations in mind the implications of this research include the acknowledgement that the co-production of a patient feedback tool and information sheet appears to make a difference to its perceived value and acceptability for both patients and psychiatrists. Secondly, the importance of information in encouraging patient feedback engagement and authenticity should not be underestimated. Thirdly, despite being involved in the co-produced activity, the inclusion and recognition of co-produced content still appears to be at the organisations' or professionals' discretion. In this instance, two safeguarding sentences were added by the ACP 360 team without any patient consultation or involvement. Many participants stated that these sentences would deter feedback engagement or response authenticity. We must therefore ask who are these safeguarding sentences protecting and what purpose are they serving? Furthermore, examination of how organisations value and respect co-produced content needs to be critically considered. As suggested by one participant, we are currently at risk of creating a "half way house" that subsequently becomes another tick box exercise.

Other implications of this research include the acknowledgement of think aloud and semi-structured interviews as a beneficial approach to exploring participant reactions, thoughts and perceptions to patient feedback tools (Charters, 2003; Taylor *et al.*, 2019). The interviews generated a vast amount of data that may have gone unnoticed if relying on quantitative measures alone (Willis, 2004). Finally, given the increasing delivery of psychiatric care online, patients have identified a need to explore whether the feedback tool created could be applied to video consultation interactions. Implications for this thesis including future research and policy requirements are discussed in the final discussion chapter below.

9.5 Conclusion

This final research cycle sought to address identified limitations with existing literature by exploring how, if at all, co-production affects the perceived value and acceptability of a patient feedback tool. Research findings provide strong support for the benefits of co-production over and above more traditional and exclusive approaches to patient feedback design. However, the inclusion or acknowledgement of co-production efforts ultimately remains at the discretion of healthcare professionals or regulatory bodies more broadly. Efforts should be made to embrace co-produced activities to avoid potential disengagement and frustration among stakeholders involved. Otherwise we are at risk of encouraging co-production to become an additional tokenistic exercise, repeating the very limitations that this research sought to avoid.

10.0 Discussion

This final chapter seeks to explore the original research aims and questions, summarise research findings and compare these findings with existing literature. The chapter concludes by discussing the impacts of this research, the strengths and limitations of the overall thesis including its methodological approach and implications for policy, practice and future research.

10.1 Research aims and question

Despite their increasing use, the value of patient feedback tools in the revalidation process has recently been called into question (Academy of Medical Royal Colleges, 2018; Archer *et al.*, 2018; Sir Keith Pearson, 2017), particularly in the context of psychiatry (Baines *et al.*, 2019c). The exclusive approach to patient feedback design has also been repeatedly criticised (Boardman, 2018; Crawford *et al.*, 2011; Rose *et al.*, 2011; Zendjidjian *et al.*, 2015a), with more collaborative ways of working frequently suggested as an alternative approach to patient feedback design and evaluation (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a). However, critical exploration of whether co-production can enhance the perceived value and acceptability of a patient feedback tool is limited. This research therefore sought to:

i) Identify the extent to which patients and the public are involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists

ii) Explore and compare patient and psychiatrist experiences, perceptions and aspirations for patient feedback tools for revalidation purposes

iii) Co-produce a patient feedback tool with both patients and psychiatrists

iv) Explore the impact of co-production on the perceived value and acceptability of a patient feedback tool from both a patient and psychiatrist perspective.

Using a combination of action research (Baum, MacDougall & Smith, 2006) and co-production within a critical research paradigm (Guba & Lincoln, 1994), this research used primarily qualitative methods to address the following research questions:

i) How, if at all, are patients and the public involved in the design, delivery and evaluation of patient feedback tools for practising psychiatrists?

ii) What are patient and psychiatrist perceptions, experiences and aspirations for patient feedback tools in the revalidation process?

iii) How do these perceptions, experiences and aspirations differ, if at all?

iv) Can the perceived value and acceptability of a patient feedback tool be improved for both patients and psychiatrists through its co-production?

Seven inter-related research cycles were used to address these questions in turn as summarised below.

10.2 Summary of findings

The systematic review completed in cycle one (chapter three) demonstrates that patients and the public are rarely involved in the design, delivery or evaluation of patient feedback tools for practising psychiatrists (Baines *et al.*, 2019b). In most instances, professional opinion and authoritative guidelines are used as a proxy measure for the patient voice. Although large numbers of patients often participated in the validation of proposed tools, validation was often passive with limited opportunities to influence change. In some instances, psychiatrists selected the patients involved in the validation process, introducing possible bias.

Comparison of online reviews with existing patient feedback tools in cycle two (chapter four) found that patients describe a number of psychiatrist behaviours, attitudes or skills that are not included in existing feedback tools. The language patients use to describe these psychiatric care domains also differs to that used in existing feedback tools.

Exploration of patient and psychiatrist perceptions, experiences and aspirations in cycles three and four identified a number of perceived limitations with existing feedback tools and subsequent suggestions for improvement. Limitations described by participants often related to feedback design, content, processes, perceived purpose and provision of insufficient information. The comparison of patient and psychiatrist perceptions in cycle five (chapter seven) identified more areas of commonality than divergence, justifying the exploration of more collaborative approaches to patient feedback design and evaluation.

Finally, following the co-production and refinement of a patient feedback tool in cycle six (chapter eight), details shared by participants in their think-aloud (Van Someren, Barnard & Sandberg, 1994; Willis, 2004) and semi-structured interviews strongly supports the suggestion that co-production can enhance the perceived value and acceptability of a patient feedback tool for both patients and psychiatrists (cycle seven, chapter nine). For example, with the exception of one psychiatrist who preferred the brevity of the hybrid version, all participants unanimously identified the co-produced information sheet as their most valued and acceptable version due to its empowering message, engaging layout and repeated assurances of anonymity that enabled participants to feel more trusting and at ease with the information shared. Similarly, with the exception of two participants (one patient and one psychiatrist) who preferred the hybrid feedback tool due to its shorter length, all participants unanimously identified the co-produced feedback tool as the most valued and acceptable version following its perceived relevance, enhanced ability to freely describe care experiences, increased sense of ownership and choice, ease of understanding and engaging design. Such outcomes would arguably not have been achieved without the involvement of both patients and psychiatrists.

10.3 Comparison with existing literature

Findings from this research align with existing literature in the following ways. Firstly, this research supports the suggestion that patients are rarely involved in the design, delivery or evaluation of patient feedback tools (Biringer *et al.*, 2017; Boardman, 2018; Crawford *et al.*, 2011; Trujols *et al.*, 2013). Research findings also suggest that there is often a mismatch between the domains of care most valued from a patient perspective and those included in existing feedback tools (Crawford *et al.*, 2011; Farrelly & Lester, 2014; Trujols *et al.*, 2013). Participants in this research repeatedly identified the importance of interpersonal skills in facilitating a therapeutic relationship. The importance of such skills in psychiatric care has been repeatedly reiterated, particularly in the past few decades (Gilburt, Rose & Slade, 2008; Gunasekara, Patterson & Scott, 2017; Mead & Bower, 2000; Narayanan, Farmer & Greco, 2018; Perry *et al.*, 2013). Our research findings provide an alternative explanation to a comment made in Hill et al's., research, where a participant suggested that patient feedback is a reaction to the interpersonal style of a doctor as opposed to their skills (Hill et al., 2012). As evidenced in this research and others, the 'interpersonal style' of a psychiatrist appears to be the essential skill in psychiatric care (Gunasekara, Patterson & Scott, 2017). For example, as recently described by Santos, the therapeutic relationship which is often formed of interpersonal skills *"is the most important element of psychiatric care"* (Santos, 2017, p.3). The successful development, nurturing and evaluation of interpersonal skills in the training and education of healthcare professionals is therefore imperative (Gunasekara, Patterson & Scott, 2017).

Other areas of support for existing literature includes the limitations of patient feedback tools identified by participants; namely their design, content, process and perceived purpose. For example, participants frequently question the absence of a feedback loop (Mathie *et al.*, 2020), the perceived bias towards criticality (Baldie *et al.*, 2018), the irrelevance of existing questions (Gayet-Ageron *et al.*, 2011) and inadequate size and number of free text comments (Baldie *et al.*, 2018; Beattie *et al.*, 2014; Edwards *et al.*, 2011; Eriksson, 2013). Similar to existing research, participants also expressed dissatisfaction with the formal appearance of existing tools (Gayet-Ageron *et al.*, 2011; Sir Keith Pearson, 2017) and opportunities for both patients and psychiatrists to ‘game’ the system through bias patient selection (Asprey *et al.*, 2013; Baldie *et al.*, 2018; Carter *et al.*, 2016; Gayet-Ageron *et al.*, 2011) and responses due to a shared fear of repercussions (Carter *et al.*, 2016; Edwards & Staniszewska, 2000; Fernandes *et al.*, 2019; Lelliott *et al.*, 2008; Narayanan, Farmer & Greco, 2018). Although often different in their focus, i.e. service evaluation vs professional regulation, the limitations identified by participants in this research echo those found in existing literature (Baldie *et al.*, 2018; Gayet-Ageron *et al.*, 2011).

Finally, underpinning many of the concerns and limitations identified by participants were concerns of culture, language and power (Berzins *et al.*, 2018; Patterson, Trite & Weaver, 2018; Sitzia & Wood, 1997; Staniszewska & Henderson, 2004; Steslow, 2010; Stickley, 2006). Such issues were discussed at length by participants in this research. For example, patients often questioned whether existing patient feedback tools measured the domains of care that mattered most to patients, or domains of care that had already been decided for them. The inability to frequently construct their experiences in their own words, as opposed to learning the language of the ‘dominant’ and the powerful was also repeatedly questioned by patients and some psychiatrists. As suggested by Eriksson, the context in which stories and experiences are shared can be understood as containing an inherent power asymmetry in which the narrators, in this instance patients, hold a subordinate position relative to healthcare professionals or the organisation (Eriksson, 2013). While narratives can often become a way for the less powerful party to “*to give voice to her or his understanding”,* offering some “*kind of emancipation from the care sometimes violently forced on patients”,* patient “*narratives are heavily controlled and directed by the organisation”* meaning they often lose their “*emancipating and countering power”* (Eriksson, 2013). The inability to challenge and influence existing practise was often experienced in this research, as was the maintenance of control as later described. Such findings reiterate the influential nature of existing practises in psychiatric care that either sustain, or challenge existing power hierarchies that continue to be identified in psychiatric care (McCubbin & Cohen, 1996; Rahimi, 2014; Szasz, 1994). As suggested by a participant in this research, perhaps a new language needs to be created in psychiatric care, one that is accessible to all? Such an outcome can arguably only be achieved if all stakeholders are involved in its generation and definition.

10.4 Contribution to new knowledge

This research also contributes new knowledge to the existing field in the following ways. Firstly, as evidenced by its publication, this research provides unique insight into the presence, or absence, of patient and public involvement in the design, delivery and evaluation of patient feedback tools for practising psychiatrists (Barbato *et al.*, 2014; Bjertnaes, Iversen & Kjollesdal, 2015; Delaney, Johnson & Fogg, 2015). This research also compares the content of online reviews with existing patient feedback tools, providing new insights and understanding as demonstrated in its related publication. Other contributions of this research include the identification of behaviours, attributes and skills that both patients and psychiatrists consider most conducive to the therapeutic relationship (Brenner, 2017; Eiring *et al.*, 2015; Farrelly & Lester, 2014; Trujols *et al.*, 2013). Furthermore, this research explored both patient and psychiatrist perceptions of current patient feedback tools for revalidation purposes using primarily qualitative methods (Boardman, 2018; Crawford *et al.*, 2011; Godolphin, 2011; Trujols *et al.*, 2013; Williams, Coyle & Healy, 1998; Zendjidjian *et al.*, 2015a). To the researchers' knowledge, this is the first research of its kind, helping to address identified gaps and methodological concerns in existing knowledge.

10.5 Research impact

10.5.1 Academic impacts

Academic impacts of this research include peer-reviewed publications (Baines *et al.*, 2018b; Baines *et al.*, 2019a; Baines *et al.*, 2019b) conferences and poster presentations (pages 4-6), international implementation of a co-produced patient feedback response framework (Baines *et al.*, 2018b; Care Opinion Australia, 2020) and national implementation of a new patient feedback tool for revalidation purposes by the Royal College of Psychiatrists (Appendix 19).

10.5.2 Personal impacts

Personal impacts of this research are also extensive. As suggested by Staley and others, while it is important to consider traditional markers of academic 'success', the personal impacts of collaborative working should also be examined (Boylan *et al.*, 2019; Staley, 2015). The impacts of co-production as perceived by the patient research partner are therefore outlined below:

“Come on Oriel… it will be challenging, mentally invigorating… An opportunity to be part of something important.” Although these weren’t the lead research partners’ exact words way back in 2016 it’s actually what I felt inside as we started out on this research journey together…

Working on a project that not only embraced a collaborative partnership with myself, a non-academic research partner, but also co-production as an all-encompassing colour wash covering all aspects of the research: groups sessions with patients; group sessions with psychiatrists; conferences, workshops all landing back to liaison groups giving everyone the chance to listen, learn and input…The chance to be part of a team, reviewing, challenging and eventually changing a current patient feedback tool, the ACP 360 which presently promotes the tool with the conceit that it is a tool ‘designed by psychiatrists for psychiatrists’, clearly negating the notion that the patients voice could, or should, be of any importance.

Did I want a chance to be a part of all this… heck, yes. What’s not to like? Sign me up please and then some! A chance to kick start my life again after a major mental breakdown, when it was difficult to re-engage my mind, and although challenging (what decent project in life isn’t?), the research project has given me back my voice… to not only talk about my own circumstances (routinely abused and raped as a child, traumatised at a young age and subsequently diagnosed with schizophrenia, multi-personality disorder and psychosis), but act (I hope) as a voice for other patients with mental health circumstances and conditions, where the patient voice is *so often overlooked. A chance to make a difference then. To raise a flag. Make a stand against the stigmas and pathologies that spin like a centrifuge around mental health issues within the medical, academic and public worlds, threatening to leave patients abandoned, vulnerable and without a stake in society for yet another generation.*

This patient research partner can only hope that their input into the research has been beneficial, will be beneficial to general perceptions and specific outcomes but would argue anyway that without an interested party's input all research work is diminished per se…

As for how that research, embracing collaboration/partnership from the outset and co-production as a prerequisite to thorough, professional analysis, achieved its purpose: this partner hopes the reader, having analysed the research paper, can (begin to) understand patient frustration at not being co-opted from the start, leading to existing professional feedback tools reinforcing subjective speculative thought and giving rise, at worse, to stale academic and professional thinking. This partner has benefited too, from sharing the circumstances of other patients voice and in sharing, to reduce their own feelings of isolation, anger and depression perhaps it's inevitable for a non-academic to feel overwhelmed by the linguistics associated with the subject matter…But I hold a degree in jurisprudence and still found the language used within the field of mental health not just baffling but contradictory at times. Clarity of language, simplicity of text should always be praised and this at times presented its own problems. Sometimes things said by others would quite simply be lost in translation and this partner hopes this research with its clarity of language and lead researchers trademark insight will persuade doubters and potential co-producer teams and partnerships to follow this lead and take that plunge.

Some of the challenges faced in co-production, especially within the field of mental health, are obvious… A partner could find themselves unable to deal with, either their own circumstances at any given time, or circumstances arising perhaps within a groups, workshop or conference, when their input is required. This patient research partner faced exactly this problem at a London conference and thought that they had surely failed themselves and the research project miserably. In fact, as it transpired, my inability on that day to publicly articulate my thoughts as my mind tail spinned was perceived by all sections of the conference as a sign of the authenticity of the research and not as an articulation of the unacceptability of co-production per se and the unsuitability of patient research partners within research projects. So, the answer to the question 'should those not academically qualified be allowed to have input as partners in co-production research papers' is an emanating yes...

Medical science has long relied on volunteer patients to aid outcome and improve results. Should that go further? Why not. A doctor is not a guardian or custodian of truth. A psychiatrist not a God. Truth in research in this century lies not in ivory towered academic laboratories, nor in power plays between patient and professional but in concepts of partnership. One can at least hope it is the patient experience that should be embraced, not an inward war of academic isolation that potentially illegitimises their work. In law a victim's voice is crucial to understanding and grasping a forensic insight into the case. Without that voice, everything becomes superstition and subjective extrapolation. As a patient I can also suggest that patient intervention in co-production is not limited to top down questions, naturally selective, biased and contextually loaded e.g. the current ACP 360 feedback tool which misunderstands and miscomprehends the whole concept of patient input and partnership and how to deliver it.

For those thinking of co-production and partnership in the general field of research these may seem innovative and challenging concepts to take on board… but with regard to patient input and co-production in mental health… heaven help us. Do we as patients have to cry out loud to be heard? Not a voice to be interrogated as the researched, or worse professional body subjectively suggests to be important, but for them to open wide their arms and embrace the most important voice.

This research represents an opportunity, acting as a road map which can lead both to academic acceptance of co-production in research per se and academics and professional alliances with patients as partners. The results contained within this piece of research point to this being the way forward, engaging with groups, attending conferences with research partners, setting up workshops and liaison hubs so that co-production and partnership become the buzz words in a live wire discussion.

As for the future, let's not define it with a backward step and definitely not an inward glance… Perhaps the future lies in all our voices, academic and otherwise being heard.

As for me, reading this I hope it's obvious that the benefits have been manifold. My spirit lifted, my mind more in control…How have I found being involved in this research? Unbelievable. The research like a totem pole of hope for me and I'm sure for others yearning for stability within the circumstances that describe and circumscribe our lives. And I can only hope that my non-academic contribution is justified and has enriched this research paper.

The challenges I hope I have already described, how to overcome them? With clarity, simplicity of language and coherent thought which should be one of co-

productions hallmarks and which I hope has been achieved in this research paper. Perhaps the reader might think this biased, but think on this… without research such as this it would not have been possible to have reached this junction… to turn back isolated in an ivory tower, backward looking at the future or grab the horns and choose the path of co-production, always reminding yourself, if you are a lead researcher to act with warmth, empathy, and always equality of spirit which my lead researcher always displayed.

Choose the path of co-production. That's the choice and one this patient research partner hopes that all readers whether or not they are working or researching in the field of mental health, will embrace… Grab those loose reins and bring on board, without prejudice and without fear, your co-worker and partner of the future to kick-start your research of today.

Oriel and Amber Della Francesca

Impacts on the researcher as a result of the research undertaken including difficulties encountered and perceived rewards are described in her reflective diary (Appendix 1).

10.6 Thesis strengths and limitations

10.6.1 Strengths

Strengths of this thesis include its: response to identified limitations in existing literature and feedback design methodologies (Berzins *et al.*, 2018; Boardman, 2018; Zendjidjian *et al.*, 2015a); inclusion of marginalised or seldom heard individuals including those in an in-patient setting (Gill *et al.*, 2015) and participants experiencing schizophrenia, psychosis or personality disorders (Farrelly & Lester, 2014). In comparison to potentially restrictive methods that seek to quantify and generalise, this research also used qualitative methods that have been identified as particularly useful when exploring human experiences (Willig, 2013). For example, qualitative methods area considered to provide invaluable "*access to people's ideas, thoughts and memories in their own words, rather than the words of the researcher*" (Reinharz & Davidman, 1992, p.19). As a result, qualitative methods are often considered to provide richer insights into complex social processes and experiences (Waterman *et al.*, 2001) than that achieved by quantitative methods (Edwards & Staniszewska, 2000). Given the methodological limitations acknowledged in existing literature (Staniszewska & Henderson, 2004) and historical silencing of the patient, and at times, psychiatrist voice, the extensive use of qualitative methods in this research could be considered a particular strength.

The use of a critical research paradigm and dialectical methodologies in the form of co-production and action research could also be seen as a strength of this research. Although a positivist paradigm could have been applied, the application of a critical research paradigm arguably enabled the historically exclusive practise of patient feedback design to be challenged and the subjective nature of both patient and psychiatrist experiences to be explored beyond the confinements of quantitative methods that often seek to predict and control. The outcomes achieved in this research, including the co-production of a patient feedback tool, may not have been possible if relying on a positivist paradigm alone. For example, if a positive paradigm had been applied, (one that considers reality to be objective as opposed to socially constructed), the subtle, yet important nuances in participant experiences and their intricate association with historical, political and cultural contexts may have gone unnoticed. Furthermore, positivist research paradigms often privilege academic, or scientific knowledge at the expense of others (Edwards & Staniszewska, 2000).

