The Value of a Person-Centred Approach to Intervention Format and Delivery in Facilitating Patient-Led Identification, Expression and the Addressing of Unmet Support Needs in Patients with Long-Term Conditions

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Declaration

This thesis is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. I further state that no substantial part of my thesis has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. It does not exceed the prescribed word limit for the relevant Degree Committee.
Abstract

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Background

Strategy documents recommend a patient-led approach to identifying and addressing the unmet support needs of patients with long-term conditions. Further recommendations advocate an intervention-model to systematically assess need based around the use of a needs-assessment questionnaire or prompt completed with, or by, the patient, and a patient-HCP conversation. However, despite enthusiasm for these interventions within the qualitative literature, their usefulness in supporting a patient-led approach remains unclear, and there has been limited attention to exploring the case for an alternative person-centred approach to intervention format and delivery.

Aim

The aim of this thesis is to critically analyse the nature and usefulness of the Systematic Needs Assessment intervention model as a means to enable a patient-led approach to identifying, expressing and addressing unmet support need, and to make the case for an alternative person-centred approach to intervention format and delivery. In addition, the thesis aims to investigate whether, and how, this alternative approach can support patient-led identification and expression of their unmet support needs in practice through the exploration of an ‘exemplar’: the Support Needs Approach for Patients (SNAP): consisting of a five-stage approach to delivering person-centred care underpinned by the SNAP Tool.

Methods

A mixed methods approach was adopted involving three stages:
1) a thematic synthesis of the relevant qualitative literature;
2) a mixed methods study to assess the face, content and criterion validity of the SNAP Tool;
3) a qualitative study to explore the use of SNAP in clinical practice.

Results

The thematic synthesis identified that interventions based around the systematic assessment of patient need tend to support enhanced patient involvement in an HCP-led approach to identifying and addressing support need, rather than a more person-centred patient-led process. Findings also suggested this was a function of intervention characteristics that emphasised the HCP role (e.g. use of instruments designed to measure symptoms). In contrast, elements of a patient-led approach were evident where interventions incorporated features orientated towards person-centred care and support needs (rather than symptoms). Together these limitations exposed a weakness in the evidence base of existing interventions, and lent support for the exploration of an alternative person-centred approach to intervention format and delivery. Consideration of this alternative person-centred approach, via an exemplar intervention (SNAP,) found that SNAP had value in clinical practice and was able to support a person-centred patient-led process. Validity testing of the SNAP Tool found it has good face, content and criterion validity. The qualitative investigation of SNAP further identified that, when delivered as intended, SNAP operationalised person-centred care thereby enabling patient-led identification, expression, and addressing of their unmet support needs.

Conclusion

This thesis found that interventions based on a Systematic Needs Assessment intervention model are orientated to supporting enhanced patient involvement in an HCP-led approach to identifying and addressing patient support need, rather than a patient-led approach. In contrast, SNAP provides an alternative person-centred approach to intervention format and delivery that can directly enable patient-led identification, expression, and addressing of their unmet support needs.
Acknowledgements

This PhD was based on work undertaken for the wider Marie-Curie SNAP 2 Study designed to test the validity of the SNAP Tool and examine the feasibility of delivering SNAP in clinical practice. Although this PhD was self-funded, the Marie Curie study funded my position as a Research Assistant, which in turn enabled me to undertake this PhD. In addition the NIHR School for Primary Care Research provided funding that supported additional work on the PhD once the Marie Curie study was complete.

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Chapter 1: Introduction

1.1 Introduction

Identifying, expressing and addressing a need for support in managing life with a long-term condition ought to be straightforward between patients and health care professionals (HCPs). In reality, however, these conversations rarely happen effectively. Patients face a range of taken-for-granted beliefs and clinical working practices that prevent, or limit, opportunities for discussion of support needs. Similarly, when patients do ask for help the response is usually determined through the HCPs’ clinical or organisational lens rather than through a shared discussion and response by the patient and HCP together. Initiatives to address this have focused on the use of clinical interventions to proactively engage patients in this aspect of their care: typically, via a Systematic Needs Assessment intervention model based around the use of a needs assessment questionnaire to support a patient-HCP conversation in order to explore and address needs. The focus of this thesis is on analysing the nature and usefulness of these systematic interventions, whilst making the case for a more person-centred approach to intervention format and delivery. In addition, the thesis investigates whether, and how, this alternative approach can support a patient-led approach to identifying, expressing and addressing their unmet support needs through the exploration of an ‘exemplar’ – the Support Needs Approach for Patients (SNAP). A pragmatic, mixed-method approach was adopted to enable choice of research methods appropriate to answering each individual research question.

1.2 Key definitions

Within the health and social care literature many terms are used to describe interventions, long-term conditions, support needs and person-centred care. The definitions adopted here are presented below in Box 1 to facilitate reading and understanding of the thesis. Related terminology commonly used in the wider literature, and the rationale for the definitions below, are discussed further in Chapters 2 and 3.
People with long-term conditions often need help to manage life with their illness (i.e. they have support needs), however many of these needs remain unacknowledged and unaddressed. In response, clinical strategy documents have recommended a patient-led approach to identifying and addressing individual needs, enabling a response that is holistic and tailored to the patient’s circumstances.\textsuperscript{2, 8} This, in turn, resonates with wider moves within the health care literature away from a traditional biomedical model of care delivery towards a more person-centred approach.\textsuperscript{9}

Despite the enthusiasm in the clinical literature for directly involving patients in identifying and managing their support needs, it is widely recognised that there are a number of key challenges to delivering this approach in practice. Patients face a range of taken-for-granted beliefs and clinical working practices that hinder their ability to raise, and negotiate responses to, their individual concerns and support needs. For example, patients often lack the opportunity to express their support needs within a consultation,\textsuperscript{10, 11} or alternatively they may feel that their particular issues lack legitimacy within a medical setting.\textsuperscript{12, 13}

\begin{table}[h]
\centering
\begin{tabular}{|l|l|}
\hline
\textbf{Box 1: Key definitions} & \\
\hline
Long-term condition & ‘an illness that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies’ [DH/Long-term Conditions, 2012, p. 3]\textsuperscript{3} \\
\hline
Clinical intervention & ‘any intentional action designed to result in an outcome’ [Eldh et al 2017, p. 3]\textsuperscript{4} \\
\hline
Support need & ‘the additional help some adults need in order that they can live in the best way they can, despite any illness or disability they might have’ [King et al 2019, p. 2]\textsuperscript{5} \\
\hline
Person-centred care & ‘a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs’ [Health Innovation Network c2018 https://healthinnovationnetwork.com].\textsuperscript{6} \\
\hline
\end{tabular}
\end{table}

1.3 Background
Against this background academic papers and strategic guidance within supportive care has recommended the use of clinical interventions to actively support patients in the process of identifying and addressing their need for support.\textsuperscript{2, 14, 15} To date, the dominant overarching approach to intervention format and delivery in this area has taken the traditional practitioner-led approach to identifying need (or aspects of it) as its starting point, then adapting it to emphasise the patient’s voice and perspective within a systematic assessment and decision-making process. In practice, this is a heterogeneous approach that typically involves the use of a needs assessment questionnaire or prompt completed with, or by, the patient to facilitate a conversation based around the patient’s responses (which, in this thesis, is referred to as a ‘Systematic Needs Assessment’).\textsuperscript{15}

In the UK, guidance in relation to using this approach has been developed in the form of the Holistic Needs Assessment (HNA),\textsuperscript{14} which outlines a number of areas that should be addressed in the assessment process, together with recommendations for suitable questionnaires to enable it. The academic literature suggests that, in practice, there is even wider variation in the choice of questionnaires used and the way this approach is integrated into patient-HCP consultations.\textsuperscript{16, 17}

Qualitative research exploring the use of this approach within clinical practice suggests that both patients and HCPs frequently perceive this model as successful in enabling patient involvement in determining their needs, and consequently supporting a response that is holistic and personalised.\textsuperscript{18, 19} However, despite its apparent popularity, commentators such as Osse et al (1999),\textsuperscript{1} Richardson et al (2005)\textsuperscript{2} and Johnston et al (2019)\textsuperscript{16} have questioned how far Systematic Needs Assessment interventions specifically involve patients in identifying their support needs and, therefore, how far they are able to produce a response that is tailored to the individual. For example, Osse et al and Richardson et al both identified that very few needs assessment questionnaires incorporated questions that specifically asked patients about their perceived support needs. Instead, they found that the questionnaires were typically developed for other professional purposes such as the assessment of health-related quality of life, symptoms and problems, or satisfaction with services. This led both authors to argue that the questionnaires were therefore more likely
to support professional, rather than patient, understanding and interpretations of need for care. Similarly, Johnston et al noted the tendency overall for interventions to be focused around the ‘holistic’ attributes of the needs assessment questionnaire, with much less emphasis placed on the integration of ‘holistic processes’ to directly support patient (rather than professional) involvement in discussing and addressing their particular needs once identified via the questionnaires. Together these raise questions as to whether the enthusiasm for these interventions simply reflects a positive response to greater involvement within a traditional HCP-led assessment and care planning process, rather than one that supports a patient-led approach to identifying and addressing their support needs.

An alternative intervention model is one that moves away from the adoption of professional conceptualisations of need and needs assessment, and focuses instead on interventions that are developed to incorporate features that are purposively developed to operationalise and safeguard person-centred values in supporting the identification and discussion of patient need. For example, commentators within social care have argued for the development of strategies and interventions that actively emphasise the individual service-users’ perspectives on need by:

1) acknowledging the difference between service user and agency/practitioner understandings of need and proactively conceptualising service user need as need arising from the individual’s lived experiences

2) positioning assessment of need as ‘a process of facilitation and negotiation based around the individual’s lived experience’ [Godfrey and Callaghan 2000, p. 19].

In practice, it has been suggested that this could include self-assessment and review of need, patient-led conversations and a care management process that is doing with, not to or for, someone.