Adopting such an approach may have therefore perpetuated existing worldviews that frequently privilege the dominant and the powerful (Baum, MacDougall & Smith, 2006; Kidd *et al.*, 2018; Smith *et al.*, 2010; Waterman *et al.*, 2001), while disregarding experiential knowledge (Scotland, 2012). As a result, many people who have been discriminated against, or oppressed as a result of their experiences, identity, or diagnoses, are often branded as less reliable, or less valid in positivist research (Beresford, 2013). Given the acknowledged exclusion of psychiatric patients and reports of psychiatrist disempowerment in chapter one, such an approach was considered to be inappropriate and detrimental.

Others strengths of this research include its co-production with a patient research partner. By doing so, the distance between direct experience and interpretation was arguably shortened. As suggested by Beresford, the shorter the distance between direct experience and its interpretation, the less distorted, inaccurate and damaging the resulting knowledge may be (Beresford, 2013). Other identified benefits of co-producing this research include the personal empowerment of the patient research partner as evidenced in his impact statement, the quality and richness of data collected (Ennis & Wykes, 2013) and enhanced insight, or breadth and depth of the analysis process achieved that may have otherwise been missed (Gillard *et al.*, 2010; Locock *et al.*, 2019; Mjøsund *et al.*, 2017). Furthermore as suggested by Mjøsund et al., the involvement of more than one analyst in the analysis process may have helped to reduce the potential bias that comes from a single researcher (Mjøsund *et al.*, 2017), although the inherently subjective nature of this process is acknowledged justifying the need for reflective practice throughout. Finally, aspects of this co-produced research have been used as a case study for national co-production guidance demonstrating further impact (INVOLVE, 2019b).

10.6.2 Limitations

However, the limitations of this thesis must also be acknowledged. Firstly, while the benefits of co-production and AR are well documented, their limitations, complexities and ‘messiness’ (Baum, MacDougall & Smith, 2006) must also be acknowledged (Cornwall & Jewkes, 1995; Lambert & Carr, 2018; Waterman *et al.*, 2001). For researchers who are used to defining and controlling research, “*co-production can be both intimidating and liberating”* (Kagan, 2013, p.4). Similarly, AR can leave researchers “*feeling exposed and rudderless”* (Smith et al., 2010, p.407). As demonstrated in Appendix 1, such feelings were often experienced by the researcher.

Furthermore, although not necessarily a weakness of this thesis, the co-produced knowledge of this research was not accepted in its entirety by the Royal College of Psychiatrists. As recently suggested by Williams et al., such outcomes should not be used as justification for dismissing co-production; rather “*greater consideration of the structural inequalities in academia and beyond that impede co-production”* (Williams *et al.*, 2020, p.2) is required. As stated by Williams et al., “*research predominantly provides a context for which co-production is ill-fitted. This is not, as suggested, because the practice of co-production is inherently flawed but rather because the current context and norms of research are corrupting*” (Williams *et al.*, 2020, p.8). As such, there is a need to question the extent to which co-production can truly operate on an ‘equal footing’ (Locock *et al.*, 2017) and support a cultural change if co-production is to achieve it egalitarian and utilitarian potential (Boylan *et al.*, 2019).

Similar to existing literature (Brooks *et al.*, 2017), this thesis also largely relied on a volunteer sample. Biases inherent with this recruitment method are therefore acknowledged. Despite a variety of recruitment strategies, participants in this research were also largely from the South West or central England. Research findings may not therefore be applicable to other geographical areas, although research findings often align with those in existing literature as previously described.

Furthermore, due to resource constraints, this research did not include participants unable to speak or understand the English language. Possible bias as a result of this exclusion criterion is therefore also acknowledged. Similarly, this research excluded participants who were under the age of 18, or had psychiatric care experiences related to learning difficulties, Alzheimer's or Dementia care alone (justification for this approach is provided on pages 157 and 109 to avoid repetition). Research findings may not therefore be applicable in these settings or community groups.

In addition, although several measures were put in place including the rotation of information presented, removal of any information that indicated the tool had been co-produced and only sharing the background information when all relevant questions had been asked, it may have been beneficial for the think-aloud and semi-structured interviews to be conducted by an independent researcher to limit any potential bias. However, some assurances can again be provided given the measures taken above, adherence to think-aloud processes including limited interjections by the researcher (Willis, 2004), equal opportunities for participants to speak about each of three tools reviewed and alignment with existing research and preceding six cycles. The involvement of the patient research partner in the analysis process also provided additional insight into the analysis process.

Finally, in addition to the Covid-19 pandemic, this research struggled to recruit high numbers of psychiatrist participants, particularly in the co-production process. While difficulties in recruiting healthcare professionals for unfunded research is not uncommon (Parkinson *et al.*, 2015), further exploration of research findings with additional psychiatrists may be beneficial. However, some confidence in the conclusions drawn can again be provided given the level of data saturation repeatedly achieved and similarities with existing literature.

(Please note, the individual strengths and limitations of each research cycle are discussed in their respective chapters to avoid repetition).

10.7 Implications

With these limitations in mind, the implications of this research for policy, practice and future research are discussed below.

10.7.1 Policy

Firstly, the purpose of revalidation and its subsequent inclusion of patient feedback needs to be clearly defined and agreed (Archer *et al.*, 2018; Archer *et al.*, 2015; Edwards *et al.*, 2011; Hill *et al.*, 2012). Specifically, is revalidation and the subsequent inclusion of patient feedback a formative or summative exercise? And an organisational or personal activity? If formative in nature as often desired (Hill *et al.*, 2012), than the use of psychometric validation, patient participation or absence of missing data to determine patient acceptability and validity alone is insufficient (Schröder, Wilde Larsson & Ahlström, 2007). As repeatedly demonstrated in this research, both patients and psychiatrists reported falsifying their feedback scores or intentionally selecting ‘appropriate’ patients to complete ‘validated’ feedback tools due to a fear of repercussions. Such behaviours challenge and undermine existing declarations of ‘validity’, (the degree of confidence that an assessment measures what it is intended to measure (Salmon & Pugsley, 2017), while simultaneously distorting the patient voice, often giving rise to inaccurate and potentially inflated assessments of patient experience (Edwards & Staniszewska, 2000; Salmon & Pugsley, 2017). As suggested by Downing et al., once one validity domain is undermined, (in this instance content and response process validity), so is that tool's ability to be used as an equitable form of assessment (Downing, 2003). A broader definition of validity such as that provided by van der Vleuten (van der Vleuten, 1996a) that extends beyond tool content is therefore required when evaluating patient feedback tools.

Research findings also challenge the assumption that the introduction of revalidation by the GMC assures "*patients that their doctor is being regularly checked by their employer and the GMC"* (General Medical Council, 2018). As evidenced in this research, participants are sceptical about the ability and acceptance of existing patient feedback tools to facilitate reflective practice and professional development, particularly given its current perception as a tick box exercise. Such findings are concerning as the impact of revalidation and its ability to support professional development, patient safety and quality of care is largely dependent on how it is perceived by those involved (Tazzyman *et al.*, 2019; Tazzyman *et al.*, 2020; Tazzyman *et al.*, 2017).

Other policy implications include a need to critically examine the infrequency of feedback opportunities and limited number of feedback responses currently required (Jones *et al.*, 2020). Whether intentional or not, the requirement to collect patient feedback so infrequently was often described by participants as tokenistic, reflecting the limited value attributed to patient experience by regulatory bodies and healthcare professionals more broadly. Questions must therefore be asked of why patient feedback is collected so infrequently and why it is collected in the restrictive way that it is, i.e. clinician dependent as opposed to patient led. As suggested by Tritter, the mandatory inclusion of patient feedback in revalidation may be symptomatic of a ‘target culture’ that fails to critically consider why such involvement may be important, what impacts such involvement hopes to achieve and how such impacts can best be achieved (Tritter, 2009). Patients repeatedly described a number of motivations for providing patient feedback for revalidation purposes, provided there was an opportunity to influence and evidence change, praise healthcare professionals and identify quality improvement opportunities. Such findings suggest that the low number of responses required, infrequency of feedback opportunities and current feedback methods do not reflect patient motivations or aspirations.

Finally, critical attention should be paid to the impact of mandating patient feedback collection as part of the revalidation process. As demonstrated in this research, psychiatrists repeatedly identified the connection of patient feedback to revalidation outcomes as detrimental. For example, several psychiatrists reported an observed increase in defensive practise and bias patient selection due to anticipated outcomes. Exploration of ways to mitigate such behaviours is required.

10.7.2 Practice

In practice, the assumption that the inquirer, often a researcher or clinician, knows what is best and how best to ask it is no longer acceptable or permissible (Edwards *et al.*, 2011; Edwards, Staniszewska & Crichton, 2004). As demonstrated in this research, co-production appears to enhance the perceived value and acceptability of patient feedback tools over and above more traditional and exclusive approaches. Efforts should therefore be made wherever possible to co-produce patient feedback tools.

Concerns about the perpetuation of patient passivity in feedback design, collection and response should also be addressed. As acknowledged in chapter two, patients have historically been assigned the role of passive participants, dependent on clinical expertise and knowledge (Farre & Rapley, 2017; Kaba & Sooriakumaran, 2007). Similar to the reduction of a patient's report of illness to a set of symptoms and signs in the biomedical model of care (Mead & Bower, 2000), the overreliance, and at times exclusive reliance on professional knowledge and expertise to define patient experience arguably preserves patient passivity and inaction. For example, as stated by Davidson et al., failure "*to invite the perspective or input of the person with the disorder"* in feedback design *"further exacerbates the passive and helpless role of the mental health patient"* (Davidson et al., 1997, p.767). Could the repeated failure to include patients and the public in defining patient experience and creating patient feedback tools represent a further form of "*abuse"* (Stickley, 2006, p.570) in psychiatric care? As suggested by Mead and Bower (2000) in their description of patient-centred care, "*in order to understand illness and alleviate suffering, medicine must first understand the personal meaning of illness for the patient"* (Mead & Bower, 2000, p.1089). Similar to Miller et al., (Miller *et al.*, 2015), we argue that in order to accurately understand patient feedback and experience, researchers and healthcare professionals must first understand the personal meaning of experience and patient-centred care for patients and their carers.

The importance of information in facilitating patient feedback engagement and authenticity should also not be underestimated (Fukui, Matthias & Salyers, 2015; Longtin *et al.*, 2010). Information provision is often overlooked when designing patient feedback tools as acknowledged in this research. For example, the ACP 360 representative frequently acknowledged that they provided staff with information, but rarely passed such information on to patients, the ultimate end users. Many participants stated that they would no longer complete two of the patient feedback tools reviewed due to the limited, or inadequate information provided.

The inclusion of safeguarding sentences and subsequent lack of confidence in anonymisation also requires attention. Questions must be asked about the relevance and appropriateness of including safeguarding sentences in anonymised patient feedback tools. If organisations and healthcare professionals are trying to assure patients that their feedback is anonymous, sentences and behaviours that suggest they could be identified are contradictory and unhelpful. The provision of anonymity must therefore match the perceived purpose, focus and intended use of feedback tools. Failure to do so means we are at risk of perpetuating a fear of repercussions that already exists between both patients and psychiatrists (Berzins *et al.*, 2018).

Other implications for practice include the importance of regularly reviewing patient feedback tools. What constitutes care quality from a patient perspective is likely to change over time (Beattie *et al.*, 2014; Biringer *et al.*, 2017; Riiskjær *et al.*, 2010). For example, aspects of care included in the original ACP 360 tool designed in 2005 were frequently described as irrelevant by participants in this research. Patient feedback tools should therefore be regularly reviewed to ensure they remain both up to date and fit for purpose (Beattie *et al.*, 2014).

Furthermore, both patients and psychiatrists must feel safe and supported in providing, receiving and acting upon patient feedback (Baldie *et al.*, 2018; Edwards *et al.*, 2011; Hill *et al.*, 2012; Jones *et al.*, 2019; Locock *et al.*, 2020a; Locock *et al.*, 2020b). This ultimately relates to existing cultures of learning, change and development (Archer, 2010). Opportunities to provide patient feedback should be clearly visible and ‘permissible’ to patients. Similarly, healthcare professionals should be empowered (Locock *et al.*, 2020a) and supported in collecting and receiving patient feedback (Archer, 2010), particularly if feedback is critical in nature (Jones *et al.*, 2020). The potential difficulties of receiving critical feedback has recently been identified (Jones *et al.*, 2020), accentuating the importance of suitable support structures and processes.

Finally, underpinning many of the implications for both practice and policy is the need to pay greater attention to the quality of patient feedback reflection, as opposed to quantity of its collection. Every effort should be made to facilitate reflective practice and development of actionable changes following patient feedback activities if required. As repeatedly requested in this research, efforts should be made to facilitate a feedback loop between patients and psychiatrists that demonstrates a response to experiences shared. As previously suggested (Edwards & Staniszewska, 2000; Williams, Coyle & Healy, 1998), what are the ethics of collecting patient feedback that leads to minimal direct benefit? Sheard et al., recently suggested that all patient feedback tools must have the ability to be meaningfully used by those providing frontline care. Otherwise it becomes “*unethical to ask patients to provide feedback which will never be taken into account”* (Sheard et al., 2019, p.51). Responses from participants in this research suggest that the exclusive approach to patient feedback design, absence of a feedback loop and repeated focus on quantity of feedback collection as opposed to feedback reflection supports the *“self-perpetuating industry”* (Sheard et al., 2019, p.46) that patient feedback currently finds itself within.

10.7.3 Research

Finally, implications for research include a need to acknowledge the added value of action research and co-production (Mjøsund *et al.*, 2017; Patterson, Trite & Weaver, 2018). Although often described as ‘soft’ or inferior to other research methodologies (Oliver, Kothari & Mays, 2019; Williams *et al.*, 2020), such descriptions can be detrimental and may ignore the substantial amount of work and skill required in delivering such methodologies (Crocker *et al.*, 2016; Mathie *et al.*, 2020). As suggested by Williams et al., and others, similar to qualitative and quantitative methods, assessing the ‘success’ of dialectical methodologies may require different criteria and outcome measures to those used in positivist research (Crocker *et al.*, 2016; Staley, 2015; Williams *et al.*, 2020). However, regardless of how it is assessed, researchers need to be supported in undertaking research of this kind (Locock *et al.*, 2019; Mathie *et al.*, 2020; Oliver, Kothari & Mays, 2019; Williams *et al.*, 2020), due to its potential challenges including the questioning of traditional research practices meaning research experiences “*can be both intimidating and liberating”* (Kagan, 2013, p.4); the enhanced complexity and ‘messiness’ of such research (Baum, MacDougall & Smith, 2006) and the hidden emotional and skill resources required (Boylan *et al.*, 2019; Mathie *et al.*, 2020).

With this in mind, co-producing research that contributes to a PhD thesis should be supported and encouraged wherever possible. Although co-production is not yet common practice in postgraduate research, the experience has been invaluable on both a personal and professional level (please see Appendix 1). Experiences of co-production may also better prepare researchers for the realities of future research providing further justification for this approach.

10.8 Future research

Finally, there are a number of areas for future research. Firstly, the researcher recognises a desire to trial the three patient feedback tools reviewed for an extended period of time (co-produced, hybrid and original ACP 360 tool), examining any reported differences in levels of patient engagement, feedback responses and quality of reflective practice achieved. Secondly, closer examination of whether the perceived value and acceptability of a patient feedback tool affects the provision of more positive scores may be of significant value as suggested by a participating psychiatrist. Furthermore, examination of how the co-produced feedback tool may be applied to psychiatric care delivered online as a result of Covid-19 may be beneficial. Examination of how the co-produced patient feedback tool and its process of design could be applied to carer experiences or other settings is also warranted given acknowledged disparities between patient and carer experiences (Barbato *et al.*, 2014; Lelliott *et al.*, 2008) and frequent requests by participants in this research for such involvement to be explored.

Finally, in recognition of the limitations of this research, future research should explore any differences in perceived value and acceptability among non-English speaking patients and minority ethnic groups (Carter *et al.*, 2016). Exploration of whether the co-production of a patient feedback tool affects its perceived value and acceptability in paediatric, learning difficulties, Alzheimer or Dementia psychiatric care settings may also be beneficial given the exclusion criteria applied in this research.

Conclusion

In conclusion, this research suggests that the perceived value and acceptability of a patient feedback tool can be improved for both patients and psychiatrists through its co-production. Based on the benefits identified, patient feedback tools should be co-produced wherever possible. However, the recognition and acceptance of co-produced knowledge ultimately remains at the organisations or healthcare professional’s discretion. There is therefore a risk that co-production could become a tick box exercise that continues to oppress, as opposed to empower. It is therefore imperative that individuals remain open to the concept of co-production and challenge any form of ‘co-production’ that perpetuates existing power hierarchies. Although potentially extensive in scope, the benefits and impact of co-production can ultimately only be achieved if and when permitted.

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Appendices

Appendix 1 Reflective diary

Introductions

I met a really interesting person today while at the homeless shelter. [Hostel worker name] introduced us and we're hoping to meet next week to talk about the PhD which could be good? In comparison to everyone else, he seems very shy, quiet and reserved but I also think that he's absorbing everything that's going on around him – which is a lot! I'm surprised at how loud and chaotic the hostel is. As soon as we began the focus group, I was disheartened to hear how many people felt unable, or unwilling, to provide critical feedback on their doctor. Many of the individuals repeatedly said that their feedback doesn't mean anything, they're not seen as 'credible' or 'valued' in society, people walk past them in the streets and ignore them. So why would healthcare be any different? I wondered if these perceptions are unique to the homeless community or also shared in other settings?

People shared their experiences and various journeys to becoming homeless, some were utterly harrowing and difficult to hear. I often found myself in a tug of war between: the emotional difficulties of hearing stories of abuse, neglect and trauma; a sense of privilege that people felt so comfortable in sharing their stories with me; happiness at the quality of data being collected from a selfish point of view and then the realisation of the seemingly unimportant topic of our focus group, feeding back on your doctor, when compared with some of the difficulties people were facing. At the back of my mind was also the issue that being 'detached' and objective is 'gold standard' in research. I'm not sure how you can be detached or unaffected by the stories I'm hearing? I wonder if participants would have felt so comfortable sharing their personal stories with someone taking a more removed, observatory or distanced approach? I know it may leave researchers feeling more vulnerable or exposed, but I think it's incredibly important that participants feel you are actively listening and reacting to their stories, whether that's through your body language or words?

Many individuals referred to themselves as a '*shadow of their former selves'*, '*neglected*', '*at the bottom of the pile'* or '*judged*'. One gentleman shared how he felt the stereotype of being homeless, having mental health issues and previous encounters with the local A&E department had affected the care provided to his young child. Gravely concerned about his child's health, the participant took him to the A&E department where he was told to 'go home' or that he was 'overacting' because of his mental health and substance abuse related issues (the participant often went to A&E when drunk). It transpired that his child had meningitis and is now profoundly deaf. This experience and many others participants shared today made me think about how the social rules and positions we find ourselves in, can strongly influence our experiences of care. However, I was also struck by the positivity and life changing experiences most participants attributed to one doctor in particular. Participants described this doctor as a diamond in the rough – listening, non-judgemental and respecting. Although these behaviours are things that I would hope are intrinsic in all healthcare practise, their impacts were clear to see.

Initial meeting

Today I met with Oriel, it was fascinating! We met at his local library, (which was beautiful), where he shared a bit about his background including going to University to study law, working in London on a number of architectural projects and his local ties to Plymouth. I constantly found myself wondering how he ended up at the homeless hostel but didn't want to pry. Oriel soon told me that he recently had a mental breakdown and had been placed in the hostel after being discharged from the local intensive care unit. He couldn't remember how he got to Plymouth, where he had been, or what he had done for several months before now. The only clues he has are some receipts – this sounded like quite a scary and unsettling situation to be in.

We got chatting about how he thought the focus group had gone last week in the hostel. He asked me about any plans I had for the PhD so explained that it was would be very similar to what we had spoken about last week but in psychiatry, beyond that I wasn't really sure! We spoke for some time about his psychiatric care experiences and *'loss of identity'* he often felt when recalling these experiences. Although not particularly favourable of psychiatrists during his time in ICU, he could clearly remember a nurse with blue hair and the beneficial impact she had had on his experience. Hearing Oriel's experiences first hand gave me a real sense of enthusiasm and confidence that the research topic I'm hoping to explore is of some importance and meaning to patients. However, when describing his experiences I also became increasingly aware that this topic may not be the easiest to approach. Having not experienced psychiatric care first hand, I'm growing increasingly aware that I have some knowledge and understanding, but by no means all. I haven't experienced what it's like to be sectioned. I haven't been forced to take medications against my will. I haven't 'lived' on a ward…

Towards the end of our discussion today Oriel asked if he could be involved as he's looking for something that can give him some structure and distraction. I'm really surprised, excited and not entirely sure what to do. The University didn't exactly cover this in our very brief introduction to postgraduate research that was mainly about where to find things and complain! I have a million and one questions running through my mind what will my supervisors think? Is this kind of thing allowed? Will it affect how I can progress in anyway? Do I need to get permission? Why? Are there any forms I need to fill out? Who do I need to ask if this is ‘ok’? Despite all of this, on a gut feeling that this was the right thing to do, I asked Oriel what will work best for him and what he wants to get out of being involved.