However, despite an increasing emphasis within policy documents towards the adoption of person-centred, and more recently personalised care the development and use of person-centred interventions to enable patients with long-term conditions to identify and address their needs is barely visible within the literature. Instead, interventions have
focused around the operationalisation of other approaches associated with these frameworks such as care-planning, self-management and shared-decision making, in which increasing attention has been paid to patient choice in relation to available services rather than expression and exploration of the patient’s underlying need for support.\textsuperscript{25,26} Where patient expression of need is acknowledged, recommended approaches continue to draw on the HNA,\textsuperscript{14} or appear to be based on the assumption that expression of need will naturally emerge via the creation of a wider person-centred, or personalised, context.

More recently, however, a person-centred intervention aimed at identifying and addressing support need has been developed to facilitate delivery of supportive care for informal carers (family members or friends who provide help and support) in end-of-life care. Developed by Ewing and Grande, the Carer Support Needs Assessment Tool Intervention (CSNAT-I)\textsuperscript{27,28} was specifically designed to support a practitioner-facilitated but carer-led approach to identifying, expressing and addressing carers’ prioritised support needs within a clinical context. CSNAT-I is now being used in clinical practice nationally and internationally and the findings of empirical work suggests that use of CSNAT-I enables informal carers to identify their support needs, express them to practitioners and participate in the development of a shared response.\textsuperscript{29} The success of CSNAT-I with informal carers in supportive care suggests there may be merit in adopting a similar approach to enable patients with long-term conditions to identify, express and discuss their support needs with HCPs.

Building on the above (i.e. the potential problems identified with the existing interventions, together with the success of CSNAT-I), this thesis will consider the theoretical and practical case for the use of interventions informed by a person-centred approach to intervention development and delivery. The aims of the thesis are firstly to identify whether and how existing interventions enable patients to identify, express and address their unmet support needs, and build a case for the adoption of a person-centred approach to intervention format and delivery. Secondly, this thesis will determine the usefulness of a person-centred approach in supporting patient-led identification, expression and discussion of their needs through the exploration of an exemplar intervention – the Support Needs Approach for Patients (SNAP).\textsuperscript{30} SNAP is modelled on CSNAT-I and comprises a concise evidence-based validated tool (a set of 15 questions: the ‘SNAP Tool’) to help patients directly consider
areas where they may need (more) support, which then informs a needs-led conversation between patient and HCP to identify, express, and address the patient’s self-identified unmet support needs. SNAP was originally developed for patients with advanced Chronic Obstructive Pulmonary Disease (COPD) and has subsequently been endorsed for use in a range of long-term conditions. SNAP was chosen as the exemplar alternative intervention because it provides a new way of thinking about intervention format and delivery to patients with long-term conditions. In addition, my role as part of the SNAP development team has enabled me to immerse myself in exploring and understanding this distinction.

1.4 Outline of thesis

The objectives of this thesis are to:
1) identify whether, and how, existing interventions enable patients to identify, express and address their unmet support needs
2) outline an exemplar person-centred intervention (SNAP), and evaluate the validity and usefulness of SNAP in enabling patients to overcome barriers to identifying and expressing their unmet support needs to HCPs, and having those needs addressed.

These objectives will be addressed by answering five research questions (RQs):

RQ1) What can the current research tell us about patient and HCP experiences of identifying, expressing and addressing patient support need within existing interventions?

RQ2) What features within these interventions enable or hinder patient involvement in identifying, expressing and addressing their support needs?

RQ3) Is the evidence-based tool, integral to SNAP, valid for patients with advanced COPD?

RQ4) How do patients and HCPs engage with SNAP to identify and manage patient unmet support needs?

RQ5) What factors enable or hinder patient-led identification, expression and involvement in addressing support need through delivery of SNAP?
1.5 Approach

To address these research questions a three-stage approach was adopted:

1) A thematic systematic review of qualitative studies considering interventions that aim to involve patients with long-term conditions in the process of identifying, expressing and addressing their support needs

2) A mixed-method validation study of the SNAP Tool

3) A qualitative study of HCP and patient experiences of using SNAP in clinical settings

1.6 Philosophical framework

The work reported in this thesis was informed by a pragmatic framework supporting what Burt (2015),31 and Fetters and Molina-Azorin (2016),32 have described as a ‘multiple study’ mixed-method approach - enabling different studies (using different methods) to be conducted separately, but which together have the potential to contribute to an overall understanding of the question under consideration.

Within the social sciences the choice of philosophical framework, such as the above, is important both in informing how the knowledge created by research is understood, and the methodology required to support this understanding.33 Traditionally, thinking in this area has been dominated by two differing philosophical paradigms: positivism (which asserts that reality is objective and therefore identifiable and measurable via quantitative methods) and social constructivism (which argues that understanding of the world is variably shaped by pre-existing concepts, shared assumptions and interactions with others and therefore draws on qualitative methods to understanding how these individual experiences are constructed and reinforced).

The dominant view has been that these differing philosophical positions, and their associated methodology, are fundamentally irreconcilable, due to the incompatibility of the epistemological assumptions adopted by each paradigm.34 As such the expectation has been that a researcher should be located within one paradigm and incorporate one set of methods into a research study. More recently, however, there has been a growing interest
in alternative paradigms that support the adoption of a methodology enabling the use of both quantitative and qualitative methods in either one study or a series of studies. For example, critical realism has challenged accounts that the world is either measurable or subjective and argued instead that whilst many aspects of our world exist independently of our experiences they also occur within, and are understood via, a social reality – this it is suggested highlights a need to draw on both qualitative and quantitative methods. In contrast, pragmatism rejects the idea that methodology should be determined by a particular philosophical paradigm and emphasises instead the choice of philosophy or methodological approach that is most suitable to the particular research question under investigation.

The rational for the choice of a pragmatic paradigm in this thesis was twofold. Firstly, this thesis is not concerned with identifying an ultimate truth - instead the work aims to contribute to finding a practical solution to supporting patients with long-term conditions overcome the challenges they face in identifying, expressing and addressing their needs. The focus is, therefore, on listening to stakeholder voices, and ultimately allowing them to inform, and engage with, the interpretation of any findings. Secondly, as the above process also involves considering different features of SNAP, the flexibility offered in relation to methodology by a pragmatic paradigm allows the different features to be explored by methods that are the most suitable for investigating these different areas.

1.7 Thesis structure

The thesis structure, following on from this introductory chapter (Chapter 1), is outlined below and summarised in Box 2.

Chapter 2 presents key background information about the nature of long-term conditions, the support needs of patients with these conditions and the rationale for involving these patients in identifying and addressing their need for support.

Chapter 3 identifies the major challenges faced by patients in identifying, expressing and addressing their needs with HCPs, together with the rationale for interventions used to
address these barriers. The chapter then goes on to discuss what is currently known about intervention use in this area and highlights the rationale for considering further both the nature and usefulness of this model, and the potential of an alternative person-centred approach to intervention design and delivery.

Chapter 4 presents a thematic systematic review of the literature concerning interventions designed to support patients with long-term conditions participate in the identification and expression of their unmet support needs. In particular, the review focuses on whether, and how, they facilitate a patient-led approach to identifying, expressing and addressing unmet support needs. This addresses RQs 1 and 2:

- **RQ1** What can current research tell us about patient and HCP experiences of identifying, expressing and addressing patient support need within existing interventions?
- **RQ2** What features within these interventions enable or hinder patient involvement in identifying, expressing and addressing their support needs?

Identified strengths and limitations within existing interventions are discussed, which in turn evidence the case for a more person-centred approach to intervention format and structure in this area.

Chapter 5 outlines an exemplar alternative person-centred intervention – the Support Needs Approach for Patients (SNAP) and draws attention to the need to further evaluate SNAP in order to explore whether and how this alternative approach can support a patient-led approach to identifying, expressing and addressing their unmet support needs.

Chapter 6 presents the methods adopted to assess the validity of the SNAP Tool and the results of the SNAP Tool validation. The study outlined in this chapter was designed to address the following research question:

- **RQ3** Is the evidence-based support needs tool, integral to the Support Needs Approach for Patients (SNAP), valid for patients with advanced COPD?
Chapter 7 describes the methodology for exploring the usefulness of SNAP. This was a qualitative study comprising patient interviews, HCP interviews, and focus groups with HCPs who experienced SNAP, designed to answer RQs 4 and 5. The analysis was informed by Habermas’ Theory of Communicative Action,\textsuperscript{37} which provides a framework for exploring differences in patient and HCP interactions in relation to SNAP.

Chapter 8 presents the results from interviews with HCPs and patients who experienced SNAP, and explores how SNAP shapes the understanding, processes and experience of identifying and expressing patients’ unmet support needs, answering the following research questions:

\begin{align*}
RQ4 & \quad \textit{How do patients and HCPs engage with SNAP to identify and manage patient unmet support needs?} \\
RQ5 & \quad \textit{What factors enable, or hinder, patient–led identification and expression in addressing of support needs through delivery of SNAP?}
\end{align*}

Chapter 9 brings together the findings of the results chapters (Chapters 4, 6 and 8) and discusses them in relation to the existing literature. Methodological strengths and weaknesses are considered, together with implications for future research and practice.
Background to the thesis

This thesis is both a component, and a complementary extension, of the Marie Curie funded SNAP2 Study. SNAP2 was an MRC Phase I study designed to test the validity of the SNAP Tool (which underpins SNAP) and examine the feasibility of delivering SNAP in clinical practice. As a co-applicant and research assistant on SNAP2, I directly contributed to the design of the study protocol, its operationalisation and delivery together with Prof Morag Farquhar (MF) and Dr Gail Ewing (GE), and supported by other members of the SNAP2 co-applicant team. Some of the work reported in this thesis was conducted within my research assistant role on SNAP2, e.g. the SNAP Tool validation and SNAP pilot study within which the qualitative patient interviews reported here were conducted.

However, the literature review, the detailed exploration of the theoretical case for the adoption of a new approach to intervention format, tool validation, and the in-depth analysis of patient and HCP
experiences and perspectives form my unique contribution to learning through the discovery of new knowledge.
Chapter 2: Living with a long-term condition and patient support needs

2.1 Introduction

In this chapter, key background information is presented regarding long-term conditions, the support needs of those living with one or more long-term conditions and the interest within supportive care and person-centred care in involving these patients in the identification, expression and discussion of their support needs. This is presented in order to set the scene for the subsequent investigation into the usefulness of interventions in supporting patients with long-term conditions to identify, express and address their support needs.

2.2 Long-term conditions

As noted in the introduction, a long-term condition is defined by the Department of Health as a medical condition ‘that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies’ (Department of Health /Long-term Conditions 2012, p. 3). More broadly, terms such as ‘long-term physical health condition’ or ‘chronic condition’ are also used to refer to health problems for which there is no current cure and which require ongoing management over a significant period of time. Patients can also experience multi-morbidity which has been defined as the co-existence of two or more long-term conditions.

Across the clinical and academic literature there is some variation regarding which individual diseases are labelled as long-term. For example, the UK Department of Health lists 15 long-term conditions in its compendium of information on the subject (see Box 3), whereas Bernell and Howard (2016) note that the US-based National Center for Disease Prevention and Health (NCCDPHP) list has a more limited number of six chronic conditions.
i.e. heart disease, stroke, cancer, type 2 diabetes, obesity, and arthritis. Bernell and Howard note further that inconsistencies in the classification of conditions as ‘long-term’ also commonly arise in relation to the inclusion, or not, of mental health, musculoskeletal conditions, dementia and oral health.

The literature on chronic disease also acknowledges that conditions, once classified as ‘terminal,’ can transition to chronic in response to improvements in disease management. Particularly noteworthy is the recognition that cancer is increasingly seen as a long-term condition as a result of the growing number of people who now live with the disease over a longer period of time due to improved treatments. As a result, the Department of Health and the NHS both include cancer in their classification of long-term conditions, in line with a range of influential international organisations such as the NCCDPHP and the World Health Organisation (WHO 2020).

Long-term conditions have now emerged as one of the most significant challenges facing healthcare systems today. In a 2015 UK Government policy paper on long-term conditions, it was noted that more than 15 million people in the UK were living with a condition that can be classified as long-term. In addition, it was highlighted that this figure was set to rise over the course of the next decade. Particular attention was also drawn to the rise in multi-morbidity, a trend confirmed by the 2021 Taskforce on Multiple Conditions which identified that around one in four people in the UK now live with two or more long-term conditions. Predictive modelling by Kingston et al (2018) also suggests that by 2035 approximately 17% of the UK population could be living with four or more

| Hypertension | Chronic Kidney Disease | Cancer |
| Asthma | Hypothyroidism | Depression |
| Diabetes | Stroke or Transient Ischaemic Attacks | Heart Failure |
| Coronary Heart Disease | Chronic Obstructive Pulmonary Disease | Mental Health |
| Epilepsy | Atrial Fibrillation | Dementia |
chronic conditions. In response, government and organisational documents from the Department of Health\(^3,48\) have considered the impact of these trends on health and social care services. Currently, the NHS\(^51\) reports that ‘70% of each health pound is spent on supporting people with LTCs [long-term conditions], who also account for 50% of all GP appointments and 70% of hospital beds’ [NHS c2021,]\(^51\)

Similar trends have also been identified internationally. In 2002 the World Health Organisation (WHO)\(^47\) estimated that major chronic diseases accounted for 60% of all deaths worldwide and 43% of the global disease burden. In their more recent 2021 report\(^46\) on non-communicable diseases (NCDs), they noted that 71% of annual deaths globally can now be attributed to NCDs. Of these deaths, they further noted that 80% can be attributed to four major long-term conditions (heart disease 17.9 million, cancer 9.3 million, respiratory disease 41.1 million and diabetes 1.5 million).

In response, supporting and optimising the day-to-day management of individuals with long-term conditions (alongside prevention and monitoring) has, therefore, been identified as a priority both nationally and internationally.\(^46-48\)

### 2.3 The experience of living with a long-term condition

Individual experiences of living with one or more long-term condition vary in response to differences in disease type, disease combinations, disease severity and individual circumstances.\(^52\) Despite this, the literature has highlighted a number of broad areas of disease-impact shared by many of these patients.\(^53\)

Firstly, patients with long-term conditions are known to experience a range of distressing and often hard-to-manage physical symptoms, particularly as conditions progress.\(^54,55\)

Common symptoms include pain, breathlessness and weakness.\(^54\) In addition, patients and their informal carers\(^56\) are often required to monitor these symptoms, adhere to complicated treatment and/or management regimes, and navigate their way around often fragmented healthcare systems.\(^57,58,59,60\)
Secondly, research has also identified the wider psycho-social impacts of living with a long-term condition. Quantitative studies have shown that many people with long-term conditions have higher levels of mental illness and poorer health-related quality of life than the general population. Where studies have explored this in more depth, a range of common concerns and problems have been identified. Based on interviews with people with a chronic condition or disability, the classic work by Corbin and Strauss (1985) noted that many participants faced a range of psycho-social challenges. These included practical problems in relation to day-to-day functioning (e.g. managing the house, personal care, employment and childcare), together with issues related to relationship strain, identity, anger, fear and depression. More recent work continues to support these findings. For example, Fitzsimons et al (2007) interviewed 18 patients diagnosed with end-stage heart failure, renal failure and respiratory disease. They identified that these patients commonly described decreased independence, increased social isolation and concerns about the future. Interviews with family members also suggested high levels of carer burden. Similarly, Mahon (2013) reported patients with long-term conditions describing a sense of loss, anger, frustration, uncertainty, problems adjusting to a new life, and financial difficulties. Many patients also recount having to come to terms with the fact that their condition may be progressive and life-limiting. Further evidence of these impacts is also reported in studies exploring the experience of living with a long-term condition in the context of specific diseases or multi-morbidity. For example, The Richmond Group of Charities (2018) recently explored the particular impact of living with multi-morbidity and found: ‘a clear and overarching theme of how those living with multiple conditions experience a series of losses as they develop multiple conditions. These losses can vary from the practical to the highly personal, and while experiences differ between individuals, some clear patterns emerge. As impact accumulates over time, we see a progression of losses that take in loss of independence, loss of professional identity, loss of earnings, loss of security, loss of relationships and in the widest sense loss of a person’s former ‘healthy self’ [Richmond Group of Charities 2018, p. 55].
2.4 The need for support to manage life with a long-term condition

The literature has also drawn attention to the way in which the experience of being diagnosed with, and coming to terms with living with, one or more long-term condition can be understood as a significant life event (or series of events). This in turn prompts affected individuals to appraise how they cope with these impacts, and what they need in order to maintain a sense of well-being within this new reality. For example, drawing on qualitative data collected from patients with rheumatoid arthritis, Bury’s classic work (1982) concluded that the experience of living with a chronic illness could be considered a ‘biographical disruption’ which compromises the patients’ existing strengths and support. This subsequently requires them to adapt through acquiring additional skills, practical resources and help from others. Data from patients’ accounts of their experiences support Bury’s conclusions and have highlighted more specifically a range of areas where they commonly report needing support to manage. These are outlined below:

- understanding the nature, and implications of, a long-term condition
- managing symptoms
- exploring and processing feelings
- getting out and about
- managing day-to-day tasks (e.g. help to get dressed or with shopping)
- dealing with financial worries
- help accessing services
- maintaining relationships with family, friends and peers
- planning for the future
- dealing with a crisis

There is also clear evidence of wide variation in the way people experience, and respond to, the disruption of a long-term condition and their subsequent need for support. In a study of people with thrombophilia or asthma, Roddis et al (2016) found that some patients were able to accept their condition and achieve well-being with limited input, whereas others faced an on-going struggle to integrate their condition into their lives. Steele and Fitch (2008) reported similar findings in relation to people with cancer.
The 2021 Taskforce on Multi-Morbidity\textsuperscript{49} has also drawn particular attention to the way some social determinants such as communication difficulties, financial problems and poor housing can make it particularly difficult for some individuals to adapt and achieve well-being. In response those experiencing these issues can require a greater need for support to manage the impact of their condition. Further, it has been identified that individual need for support can change throughout the course of an illness trajectory.\textsuperscript{67} However, despite variation in both the nature and extent of support needed, overall findings indicate that most people with a long-term condition require some level of additional support during their illness experience.

In spite of this, evidence overwhelmingly suggests that many patients still lack key aspects of the support that they need. A report by IPSOS Mori (2017)\textsuperscript{71} which investigated the unmet care needs of older people, including people with long-term conditions, identified unmet need for support across a range of areas. These included access to equipment, help with personal care, eating well, transport, interaction and companionship.\textsuperscript{74} Fitzsimons et al (2007)\textsuperscript{61} similarly found that patients who were in the advanced stage of a chronic illness described needing support to access necessary equipment, deal with financial concerns and identify useful community resources. Fitzsimons et al concluded that, for the participants in their study, personal resources such as family, friends and professional help were very important in enabling living with a long-term condition: ‘but that they felt their need for such resources exceeded their availability. Most patients and carers expressed a desire for greater support’ [Fitzsimons et al 2007, p. 318].\textsuperscript{61} Most recently, the 2021 Taskforce on Multi-Morbidity\textsuperscript{49} found evidence of people living with more than one long-term condition who felt they had not been supported to understand their conditions, manage their medications, or develop strategies to prevent further decline.
2.5 Supportive care

Recognition of the extent to which living with a long-term condition can impact on someone’s day-to-day life, and the need to improve access to support, has led to a focus on the provision of supportive care for this patient group.\(^8\)

Developed originally for cancer patients, supportive care is an approach to delivering care that looks beyond a medically-dominated response to illness in order to address the impact of disease within the wider context of the patient’s daily life. Fitch (2008)\(^8\) and Page (1994)\(^75\) have defined it as:

‘the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social or physical need during their diagnostic treatment or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation and bereavement....’ [Fitch 2008, p. 11]\(^8\)

‘anything one does for the patient that is not aimed directly at curing his disease but rather is focused at helping the patient and family get through the illness in the best possible condition. Clearly this type of help would need to be broad in scope and as varied as the individuals requiring it’ [Page 1994, p. 62]\(^75\)

Whilst inconsistencies have been noted in the way in which supportive care is understood across the literature,\(^76-78\) in particular the extent to which it is perceived to overlap with palliative and end-of-life care, Hui (2013)\(^77\) and Olver\(^76\) [2020] have identified key features that are predominantly used to conceptualise this approach:

1) recognition of the holistic nature of patient need,
2) the facilitation of supportive input tailored to individual need, and
3) access to supportive care from diagnosis to bereavement.