By the end of the session we agreed to meet every two weeks at the same time and place for consistency and routine. The library is a short walk from the hostel. This is important because Oriel is experiencing balance issues since leaving ICU and it’s also a more ‘neutral’ ground. It feels wrong to expect Oriel to travel to the University. Why shouldn’t we meet in the library?

I’m not entirely sure how things are going to work out, what the reactions of my supervisors are going to be, or what I can bring to the table but I’m willing to give it a go. I’m wondering if the self-funded nature of this PhD might give me a bit more autonomy in how it’s run? Not sure…

I explained to Oriel that I’m paying for the PhD and won’t be able to pay for his time. This felt very massively uncomfortable. I’m stuck in a mental/ethical tug of war between wanting to pay Oriel in respect of his time and knowledge and not being in a position to do so. I’d have completely understood if he wanted to step away. How many people truly give up their time for free? But he’s said that he doesn’t want paying and is seeing this as an opportunity to ‘ground’ himself with something that has a routine. I’m starting to realise the potential importance of this research for Oriel’s health as opposed to seeing his involvement as something that would benefit the research, there's something about reciprocity but how equal the benefits are going to be I'm really not sure. I'm feeling an additional level of pressure and almost responsibility, to deliver this research, and deliver it well.

First meeting and literature review development

I met with Oriel again today for our first 'meeting', not really sure what to call them as they're not meetings in the 'traditional' sense, they're much more informal and relaxed. We spoke about our interests, I shared some of my family related experiences with psychiatric care and a subsequent interest in this area. Sharing this information generated a lengthy discussion about psychiatric care, family reactions to such care and the stigma that still surrounds mental health. I found myself wondering if these discussion would have happened if I hadn't shared my personal experiences? Was this ok to do? Have I crossed any 'boundaries'? Who decides these boundaries? Is being more involved, or how I see it more 'open' in research as bad as traditional researchers make out? I'm struggling to see how remaining closed and objective can achieve the same level of insight and sense of trust I'm starting to feel between myself and Oriel?

During the conversations today we've both agreed that patients should be involved in psychiatric care far more then they currently are. We talked about partnership working, difficulties in challenging psychiatric care and a desire to do something different, or at least in a different way. I spoke about how 'traditional' PhDs are typically approached, often beginning with a literature review of some description. However, I made it very clear that this was very much open for debate, we can do things differently if we wanted.

I tried and (probably failed) to explain the processes of a systematic review, I was often drawing diagrams and finding it almost amusing at how over complicated academia makes things! Oriel said that he didn't want to be involved in running the searches but did want to be involved in other aspects of the review – just at a slower pace. This again caused another tug of war in my mind between this being entirely rational and fair, vs the typical milestones, competing deadlines and demands of full time work. I'm quickly learning that academia and involvement don't seamlessly go together….

But, sticking with my gut feeling, we've worked out what is going to be manageable and feasible for Oriel. Luckily for me, he's set some deadlines of when he's going to need things by and when I can expect a response. This has also given me some much needed structure and added sense of responsibility – there is someone else involved now and they're expecting things from me. Although this is often the cause with supervisors, its feels more personal this way. I'm not sure why, but it feels more important.

Due to his personal situation, Oriel mentioned that everything we do needs to be printed off as he doesn't currently have access to his emails. Oriel's told me to leave any information at the hostel front desk with his name on it. We've agreed to each go away and think about some search terms ready of our next meeting.

Another great meeting today with Oriel, we've come up with some strong search terms, I just need to get these reviewed by an information specialist. As soon as this is done I'll get going with the search terms.

Search terms all returned, couple of minor edits but nothing too bad. Have let Oriel know via text that we're good to go and I'll hopefully have some numbers for him next time we meet.

Shared the numbers with Oriel today, I was secretly a bit worried that this might overwhelm him, systematic reviews aren't exactly the easiest of things to do or get your head around. But at the moment things seem to be ok. I explained that the next thing to do is to go through each abstract but we needed a process to do this first. We set about creating a number of clear yes or no questions that we could use to exclude or include relevant abstracts, this formed our inclusion criteria form. We went through five random abstracts in the session using this form at Oriel's request so he could see the process in action. Oriel's agreed to go through some abstracts, I just need to print these out and get them to him.

We went through the abstracts today and no 'conflicts'. I'm starting to really realise how academic language really isn't that personable or friendly… We've a list of the potentially relevant papers to include at the full text stage, I just need to print these out. Oriel also made some really heart-warming comments today that doing these abstracts gave him something to focus on when everything at the hostel was so chaotic and lacking in routine. They had two fire alarms this morning alone! I'm really enjoying working with Oriel, it's giving me some structure and forcing me to do the PhD in evenings and weekends when I'm not at work which is a good thing. I think it would be very easy for me to keep saying 'tomorrow' or 'I'll do that next week…' I don't have many supervision meetings booked in so this is really keeping me on my toes but in a way that doesn't feel so formal. I think it's helping 'humanise' this research if that makes sense and keeping the lived experience of people at the forefront of my mind.

Oriel has done an incredible amount of work. Last week I provided some short ‘training’ on thematic analysis. I didn’t refer to it as training as this felt too ‘top down’. I also didn’t initially refer to it as thematic analysis until we’d completed the process on an example paper. I intentionally kept things simple at the beginning and had printed out the same paper for us to work on in the session. We took it paragraph by paragraph. Reading each paragraph for familiarity first, then re-reading the paragraph making initial thoughts and comments in the right hand column, then transforming these thoughts into overarching themes in the left hand column. I noticed at the beginning that Oriel was frequently asking if what he had put was ok? This made me realise the potentially unnerving experience of doing something new particularly thematic analysis where it’s quite subjective in nature. Interestingly many of our initial thoughts and comments were the same, just described in slightly different ways. I could see Oriel’s confidence growing with each paragraph that we were going through. Once we’d gone through the paper, I asked Oriel if he felt comfortable in doing this on his own? I’d bought coloured pens and multiple post it notes to help facilitate the process. We again agreed on number of papers for Oriel to tackle on a fortnightly basis, Oriel mentioned that he was ‘looking forward to it’.

We discussed our findings today, although the process has definitely taken longer, I’m confident it’s been worthwhile. We talked about the detrimental language used in many of the papers including “*their patients”, “only by psychiatrists”.* This appeared to confirm our suspicions that patients are rarely involved in creating patient feedback tools. Oriel became dismayed and frustrated at times by the language used and expressed concern at how psychiatric patients are often described in academic research. I made a mental note to ensure that our research didn’t fall into the same category. Is there such a risk if Oriel is involved throughout? From a selfish perspective I found it really humbling to see the impact of academic language and descriptions on a member of the community it were often describing. It really highlighted the disparity between academia, practise and ‘real life’ for me. It’s also added another level of anxiety for me in the sense that I hope I never become a researcher that makes someone feel that way – language is key.

We’re starting to start write up the literature review and I’m really enjoying the challenges of making academic processes work with community or patient interpretation. It’s by no means easy, but I also think that having to explain things in a more accessible language is forcing me to have a better understanding of the topic. I’m starting to find the balancing act of working full time, co-production and PhD commitments difficult, given the increased layer of complexity, but the benefits are almost immediate to see. I firmly believe that the interpretation of the review findings have been strengthened, not diminished through Oriel’s involvement. I think we’ve asked more practical and applied questions and I’ve also been forced to question typical descriptions of patients in psychiatric care. I don’t think this would have happened to the same extent without Oriel’s involvement.

The paper is now ready to submit! How exciting! Oriel is delighted to have his name on the paper but I found it demoralising in a way to try and explain the high risk that the paper may not get accepted in the first instance. It’s a difficult expectation to try and manage as I know we’ve both worked so hard on the paper and believe in its value.

With a few revisions the paper has been accepted! Oriel seems over the moon and has asked if he can share it with his brother and other family members.

Online review comparisons

I've recently been doing some work with Care Opinion and wondering if this would be a good way to explore what people share about their psychiatric care experience when given 'free reign'? I've shared the website with Oriel today and he immediately wanted to explore what people had said about the hospital he'd recently been at. We both think the online reviews might offer some good insight into people's experiences.

We agreed to use a similar process to the systematic review, coming up with relevant search terms, me conducting the searches and then sharing what comes back in an accessible and manageable format.

With Oriel's permission I introduced him to the CEO of Care Opinion as he was at a local event. Oriel later shared that attending this event and meeting the CEO was a big deal for him as at this point in time, the only external contact he has with the world is myself, his healthcare team and hostel worker. This struck me as an important learning point – never to underestimate the potential difficulty of each individual task, even if people do not immediately share these difficulties.

I've just finished running the searches on Care Opinion and I'm surprised at how few stories have been returned… wondering if this relates back to the fear, or perceived inability to feedback on doctors mentioned in the hostel focus group? Or could it be a lack of awareness that Care Opinion exists, or the particularly narrow focus of this research?

Ahead of our meeting today, I've looked through the printed stories and am slightly concerned about the potential impact of these stories on Oriel. They could either be potentially triggering, or validating in the sense that other patients have had similar experiences and he’s therefore not alone? This is causing another tug of war situation going around in my mind between do you assume what is ‘appropriate’ or ‘triggering’ for someone and then what gives you the right or expertise to do this? Or do you let that person decide for themselves, by which point it might be too late? I’m edging towards the second option. Deciding what is ‘triggering’ for someone else feels top down and at odds with what we are trying to achieve here. I just need to be particularly mindful and observant of how Oriel reacts to the information shared in today’s session.

I think it was right to go with the second option. Although Oriel did find the process of reading some stories disappointing in the sense that people had had bad experiences, there were also a number of positive stories that showed this was not always the case. As anticipated, Oriel suggested that he felt ‘assured’ in a way that other people had had similar experiences to his own. This meant his experiences weren’t a reflection on him as a person but rather the current culture and delivery of psychiatric care.

An unexpected outcome of this session was Oriel’s suggestion that organisational responses to patient reviews, (a unique feature of Care Opinion), need significant attention and development. I hadn’t even considered this as an issue as I was so focused on conducting the searches, excluding/including stories in a rigours process and undertaking reliable analysis etc. For me this experience has forced me to realise the blinkered approach to academic research, the risk that this approach omits a vast amount of work that matters to patients and need to adopt a more adaptive and flexible way of working that luckily co-production and action research allows. However, I’ve also noticed that in a way Oriel is asking my ‘permission’ if we can explore this avenue? The opportunity and commitment to patient generated needs therefore ultimately sits at the researchers' discretion or control. How truly 'equal' is co-production then? How do I remove this sense of 'permission? Can I? From a moral standpoint it feels wrong to have committed to working with Oriel in a partnership way and then dismissing his suggestions or identified critiques. I can see the potentially damaging outcomes of receiving a poor response, particularly if you have had a negative experience. Out of respect to Oriel and reminding myself of the social justice and egalitarian underpinnings of the methodologies used, we've committed to exploring this opportunity further.

Recognising that this work needed more than just ourselves, I've got in touch with a local mental health support group to see if they would like to be involved. I've discussed with Oriel how he wants to be involved given the previously acknowledged learning point of never assuming each individual activity and its potential impacts/demands. Oriel's met with the facilitator of the mental health group prior to the focus group to help ease the process. At his suggestion, participants involved in creation of the response framework have also been asked to introduce themselves at the beginning of the workshop. I could almost physically see people's shoulders relaxing as they learned about Oriel's lived experience and personal involvement in the research – this is something I can't provide. I don't share the same lived experience. I bring a different experience, one that isn't always valued or respected, academia.

Following this workshop Oriel and I have worked up the paper publication using a similar approach to the literature review. I've written the background and methods section of the paper, we've analysed the workshop transcript independently and then compared results. Based on this, I've drafted the results write up, and we've edited this together, coming up with our key discussion points. We've again had the slightly disheartening conversation of the publication potentially not being accepted but had the added assurance that Care Opinion has already written a blog on our findings and were encouraging its implementation within practice. This was identified by Oriel as another great achievement. One comment from our discussions particularly stands out, “*we’re starting to make a real difference here.”** Would this difference have been achieved if I was working in isolation? Probably not. I hadn’t even noticed the issue.

(*This feedback response framework has now been used on an international scale and transformed into a mouse mat which Oriel has at home)

Having completed the feedback response framework we’ve turned our attention back to the online reviews. I think this was another learning point for me - it being ok to diversify and adapt your research to participant needs. I keep coming back to the question of why and who do we do research for? For me, it’s to make a difference or a change. Deadlines can be changed. Flexibility and innovative ways of working are just required.

This being said, Oriel and I have worked through the online reviews identified. I’m interested to see how our findings compare with the domains of care used in existing patient feedback tools. I chose the two most commonly used feedback tools in psychiatry to compare. Together, we’ve written the most frequently identified care domains in the online reviews we’ve just reviewed and those used in the existing feedback tools on colour coordinated post it notes. It’s great to have the space available in the library to do this exercise because we had the post it notes all over the walls.

It soon became apparent that many of the care domains we identified in the reviews are missing from existing feedback tools. The post it note comparison also showed that the language used by patients differs to that in existing tools. I feel that this reflects some of my previous concerns of how inaccessible academic language is and the increasing disparity between academia, practise and patients….

We've again started to write this publication up using a similar process to before.

Patient experiences and perceptions

Having seen what we've done so far, Oriel and I met today to talk about next steps. We've both recognised a need to explore patient experiences and perceptions in more depth. While the online reviews were really interesting and helpful we haven't yet had the opportunity to delve into these experiences further, or ask any related follow up questions. Oriel and I discussed the possibility of speaking to a variety of patients with experience of psychiatric care. Oriel rightly acknowledged that not everyone will feel comfortable in a group setting. We've therefore agreed that interviews should also be conducted.

We talked about Oriel being involved with the focus groups and interviews, similar to the process used for the response framework. Oriel acknowledged that such involvement would be desirable, but need to balance this with his level of comfort and availability.

Similar to before I've seen how relaxed people become when they learn about Oriel's lived experience. These learning experiences or 'light bulb' moments have been plentiful during the data collection and transcribing process. I've recorded some of these below as a reminder to myself:

- **Inaccessibility of academic practise and its disruption to meaningful involvement -** when describing the consent forms one participant noted “*it’s relatively simple with the ticks but it’s still long!”* Got me questioning why are consent forms and information sheets so horrifically long? Who do we create them for and are they tailored to the right audience?
- **Influence of language in psychiatry** - one participant stated “*I don’t know the right language.”* The word “*right”* might suggest that she sees the language used by psychiatrists or medical discourses more generally as the ‘correct’ language. I’m wondering how and by who, the ‘right’ and wrong languages have been created by? Is it time to create a shared language, one that doesn’t rely on hierarchy and exclusivity? Other interesting aspects of language include the word choice ‘beginner’ – beginner at playing the game of psychiatrists? Learning to play the system? Navigating this new world? Similarly, interesting that patients describe and pathologise their experience of psychiatrists e.g. PTSD, trauma, “*he was a narcissist.”* Is this s a way of encouraging psychiatrists to understand and/or respect their perspectives? You won’t listen to my language so I’ll speak to you in yours sort of thing?
- **Power in psychiatry -** both from the perceived power psychiatrists have and the sense that you are “*under*” a psychiatrist and “*your power becomes taken away*.” Do patients have power before they encounter a psychiatrist? At what point does power become removed and by who? Is it only when they become ‘under’ a psychiatrist that problems begin to happen? Is this a rhetoric created by patients or a lived experience? “*You do feel like all of your power, that was my experience, all of my power had been taken away, so*,”; “*you know up until two years before, he'd had no contact with mental health services, and I think a lot of people when they first come up against a psychiatrist”* – is it a battle from the get go?
- **Patient identities -** interesting concept that one patient used the word client instead of patient. The participant had had a particularly bad experience. Does quality of experience affect the way patients refer to themselves?
- **Confessions of a psychiatrist -** interesting dynamic in two focus groups where retired psychiatrists were also service-users: “*I should probably confess that I’m a retired psychiatrist as well as service-user”.* Interesting choice of the word confess, almost encourages the sense that they have done something wrong? Similarly, “[psychiatrist and service-user] *so let me tell you how the feedback is supposed to work”* very top down, hierarchical language.
- **Power disparity between crime and mental health -** Interesting parallels drawn between criminals and mental health. Some participants suggested criminals have more power, more autonomy and opportunities to challenge or defend their side of the story shared: “*It comes back to the power thing, they have a hell of a lot of power, OK, they have more power than the Police. I mean if you think about what they're doing here, they can actually go into your room, your house, you have no right to have a solicitor present, or your social worker, and they'll say ‘oh you’re not very well, we're going to lock you up’, and they can just do it you haven't got a trial. What if you were a criminal? If someone’s in prison right, and they came out of prison after having committed a crime, say they were a drug addict, robbed somebody's house, done a violent robbery you know and then they got out. You wouldn't then be able to*

lock that person up again because they might do another robbery. If that person goes back to using drugs, you wouldn't be able to lock them up again because of their drug use. I mean I don't agree with any of that any way but I'm using it as an example. If you're a person, who's been sectioned under the mental health act, and you came out and they decide that you're ill, you might be a danger to yourself or others, they can lock you up. No questions asked, just on the premise that you might do something. You don't have to ever have done something, you might do something. A criminal that's actually robbed and done this and that already, comes out of prison they can't lock him up because he might just do something. If you've got a so called mental illness you just might do something, they can lock you up, they're the thought police!" These thoughts seem to strongly reflect the power imbalance other people have frequently referred to?

- **Fine balance between involving family members and carers** in health care but not at the expense of isolating, or excluding patients. How does this relate to shared decision making? Particularly in a mental health setting?
- **Recognition that the sharing of experiences isn't necessarily easy or comfortable for anyone –** acknowledged difficulty in sharing personal experiences, but also experiences shared by a retired psychiatrist - "*thank you because it's not easy for you, you siting around service users and carers here it's very brave of you*"
- **Humour in the face of adversity** – when asked if there's any questions you'd like to ask a psychiatrist? One participant replied "*are they single?"*
- **Sense of accountability** – "*if people have to fill the questionnaire in, spend their time doing it, then psychiatrists and doctors should take the time to do something about it.*" Indication that patient time is just as important as clinical time. Existing processes may encourage the perception that it's not?
- **Perpetuation of patient passivity in existing feedback design – "***why can't you just write down your feelings*" A sense that agreeing to pre-defined questions is a further way in which patients feel disempowered and forced to comply with rules set by the organisation
- **Shared understanding** that patients at times feel overwhelmed but then acknowledge that psychiatrists must also have the same feelings

During one of the focus groups Oriel was unable able to attend, I experienced a particularly poignant encounter. While sat in a church hall surrounded by homemade cakes, one participant stated that the research we were hoping to undertake was a "*complete waste of time, they* [psychiatrists] *won't make a change…"* I initially took this reaction to heart and saw it as personal critique of the integrity, or lack of my ability as a researcher and individual. However, the participant went on to explain that despite everyone's best intentions, nothing ever changes. I was explicitly told to:

> "*Remember this meeting, remember how it made you feel…it needs someone with a big hearted, strong personality to turn around and say we need to change"**

(*The important words of "*remember how this made you feel*" has stuck with me throughout the research, as is a feeling of inadequacy that I don't have the power or level of influence to instigate the change people are desperately seeking)

The community group I was working with has become very selective in who they allow in to do research with them as a result of this perceived inactivity. For example, "*you know with consultations of any type, particularly in the community, people get fed up because people say nothing every changes and often it's a really valid point. And I think, which is again why we pick and choose, if we're asked to do research, we say, yes please come in, otherwise we could do this all the time…"*

Although originally wounding, (perhaps reflecting my own insecurities as a junior researcher), I've now drawn on this experience as a further motivation to try and at least evidence the need for change. Similar to the way participants are passively described in academic research, I don't want to become another researcher who despite their best intentions, doesn't do, or change anything. That isn't an option. I feel like I owe it to the people I met today and all the other individuals so far who feel let down by the lack of activity or change experienced as a result of previous research engagement.