Although much of the policy and research in this area is still dominated by cancer, the key concepts and characteristics of supportive care are now seen as having relevance to patients
with other long-term conditions. For example, NICE (2016)\textsuperscript{79} announced their intention to write additional guidelines to support the delivery of supportive care for patients with progressive and chronic disease. Their initial consultation guidelines suggest that they see the fundamental principles of supportive care as relevant not just to cancer patients but all patients whose condition may be progressive or life-limiting. Together, these key features, guidelines, policy and research suggest a shift toward a more patient-focused response to need.

In addition, these aspirations are further reflected in wider ideas about healthcare delivery where there has been a strong call for a move away from the traditional biomedical approach towards one that is based around the notion of person-centred care. Whilst there is currently no consensus on how person-centred care should be defined,\textsuperscript{25} reviewers have identified common ways in which delivery of care is framed within the person-centred literature, and how this can be distinguished from more traditional ways of working (see Box 4). Recommendations for the adoption of a person-centred approach to working with people with long-term conditions have, therefore, been visible not just within supportive care but also within practice guidelines both across health and social care nationally and internationally.\textsuperscript{25, 80, 81} This approach has been usefully defined by the Health Innovation Network (c2018)\textsuperscript{6} as ‘a way of thinking and doing things that sees the people using health and social services as equal partners in planning, developing and monitoring care to make sure it meets their needs’ [Health Innovation Network c2018].\textsuperscript{6}
2.6 Patient involvement in identifying, expressing and addressing their support needs

As outlined in the previous section, one of the key features of improving delivery of supportive and person-centred care to patients with long-term conditions has been highlighted as the on-going identification of individual patient need. Furthermore, as noted, the above guidelines have emphasised that this should take account of individual values, goals, culture and circumstances in order to ensure that any resulting supportive input is tailored to the individual’s specific circumstances.

In her influential paper outlining the ‘Supportive Care Framework for Cancer Care’, Fitch (2008)⁸ argued strongly that, in practice, the above should involve patients in identifying and addressing their need for support, highlighting the known variation in how people

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**Box 4: Key elements associated with the traditional biomedical vs person-centred approach within health and social care**

(Summary of relevant key features of person-centred care presented within the Scottish Social Services Council report ‘Personal outcomes, person-centred working and personalisation: Thinking about different approaches in health and social care in Scotland’ 2018)⁹

<table>
<thead>
<tr>
<th>Biomedical model</th>
<th>Person-centred care</th>
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</thead>
<tbody>
<tr>
<td>A disease-centred (biomedical) approach to health and healthcare</td>
<td>A holistic (biomedical, psychological and social) approach to health and healthcare</td>
</tr>
<tr>
<td>The assumption that the needs of a particular patient or service user group can be universally defined</td>
<td>Acknowledgment of the requirement to take into account subjective lived-experiences of illness, and respond to, and act on, an individual’s particular needs, priorities, aspirations and strengths arising from those experiences</td>
</tr>
<tr>
<td>The assumption that professionals, or organisations, are best placed to make decisions about the nature of the support individual patients and service users receive</td>
<td>A focus on empowering and enabling patients to share responsibility in identifying and enacting the care and support they need</td>
</tr>
<tr>
<td>The expectation that people fit into a ‘one-size-fits-all’ service based around supply-driven and biomedical models of service delivery</td>
<td>Tailoring services and responses to individual needs</td>
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</table>
respond to living with cancer, and the difficulties this poses for practitioners in identifying appropriate support for any given individual. She concluded that: ‘it is critically important to explore with the individual the options for intervention, desire for assistance and how best to provide the required assistance’ [Fitch 2008, p. 8]. In addition, she argued that this is best achieved via person-centred, rather than HCP-led, conversations.

Early UK guidelines concerning the delivery of supportive care also outlined the need for a similar approach in relation to both cancer and long-term conditions. The National Institute for Health and Care Excellence (NICE) Guidance on Improving Supportive and Palliative Care (2004), which played a major role in driving forward the need to improve the assessment and management of patient need in the context of cancer, noted that: ‘assessment of individual need is a critical first step in ensuring [patients] receive the services they require. Patients should be offered support to help them assess their own needs so that the process becomes one of partnership between patients and professionals’ (NICE 2004, p. 39).

The nature of this participation was given further consideration in a report by Kings College London (2005), commissioned by the Department of Health and the National Cancer Action Team (NCAT), to advise on interventions to support the NICE recommendations. The review positioned discussion of patient needs as a bridge in communication between patients and professionals. In addition it was argued that this should involve patients both in giving an account of their needs and in identifying those issues with which they would like professional attention. Later work by Coulter et al (2013), in their report ‘Delivering better services for people with long-term conditions, also noted the need for ‘clinicians and patients to work together to identify support needs’ [Coulter et al 2013, p. 1].

However, despite this, there has been a reframing in UK strategy guidelines in which the emphasis on patient involvement in identifying and addressing their need for support has become notably less visible. Firstly, UK guidelines in supportive care continue to highlight patient expression of need. However, instead of emphasising patient involvement in identifying priorities for support, the guidelines typically refer to ‘patient need’ without further discussion about what this means in practice. Alternatively, the guidelines suggest asking patients ‘what matters to them’ or exploring with the patient their ‘goals and values.’
but providing no opportunity to articulate specific needs and no mechanism to facilitate patients doing so. Secondly, a broader shift in NHS strategy away from emphasising person-centred care to one that focuses on ‘personalisation’ has also led to a similar change. Here the focus on personalisation can be understood as arising not only from a desire to better respond to the needs of individual patients, but also on how to manage the growing demands of this patient group. In response, the concept of personalisation is currently strongly associated with notions of self-management, patient activation and consumer choice with a focus on involving patients in choosing the most appropriate HCP/service-led response to care rather than one in which the care delivery process is led by patient-identified need.

2.7 Need or support need?

The ambiguity around how patients’ expressions of need and need for support are represented in strategy and policy documents therefore raises a key question: what should patient identification and expression of their support needs look like in the context of supporting patients with long-term conditions?

Typically, concepts of need, and how they are understood within a healthcare context, are strongly influenced by theoretical and abstract notions of need derived from the wider social sciences. Reviews on need outline their varied origins (e.g. psychology, sociology, health economics, philosophy) and their lack of agreement about what need is and how it can be understood in practice.

On a very general level, debates in this area have significantly influenced ways of thinking about patient need, in particular by drawing attention to the way in which expressions of need in a healthcare context can predominantly be considered as ‘relative’. Thus, whilst work by Maslow (1968) and others emphasised the objective requirements each individual requires for survival, criticism of how far these ‘absolute’ notions of need apply in a day-to-day context led to the awareness that need is largely determined by the motives, position and wider social context of those making the judgement. Exploring this relative conception of need further, Bradshaw’s (1972) influential work, ‘A Taxonomy of Need’,
proposed four different dimensions of need linked to who was defining need, enabling a useful distinction to be made between patient need (felt and expressed need) and HCP expressions of need (normative need) (see Box 5).

<table>
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<tr>
<th>Box 5: Bradshaw’s Taxonomy of Need&lt;sup&gt;94&lt;/sup&gt;</th>
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<tr>
<td><strong>Normative</strong></td>
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<td><strong>Felt</strong></td>
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<td><strong>Expressed</strong></td>
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<tr>
<td><strong>Comparative</strong></td>
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Others<sup>20, 95, 96</sup> have gone on to consider the socially constructed nature of these different expressions of need. Here it is suggested that professional understandings of need are predominantly determined by policy, organisational and professional factors (e.g. the availability of resources, professional and political ideologies, eligibility criteria, economic factors, practical constraints and organisational priorities). Similarly, patient perceptions of need are understood to be informed by their lived experiences, their personal aspirations for independence or support and their expectations about what is appropriate, or useful, to seek help about.

However, despite drawing attention to the way expressions of need can differ depending on who is defining need and the factors influencing those judgements, it has also been noted that theoretical considerations are limited in how far they shed light on what patient expression of need actually looks like in practice. Harrison et al (2013)<sup>90</sup> noted firstly the general failing of most theories to consider how need is understood and assessed in practice, and the limited relevance of many of the theories to healthcare. More specifically, they identified that even common theoretical conceptualisations within healthcare, such as ‘capacity to manage’ and ‘unmet need’, primarily position need in terms of organisational
capacity, service delivery and outcomes rather than in relation to patient expressions of need. Even Bradshaw’s definitions of ‘felt’ and ‘expressed’ need can be understood as falling short of fully capturing patient experiences of need versus non-need. For example, it is not certain how ‘felt needs’ can be distinguished from other feelings and experiences, nor whether expressed requests for supportive input and services are motivated by need or determined by factors such as want or entitlement.\textsuperscript{90, 91} As a result, theoretical ideas of need appear to offer little guidance in terms of what patient identification and expression of their support needs should look like, leading potentially to needs being misrepresented and supportive input being ineffective.

An alternative to the theoretical approach to thinking about and defining patient need has been to examine how the concept is actually understood and operationalised in day-to-day practice. In 1993 Spiker\textsuperscript{97}, considering the issue in a social policy context, argued that need is typically characterised as:

1) a problem,
2) a requirement for a particular response to address a problem, or
3) the relationship between a problem and responses (a deficit/need for something to address the problem).