On a slightly more positive note, I've also found myself frequently smiling in many of the focus groups carried out so far. The resilience, comradery and supportive nature of these groups is amazing to see. It paints a stark contrast to the frequent depictions of mental health patients as violent, aggressive and deranged. The only time such perceptions have felt enforced was when I attended the in-patient psychiatric ward. Although not initially nervous waltzing in with my home made cakes, the strict procedures in place quickly put me on edge and felt at odds with the more welcoming and friendly receptions we had experienced in the other focus groups.

Analysis with Oriel of the patient data is starting to really highlight the richness of data collected. There is so much in the data we have collected, it's a mammoth task! It's been really reassuring to talk through research findings with Oriel and compare identified themes. While not widely different, (which I'm taking as a positive sign), I've noticed the specific attention to detail Oriel places on the subtle nuances in language. Two minds are definitely better than one in the analysis process!

Psychiatrist experiences and focus groups

So, the reception we've had from patients and psychiatrists is very different. At an event today that I'd travelled two hours to attend I was due to conduct some focus groups. Psychiatrists had received the relevant information ahead of time and knew that I was coming. When I got there, before I'd even spoken, three psychiatrists walked out of the room with one acknowledging "*I look too young to know what I'm talking about."* I was really shocked and kept replaying the feelings and experiences patients had shared with us in my mind about feeling disrespected and at the bottom of the pile. I felt so small in that room, like a bullied child. The reaction of these psychiatrists, (importantly not all), really threw me.*

(*and has had quite an impact on my confidence since)

Despite the comments made, I carried on with the focus groups and was surprised by the clear distinction between psychiatrists who viewed the collection of patient feedback as essentially a good exercise and those who disregarded the process entirely. I felt really disappointed when a focus group laughed at the idea of feedback tools causing psychosis. I found the laughing difficult to accept as I'd heard the impact psychosis, prejudice and discrimination has on patients only just last week. I'm also starting to feel concerned about how Oriel may feel reading through these transcripts. Luckily, at his request, Oriel wasn't involved in collecting the psychiatrist data. Based on today's experience, I think this was the right decision.

During the transcription of psychiatrist data, I've had some more 'light bulb' or concerning moments. For example, one psychiatrist repeatedly expressed that "*one has to select who you send these things to get a good representation*" Why? Who is this protecting? What purpose is this serving? The comment reiterates the point I often hear in feedback literature, are we hitting the mark but missing the point? Could the intentional selection of patients be because psychiatrists are worried about the potential outcomes for revalidation? If so, patient feedback as it's currently practised arguably offers little value for patients or psychiatrists.

I've also been really surprised by the repeated suggestion that feedback should be interpreted differently in psychiatry. Would psychiatrists say the same if feedback was positive in nature? "*I think you have to be very care about how the feedback is interpreted really in light of the diagnosis*" ; "*to get proper feedback in psychiatrist unless you hand pick who you're going to send the questionnaires to, you know who will respond, and you know like you*" How is this 'proper' feedback? Does this not make the entire process flawed?

However, one participant stated, (although this was very much a minority perspective), "*I guess it's* [ACP 360 tool] *performing a function but if we're interested* *in what our patients experience in appointments with us, we probably need to go beyond an ACP 360 and think about what we actually want to learn from this… we don't know what's meaningful for them"* This I think is key and ultimately the fundamental problem in patient feedback tools. Psychiatrists don't know what matters most to patients and patients don't know how their feedback is used or why they are giving their feedback. I don't think anyone is to blame for how patient feedback is currently being used or responded to, I just think there needs to be better communication.

Other things that stood out to me today were the statement "*weak questions can have weak answers"* and suggestion that patients are not worried about giving negative comments as "*between five and ten percent"* of patients had given critical comments in a feedback tool. Is this is a good way to mark acceptability and patient confidence in providing critical feedback? I'm not sure.

Finally, there appears to be a clear contradiction between psychiatrists relying on narratives to diagnose and rejecting the 'validity' of patient narratives if it they critique psychiatric care in any way. Why is a patients narrative of experience valid when giving a potentially life changing diagnosis, but not when providing a narrative account of their psychiatric care experience?

Comparison of patient and psychiatrist perceptions

We've recently started comparing the research findings from both patients and psychiatrists and I think both Oriel and I are surprised at the level of commonality. A phrase coined by Jo Cox keeps coming to mind - '*there is more that unites us than divides us.*' A fear of repercussions is clear for both patients and psychiatrists, as is concerns about anonymity but how do you address this? How can I address this when I'm not part of the organisations that control these processes? The fear I think is the same, being punished; one being punished by psychiatrists or having their care altered, the other losing their license to practise. Such fears are arguably giving rise to the detrimental behaviours we've already heard and seen.

Comparing the patient and psychiatrist findings has been a really worthwhile exercise. I think it's given Oriel and I a bit of renewed enthusiasm that there is hope for a more collaborative way of working. Patients and psychiatrists are not that dissimilar in terms of what they want and their concerns.

Co-production

Oriel and I have been invited to deliver a co-production workshop in central London at the Royal College of Psychiatrists. When we first got the invite I though it sounded great but also had a number of immediate thoughts and concerns. Firstly, Oriel only recently travelled to Exeter, how will he feel about travelling to London? Again it comes back to that point of not making decisions or assumptions for people. Secondly, cost. I will of course be paying for Oriel's food, travel and accommodation, it's the least I can do, but this is an unexpected cost in a self-funded PhD. Thirdly, why have the Royal College suddenly got interested in this research? Originally it was very clear that they didn't want to be involved. I wonder what has happened, or who has happened, to change their mind? Where do we stand in regards to IP type of things? Will they claim of our research findings as their own? Is this just how things are done? I need to ensure participating patients haven't been treated by participating psychiatrists, this may severely change the workshop dynamics. I need to make it clear to participants that both patients and psychiatrists will be involved working as a collaborative team. Also, how do I manage potentially competing desires? Although we've seen in the research we've done already that there are a number of areas of commonality, that doesn't mean to suggest that everyone will have the same opinion in the workshop. How do I manage potential power disparities? I feel slightly out of my depth at this point and uncertain about what will happen but I guess that's the nature of co-production? Oriel and I know the research findings inside out, the rest is up to the people on the day.

Co-producing the feedback tool was amazing, chaotic, administratively burdensome, mentally demanding, intimidating and rewarding all at the same time. It was mentally taxing trying to keep up with everything but I really enjoyed the energy in the room and seeing everyone come together, it was really gratifying and rewarding. It was also really encouraging to see that participants in this workshop were repeating things that had already been said in the previous research cycles.

One thing that is playing on my mind though is whether the presence of the ACP 360 representative affected any of the responses given? Oriel and I discussed this on the journey home and agreed that it would be beneficial to do a 'refinement' workshop to test this theory out. It will also give us the chance to do a workshop in a different setting, one that might have less influential control maybe?

I'm a little bit disappointed that we didn't manage to recruit more than one psychiatrist. Does this reflect psychiatrist's lack of interest in this area? I'm not entirely sure that it does but it certainly highlights the difficulties in recruiting healthcare professionals. Despite this, we're chuffed with how today went. I think sending out the information packs beforehand was really helpful. It was also really nice to hear some of the comments made at the end of the session about how well people felt the workshop had been facilitated, this was another confidence boost for both Oriel and I.

The refinement workshop also went really well. Again we didn’t manage to recruit any psychiatrists, this seems to be a repeated issue... Participants kept mentioning the same issues in existing feedback design. This again gives us some reassurance. Following today’s workshop Oriel and I have put together a report of all our findings and shared this with the ACP 360 team at the Royal College, it’ll be interesting to see what their response is.

Evaluation

Today we received an unexpected email from the ACP 360 team who let us know that they have completed “*our review of the patient questionnaire and the feedback you supplied. We have in response to this produced a final version of the patient questionnaire… as you may recall after receiving the revised questionnaire we undertook a further internal review of your draft. This has resulted in some changes that we didn’t initially anticipate having to make. Though I’m afraid our final form has diverged somewhat from the version you supplied last year we hope you feel the core aspects remain. Some changes we believe offer clarity, some attempt to simplify the design/layout, others have been necessitated by technical obstacles for developing the online ACP system.”*

This email and justification for some of the core elements they have removed has left both Oriel and I feeling somewhat deflated and frustrated. Many of the core elements co-produced by both patients and psychiatrists including the word search question, frequency of free text comments, use of colour and redesigned questions have been removed. This feels like a real blow and highlights the context in which co-production arguably operates within. It’s another area we have limited influence or control over. Oriel and I can only take things so far. The language used in the email is also really interesting, the research is referred to as ‘feedback’ is this because of the approach we took? Who is ‘we’? Professionals only? Why was a further internal review undertaken? Were the views and opinions of both patients and psychiatrists not good enough? Not reliable enough?

But, after some reflection Oriel and I have seen that this represents an opportunity to compare three feedback tools, the original ACP 360, the hybrid version created by the Royal College and entirely co-produced tool created in cycle six. We’ve set out to speak to a number of patients and psychiatrists using something called a think aloud interview and semi structured interviews to hear what people think as they complete the feedback tools. We’re hoping that this will provide an additional level of insight not achieved if using quantitative measures.

Coronavirus! Something we definitely didn’t anticipate was a global pandemic. This has been really tricky to try and manage both in terms of our regular co-production sessions and deadlines of the PhD. Oriel has recently moved into independent housing (which is fantastic!) and is still getting things set up, I’ve also recently started a new job and trying to adapt to working from home. We’re still trying to figure out what the best way forward is. I’m thinking that we’re going to need another ethics application so we can conduct the interviews online but Oriel won’t have the necessary access to do this so I may have to do the last interviews alone which is slightly disappointing given our great partnership working to date.

Started the first interviews today, doing it on Zoom is hard especially when trying to share screens. It definitely feels more cumbersome than doing it face to face but this is what we have to work with at the moment. I'm also getting increasingly concerned that psychiatrists are under increasing pressure as a result of Covid-19, recruitment may therefore be particularly hard…

We're coming to the end of the process now and I've started to post some of the transcripts to Oriel, (this is the best we can come up with at the minute). I'm really excited at the level of detail being provided in the think aloud and semi-structured interviews, I think it was a really good choice of methods. It certainly feels like we're hearing more of the processes and reactions to the information shared than we might have picked up if using a satisfaction questionnaire?

Finally been able to meet Oriel today, it's been great! Was fantastic to see him and we have a new co-production location!

Challenges or difficulties encountered

Now we're nearing the submission of the PhD, I wanted to take some time to reflect on the 'challenges' or 'difficulties' of this research. This language feels slightly uncomfortable because I don't see these experiences as negative or detrimental but I equally can't think of any relevant alternatives...

For me, some of the biggest challenges I've faced in this research, was the number of 'unknowns' and the anxieties, uncomfortable, but also liberating feelings that this came this. Many times I felt that I didn't have the answers to things, I couldn't predict or control what the outcome would be, where we might be in six months time for example. For the majority of the research, I was in an internal battle between what I had been taught about 'good, rigorous research' and the research I was doing, feeling and experiencing with Oriel. Was our research not research? What makes research rigorous and who has decided this? Does rigorous research look different from a patient and professional perspective? I struggled, and arguably still struggle to understand how Oriel's involvement and co-production with both patients and researchers makes this research any less rigorous, or its findings any less 'valid'. I personally think the process we've undertaken has made the research findings more reliable, more in-depth and more insightful.

Other difficulties I faced in this research was the variety of emotions I experienced (both good and bad), the emotional labour encountered and need to develop some level of emotional resilience/management. Some of the more uncomfortable feelings I experienced including inadequacy in the sense that I hadn't done this before, I hadn't received any training, psychiatrists were walking out of the focus groups because I was "*too young"* I couldn't provide participants with what Oriel could, that shared understanding of lived experiences. I also felt intimidated at times by the scale and scope of this research, including the need to go to new places, meet new people and form new relationships with both healthcare professionals and patients – this isn't easy.

However, one of the strongest feelings I felt was guilt. Guilt that I couldn't pay Oriel or truly convey to him how much his time, involvement and expertise meant to me ,(I recognise money is a material way of demonstrating value but given Oriel's experience of living in a homeless hostel at the time, this felt even more poignant than usual); guilt of the frequent disparities and inequalities between my personal situation and that of Oriel's; guilt that people had experienced such detrimental experiences in psychiatric care and previous research encounters; and remorse that both patients and psychiatrists feel so disempowered in current practice and policies.

I also felt high levels of frustration, defence and at times, disbelief. I often felt embarrassed and frustrated at how unhelpful university, or academia processes are in facilitating meaningful, or smooth engagement. For example inflexibility of consent forms and information sheets? Inability of ethics proposal to respond to collaborative ways of working. It's almost like institutes want to say they work in collaboration with others but put necessary measures in to ensure the ivory tower remains unchallenged? I found the comments made by some psychiatrist participants and senior colleagues difficult to process on a personal level. Many of the comments made often related to prejudice or mental health stereotypes. Two instances stick in my mind in particular.

Firstly, there were the comments made by a peer reviewer. At the beginning of the review they stated: "…*the true expert in understanding what the patient experience is and what is most important to patients in evaluating that experience. It is for that reason that I personally advocate for patients to have a significant role…"* However, at the end of that same page the reviewer commented:

> *"Because the thinking of psychiatric patients is not representative of the norm, I believe that they are an inappropriate choice as subjects for such a study. Because the group of patients being studied are under medical care specifically for mental health issues, their perceptions of care may be influenced by aspects of their disease more than might be the case for other categories of patients. Perceptions may also be influenced by psychotropic medications that effect their thinking and emotional state"*

I remember these comments really irritating me as they bought to the foreground the possessive language still frequently used to describe psychiatric patients and the repeated dismissal of their experiences due to assumed vulnerabilities. I again had another internal battle of how whether to encourage Oriel in reading and responding to these comments or ‘protecting’ him from it. I choose the former option.

The other experience that has stuck with me are comments made by a senior colleague in the University in response to a request for Oriel to ‘sit in’ during my transfer. Oriel has been an integral part of the research and I wanted him to be able to experience the entire research process. In my mind, (perhaps wrongly), I assumed that Oriel would be able to attend as supervisors could. While my DoS and examiners were supportive of this request, I hadn’t anticipated the response from the Doctoral College that seemed to again highlight the inadequacies of academia in supporting more collaborative ways of working. As described by one colleague, this is:

> “*A most unusual request…the Faculty has been put in a somewhat difficult position not to deny this opportunity. It is with slight apprehension that I agree the request should go ahead as requested but I would like some clarification of what “co-production with a mental health service user” means please. Also why do the examiners feel that Oriel should be present? This is not obvious. There are indeed no criteria in the regulations to say this cannot happen. Conversely, the RDC2 form normally involves the candidate and two examiners only”*

Following the disclosure of Oriel’s diagnoses at the request of the Doctoral College, my ‘safety’ was also called into question. No previous questions about my safety had been asked prior to the disclosure of this information. This again felt like a further demonstration of how people with a mental health condition are frequently marginalised or discriminated against. It also highlighted the cultural practices within academic institutions that directly challenges, or suppresses collaborative ways of working with the ‘othered’, i.e. those not in academia.

Many comments were also made throughout this research about how I would be good at doing "*this softer side of research"* because I'm female and "*have a nice personality". *In one instance our research approach was described as "*pink, fluffy and nice".* It's not, it's hard and emotionally intense for all those involved. I've found myself continually questioning the institution and 'profession' I may soon represent.

Although not necessarily a challenge, I found the level of vulnerability required to do this kind of research an interesting journey to be a part of. I found myself sharing personal experiences with Oriel and participants that may not have otherwise been shared. This again contrasted against the neutral and distanced positioning researchers are taught to assume and made me question myself on multiple occasions as result. Other vulnerable experiences encountered included the feeling of rejection from the three psychiatrists who walked out of the room because I looked "*too young*" I wonder if this was also because I'm a young female research student who has no medical background? Either way, I felt very much aligned with the experience shared by patients on this occasion and the encounter had a long lasting impact on my confidence going forward.

Finally I think the financial costs, level of administrative and emotional labour (hearing distressing and traumatic experiences, working with marginalised communities, contradicting previous research training) required for this research was difficult and hidden at times. I only really realised the true emotional extent of this research when giving a presentation at a conference. I had presented our research findings including the impacts this research had had on Oriel when I was asked a very simple question – what impact has this had on you? Tears starting rolling down my cheeks. During this PhD I was working full time, had gotten married, got made redundant and experienced a number of bereavements. At this point, and only at this point, did I realise I had often been putting the emotional welfare of others ahead of my own and failing to examine the emotional and personal impacts of this research on myself. Is this because some of the detached and removed discourses of research were still influencing me, or because researchers are not actively encouraged or supported in doing this kind of activity? Managing the mental, practical and emotional demands of collaborative research is a skill I am very much still honing in on.

Rewards

Despite it's 'challenges' this research has undoubtedly made me a better person and a better researcher. I have learnt so much about the experiences of patients and psychiatrists, explored alternative ways of doing research and pushed myself way out of my comfort zone on multiple occasions. Working alongside Oriel has allowed to be to grow in confidence and find the kind of researcher I want to become.

There have been multiple learning points for me, I am in no way claiming to have got this process right. I've learnt about the impact academic research can have, both in liberating and oppressing individuals. I've also learnt about the importance of never underestimating the difficulties involved in individual tasks and learning to be comfortable with uncertainty. The importance of language will continue to remain at the forefront of my mind. I frequently question people when they refer to "*using"* patients or healthcare professionals.

I've feel extremely honoured and privileged to have watched the progression and development of Oriel over the past four years. I've enjoyed being part of the process that saw him leave Plymouth for the first time in three years, go to London for the first time in five years, give numerous public presentations and recognise the importance of his voice. I hope that he recognises that he is valuable and valued. In one of our sessions Oriel acknowledged that following the patient data collection, he now understood that “*their* [psychiatrists] *time is important but so is mine”.*

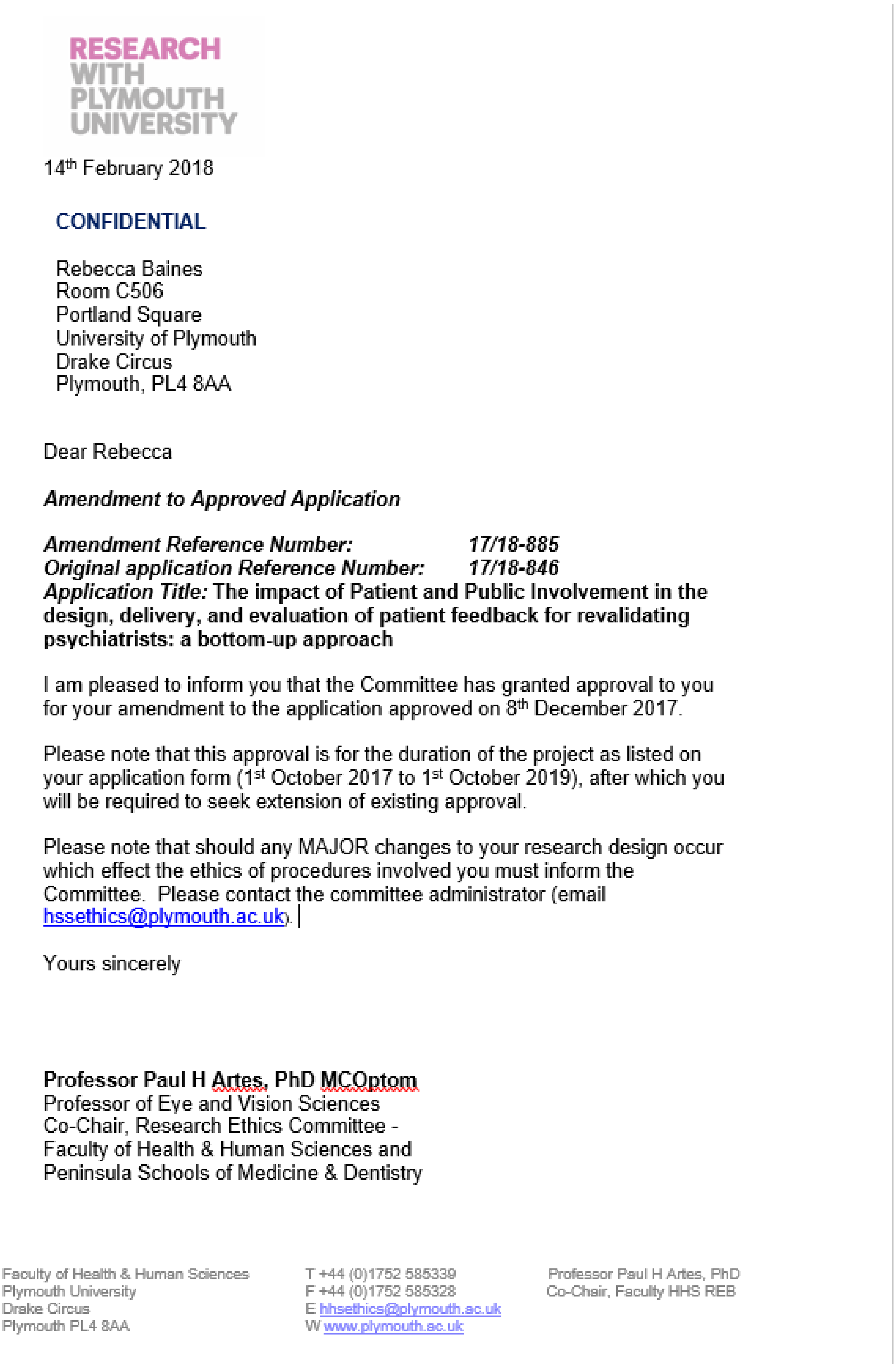
Just as much as Oriel described being involved in this research as therapy for him, it’s also been therapy for me. Working with Oriel has provided me with much needed structure, responsibility and accountability. He has been a constant throughout this PhD, an experience that can often be isolating and lonely.