Similarly, Liss (1993)\textsuperscript{98} identified that, within healthcare settings, need is typically understood as ill health, treatments and services, normative or instrumental (health care as a need for something). Since then there appears to have been no further analysis in this area. However, examination of the contemporary supportive care literature suggests that patient need continues to be similarly understood and operationalised as:

1) disease impact (symptoms/problems/concerns) \textsuperscript{68, 99, 100}
2) supportive input received or required \textsuperscript{68, 99, 100}
3) the patients’ perceived need for more assistance with the impact of the disease.\textsuperscript{68, 99, 100}

Whilst theoretical definitions of need can be useful in examining differences between different dimensions of need and want, or population drivers behind expression of need,
the above approach of considering how need is operationalised has particular usefulness when examining need in a practice discipline. Within the context of patient identification, expression and discussion of their support needs, this approach has firstly drawn attention to differences in whether, or how, these different ways of operationalising need reflect a patient’s needs for support. For example, Fitch (2008)\textsuperscript{8} and McElduff (2004)\textsuperscript{101} both argued that it is wrong to assume that burdensome symptoms and problems will always result in the patient wanting help. Similarly, Richardson et al (2005) has suggested that, whilst need is often discussed in terms of supportive input, this may not correspond directly with the patient’s original perception of whether or where they felt they needed help. In contrast, attention has been drawn to the way in which operationalising need as ‘the patients’ perceived need for more assistance with the impact of the disease’ directly places the focus on specific areas with which the patient describes needing help (McElduff 2004, p. 2).\textsuperscript{101}

Secondly, consideration of these different ways of operationalising need has enabled a useful distinction to be made between expressions of need that act as indicators of a potential need for support (where another process is required to identify their specific support needs) or as a direct expression of where help is needed (where the patient articulates their individual support needs). Here it has been noted that patient-expressed indicators of a potential need for support (e.g. symptoms) are vulnerable to HCP assumptions about where help is needed and decisions about what supportive-input is delivered.\textsuperscript{101} In contrast, direct expression of support needs by a patient has the potential to reduce this vulnerability and pro-actively support discussions and decisions about the patient’s care that are based around the patient’s view and their lived experience.\textsuperscript{101} Together these suggest that King’s (2019)\textsuperscript{5} definition of support need (‘the additional help some adults need in order that they can live in the best way they can, despite any illness or disability they might have’) provides a useful way of identifying and operationalising patient expression of need in the context of supportive care.

\textbf{2.8 Summary}

Long-term conditions are often associated with distressing symptoms that can impact on an individual’s ability to manage across a range of domains resulting in a need for support to
manage life with their condition (their support needs). However, in practice, support needs often remain unidentified and unmet. There has been an increasing drive to address this via the delivery of supportive care that is holistic and tailored to individual needs. A key component of achieving this has been identified as the involvement of patients directly in articulating and addressing where they would like more support (their support needs).

The next chapter presents the rationale for using interventions to support patients in identifying and addressing their support needs, discusses what we currently know about intervention use in this area and outlines how this thesis proposes to make the case for the adoption of a person-centred approach to intervention design and delivery.
Chapter 3: Interventions to support the involvement of patients with long-term conditions in identifying and addressing their support needs (background)

3.1 Introduction

In this chapter I outline, firstly, the key challenges faced by patients with long-term conditions in identifying, expressing and addressing their support needs with healthcare practitioners. I then go on to describe the dominant intervention model that has emerged as a means to enable patients to overcome these challenges (which I have termed the ‘Systematic Needs Assessment’ intervention model), together with the current research in this area. I also highlight the rationale for further exploring both the nature and usefulness of this model and investigating an alternative person-centred approach to intervention design and delivery.

3.2 Background to intervention use: barriers to patient identification, expression and involvement in addressing their needs

Despite the enthusiasm for involving patients in identifying, expressing and addressing their support needs, there is a large body of work that has highlighted how involving patients in this process continues to be a challenge. This is either because patients are not asked about their specific self-perceived needs or because patients feel unable, or unwilling, to raise these needs within a healthcare context. Examples from research in this area have highlighted how this can arise in response to a wide range of issues:

- Coventry et al (2011)\textsuperscript{11} and Chew-Graham et al (2013)\textsuperscript{10} both identified that policy initiatives such as the Quality and Outcomes Framework promote what Coventry described as ‘highly performance managed consultations between HCPs and patients with long-term conditions’ (Coventry et al 2011, p.11).\textsuperscript{11} This, they argued, encouraged a ‘reductionist’ approach to HCP exploration of concerns and needs in line with externally defined or professional priorities.
• Pinnock et al (2007)\textsuperscript{102} and Coventry et al (2011)\textsuperscript{11} both found that patients with long-term conditions can normalise the impact of their condition as an expected part of the aging process and therefore see their symptoms as something ‘about which nothing can be done and about which they often remain silent’ (Pinnock 2007, p. 37)\textsuperscript{102}. Both authors also argued that ‘professional nihilism’ can play a part in this process as HCPs fail to notice the slow, long-term decline of their patients and unwittingly collude with the patient’s silence.

• Work I led at the University of Cambridge further identified that a characterisable sub-group of patients with advanced COPD actively avoided discussing their support needs with HCPs, and instead managed their illness themselves as far as possible. In particular, it was noted that this group were particularly reluctant to discuss future care planning (Gardener et al, 2021).\textsuperscript{103}

• Beernaert et al (2014)\textsuperscript{12} and Newbold (2012)\textsuperscript{13} identified a further unwillingness of patients with long-term conditions to discuss their future palliative care needs with HCPs, either because they did not feel they were ‘issues of concern’ for HCPs or because they perceived these discussions to be incompatible with the HCP’s role. Rogers et al (2000)\textsuperscript{104} also noted patient reluctance to request alternative approaches to symptom management on the basis that the HCP knew what was best.

• The reluctance of HCPs to raise potential patient support needs was also noted by Fitzsimons et al, (2007).\textsuperscript{61} These authors identified HCPs working in a hospital setting who reported that they often did not have the time to discuss broader social needs with patients. In addition, their study found evidence of HCPs feeling unable to raise potential care needs with patients at the advanced stage of their disease. These HCPs also felt unable to respond to need due to a lack of available resources.

Earlier work in health and social care also considered, more generally, why issues such as these rarely appeared to be resolved via a simple process of challenge and negotiation. Here commentators highlighted not just failures in inter-personal communication, but also the role played by wider policy, organisational and social factors.\textsuperscript{20, 95, 96} For example, Godfrey and Callaghan (2000)\textsuperscript{20} highlighted the socially constructed nature of need to explore how
wider beliefs about the legitimacy of patient expression of need were influenced by the way need was managed within social care agencies. Here they argued that not only were practitioner notions of need shaped by agency or professional views (as suggested in Chapter 2) but that these understandings frequently became institutionalised via a range of organisational and professional practices such as training, internal procedures, eligibility criteria, professional endorsement and technical language. This process of institutionalisation, they suggested, both empowered professionals to define need in line with these organisational priorities, but conversely made it more difficult for individuals to scrutinise and challenge the professionals’ interpretations of their needs. Furthermore, these dominant professional perspectives also served to directly influence individual service user aspirations about what could and should be considered a need in this context, thereby preventing individuals from raising issues of need arising from their particular illness experiences. Equally, service user awareness of the limited (and potentially inappropriate) response to need offered by social care agencies often led them to focus on managing their needs independently or via informal support networks.

Together, both the early findings in health and social care and the more recent observations about the experiences of people with long-term conditions, highlight the existence of enduring, widely accepted assumptions and ways-of-working that potentially prioritise HCP conceptualisations of need over those informed by the patients’ lived experiences. As such this has also drawn attention to the need to identify solutions and interventions that can address this complexity in order to better enable patients to express and discuss their needs with HCPs.

3.3 Clinical Interventions: definition

Clinical interventions have been defined as ‘any intentional action designed to result in an outcome’ (Eldh et al 2017, p3). In the UK, the National Institute for Health and Care Excellence (NICE) has further outlined how, in practice, interventions can encompass a variety of strategies: ‘In medical terms this could be a drug treatment, surgical procedure, diagnostic test or psychological therapy. Examples of public health interventions could include action to help someone to be physically active or to eat a more healthy
diet. Examples of social care interventions could include safeguarding or support for carers’

The drive towards interventions using ‘Systematic Needs Assessment’

To date, the dominant approach for intervention format and delivery, developed in
response to the challenges outlined in the first section of this chapter, has taken the
traditional practitioner-led approach to identifying need as its starting point, then adapted it
to emphasise the patient’s voice and perspective within a systematic assessment and
decision-making process.^{15} Typically, this involves the use of a needs assessment
questionnaire or prompt completed with, or by, the patient to support a conversation based
around the patient’s responses. The literature also highlights how this, in turn, has drawn
from an approach that has evolved both across health and social care disciplines and in
response to a broader range of agency requirements, including cost containment, resource
allocation and patient-reported performance indicators.^{15, 20}

In their overview of the needs assessment process with older people, Marossezeky et al
(2016)^{15} described how an early influential advocate for the move towards a systematic
approach to needs assessment within health and social care was Kane (1999)^{106}. Kane drew
attention firstly to: 1) the subjective nature of most decisions about need, 2) the way that
need was almost always defined by experts in relation to available resources, and 3) the
open ended nature of the term ‘unmet needs’ which could potentially create economic and
logistical problems in relation to supplying supportive input. In response, she argued for the
development of an intervention-model based around the use of a ‘gold standard’
assessment that could support professionals undertake a comprehensive and more
objective assessment of need. This, she envisaged, would involve a set of pre-defined
questions (identified by a team of experts) against which the assessor could establish the
salience of an individual’s particular need. Marossezeky et al (2016)^{15} noted further that this
model both drew from, and was subsequently developed by, a larger body of work that: a)
considered the broad range of patient and social care needs across different patient and
user groups and b) used this information to develop a large number of needs assessment
tools typically characterised by a set of standard questions with thresholds or trigger items
that served to highlight to the assessor key indicators linked to the absence of help for the user or patient. Overall, however, the focus within this approach remained one that aimed to better support the practitioner’s assessment of need, whereas the role of the service-user or patient was primarily to provide either observable or verbal information to support the assessor’s conclusions.