Doing this research has changed by views and opinions in the sense that psychiatrists and patients often share more areas of commonality than divergence, I just think cultural practises and language keep these communities distinct because a fear of the ‘unknown’. Similarly, mental health patients are not the aggressive, deranged and unable individuals frequently portrayed in the media. Although they may lack ‘capacity’ at times, individuals with a mental health condition do not lack the capacity to feel and experience.

I have developed new skills mainly around interpersonal and communication skills. Been forced to question existing practises and translate complex academic concepts in accessible language. This I think has forced me to become more knowledgeable of the subject area. I also strongly believe that the quality of this research has been immeasurably improved through the active involvement of Oriel. The questions we asked seem more applied and relevant, the level of information participants described appeared more authentic and in-depth, as did the level of analysis achieved.

Overall, I would describe the impacts and rewards of this research as truly life changing. It has been challenging and unexpected but also immensely enjoyable, transformative and rewarding. I am a better person and researcher for doing the research in the way that we have. For this, I will always be truly grateful to Oriel and everyone who shared their time, experiences and knowledge with me; simplicity, reciprocity and accountability are key.

Appendix 2 Amendment to ethics application



RESEARCH WITH PLYMOUTH UNIVERSITY

14th February 2018

CONFIDENTIAL

Rebecca Baines
Room C506
Portland Square
University of Plymouth
Drake Circus
Plymouth, PL4 8AA

Dear Rebecca

Amendment to Approved Application

Amendment Reference Number: ***17/18-885***
Original application Reference Number: ***17/18-846***
Application Title: **The impact of Patient and Public Involvement in the design, delivery, and evaluation of patient feedback for revalidating psychiatrists: a bottom-up approach**

I am pleased to inform you that the Committee has granted approval to you for your amendment to the application approved on 8th December 2017.

Please note that this approval is for the duration of the project as listed on your application form (1st October 2017 to 1st October 2019), after which you will be required to seek extension of existing approval.

Please note that should any MAJOR changes to your research design occur which effect the ethics of procedures involved you must inform the Committee. Please contact the committee administrator (email hssethics@plymouth.ac.uk).

Yours sincerely

Professor Paul H Artes, PhD MCOptom
Professor of Eye and Vision Sciences
Co-Chair, Research Ethics Committee -
Faculty of Health & Human Sciences and
Peninsula Schools of Medicine & Dentistry

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Professor Paul H Artes, PhD
Co-Chair, Faculty HHS REB

Appendix 3 Original University of Plymouth letter of ethical approval

8th December 2017

CONFIDENTIAL

Rebecca Baines
Room C506
Portland Square
University of Plymouth
Drake Circus
Plymouth, PL4 8AA

Dear Rebecca,

Application for Approval by Faculty Research Ethics Committee

Reference Number: **17/18-846**

HRA / External REC Reference Number: **17/YH/0353**

Application Title: **The impact of Patient and Public Involvement in the design, delivery and evaluation of patient feedback for revalidating psychiatrists: a bottom-up approach**

I am pleased to inform you that the Committee has granted approval to you to conduct this research (which has also obtained HRA approval, reference 17/YH/0353).

Please note that this approval is for the duration of the project as listed on your application form (1st October 2017 to 1st October 2019), after which you will be required to seek extension of existing approval.

Please note that should any MAJOR changes to your research design occur which effect the ethics of procedures involved you must inform the Committee. Please contact Sarah Jones (email hhsethics@plymouth.ac.uk).

Yours sincerely,

Professor Paul H Artes, PhD MCOptom

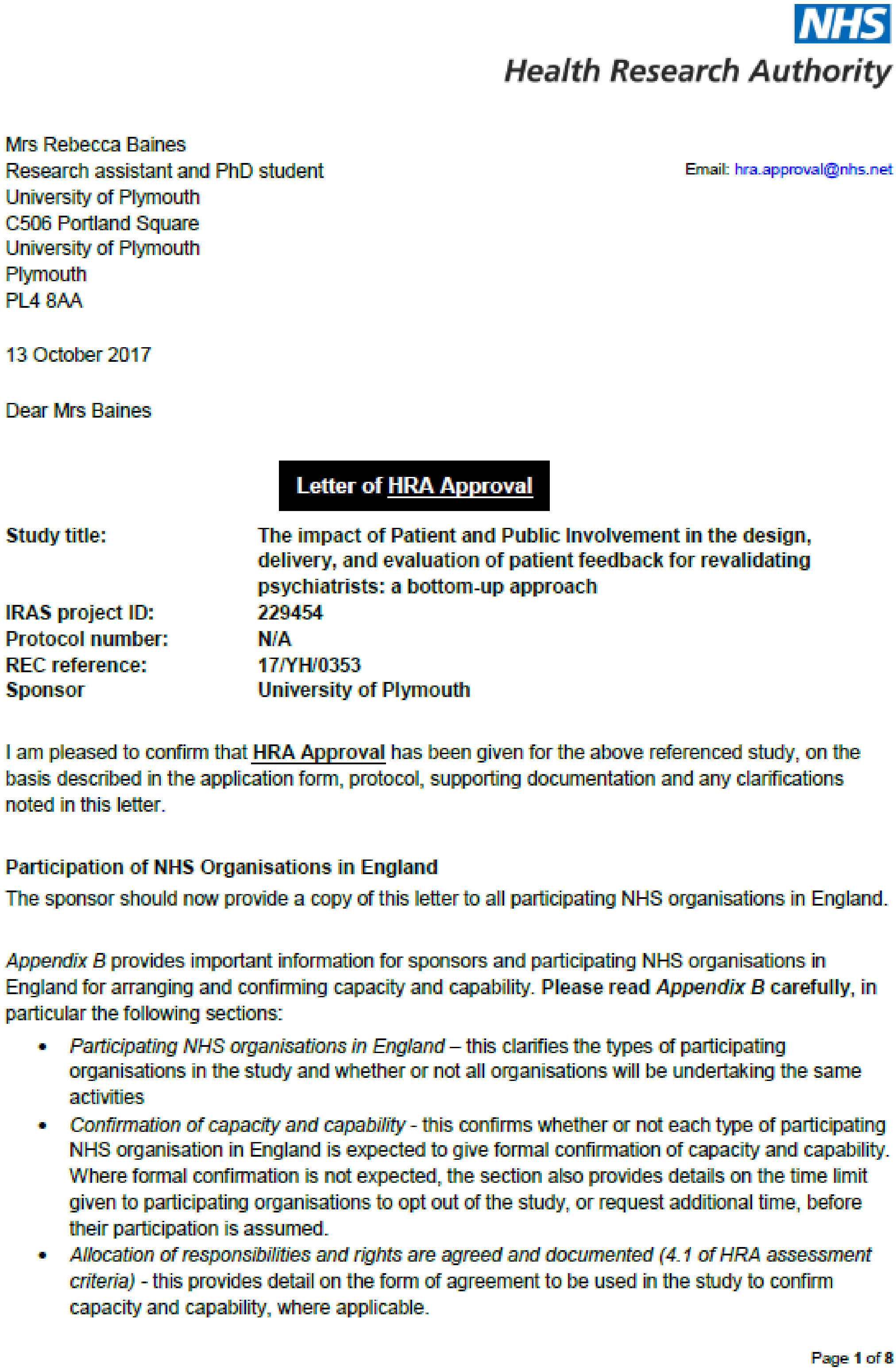
Professor of Eye and Vision Sciences

Co-Chair, Research Ethics Committee -

Faculty of Health & Human Sciences and

Peninsula Schools of Medicine & Dentistry

Appendix 4 HRA letter of study approval



NHS
Health Research Authority

Mrs Rebecca Baines
Research assistant and PhD student
University of Plymouth
C506 Portland Square
University of Plymouth
Plymouth
PL4 8AA

Email: hra.approval@nhs.net

13 October 2017

Dear Mrs Baines

Letter of HRA Approval

Study title:	**The impact of Patient and Public Involvement in the design, delivery, and evaluation of patient feedback for revalidating psychiatrists: a bottom-up approach**
IRAS project ID:	**229454**
Protocol number:	**N/A**
REC reference:	**17/YH/0353**
Sponsor	**University of Plymouth**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Page **1** of **8**

Appendix 5 Co-produced patient interview and focus group topic guide

1. Based on your experience, what do you think is most important in a psychiatrist?
2. What, if anything, would make patient feedback useful or meaningful to you?
3. How would you like to give your feedback if at all? How would you like it to look?
4. Is there anything that would motivate you to give your feedback about a psychiatrist?
5. Is there anything you would need to know before you gave your feedback? If so, what?
6. What are your perceptions of the current feedback tools being used in revalidation?
7. What do you think would make patient feedback useful for psychiatrists?
8. Is there anything else you would like to add?

Appendix 6 Patient demographic questionnaire

1. Please select the most relevant option.

- ○ Male
- ○ Female
- ○ Prefer not to say
- ○ Other

2. Please choose your age range.

- ○ 18-25 years old
- ○ 26-33 years old
- ○ 34-41 years old
- ○ 42-49 years old
- ○ 50-57 years old
- ○ 58-65 years old

3. Please select your ethnicity

- ○ Asian/Pacific Islander
- ○ Black of African American
- ○ Hispanic or Latino
- ○ Native American or American Indian
- ○ White
- ○ Other (please specify)

4. Please select the most relevant option

- ○ Patient/service-user/client/consumer/survivor
- ○ Carer
- ○ Other (please specify)

5. Please list the mental health condition(s) you, or someone you support are experiencing, or have experienced. I am asking this question to make sure I have spoken to a number of people with different experiences so a variety of voices are heard. **You do not have to provide this information if you do not wish to.**

<u>Appendix 7 Patient research invitation</u>

VOICE. CHOICE. CHANGE.

WANT TO GIVE FEEDBACK ABOUT YOUR PSYCHIATRIST?

IF SO, WHY? HOW? WHEN? WHAT MATTERS TO YOU MOST?

AGED 18-65? EXPERIENCE OF PSYCHIATRIC CARE? WANT TO MAKE A DIFFERENCE?

THEN PLEASE COME ALONG TO CHAT ABOUT THESE THINGS OVER SOME HOME BAKED CAKE.

DISCUSSIONS WILL LAST AROUND 60-90 MINUTES AND WILL BE HELD IN SMALL GROUPS. INDIVIDUAL SESSIONS CAN ALSO BE ARRANGED. EVERYTHING SHARED WILL BE KEPT STRICTLY CONFIDENTIAL.

For more information please contact
rebecca.baines@plymouth.ac.uk,
01752 586824

Appendix 8 Changes made to patient coding framework following co-production

Changes to patient coding framework

Theme: Desirable behaviours

External

1. Created new sub theme appointments
2. Moved waiting list to appointment sub theme
3. Moved sufficient time to appointment sub theme
4. Moved length of appointments to appointment sub theme
5. Moved support services between appoints to appointment sub theme
6. Created new sub theme processes
7. Moved form complexity to processes
8. Moved confidentiality to processes
9. Moved treatment pathway to processes
10. Moved lack of joined up working to processes
11. Moved pressures to discharge to funding
12. Created new sub theme job role
13. Moved workload to job role
14. Moved overload to job role
15. Moved role/purpose to job role
16. Moved continuity to access
17. Merged overload and workload into workload
18. Moved psychiatrist variability to external

Total changes made: 3 creations, 1 merge, 14 moves.

Internal

1. Created new sub theme – involves
2. Moved shared decision making to involves sub theme
3. Moved involvement of carers to involve sub theme
4. Delete inspires confidence
5. Merge confident and confident in abilities
6. Rename provides hope to offers hope
7. Merged best interest at heart with caring
8. Created subtheme of communication
9. Rename feedback to provides feedback on progress
10. Renamed equal to equal partnership
11. Moved provides praise to offers feedback
12. Moved flexible to treated holistically not just the condition
13. Merged humanity with human
14. Moved human to treated holistically not just the condition sub theme

15. Moved humility to equal partnership
16. Renamed individuality as being treated as an individual
17. Moved treated as an individual to treated holistically sub theme
18. Moved open minded to non-judgemental
19. Merged specific into clear communication
20. Merged treated like a human being and humanity
21. Merged truthful and honest
22. Merged versatile and flexible

Total changes made: 2 creations, 8 moves, 7 merges, 1 delete, 4 renames

Power dynamics:

1. Moved position as psychiatrist to culture sub them
2. Moved possessive over to position as psychiatrist
3. Created new sub theme position as patient
4. Moved passive to position as patient
5. Renamed position as patient to social positioning as a patient
6. Moved disregard from passive to social positioning as patient
7. Moved under to social positioning as patient
8. Merged under with underneath
9. Moved pathologisation to social positioning as a patient
10. Moved inability to challenge to passive
11. Moved inability to challenge notes to inability to challenge
12. Moved importance of an advocate to social positioning as an advocate
13. Created new sub theme Language
14. Moved not understanding labels to language
15. Moved using medical language to describe to language
16. Moved same language to language
17. Moved not understanding rights to passive
18. Moved similarities between patients and psychiatrists to us and them distinctions

Total changes made: 14 moves, 2 creations 1 renaming, 1 merge

Motivators:

1. Moved gift to motivators
2. Moved desire to give positive feedback to motivators
3. Deleted desire to get involved
4. Merged desire to give positive feedback with opportunity to praise
5. Renamed things will improve to service improvement
6. Moved receiving a thoughtful reply to knowing it was listened to
7. Moved feedback loop to knowing it was listened to
8. Merged knowing it will help someone to professional development
9. Moved empowerment as new sub theme

10. Moved partnership as new sub theme
11. Moved different perspective as new subtheme
12. Moved passion to part of professional development
13. Moved trust as new subtheme
14. Deleted highlighting benefits of doing it as now all covered elsewhere
15. Merged making people aware how people feel to different perspective
16. Moved hope to share good practice
17. Merged opportunity to praise with share good practice

Total changes made: 10 moves, 2 deletes, 1 rename, 4 merges

Problems with existing forms

1. Rename size of questions to font size
2. Created new sub theme frequency
3. Moved lack of opportunity to frequency
4. Moved more likely to complaint to lack of opportunity
5. Moved once every five years to frequency
6. Created new theme questions
7. Moved lack of detailed questions to questions
8. Moved not what patients want to questions
9. Moved requirement to conform to existing questions to questions
10. Moved restrictive questions to questions
11. Moved questions don’t change to questions
12. Moved unclear questions to questions
13. Moved irrelevant questions to questions
14. Created new theme design
15. Moved tiny text to design
16. Moved at the back to design
17. Moved formal to design
18. Moved intimidating to design
19. Moved feedback loop to design
20. Moved length to design
21. Moved space for practice to design
22. Created new theme process
23. Moved feedback loop to process
24. Moved getting to right person to process
25. Created new theme requirements or remit
26. Moved feedback from the system to requirements
27. Moved lack of choice to requirements or remit
28. Moved definition of patient feedback to requirements ore remit
29. Moved validity to process
30. Moved questions to design
31. Moved bias patient selection to validity
32. Moved anonymity to barriers
33. Moved tick box to design

34. Created new sub theme patient barriers
35. Moved anonymity to patient barriers
36. Moved lack of trust psychiatrists want to change to patient barriers
37. Moved not complaining in fear to patient barriers
38. Merged not complaining in fear and fear of repercussions
39. Moved process of giving form to process
40. Moved lack of evidence to support change to patient barriers
41. Moved lack of trust psychiatrists want to change
42. Merged lack of change with lack of evidence to support change
43. Moved psychiatrist resistance to feedback to lack of trust psychiatrists want to change
44. Delete patient culture as now covered in new themes
45. Merged culture with culture
46. Renamed psychiatrist fears with psychiatrist barriers
47. Moved dislike for forms to patient barriers
48. Moved feedback fatigue to patient barriers
49. Moved lack of clear purpose to patient barriers
50. Moved lack of patient understanding to patient barriers
51. Moved lack of perceived value to patient barriers
52. Moved wellbeing to patient barriers
53. Moved paper work to psychiatrist barriers
54. Moved whose monitoring who to process

Total changes made: 42 moves, 2 rename, 6 created, 1 delete, 3 merge

Solutions

1. Moved free space to write own words to both
2. Moved scale at bottom to scales
3. Moved scales to both
4. Moved breaking up text boxes to both qualitative and quantitative
5. Merged space for comments with freedom to write your own words
6. Created new theme accessibility
7. Moved easy rad to accessibility
8. Moved learning difficulties to accessibility
9. Created new theme frequency of opportunity
10. Moved frequency of opportunity to opportunity
11. Moved choice to frequency of opportunity
12. Merged optional and choice
13. Moved end of treatment to frequency of opportunity
14. Moved immediate after to frequency of opportunity
15. Moved on site to frequency of opportunity
16. Moved regular from start to finish to frequency of opportunity
17. Deleted frequency as now covered
18. Created new theme content
19. Moved cover most important aspects to content

20. Created new sub theme questions
21. Moved more detailed questions to questions
22. Moved no set questions to questions
23. Moved personal phrasing to questions
24. Moved anonymous to process
25. Moved space for carer and family involvement to design
26. Created new theme requirements or remit
27. Moved reconceptualise what we mean by valid and value
28. Moved user led to process
29. Moved use the word psychiatrist to content
30. Moved random spot check to process
31. Merged accessible and accessibility
32. Moved easy to understand to questions
33. Moved space for praise to space for good and bad
34. Renamed ease of implementation to make it actionable
35. Moved make to actionable to content
36. Merged information with making clear it is a choice
37. Merged confidentiality with need to be anonymous
38. Created new sub theme feedback to psychiatrists
39. Renamed explaining it will be constructive to facilitated feedback
40. Moved facilitated feedback to feedback to psychiatrists
41. Moved provision of help to process
42. Moved group validation to reconceptualise what we mean by valid vs value
43. Moved choice to accessibility
44. Created new sub theme electronic
45. Moved app to electronic
46. Moved email to electronic
47. Moved online to electronic
48. Moved snapchat psychiatry to electronic
49. Moved TripAdvisor to electronic
50. Created new theme face to face
51. Created new theme face to face with advocate
52. Moved face to face with advocate to face to face
53. Renamed face to face with face to face with psychiatrist
54. Moved face to face with psychiatrist to face to face
55. Moved focus groups or panels to verbally
56. Moved telephone to verbally
57. Moved interview to verbally
58. Moved text to electronic
59. Created new sub theme survey under electronic
60. Moved postal removing need for handing feedback personally to process

Total changes made: 41 moves, 5 merges, 10 created, 1 deleted, 3 renamed

Appendix 9 Strengths and limitations of patient feedback methods as identified by participants