A more widely used approach (termed in this thesis as the ‘Systematic Needs Assessment’ intervention model) emerged later in order to support greater patient or service-user participation. This intervention model has similarly taken the traditional practitioner-led approach to identifying need as its starting point, but here the focus is on pro-actively enabling service-users/patients to express and discuss their perceived needs as part of that assessment process. Described by Marossezeky et al. (2016)\textsuperscript{15} as a ‘semi-structured conversation’ they outline how, in line with Kane’s ‘gold standard model’, these interventions are based around the use of holistic needs assessment questionnaires or prompts developed for use within a clinical consultation. Again these questionnaires typically outline a list of symptoms or concerns and ask people to indicate the frequency or severity of their experience of each item. However, in contrast to the approach advocated by Kane, the role of these questionnaires is to encourage individuals to self-report their needs and priorities in a discussion structured around the completed questionnaire or prompt. Variations on this model have been widely used in health and social care across a range of patient and user groups both nationally and internationally and have been supported by the development and validation of a wide range of holistic assessment questionnaires.\textsuperscript{15, 17, 107}

3.4 Systematic Needs Assessment in policy and practice guidelines

Although the Systematic Needs Assessment approach was not specifically designed to enable patients with long-term conditions to identify and discuss their need for support, Box 6 outlines how over the last 20 years UK guidelines have recommended the adoption of interventions based around this model. Here a key focus of many of these guidelines has been the recommendation of an overarching framework for using and applying a Systematic Needs Assessment known as the Holistic Needs Assessment (HNA).\textsuperscript{84} The HNA framework
recommends core features of this process, for example, the adoption of a holistic focus: a conversational approach to the assessment process and the development of a written action plan, enabled by needs assessment tools and questionnaires (e.g. the Distress Thermometer and PEPSI-COLA). The HNA framework has been particularly influential both nationally and internationally and is now widely recommended by a range of organisations, particularly in relation to cancer, including the US based National Comprehensive Cancer Network (NCCN), the Australian Cancer Survivorship Centre and the Danish Health and Medicines Authority. As a result, the term HNA has become a widely adopted way of referring to Systematic Needs Assessment within policy documentation.
## Box 6: UK strategy documents that support the adoption of a structured needs assessment process

<table>
<thead>
<tr>
<th>Guidance/Strategy Document</th>
<th>Focus and recommendations</th>
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| Improving Supportive and Palliative Care for Adults with Cancer National Institute for Health and Care Excellence (NICE (2004)) | • Highlighted that the needs of cancer patients are not always met  
• Argued for the need for systematic assessment of patient needs and a national steer on the development of approaches or tools for assessment in routine practice. |
• Defined patient needs assessment as (i) a clearly defined process, done with, or by, the person with (or suspected as having) cancer; (ii) involving some form of consistent framework; (iii) involving regular comprehensive assessment at clearly defined intervals; (iv) based on patients’ accounts of their needs and wishes which they expect professional care to meet; and finally (v) informing the decisions of a range of health care professionals involved in cancer care  
• Further recommended that this could be supported by a national guidance on using existing tools, or a newly developed common approach. |
| Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer Kings College London (2007) | • National guidelines to support the structured assessment of patient needs in the form of the Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer.  
• Set out a common specification against which local patient needs assessment processes could be appraised  
• Recommended that the assessment process should include:  
  o development of a written plan  
  o the adoption of a holistic approach  
  o use of patient needs-assessment questionnaires to ensure identification of full range of patient needs. |
| Improving care for people with long-term conditions: at a glance information sheets Department of Health/NHS (2011) | - Personalised care planning involving a collaborative process based on an assessment of an individual’s needs to determines the level and type of support required involving the patient as much as possible  
- Process should be person centred and holistic  
- Recommends a structured approach around the Common Assessment Framework or tools such as the Kirklees Health Needs Assessment Tool |
| National End of Life Care Programme’s Holistic common assessment of the supportive and palliative care needs of adults requiring end of life care’ NHS (2010) | - Published guidance to support the use of HNA in the context of end of life care for patients with cancer and other advanced conditions.  
- Highlighted that the assessment process should be ‘conversational’  
- Set out in detail a series of questions and prompts HCPs could use to support patients identify their needs and need for help  
- Recommended the use of one or more of the existing tools to support this process (PEPSI COLA Aide Memoire and Distress Thermometer). |
- Recommended an approach consisting of three stages:  
  1) outlining what is going to happen  
  2) an assessment conversation (identifying specific needs from general needs, identifying the patient’s priority needs and focusing on solutions)  
  3) producing a care plan with the patient.  
- Recommend the use of needs assessment questionnaires to ensure that the patient’s needs remain the focus of the assessment process  
- Suggest using existing tools such as the Sheffield Profile for Assessment and Referral to Care (SPARC), the PEPSI COLA Aide Memoire or the Distress Thermometer and Problem Checklist. |
| 2016 Supportive and palliative care draft scope for consultation NICE (2016) | - Outlines plans to explore the role of holistic needs assessment in supporting adults with life limiting conditions identifying the supportive care and palliative care needs of the person, carers and those important to them. |
| End of Care Guidelines NICE (2019) | - Recommends carrying out a holistic needs assessment with adults approaching end of life. |
| Recommendations for implementing personalisation NHS (c2021) | - Recommends the use of holistic needs assessment to support patient expression of need. |
3.5 Systematic Needs Assessment in practice

The academic literature has also highlighted enthusiasm for use of Systematic Needs Assessment interventions with people with long-term conditions. Firstly, the literature has drawn attention to its application in practice for both people with cancer and people with long-term conditions. For example, in a recent review Johnston et al (2019)\textsuperscript{16} identified twenty studies that employed Holistic Needs Assessment within cancer services. Similarly, Kane et al (2017)\textsuperscript{107} reported on an intervention focused around the use of the Integrated Palliative Care Outcome Scale (IPOS) in nurse-led chronic heart failure disease management clinics, whilst McIlfatrick and Hasson (2013)\textsuperscript{110} evaluated use of an adapted holistic needs assessment tool/prompt to identify the needs of patients with a variety of long-term conditions. Secondly, this literature also suggests that there is even wider variation than indicated in the HNA guidelines in the choice of tools and ways in which Systematic Needs Assessment is integrated into clinical consultations to identify the needs of patients with a variety of long-term conditions. This is illustrated, for example, by the choice to use Patient Reported Outcome Measures, such as IPOS or the Supportive Care Needs Survey (SCNS), rather than the tools recommended in the guidelines.\textsuperscript{107, 111}

In line with the broader health and social care literature, the use of this approach for patients with long-term conditions is further supported by a large body of work on the development and validation of needs assessment questionnaires. For example, in the context of cancer, Osse et al (1999)\textsuperscript{1} and Richardson et al (2005)\textsuperscript{2} identified and assessed the validity of 19 needs assessment questionnaires available to clinicians to facilitate cancer patient involvement in the identification and discussion of their need for help, care and support. Box 7 summarises the tools recommended by these authors. A range of other reviews have explored potential tools across a range of settings or cancer types.\textsuperscript{17, 112-115} For example more recently Rimmer et al (2021)\textsuperscript{17} identified a further 15 tools for identifying the needs of patients with advanced cancer.
Whilst evidence from quantitative studies exploring the impact of this approach on key indicators of health and well-being have proved inconclusive,\textsuperscript{18, 134} enthusiasm for the use of these interventions is demonstrated by the positive feedback provided by both patients and HCPs across a range of studies that have sought to describe their perceptions concerning the feasibility and usefulness of these interventions. The review by Johnston et al (2019) considering HNA use in cancer care found that both patients and HCPs felt that using the HNA resulted in symptoms and problems being discussed that might previously have been overlooked. In addition, both groups perceived that intervention use resulted in enhanced patient–HCP communication and an uptake of services. Johnston et al also reported findings by Ristevski et al (2015)\textsuperscript{135}, who reported that 87% of 154 cancer patients who had completed and discussed their response to the Distress Thermometer with an HCP strongly

![Box 7: Tools recommended by Osse et al (1999)\textsuperscript{1} and Richardson et al (2005)\textsuperscript{2} for involving patients in Systematic Needs Assessments](image)

<table>
<thead>
<tr>
<th>Cancer Rehabilitation Evaluation System (CARES)\textsuperscript{116}</th>
<th>Oncology clinic patient checklist (OCPC)\textsuperscript{117}</th>
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<tbody>
<tr>
<td>Cancer Care Monitor\textsuperscript{118}</td>
<td>Patient Needs Scale (PNS)\textsuperscript{119}</td>
</tr>
<tr>
<td>Creating Better Health Outcomes by Improving Communication about Patients’ Experiences assessment (CHOICEs)\textsuperscript{120}</td>
<td>Patient Needs Assessment Tool (PNAT)\textsuperscript{121}</td>
</tr>
<tr>
<td>Cancer Patients Need Questionnaire (CPNQ)\textsuperscript{122}</td>
<td>Patient Information Survey (PIS)\textsuperscript{123}</td>
</tr>
<tr>
<td>Concerns checklist\textsuperscript{2}</td>
<td>Problems and Needs in Palliative Care instrument (PNPC)\textsuperscript{124}</td>
</tr>
<tr>
<td>Distress management tool\textsuperscript{125}</td>
<td>Problems checklist\textsuperscript{126}</td>
</tr>
<tr>
<td>Home Care Study-Patient Form (HCS-PF)\textsuperscript{127}</td>
<td>Self-Assessment Questionnaire (SAQ)\textsuperscript{128}</td>
</tr>
<tr>
<td>Initial Health Assessment (IHA) form\textsuperscript{129}</td>
<td>Satisfaction Scale (SAT Scale)\textsuperscript{130}</td>
</tr>
<tr>
<td>Needs Evaluation Questionnaire (NEQ)\textsuperscript{131}</td>
<td>Supportive Care Needs Survey (SCNS)\textsuperscript{101}</td>
</tr>
<tr>
<td>Needs at the End-of-life Screening Tool (NEST)\textsuperscript{132}</td>
<td>Sheffield Profile for Assessment and Referral to Care (SPARC)\textsuperscript{133}</td>
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</table>
agreed or agreed with the statement ‘The discussion helped me with my needs.’ Similarly, Kane et al (2017) concluded that using the IPOS with patients with chronic heart failure resulted in: ‘a shared understanding of patients’ symptoms and concerns, facilitating patient-nurse communication by focusing on these unmet needs and empowering patients to become more involved in clinical discussions’ [Kane et al 2017, p. 149].

However, despite the apparent popularity, commentators such as Osse et al (1999) et al, Richardson et al (2005) and Johnston et al (2019) have questioned how far these Systematic Needs Assessment interventions actively support patient involvement in identifying their support needs, and the subsequent delivery of care that is holistic and tailored to the patient’s individual support needs.

Osse et al (1991) and Richardson et al (2005) both drew attention to possible limitations associated with available questionnaires. For example, of the 19 needs assessment questionnaires reviewed by these authors only four incorporated questions that directly asked patients to consider and express their need for help or support (i.e. CARES, CPNQ, the SCNS and PNPC). Both authors noted that the majority of questionnaires were developed instead to assess health-related quality of life, symptoms, problems and satisfaction with care – without a clear discussion about the relationship between these concepts and patient need. Osse et al attributed this lack of clarity to the many meanings associated with the word ‘need’ and noted that the ‘consequence of this confusion is that these instruments provide ambiguous answers to the question of whether help was wanted or not, leaving clinicians to interpret need’ [Osse et al 1999, p.908]. Osse et al further highlighted the vulnerability of the patients’ perspective of need by observing that many of the questionnaires seemed to have been constructed without any input from patients and, thus, were prone to assess the needs seen to be important from a professional perspective.

Similarly, Rimmer et al (2021) and McElduff et al (2004) both made a distinction between questionnaires that focused on problems and those that supported patients to identify a need. In addition Rimmer et al further considered the argument that ‘having a significant problem equates to an implicit need.’ [Rimmer et al 2021, p. 4] The authors noted that some needs assessment questionnaires have validated measurement scales where any score above a specific cut-off point is understood to infer the presence of an
unmet need - raising in turn issues about the lack of clarity concerning the decision to equate a specific score to an unmet need. Osse et al and Richardson et al have further questioned how far some of the questionnaires they reviewed could be considered holistic. Both reviews noted that some of the questionnaires failed to cover all the dimensions of care, with Richardson et al suggesting that this was particularly the case in relation to items about patient need for support.

In addition to the questions raised above about the suitability of these questionnaires, Johnston et al’s (2019) review of HNA use in practice also queries how far these interventions then involve patients in the process of identifying and discussing their support needs beyond completing the needs assessment questionnaire. In particular, Johnston concluded there were differences between those interventions that emphasised the holistic element of the questionnaires, and those that saw the whole intervention as a holistic process. In the former she noted that patients are enabled to identify their needs, whereas in the latter they are also supported to use those needs to ‘facilitate discussion, structure the discussion and provide an action plan’. As with Osse et al, Johnston et al highlighted the confusion caused by language suggesting: ‘The continued use of the umbrella term of “HNA” to describe both tools and method/approach is, we suggest, too encompassing and increases the likelihood of the “tool wagging the dog”’. [Johnston et al 2019, p. 11].16 Furthermore, there appears to be a notable lack of attention within the studies reviewed by Johnson et al, and those reporting on intervention use with people with other long-term conditions, on considering how far intervention use actively supports patients to overcome the challenges outlined at the start of this chapter, such as the failure to see their support needs as legitimate or not wanting to waste an HCP’s time. This includes exploration of the ways in which these challenges to patients’ expression of need may be supported or hindered by the social relationships, biomedical agendas, organisational processes and the changing policy context within which these interventions are deployed.

Overall, this exploratory overview of the literature raises questions as to how far the positive feedback from patients simply reflects a positive response to greater involvement, and/or the greater visibility of attention to their needs within a traditional HCP-led assessment and care planning process, rather than a patient-led approach to identifying,
expressing and addressing their support needs. Currently, studies in this area have failed to provide a robust evaluation of needs assessment interventions, including an interrogation of how far patient participation in the interventions enables them to confront the challenges they experience identifying, expressing and being involved in addressing their support needs. Similarly, despite reviewers drawing attention to the way components of interventions may support HCP perceptions of need (e.g. by the lack of patient involvement in their development or by focusing on symptoms rather than support needs), these features have rarely been formally critically evaluated. As a result, there remain unanswered questions and the dominance of this approach continues unchallenged despite the lack of clear evidence.

3.6 A person-centred approach to intervention format and delivery

An alternative intervention model is one that moves away from professional conceptualisations of needs assessment and adaption of pre-existing questionnaires to a model that focuses instead on interventions that are purposively developed to operationalise and safeguard person-centred values in identifying and addressing patient need. For example, commentators within social care\textsuperscript{20, 21, 95, 136} have argued for the development of strategies that:

1) proactively conceptualise an individual’s need of support in the context of the service-user’s lived experience
2) identify and respond to an individual’s need for help via processes based around the service-user’s perspective.

In practice, Godfrey and Callaghan (2000)\textsuperscript{20, 136} have argued that this could include service user self-assessment and self-review of their needs. Alternatively, a recent report by Skills for Care suggested discussing need within ‘conversations that are led by the person rather than by following a form, so they’re shaped by their own priorities rather than the initial reason for referral’ [Skills for Care 2018, p. 9]\textsuperscript{21}. Think Local Act Personal (a group of over 30 national partners whose stated aim is to facilitate change in adult social care) have further
recommended that the care planning process could involve patients and HCPs exploring ideas and options together.

However, despite broader interest in both person-centred and personalised care as a way of delivering support to people with long-term conditions, the development and use of person-centred interventions to support patients identify and address their needs is barely visible within the literature. Instead, there has been a move to develop frameworks for the wider delivery of person-centred assessment and delivery of support across patient groups, for example the Gothenburg Person Centred Care (GPCC) framework (Ekman et al 2011)\(^{137}\) and the Person-Centred Practice Framework developed by McCormack and McCance (2006)\(^ {138}\).

Although both of these focus on eliciting the patient’s perspective via biographical narratives and seek to involve the patients in making shared decisions about their care (a process which Ekman et al notes shifts the focus to the person’s needs and resources), neither of these frameworks indicate how patient expression of their support needs is enabled, nor how far patient-identified need informs the decision making process.

In the UK, strategy documents regarding person-centred care and personalisation have also highlighted assessment and support planning as part of a process that emphasises shared decision making, self-management and personalised funding. However, as above, no guidelines or interventions have been developed or endorsed to support a person-centred approach to identifying and addressing need. In contrast, as outlined earlier in Box 6, current NHS guidelines on personalisation suggest that patient expression of need can be supported by the Systematic Needs Assessment approach. More generally, patient identification and discussion of their need appears to have been overlooked or based on the assumption that patient expression of need will naturally emerge and be responded to within the wider personalised context.

### 3.7 The Carer Support needs Assessment Tool Intervention (CSNAT-I)

A key exception is work by Ewing and Grande\(^ {27, 28}\) that has sought, specifically, to operationalise a person-centred approach for the identification, expression and discussion of support needs in informal carers to enable a tailored response. Their work focused
around the development and clinical usefulness of the Carer Support Needs Assessment Tool Intervention (CSNAT-I) \(^{27,28}\) which was designed to enable informal carers in palliative home care to identify and discuss their support needs via an approach that they describe as ‘facilitated by the practitioner but carer-led’.

CSNAT-I comprises:

1) a designed-for-purpose evidence based tool (the CSNAT) comprising broad areas of need (domains) where there is evidence that carers say they require support and which they then use to indicate where they need further support in their caregiving role (see Figure 1)

2) a five stage person-centred process which involves a needs-led conversation enabling carers to prioritise discussion of those domains where they need support, explore with the practitioner their individual needs within the prioritised domains on the CSNAT and develop a shared action plan to meet these specific needs (see Figure 2)

CSNAT-I is now being used in clinical practice nationally and internationally and the findings of qualitative work\(^{29,139}\) suggest that use of CSNAT-I enables informal carers to identify their support needs, express them to practitioners and participate in the development of a shared response. For example, in Australia, Aoun et al (2015)\(^{29}\) conducted 233 telephone interviews with family carers of terminally ill people about their experience of CSNAT-I. They
identified that carers found the tool easy to use and that use of the tool facilitated conversations about the carer’s need for help within the intervention. For example, the study quotes one patient who reported: ‘It got [my] husband and I talking about what I needed help in. It got me to sort my thoughts out and get them in order so I could think what I really did need help with at this time and what was important enough to ask for help at this time’ (Aoun et al 2015 p. 514). Carers in the study also noted that discussing their needs with an HCP enabled needs to be met, and described accessing a range of supportive inputs including information, help to develop practical care skills and emotional support. Ewing et al (2016) interviewed practitioners involved in using CSNAT-I in a UK study. They reported that the CSNAT (the tool itself) drew their attention to areas of carer support need that they had not previously been aware of and enabled them to facilitate responses to these areas of carer-identified support within CSNAT-I.

Quantitative studies have also found that CSNAT-I produces positive improvements on a range of outcomes. In a stepped-wedge cluster randomised controlled trial linked to the above qualitative study, Aoun et al (2015) found that use of CSNAT-I led to a significant decrease in carer strain compared to the control group (n=890). In a UK randomised controlled trial Grande et al (2016) found that, in comparison to the control group (n=333), the intervention group (n=348) had significantly lower levels of early grief, better psychological and physical health in bereavement, were more likely to feel the place of death for the patient being cared for was right, and patients were more likely to die at home. However, they also noted that the differences were small and implementation issues suggested the differences may have been due to an increased awareness by HCPs rather than a direct impact of intervention. Overall, Grande et al concluded that, if implemented as intended, CSNAT-I had the potential to produce substantial positive impacts for carers. A third study by Lund et al (2020), based in Sweden, followed up carers at three time points and identified that, although carers did not experience a significant decrease in caregiver strain in comparison to the controls, use of CSNAT-I: ‘demonstrated positive effects on caregiver distress, homecare responsibility and key outcomes regarding caregivers’ experience of the interaction with healthcare professionals’ Lund et al [2020 p. 1].
Ewing et al (2016)\textsuperscript{139} also highlighted key mechanisms and processes within CSNAT-I that enabled carers to better identify, express and address their support needs, including:

1) making support needs visible to carers via the 14 domains representing common areas of support need
2) legitimising carer acceptance of support via presentation of support needs on the tool which served to normalise a need for support in these areas and enable carers to ask for help
3) providing space and an opportunity for carers to express a need for support to HCPs
4) HCPs responding to carer self-defined priorities (rather than those identified by the HCP)

The success of CSNAT-I with informal carers in palliative care therefore suggests there may be merit in adopting a similar approach with other groups. Recent work by Micklewright and Farquhar (2021)\textsuperscript{143} in relation to the relevance of the CSNAT for carers of patients with COPD and by Ewing et al (2020)\textsuperscript{144} in relation to its relevance for carers of patients with motor neurone disease, has led to the adoption of the CSNAT for carers of patients with chronic progressive conditions: CSNAT v3. Subsequent validation work for CSNAT v3 with COPD carers\textsuperscript{145} confirms its potential for use with these broader populations. However the case for the adoption of a similar approach with patients with long-term conditions is still being explored.