Feedback method	Strengths	Limitations
Electronic (n=55)		
Online*	Ease/Familiarity “*If I do it online it would make it easier”* (Interview,2) “*Online is good because you do it with take away’s and you give your feedback afterwards so you could do it after seeing a psychiatrist… it’s just straight forward and easy”* (Focus group 8,pt5) Flexibility of when and where to complete it “*I enjoy completing surveys or giving comments but usually don’t have the time to do it there and then so online is useful”* (Online survey,pt1) Sense of enhanced anonymity “*An anonymous online feedback form is something I would be more likely to complete”* (Online survey, pt12) Removal of face-to-face submission *“If I do it online, I can just type it so I wouldn’t have to be in the same room when they initially get that feedback which would be easier”* (Interview,2) Alignment with modern technology *“I think we need to adapt it towards the modern technologies too”* (Focus group 4,pt5) Option to provide prompts *“One alternative probably not on written ones but online or on an app, you could have a series of drop downs that have suggested answers come up, sometimes if I’m filling in forms, I’m racking my brains of what to say. So maybe a summary of three or four drop down things and then other or something so you can put your own things in”* (Focus group 1,pt8)	Access “*If you can access it then yeah, absolutely, but not everybody can”* (Focus group 1,pt4) *“Internet access is quite limited here”* (Focus group 3,pt6) Age “*I think older people don’t use online things as much”* (Focus group 1,pt8) “*I’ve only just got the internet, maybe that’s to do with age groups”* (Focus group 8,pt1)
App	Popularity “*Apps are all the rage at the moment”* (Focus group 1,pt4)	Over popularity

	<u>Ability to voice record</u> *“I know with some apps you can voice record into your app so that might be a way of speaking out loud?”* (Focus group 1,pt2)	*“There’s an app for everything, but maybe make it central so it all links together”* (Focus group 1,pt4) <u>Privacy concerns</u> *“I am not too keen on apps due to both privacy concerns and device slowdown caused by apps hugging resources”* (Online survey, pt6)
Email	<u>Preference</u> *“Some people might prefer to do it by email if they can’t appear in person”* (Focus group 4,pt5)	
Text	-	-
TripAdvisor	-	-
Snapchat	-	-
Verbally (n=26)		
Focus groups and panels	<u>Desirable</u> *“A focus group would be good”* (Focus group 4,pt5) *“I would something like a panel like this where you discuss”* (Focus group 1,pt3) <u>More accessible</u> *“For me, what worries me about feedback is that you get people giving feedback who are able to be articulate, are able to state how they feel and what they do and some people who are very severely depressed or extremely anxious are unable to do that, so for me, some kind of gentle verbal questions and verbal feedback works best, I know that’s time consuming but that would work best for me, verbal feedback”* (Focus group 8,pt1) <u>Opportunity to have psychiatrists present</u> *“You should have focus groups with the psychiatrists there”* (Focus group 4, pt3)	<u>Time consuming</u> “*I know that’s time consuming but that would work best for me”* (Focus group 8,pt1)
Interviews	<u>Desirable</u>	-

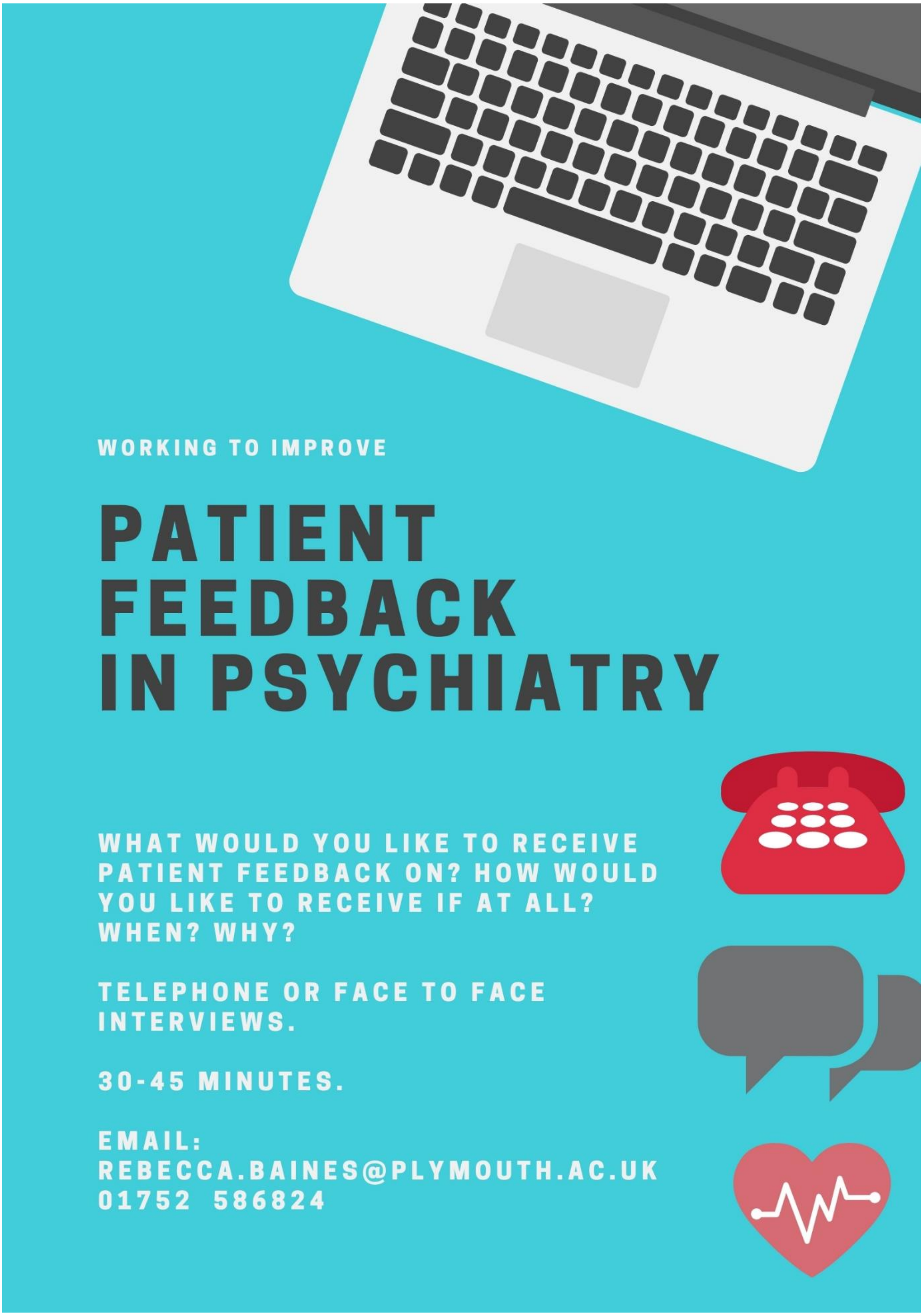
		"Maybe they could do interviews or something alternative, how would you like to give your feedback? I think it would be a one-to-one interview" (Focus group 1,pt2) Possibility to be led by someone independent *"What would be totally radical is after an appointment you had an independent person who came in and spoke to you"* (Focus group 7,pt1)	
	Phone calls	Desirable "*Phone calls also good"* (Interview 1)	-
Face to Face (n=21)			
	Face to face with advocate	Desirable *"How would you like to give your feedback? Face to face with an advocate* (Focus group 1,pt6) Believe feedback will be taken more seriously "*Face to face feedback would be quite meaningful to me as I feel like it's less easy to ignore feedback being given to you from a person in front of you than a sheet of paper/online"* (Online survey, pt1) Opportunity to avoid feeding back directly to those involved in care "*Face to face feedback would be quite meaningful to me as I feel like it's less easy to ignore feedback… however, I'd not want to give feedback to the person who provided my treatment at all"* (Online survey, pt1)	
	Face to face with psychiatrist	Desirable "*Well everybody's different aren't they but personally, I'd like to do it face to face actually, face to face would be lovely"* (Interview 1) *"Isn't it very difficult to give feedback directly to the person whose feedback it is?* Participant 2: *I thought it would be easier"* (Focus group 3, pt2&5) Similarity with other areas of life	Difficulty *"You've got to be pretty tough to say something they wouldn't want to hear in that situation even if it was true"* (Focus group 3,pt5) "*I would personally find it hard to give direct feedback particularly if I were unhappy"* (Focus group 4,pt3)

	"*I think directly would always be better, you know if somebody's got a problem with us at work or any other arena in life, we'd like to discuss it with them directly"* (Focus group 4 ,pt5) Individuality *"Another number, another form, but I think if you're actually able to speak to them as well that would be good"* (Focus group 3,pt3) Ability to see reaction *"*Interviewer: why is face to face your preferred method? Participant: *Because I would like to see how they react…"* (Interview 1) Confirmation of being heard *"To try and work out for myself do they think they're listening to me, do they seem to be hearing me? Because if I fill out a piece of paper I know most people aren't going to have the time to read it and even if they did, it would just be a quick skim over and then it will be forgotten about… Sat face to face with a client in the room would be a lot more difficult to kind of hide it under the carpet"* (Interview 1)	Confidence *"I think for it to work and for them to actually listen would have to be a case of actually giving it face to face, so people are not going to have the confidence to do that unfortunately because psychiatrist are bullies a lot of them, so people are not going to have the confidence to face them"* (Interview 1) Identification "*Not face to face, I wouldn't want to be identified at all, it would have to be completely anonymised"* (Online survey,pt4) Dishonesty *"Not face-to-face- (makes being honest when you have negative feedback) very difficult"* (Online survey,pt11)
Other		
Third Party (n=8)	Independent *"It has to be independent, it's really important to hold that space and hold it well"* (Focus group 5,pt11)	
Paper based survey (n=6)	Preference *"I would just prefer a piece of paper?"* (Focus group 8,pt2)	Not first choice *"I would be prepared to give feedback on paper but it wouldn't be my ideal choice"* (Focus group 1,pt4)
Pictures (n=3)	*"I've seen people use pictures"* (Focus group 1,pt1)	
Emotion or feedback tree (n=2)	Creative/visual "*I think they're called trees of hope or something, patients are asked to write comments about how they feel their care has been and there's no compulsion but it's then put on the wall as a tree with lots of leaves and the comments are on the leaves"* (Focus group 1,pt4)	

Appendix 10 Psychiatrist interview and focus group topic guide

1. Based on your experience, what do you think is most helpful to receive patient feedback on as a practising psychiatrist? What matters most in a psychiatrist?
2. How would you like to receive patient feedback if at all?
3. When would be best to for you to receive patient feedback if at all?
4. Is there anything that would motivate you to engage with patient feedback more?
5. What are your current perceptions of the existing feedback tools used in revalidation?
6. Could patient feedback be made more useful for psychiatrists? If so, how?
7. Is there anything you would need to know before you reflected on your feedback? If so, what?
8. Is there anything else you would like to add?

Appendix 11 Psychiatrist research invitation



WORKING TO IMPROVE

PATIENT FEEDBACK IN PSYCHIATRY

WHAT WOULD YOU LIKE TO RECEIVE PATIENT FEEDBACK ON? HOW WOULD YOU LIKE TO RECEIVE IF AT ALL? WHEN? WHY?

TELEPHONE OR FACE TO FACE INTERVIEWS.

30-45 MINUTES.

EMAIL:
REBECCA.BAINES@PLYMOUTH.AC.UK
01752 586824

Appendix 12 Changes to coding framework of psychiatrist data following co-production of analysis

Changes made to psychiatrist coding framework:

Theme: Problems with existing tools

1. Created new theme of process
2. Moved concerns of anonymity to process
3. Moved ‘not needed’ to purpose
4. Moved ‘shite’ to purpose
5. Renamed purpose to perceived purpose
6. Moved feedback fatigue to process
7. Moved lack of opportunity to process
8. Moved frequency to process
9. Moved tick box exercise to perceived purpose
10. Moved response rate to process
11. Moved ‘focus on negative’ to process
12. Moved scoring to design
13. Renamed score to ‘unhelpful scoring’
14. Moved bench marking to process
15. Merged lack of detail to solutions - specific

Total changes made: 1 creation, 1 merge, 2 renamed, 11 moves.

Theme: power and control

1. Merged language into new subtheme under power or control
2. Created taught to control

Total changes made: 1 merge, 1 creation

Theme: potential to be valuable

1. Moved to perceived purpose

Total changes made: 1 move

Theme: no feedback in training

1. Moved to problems with existing tools – process

Total changes made: 1 move

Theme: individual from the system:

1. Moved to process

Total changes made: 1 move

Theme: assumptions

1. Validity and validated merged
2. Renamed negative to negative feedback only
3. Moved definition of proper feedback to validity

Total changes made: 1 merge, 1 renamed, 1 change

Theme: solutions

1. Created process
2. Moved Enhanced opportunity to process
3. Moved random selection to process
4. Created design
5. Moved feedback loop to design
6. Moved mix of open and closed questions to design
7. Moved informal to process
8. Moved choice of who completes it to process
9. Moved celebrate good practice to design
10. Moved opportunity to do it face to face to process
11. Moved benchmark to process
12. Moved tailored to design
13. Moved interpreted differently to process
14. Moved carer feedback inclusion to design
15. Moved retrospective to process
16. Created content
17. Moved what helped what didn’t to content
18. Moved instruction to design
19. Moved secretary involvement to process
20. Moved other outcome measures to content
21. Moved simplify to design
22. Moved improving access to design
23. Moved patient involvement to design
24. Moved focus on reflection to process
25. Moved narrative responses to design
26. Moved embed to culture
27. Moved simplistic button push to design
28. Moved positive feedback mechanism to design
29. Moved ability to make changes to empower
30. Moved short to design
31. Moved patterns to process
32. Moved focus group to process
33. Moved flexibility to ask questions to content
34. Moved real time feedback to process
35. Moved specific to design
36. Moved tailored to specific
37. Moved focus group to opportunity to do it face to face
38. Merged celebrate good practice to positive feedback mechanism
39. Moved instruction on what to feedback on to content
40. Merged what helped what didn’t help into suggested improvements
41. Moved areas of feedback to content
42. Created patient choice
43. Renamed continuity to follow up with patients
44. Created third part involvement
45. Moved random selection to third party
46. Moved secretary help to third party

Total changes made: 1 renamed, 2 merge, 5 created, 38 moves

Theme: areas of feedback

1. Moved questions answered to being heard
2. Moved listened to too being heard
3. Moved understanding to relationship between
4. Moved communication to relationship
5. Moved being heard to relationships
6. Moved helpful to relationship between
7. Moved comfortable to relationship between
8. Moved areas of feedback to solutions
9. Renamed areas of feedback to desirable areas of feedback

Total changes made: 1 rename, 8 moves

Theme: changes made

No changes made.

Theme: discipline specific

No changes made.

Theme: implications

1. Moved implications to problems with existing patient feedback tools

Total changes made: 1 change

Theme: summative debate

No changes made.

Appendix 13 Pre-circulated co-production information pack

Improving patient feedback for patients and psychiatrists

Background

Thank you for agreeing to take part in this workshop. Your time and input is greatly appreciated.

The aim of the workshop is to co-design the ACP 360 tool based on some research findings John (a mental health patient research partner) and I have been working on over the past three years.

We have spoken to over 110 patients and psychiatrists about their experiences of using/collecting patient feedback for revalidation purposes. We have also analysed online feedback and survey results from over 1,600 psychiatrists.

From this data, we have identified a number of issues that could be resolved to help improve the value and acceptability of the ACP 360 tool from both a patient and psychiatrist perspective.

Research findings to date

For example, patients and psychiatrists reported that the **design** of the current patient feedback tool is:

"Too long"

Doesn't contain a "feedback loop"

Is "a tick box exercise"

Contains "irrelevant questions" and assumes what matters most to patients

Provides limited space for "free text comments" that are considered most helpful

Isn't colourful enough

Uses unhelpful and unclear scoring

And provides limited space for praise

Patients and psychiatrists also raised concerns about the feedback **process.** Many patients and psychiatrists felt that there was:

Limited opportunity for patients to provide feedback when **they wanted** to, not when they were **asked** to

A significant fear of repercussions for patients and psychiatrists – if I give/get critical feedback, that will affect the care that I receive/my revalidation decision

A lack of understanding:
- What was it for?
- Who was it for?
- Who would see it? and
- How is it going to be used?

There were also concerns that:

Patients would be overly positive because of fears of repercussions

Psychiatrists could “game” the system by selecting (and excluding) patients

And some feedback would be “pathologised”

Based on these issues, patients and psychiatrists suggested a number of ways that patient feedback could be improved. These are listed as a checklist below.

If you have any thoughts or suggestions about how these solutions could be achieved, please write them down in the column provided. We can then discuss them at the workshop. We have also provided a copy of the current ACP 360 tool for your information.

Suggestion	**Your thoughts/suggestions on how this could be achieved?**
Be designed in co-production with patients and psychiatrists	
Make things “*simple, easy to read and understand*”	
Use the word “*psychiatrists or better yet the name of the psychiatrist*”	
Provide flexibility and choice about how and when people do it	
Have “*a mixture of both*” word and number questions as “*the use of multiple choice questions alongside a couple of open ended ones is more appealing and likely to get more responses*”	
Provide sufficient space for free text comments so “*patents can use their own words*”; “*I’d prefer to have something short and a large comments box so I could freely write about my experiences rather than tick lots of boxes that don’t really feel like I can express my feedback*”	
Place multiple choice questions “*underneath*” free text comments to disrupt habitual ticking	
Use scales that are easy to understand	
Provide space for praise and critique “*encouraged to give balanced feedback*”	
Make it colourful – “*make the actual thing interesting*”	
Provide space for carer and family member input	
Incorporate pictures where possible	
Keep it “*reasonably short*”	
Build in a “*feedback loop*”	
Provide reassurance of anonymity and confidentiality	
Offer help if needed “*maybe something there right at the beginning do you need help fling in this questionnaire?*”	
Being able to submit the feedback in an anonymised way “*free post envelope, box in the waiting tool*”	
Allow feedback to be “*patient initiated*” not psychiatrist dependent – “*feedback at any time*”; “multiple opportunities”	

Provide information that it is a "*choice*" to complete	
Provide assurance "*that your treatment won't be compromised in anyway because of what you say"; "there won't be any repercussions"*	
Provide information about timeframes or what interactions patients should base their feedback on: "*I always assume it's about the last time I spoke to the psychiatrist but that's not made clear enough"*	
Provide information about what it is going to be used for: *"How will this feedback be used? What do they do with it? What happens to it?"; "case notes?"*	
Provide information about the importance of patient feedback for both patients and psychiatrists *"it's got to be communicated that their feedback is important, you know there are benefits to you filling this form in"; "if a psychiatrist actually gave the message it's really, really beneficial for both me and you that you fill this in because…"*	
Provide information or advice on how to make patient feedback effective *"encourage feedback that is specific"; "constructive, give ideas/ways of improving"*	

Finally, patients and psychiatrists were asked the question of what mattered most to them in a psychiatrist. On the next page, there is a table of the words that were most frequently described. Please circle or rank those that you consider to be of most importance. This will help to begin our workshop session.

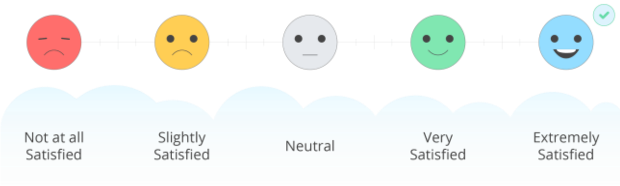
Thank you once again for agreeing to take part in this workshop and for taking the time to read through this document. We are really looking forward to meeting you on the 14th of June.

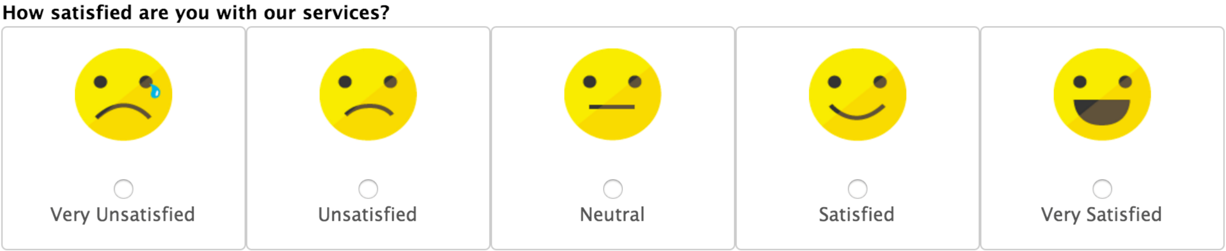
Any questions or queries, please do not hesitate to contact me Rebecca.baines@plymouth.ac.uk or 07508916450.

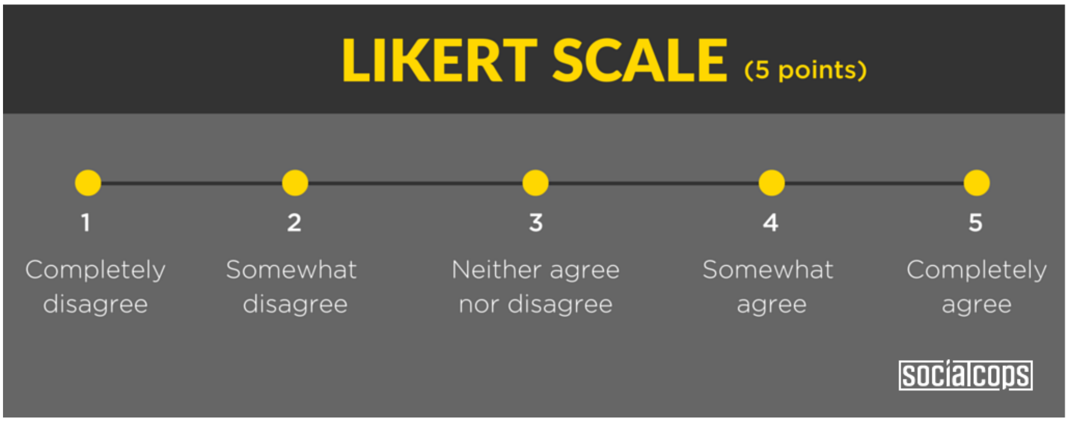
Best wishes,

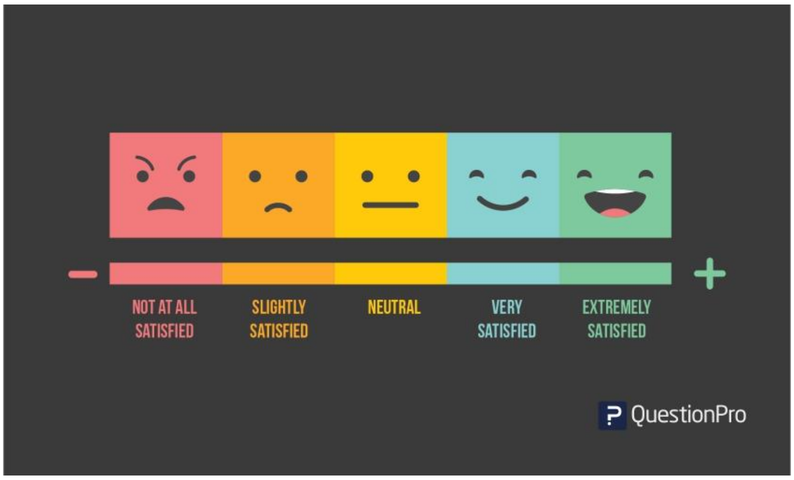
1. Accurate note taking
    - *Ability to see notes*
2. Approachable
3. Attentive
4. Authentic
5. Caring
6. Clear communication
    - *Clear explanation*
7. Comfortable
8. Compassionate
9. Confident in abilities
10. Dedicated
11. Discusses medication
    - *discusses side effects of medication*
    - *possibility of coming off medication*
    - *reasons why they are being medicated*
    - *reviewing medication*
12. Empathetic
13. Encouraging
14. Enthusiastic
15. Equal partnership
16. Fair
17. Feeling safe
18. Feeling valued
19. Gentle
20. Helpful
21. Honest
22. Human dress code
23. Inspires confidence
24. Involves
    - *Involves carers and family members*
    - *Shared decision making*
25. Kind
26. Knowledgeable
27. Modesty
28. Non-judgemental
    - *Open-minded*
29. Not feeling rushed
30. Offers help
31. Offers hope
32. Offers reassurance
33. Open
34. Passionate
35. Patient
36. Patient centred
37. Polite
38. Provides feedback on progress
    Offers praise
39. Reads patient history
40. Reliable
41. Respect
42. Supportive
43. Sympathetic
44. Timely
45. Tolerant
46. Treated holistically not just the condition
    - *Treated as an individual*
    - *Treated like a human being*
47. Trust
48. Understanding
49. Understanding of systems or services external to psychiatrist
50. Warm
51. Welcoming
52. Willingness to really listen

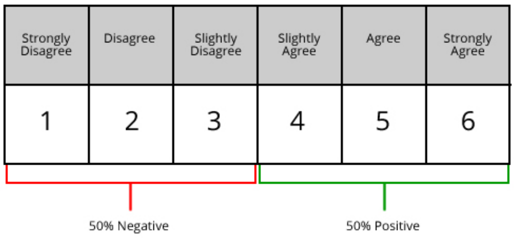
Scale examples







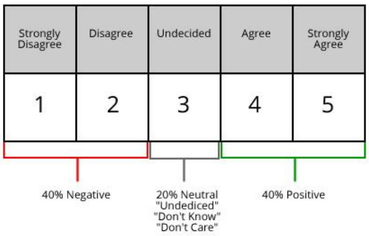




Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree
1	2	3	4	5	6

50% Negative

50% Positive

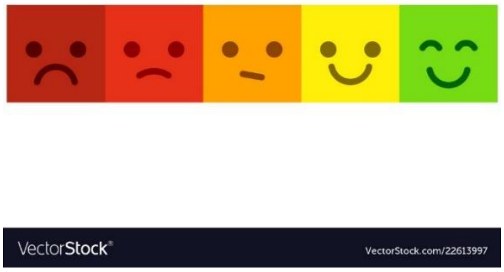


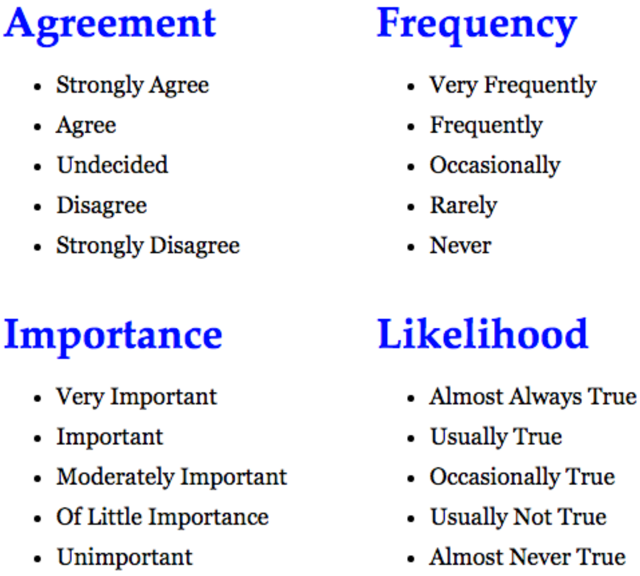
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1	2	3	4	5

40% Negative

20% Neutral
"Undediced"
"Don't Know"
"Don't Care"

40% Positive





Agreement

- Strongly Agree
- Agree
- Undecided
- Disagree
- Strongly Disagree

Frequency

- Very Frequently
- Frequently
- Occasionally
- Rarely
- Never

Importance

- Very Important
- Important
- Moderately Important
- Of Little Importance
- Unimportant

Likelihood

- Almost Always True
- Usually True
- Occasionally True
- Usually Not True
- Almost Never True

Cut and stick exercise

Information:

- Psychiatrist or name of psychiatrist, choice, explanation of importance, assurance that it is anonymous and confidential, how will it be used, no repercussions on care, timeframe, help information, advice on how to make feedback effective

Carer/family member input: are you filling in this questionnaire as a patient, carer, family member or other/free text comment, if you are a carer/family member, please use this box to describe your experience

Free text comment:

e.g. How was your experience with Dr….?

Free text comment:

e.g. What, if anything did Dr…. do that you found helpful?

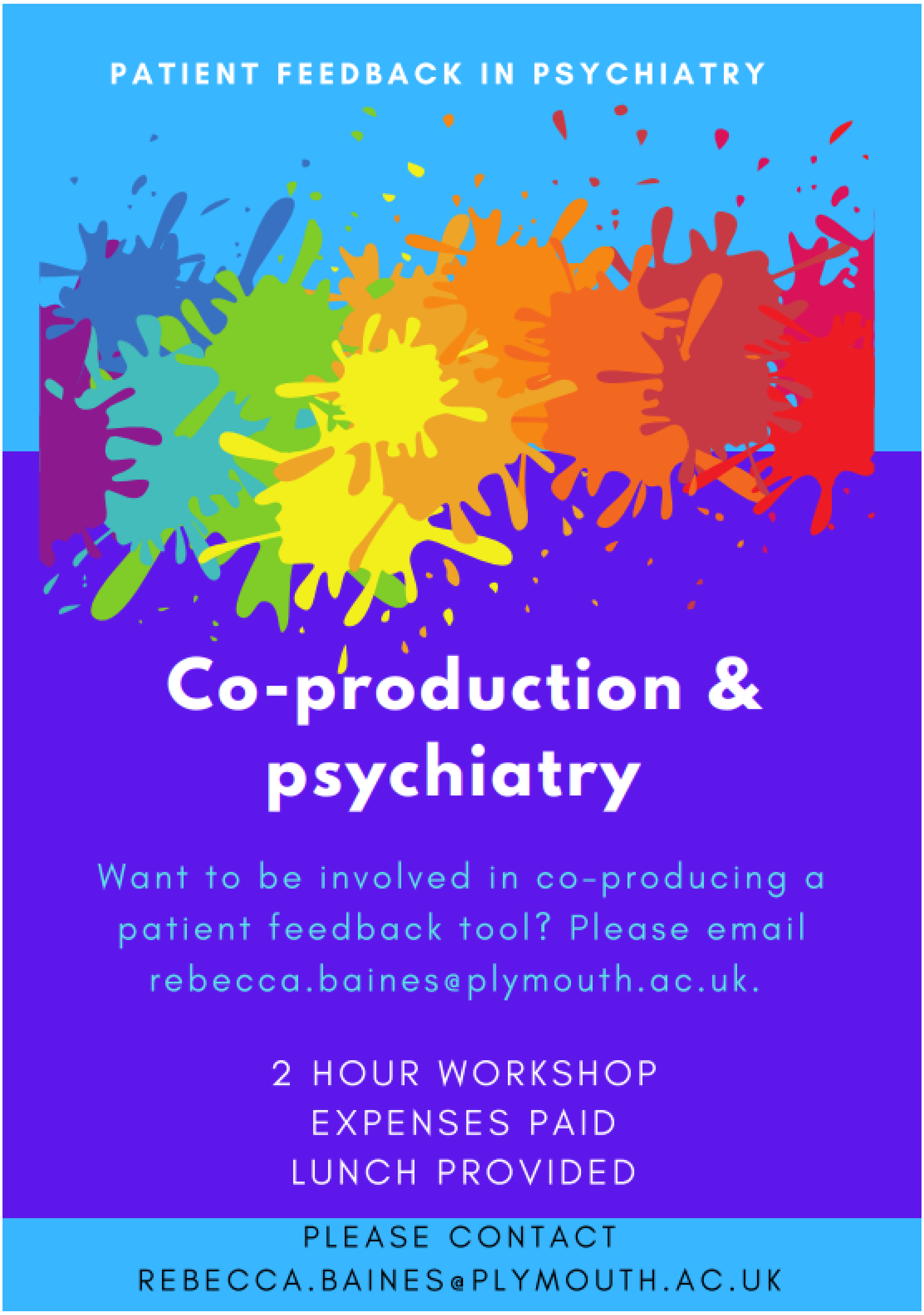
Listened
Involved me in all decisions
Made me feel comfortable
Treated me with respect
Treated me as an equal
Cared
Communicated clearly
Discussed side effects of medication
Was encouraging
Was non judgemental

Free text comment:

e.g. What, if anything could Dr…. do to improve? How might they do this? Please provide some examples wherever possible.

Multiple choice questions with scales (4-8)

Appendix 14 Research invitation for co-production and refinement workshop



PATIENT FEEDBACK IN PSYCHIATRY

Co-production & psychiatry

Want to be involved in co-producing a patient feedback tool? Please email rebecca.baines@plymouth.ac.uk.

2 HOUR WORKSHOP
EXPENSES PAID
LUNCH PROVIDED

PLEASE CONTACT
REBECCA.BAINES@PLYMOUTH.AC.UK

PATIENT FEEDBACK IN PSYCHIATRY

Co-production & psychiatry

Want to be involved in reviewing and refining patient feedback tools for practising psychiatrists? Please email rebecca.baines@plymouth.ac.uk.

2 HOUR WORKSHOP
REFRESHMENTS PROVIDED

PLEASE CONTACT
REBECCA.BAINES@PLYMOUTH.AC.UK

Appendix 15 Comparison of refined co-produced information sheet and patient feedback tool

Participant suggestions	Checklist	Yes/No
Content		
Use the word "*psychiatrists or better yet the name of the psychiatrist*"	Does the tool use the word psychiatrist or name of the psychiatrist?	**Yes**
Provide space for praise and critique "*encouraged to give balanced feedback*"	Does the tool ask for balanced or positive and critical feedback?	**Yes**
Provide reassurance of anonymity and confidentiality	Does the tool provide reassurances about feedback being anonymous and confidential?	**Yes**
Use scales that are easy to understand* *RB to provide a list of examples	Are the scales used for the multiple-choice questions easy to understand? Are they clear/purposeful?	**Yes**
Provide space for carer and family member input** **either, are you filling this in as a patient or family member/carer **or** if you have/are a carer or family member and would like to provide some feedback, please use the space provided below.	Does the tool allow for carer/family member input?	**Yes**
Provide information that it is a "*choice*" to complete	Is it clear that it is a choice to complete the tool?	**Yes**
Provide assurance "*that your treatment won't be compromised in anyway because of what you say*"; "*there won't be any repercussions*"	Does the tool provide assurance that peoples care will **not** be affected by the content of their feedback?	**Yes**
Provide information about timeframes or what interactions patients should base their feedback on: "*I always assume it's about the last time I spoke to the psychiatrist but that's not made clear enough*"	Is the timeframe patients should be basing their feedback on, (i.e. their last interaction, the last six months, their first interaction etc.) made clear?	**Yes**
Provide information about what it is going to be used for: "*How will this feedback be used? What do they do with it? What happens to it?*"; "*case notes?*"	Is information provided about how the feedback will be used? Is this explanation clear?	**Yes** **Yes**
Provide information about the importance of patient feedback for both patients and psychiatrists "*it's got to be communicated that their feedback is important, you know there are benefits to you filling this form in*"; "*if a psychiatrist actually gave the*	Is the importance of patient feedback for both patient care and psychiatrists explained? Is this explanation clear and meaningful?	**Yes** **Yes**

message it's really, really beneficial for both me and you that you fill this in because…"		
Provide information or advice on how to make patient feedback effective "*encourage feedback that is specific*"; "*constructive, give ideas/ways of improving*"	Does the tool make it clear about how to give effective feedback?	**Yes**
Layout		
Have "*a mixture of both*" word and number questions as "*the use of multiple choice questions alongside a couple of open ended ones is more appealing and likely to get more responses*"	Does the feedback tool have a mixture of both free text and multiple-choice questions?	**Yes**
Provide sufficient space for free text comments so "*patents can use their own words*"; "*I'd prefer to have something short and a large comments box so I could freely write about my experiences rather than tick lots of boxes that don't really feel like I can express my feedback*"	Does the feedback tool provide sufficient space for free text comments?	**Yes**
Place multiple choice questions "*underneath*" free text comments to disrupt habitual ticking	Are the multiple choice questions underneath the free text comments?	**Yes** (on the whole)
Make it colourful – "*make the actual thing interesting*"	Is the patient feedback tool colourful?	**Yes**
Incorporate pictures where possible	If possible, does the patient feedback tool include pictures?	Not the **tool but the information sheet**
Process		
Provide flexibility and choice about how and when people do it	Do patients have a choice about how and when they complete the feedback?* *This may not be achievable in this workshop and require a policy change	**Unclear**
Being able to submit the feedback in an anonymised way "*free post envelope, box in the waiting room*"	Can patients freepost their questionnaire/leave it in a waiting room or designated area?	**Yes**
Allow feedback to be "*patient initiated*" not psychiatrist dependent – "*feedback at any time*"; "multiple opportunities"	Is the patient feedback tool available to patients at all times? Can they complete it independently of a feedback invitation?	**Unclear**
Sense checking at the end		
Make things "*simple, easy to read and understand*"	Is it simple, easy to read and understand?	**Yes**
Keep it "*reasonably short*"	Is the patient feedback tool short?	**Yes**
Build in a "*feedback loop*"	Is there a feedback loop?	**Unclear**

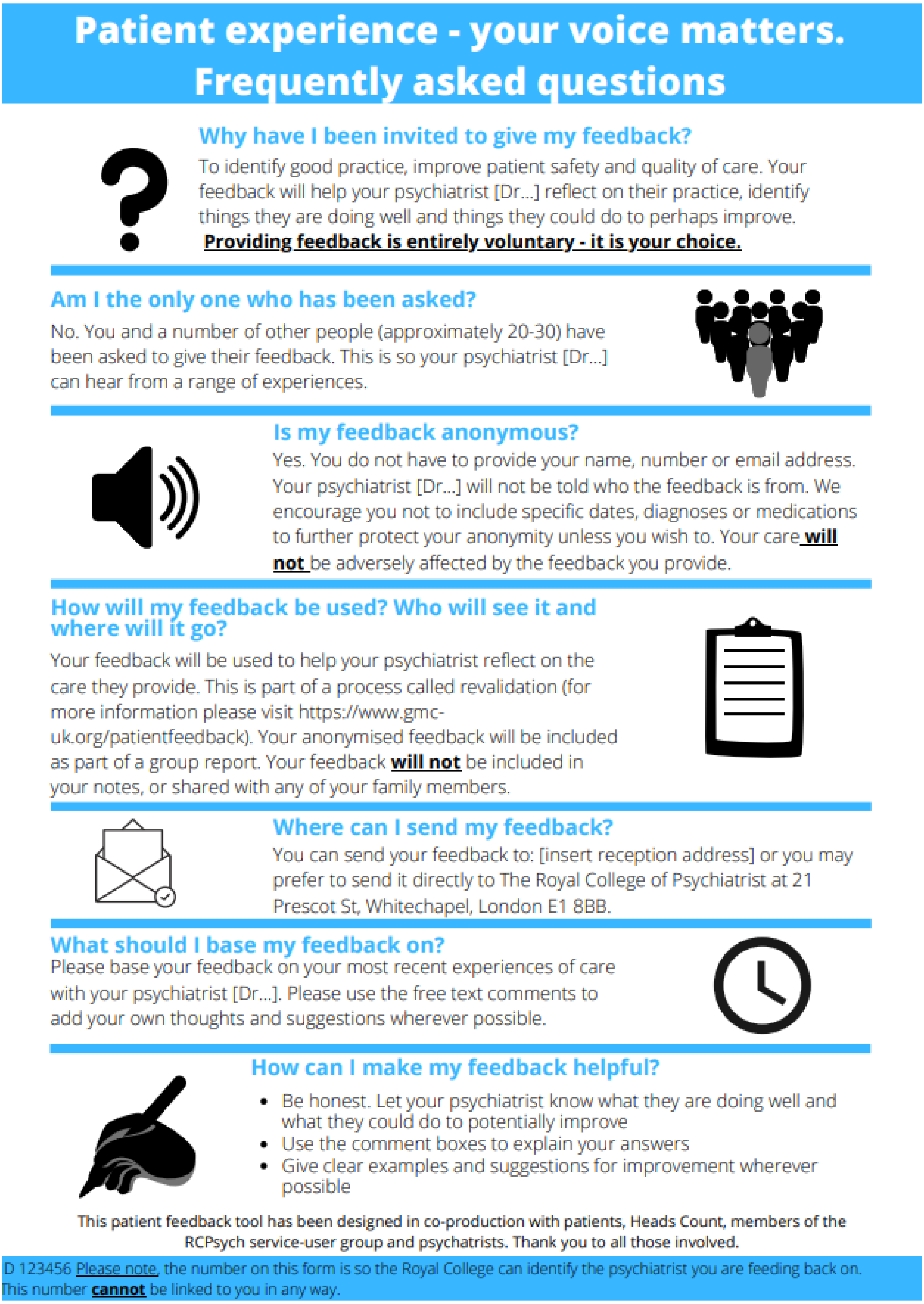
Appendix 16 Original ACP 360 tool

REMOVED DUE TO COPYRIGHT

Appendix 17 Hybrid information sheet and patient feedback tool now being used in revalidation processes

REMOVED DUE TO COPYRIGHT

Appendix 18 Co-produced information sheet and patient feedback tool



Patient experience - your voice matters. Frequently asked questions

Why have I been invited to give my feedback?

To identify good practice, improve patient safety and quality of care. Your feedback will help your psychiatrist [Dr...] reflect on their practice, identify things they are doing well and things they could do to perhaps improve.

Providing feedback is entirely voluntary - it is your choice.

Am I the only one who has been asked?

No. You and a number of other people (approximately 20-30) have been asked to give their feedback. This is so your psychiatrist [Dr...] can hear from a range of experiences.

Is my feedback anonymous?

Yes. You do not have to provide your name, number or email address. Your psychiatrist [Dr...] will not be told who the feedback is from. We encourage you not to include specific dates, diagnoses or medications to further protect your anonymity unless you wish to. Your care **will not** be adversely affected by the feedback you provide.

How will my feedback be used? Who will see it and where will it go?

Your feedback will be used to help your psychiatrist reflect on the care they provide. This is part of a process called revalidation (for more information please visit https://www.gmc-uk.org/patientfeedback). Your anonymised feedback will be included as part of a group report. Your feedback **will not** be included in your notes, or shared with any of your family members.

Where can I send my feedback?

You can send your feedback to: [insert reception address] or you may prefer to send it directly to The Royal College of Psychiatrist at 21 Prescot St, Whitechapel, London E1 8BB.

What should I base my feedback on?

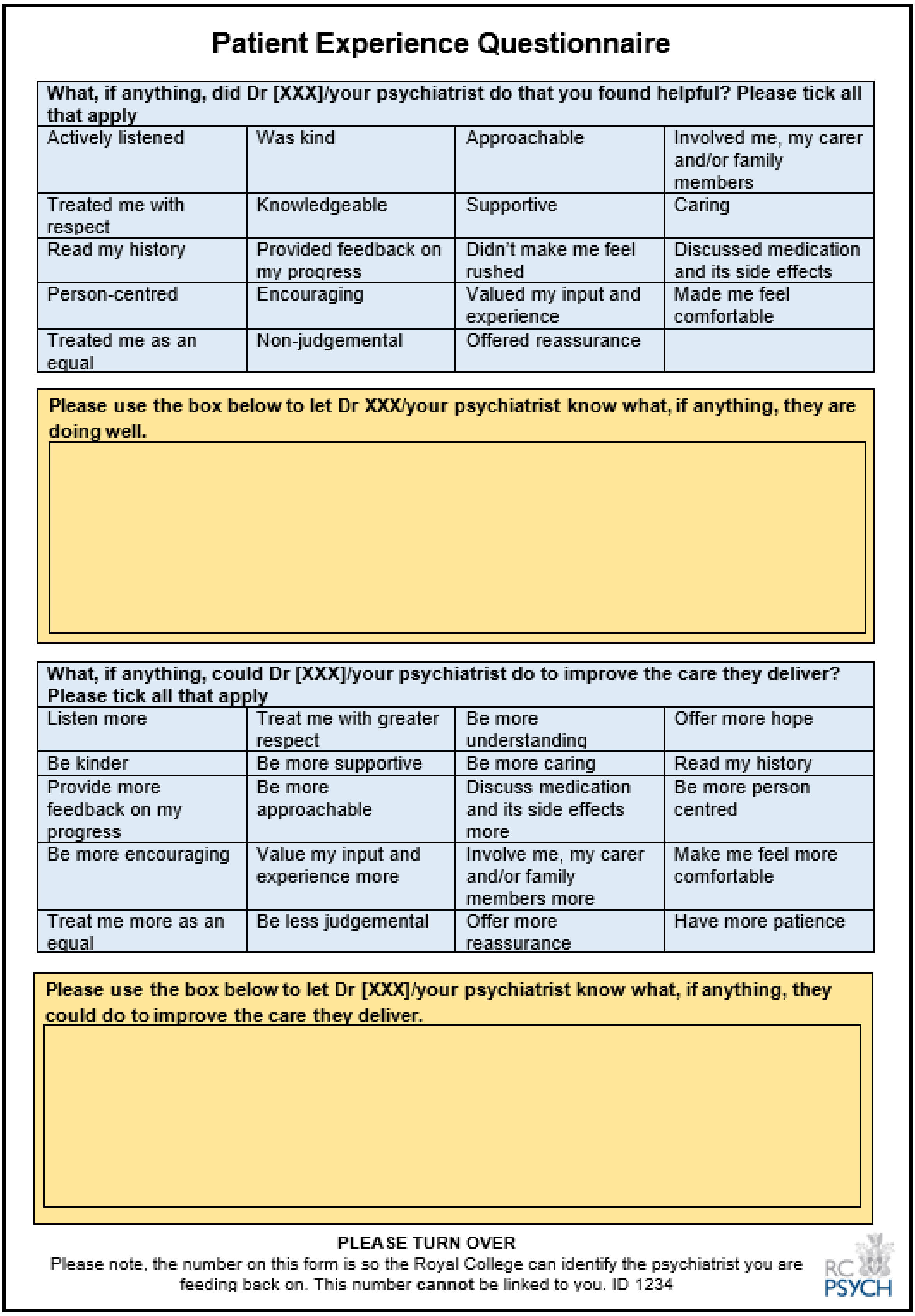
Please base your feedback on your most recent experiences of care with your psychiatrist [Dr...]. Please use the free text comments to add your own thoughts and suggestions wherever possible.

How can I make my feedback helpful?

- Be honest. Let your psychiatrist know what they are doing well and what they could do to potentially improve
- Use the comment boxes to explain your answers
- Give clear examples and suggestions for improvement wherever possible

This patient feedback tool has been designed in co-production with patients, Heads Count, members of the RCPsych service-user group and psychiatrists. Thank you to all those involved.

D 123456 Please note, the number on this form is so the Royal College can identify the psychiatrist you are feeding back on. This number **cannot** be linked to you in any way.



Patient Experience Questionnaire

What, if anything, did Dr [XXX]/your psychiatrist do that you found helpful? Please tick all that apply			
Actively listened	Was kind	Approachable	Involved me, my carer and/or family members
Treated me with respect	Knowledgeable	Supportive	Caring
Read my history	Provided feedback on my progress	Didn't make me feel rushed	Discussed medication and its side effects
Person-centred	Encouraging	Valued my input and experience	Made me feel comfortable
Treated me as an equal	Non-judgemental	Offered reassurance	

Please use the box below to let Dr XXX/your psychiatrist know what, if anything, they are doing well.

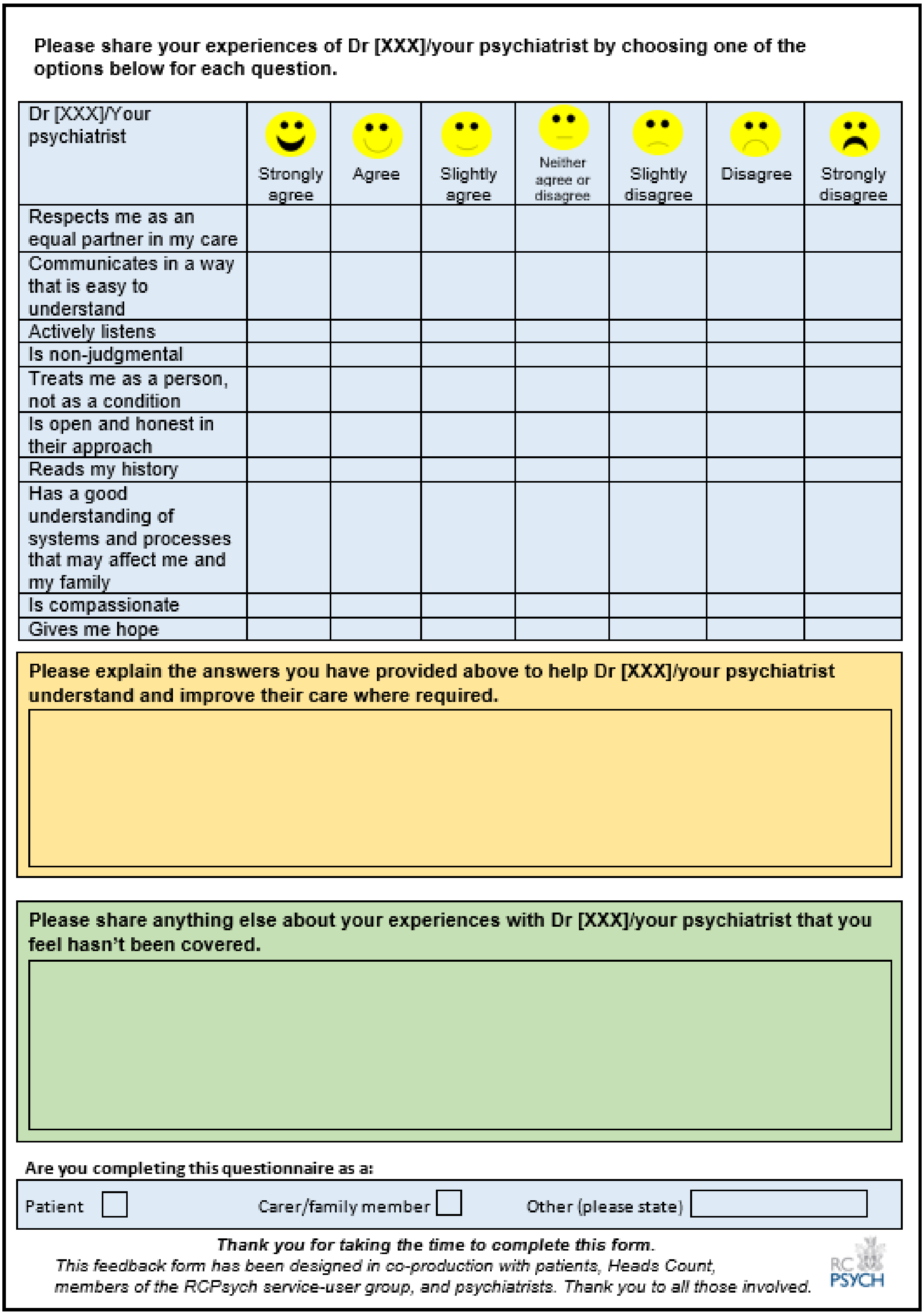
What, if anything, could Dr [XXX]/your psychiatrist do to improve the care they deliver? Please tick all that apply			
Listen more	Treat me with greater respect	Be more understanding	Offer more hope
Be kinder	Be more supportive	Be more caring	Read my history
Provide more feedback on my progress	Be more approachable	Discuss medication and its side effects more	Be more person centred
Be more encouraging	Value my input and experience more	Involve me, my carer and/or family members more	Make me feel more comfortable
Treat me more as an equal	Be less judgemental	Offer more reassurance	Have more patience

Please use the box below to let Dr [XXX]/your psychiatrist know what, if anything, they could do to improve the care they deliver.

PLEASE TURN OVER

Please note, the number on this form is so the Royal College can identify the psychiatrist you are feeding back on. This number **cannot** be linked to you. ID 1234

RC PSYCH



Please share your experiences of Dr [XXX]/your psychiatrist by choosing one of the options below for each question.

Dr [XXX]/Your psychiatrist	Strongly agree	Agree	Slightly agree	Neither agree or disagree	Slightly disagree	Disagree	Strongly disagree
Respects me as an equal partner in my care							
Communicates in a way that is easy to understand							
Actively listens							
Is non-judgmental							
Treats me as a person, not as a condition							
Is open and honest in their approach							
Reads my history							
Has a good understanding of systems and processes that may affect me and my family							
Is compassionate							
Gives me hope							

Please explain the answers you have provided above to help Dr [XXX]/your psychiatrist understand and improve their care where required.

Please share anything else about your experiences with Dr [XXX]/your psychiatrist that you feel hasn't been covered.

Are you completing this questionnaire as a:

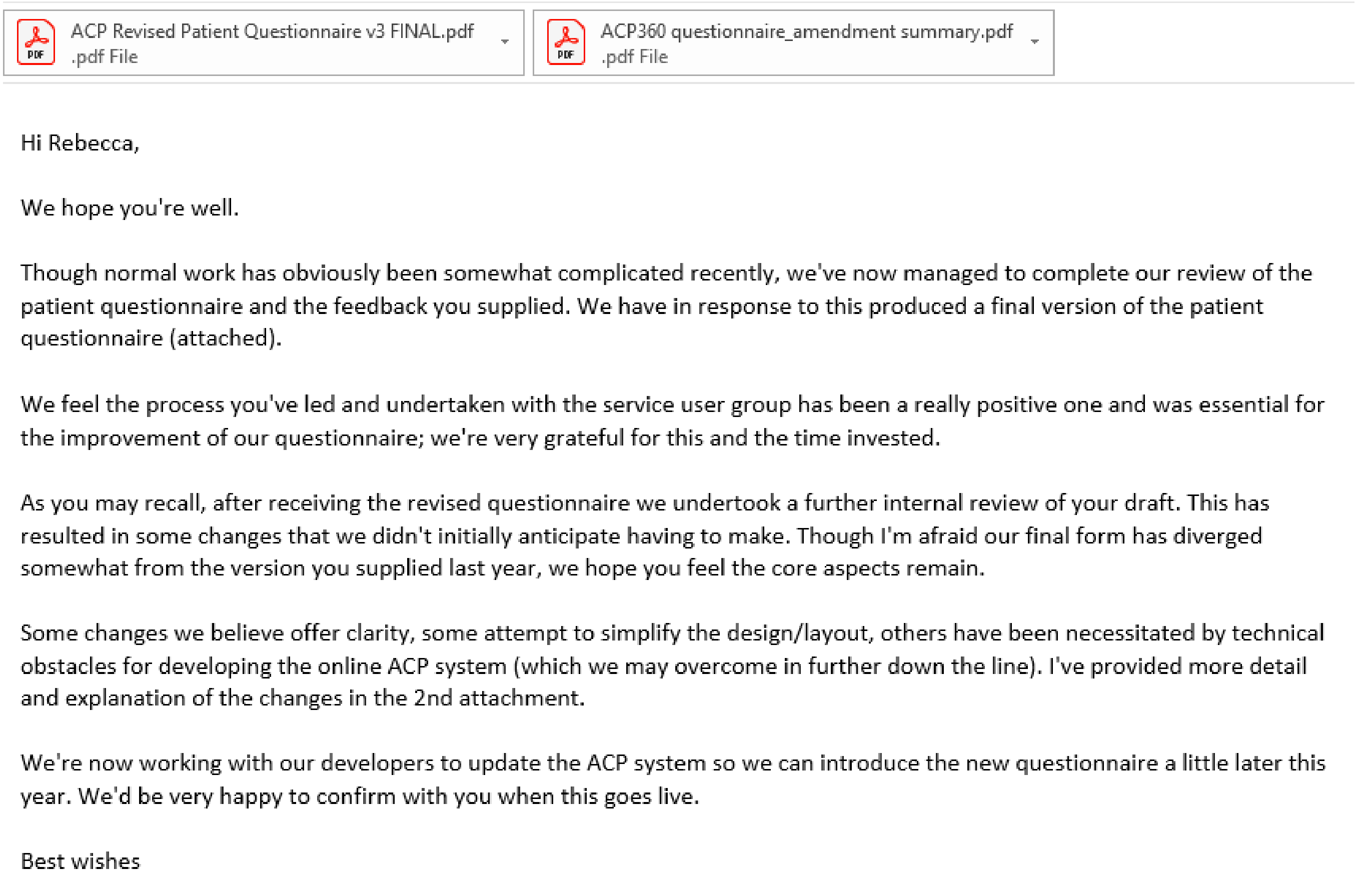
Patient ☐ Carer/family member ☐ Other (please state) ☐

Thank you for taking the time to complete this form.

This feedback form has been designed in co-production with patients, Heads Count, members of the RCPsych service-user group, and psychiatrists. Thank you to all those involved.

RC PSYCH

Appendix 19 Changes made by ACP 360 and provided justification



ACP Revised Patient Questionnaire v3 FINAL.pdf
.pdf File

ACP360 questionnaire_amendment summary.pdf
.pdf File

Hi Rebecca,

We hope you're well.

Though normal work has obviously been somewhat complicated recently, we've now managed to complete our review of the patient questionnaire and the feedback you supplied. We have in response to this produced a final version of the patient questionnaire (attached).

We feel the process you've led and undertaken with the service user group has been a really positive one and was essential for the improvement of our questionnaire; we're very grateful for this and the time invested.

As you may recall, after receiving the revised questionnaire we undertook a further internal review of your draft. This has resulted in some changes that we didn't initially anticipate having to make. Though I'm afraid our final form has diverged somewhat from the version you supplied last year, we hope you feel the core aspects remain.

Some changes we believe offer clarity, some attempt to simplify the design/layout, others have been necessitated by technical obstacles for developing the online ACP system (which we may overcome in further down the line). I've provided more detail and explanation of the changes in the 2nd attachment.

We're now working with our developers to update the ACP system so we can introduce the new questionnaire a little later this year. We'd be very happy to confirm with you when this goes live.

Best wishes

ACP360 patient questionnaire – final amendment summary April 2020

Amendment	***Reason***
Information page layout, text, icons	To aid readability, reduce word count and align with branding guidelines.
Safeguarding statement	The college has a duty of care and safeguarding policy, requiring appropriate action to protect the safety of a vulnerable person if we receive information of concern. Identification will be dependent on information volunteered (it may not always be possible to identify them).
Removal of the 'word search' question (page 2)	Addition of this functionality is a challenge for system development. Reduction from 3 pages to 2 pages reduces risk of lost/separated pages of printed questionnaires (the majority of returns).
Free text boxes • 'what your psychiatrist is doing well/ could improve' - moved to end • box to explain scores – combined • box for any other comments - removed	To create a more concise questionnaire, the option to add an explanation of scores has been combined with the free text boxes on what's been done well/could be improved. The other feedback box was removed for similar reasons.
Removal of coloured backgrounds to boxes	Patient questionnaires are typically printed locally and not in colour.
Removed multiple options on who is completing the questionnaire	To reduce potential inconsistency/simplify reporting, just one option remains to confirm if the form is completed on behalf of a patient.
Change of 'Respects me as an equal partner in my care'	We thought this was a 2-part question; that respect and being treated equally could be seen as two separate questions.
Removal of 'Actively listens'	We thought that 'Listens well to what I say' incorporates active listening and is more reader friendly.
Removal of 'Treats me as a person, not a condition'	We felt not all patients would understand what this question might be referring to, and not all patients believe they have a 'condition' or that they are ill.
Change of 'Reads my history'	By expanding this, we thought it would make it clearer that it can refer to background history, treatment history etc.

Change of 'Has a good understanding of systems and processes that may affect me and my family'	We felt this isn't very reader friendly and it's not clear what 'systems and processes' refer to, so we split it into two questions based on the patient comments within RB's report (providing holistic care and ensuring continuity of care).
Removal of 'Is compassionate'	We thought this is captured in the respect, equal partner and non-judgemental statements.

Appendix 20 Semi-structured interview topic guide

1. How did you find that experience?
2. What, if anything, did you like about the information reviewed?
3. What, if anything, did you find difficult or confusing?
4. Which feedback tool and information sheet is most valuable to you? Why?
5. If we were to put them in order of value and acceptability, what would you say and why?
6. Based on the information I have just shared, do you think co-production makes a difference?

Appendix 21 Think aloud research invitation email

Making patient feedback work for all

RESEARCH OPPORTUNITY

PATIENT FEEDBACK IN PSYCHIATRY

Explore three patient feedback tools and share your thoughts, views and opinions.

30-45 MINUTES
CAN BE CONDUCTED OVER THE PHONE, ZOOM OR SKYPE
NO RIGHT OR WRONG ANSWERS!

Please email
rebecca.baines@plymouth.ac.uk
to find out more

Appendix 22 Final ethical amendment approval letter

UNIVERSITY OF
PLYMOUTH

20th July 2020

Rebecca Baines
School of Nursing and Midwifery
Faculty of Health
C506, Portland Square
University of Plymouth
Drake Circus
Plymouth
PL4 8AA

Dear Rebecca

Application for Amendment Approval by Faculty Research Ethics and Integrity Committee

Reference Number: **19/20-1286**
Original Reference Number: **17/18-885**
Application Title: **The impact of Patient and Public Involvement in the design, delivery, and evaluation of patient feedback for revalidating psychiatrists: a bottom-up approach**

The Chair has granted ethical approval for the amendment to your research originally approved on 8th December 2017.

This approval is until 31st October 2020. Please note that if you wish to make any MAJOR changes to your research you must inform the Committee. Please contact the Faculty Research Administrator, Maurice Bottomley (email hhsethics@plymouth.ac.uk).

Yours sincerely

Professor Sarah Neill,
PhD, PGD Res. Deg. Sup., PGDE, MSc, BSc (Hons), RGN, RSCN, RNT
Professor of Nursing
Co-Chair, Research Ethics and Integrity Committee - Faculty of Health