3.8 Systematic Needs Assessment versus a person-centred approach

Initial observations of the current literature have suggested a number of questions around how far interventions based on the Systematic Needs Assessment approach are useful in enabling patients to identify and express their support needs with HCPs. In particular, understanding in this area appears to have been hindered by the limited critical evaluation of Systematic Needs Assessment despite the complex social and clinical processes that exist as barriers to patient participation in identifying and expressing their support needs to HCPs (such as not wanting to take up HCP time or the engrained power relationships between patients and professionals). In contrast, the development and testing of CSNAT-I (as an
intervention designed specifically around a person-centred approach to support informal carer identification, expression and discussion of their support needs) demonstrates not only the ability to engage informal carers in this process but also how participation in the intervention works to overcome the challenges they face in terms of the legitimacy of raising their needs or initiating discussions about their needs in a context dominated by medical and organisational concerns. This further suggests there is merit in considering the case for the adoption of this approach for patients with long-term conditions. On this basis, the next focus of this thesis is therefore on conducting an enhanced review of the literature in order to undertake a more critical analysis of standard interventions and explore further the case for the adoption of an alternative person-centred approach to intervention format and delivery.

3.9 Summary

Patients with long-term conditions can find it difficult to identify, express and discuss their support needs with HCPs due to the existence of widely accepted assumptions and ways-of-working that prioritise HCP conceptualisations of need over those informed by the patient’s lived experience. Interventions based on a Systematic Needs Assessment approach have subsequently been widely adopted in strategy documents, and in practice, in order to address these issues. However, an exploratory overview of the literature suggests that it is unclear how far these interventions actively support patient involvement in this area. In contrast, the development of a person-centred intervention (CSNAT-I), which was designed to enable carers to identify and discuss their support needs with a practitioner, suggests there is merit in exploring the case for the adoption of a person-centred approach to intervention development and format in the context of patients living with long-term conditions.

The next chapter therefore presents a critical review of the literature in order to explore this in more detail:

1) how far existing interventions enable patient identification, expression and discussion of their support needs;
2) what features within these interventions support or hinder this process in practice; and

3) the case for considering further an alternative person-centred approach in this area.
Chapter 4: Thematic synthesis of studies reporting on interventions used to support patient involvement in identifying and addressing their support needs

4.1 Introduction

The previous chapter highlighted the current lack of clarity about how far Systematic Needs Assessment interventions actively support patient involvement in identifying, expressing and addressing their support needs, and the current lack of emphasis on alternative person-centred models. Chapter 4 addresses this by reporting on a thematic synthesis of the literature in order to investigate the role of existing interventions in supporting patients with long-term conditions to identify, express and address their support needs and consider further the case for alternative more person-centred approach to intervention format and delivery. The aims of the review, the choice of review methodology, the methods undertaken and the review findings are all presented below.

4.2 Background and aims

In the previous chapter, an initial exploration of the qualitative literature suggested that both patients and HCPs perceive the Systematic Needs Assessment intervention model as useful in enabling patient involvement in identifying and addressing their support needs. However, the descriptive, rather than interrogative, nature of this literature, means there has been little exploration of how far this reflects greater patient involvement within a traditional HCP-led approach to assessment and planning supportive responses, or one that actively enables patients to overcome challenges they face by adopting a patient-led approach to identifying and addressing their support needs. There is also some discussion within the academic literature about the way in which some of the features within these interventions may be orientated towards supporting HCP identification and management of patient support needs rather than a patient-led approach.\(^2\) However it remains unclear how this plays out in practice. There is therefore a need to better understand whether and how current interventions enable patient involvement in identifying and addressing their support needs. The aim of this review was therefore to seek out evidence concerning, and
consider more critically, the nature of patient participation in identifying, expressing and addressing their support needs within existing interventions and identify features within these interventions that enable or hinder a HCP or patient-led approach to these processes.

The research questions this review addresses were therefore:

RQ1) What can current research tell us about patient and HCP experiences of identifying, expressing and addressing patient support need within existing interventions?

RQ2) What features within these interventions enable or hinder patient involvement in identifying, expressing and addressing patient support needs?

4.3 Methods

4.3.1 Review methodology

One review method that offers the potential to address the above questions is a synthesis of the relevant qualitative literature: an approach that has been defined as ‘pooling qualitative and mixed-method research data, and then drawing conclusions regarding the collective meaning of the research’ [Bearman and Dawson 2013 p. 252]. Bearman and Dawson (2013) argue that synthesising qualitative studies in this way enables the phenomena under investigation to be enriched by bringing together findings from different settings and methods, and through different interpretive lenses. Others such as Dixon-Woods et al (2005) and Greenhalgh (2018) have highlighted that this approach can also provide the opportunity to ask new questions of the data and develop theoretical or conceptual understandings that go beyond the interpretations provided in the original studies. However, counter-balancing this, qualitative reviews have also been widely criticised for their heavy reliance on reviewer interpretation (leading to concerns about bias), and the limitations in drawing generalisations beyond the original studies under the review. In response, there has been a call for qualitative reviewers to adopt some of the structured processes that underpin systematic reviews (e.g. conducting structured searches, critical appraisal of identified studies and greater transparency of the analysis).
This tension between richness and rigour has led to a range of methodological approaches being developed offering researchers a range of approaches to choose from. In their ESRC-commissioned review of methods for the synthesis of qualitative research, Barnett-Page and Thomas (2009)\textsuperscript{150} list nine established approaches including: meta-ethnography,\textsuperscript{151} grounded theory,\textsuperscript{152} thematic synthesis,\textsuperscript{149} and critical interpretive synthesis.\textsuperscript{147} As a means of characterising how these approaches address the above tensions, commentators have identified three dimensions of difference:\textsuperscript{150} 1) epistemological standpoint, 2) the extent to which each approach positions the role of data synthesis as interrogative or descriptive, and 3) the extent to which the various methodologies emphasise producing reproducible searches and quality indicators. For example, in this context, critical interpretive synthesis and meta-ethnography can be understood as tending towards understanding knowledge as subjective, emphasising an iterative approach to the identification of relevant studies and adopting an interrogative approach to data analysis. In contrast, thematic synthesis, whilst still adopting an interrogative approach, positions knowledge as less contested and highlights the need for adopting strategies that support reproducibility.

A consideration of these dimensions and their relevance to the review question informed the choice of methodological approach to synthesis adopted within this review. The approach chosen was a thematic synthesis, developed by Thomas and Harden (2008)\textsuperscript{149} to specifically support reviews ‘that addressed questions relating to intervention need, appropriateness, acceptability’ [Thomas and Harden 2008, p. 2].\textsuperscript{149} This approach adopts an interrogative approach to data analysis in order to ask new questions that can ‘facilitate the explicit production of new concepts and hypothesis’ [Thomas and Harden 2008, p. 1].\textsuperscript{149} Furthermore the approach emphasises achieving this via the use of rigorous and transparent methods to support the production of findings that have relevance beyond the original studies. More specifically, thematic synthesis draws on ideas from grounded theory and meta-ethnography but seeks to combine this with a structured search using PRISMA guidelines,\textsuperscript{153} critical appraisal of papers identified in the search and rigorous documentation of the analysis process. In order to ensure the latter, Thomas and Harden (2008)\textsuperscript{149} developed a three-step approach to analysis involving: 1) the identification of free codes via line-by-line coding, 2) the development of data-driven descriptive themes, and 3) the generation of analytical themes using a theoretical structure (provided by the review
questions) to interrogate the descriptive themes. The authors argue that use of this approach ensures there is a well-documented link between the newly identified theory-driven-analytical themes and the original findings.

In the context of the review presented here, this approach can be understood as a useful way of addressing the research questions for two reasons. Firstly, the focus on developing analytical themes provides a means of exploring new questions that goes beyond the issues of feasibility, acceptability and usefulness which were identified as the main focus of the literature to-date. This supports the opportunity to ask further questions about how far patients are specifically involved in identifying and addressing their support needs. Secondly, the commitment to analytical rigour potentially supports the development of generalizable conceptual understandings that can support consideration of more recent or future interventions developed to support patient identification and discussion of their support needs. This approach therefore contrasts with alternative approaches to reviewing the qualitative literature that primarily adopt an inductive approach to data synthesis (e.g. grounded theory and meta-ethnography), and which therefore do not directly facilitate consideration of predetermined questions beyond the scope of the original studies such as those reviewed here. A thematic synthesis was also chosen over other integrative approaches, such as a critical interpretive synthesis, as these tend to emphasise a broad, iterative and reflexive approach rather than one that has the potential to highlight generalizable concepts supported by an evidence base.

4.3.2 Inclusion criteria

Types of Participants

The review considered studies that involved human subjects who were adult (18 years and older) and diagnosed with a long-term condition. As noted earlier, the Department of Health (2012)\(^3\) has defined a long-term condition as ‘an illness that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies’ [DH/Long-term Conditions, 2012, p. 3],\(^3\) for example chronic obstructive pulmonary disease (COPD) and heart failure. Patients with any severity of illness were included.
Types of intervention

Interventions were included if: 1) their primary or secondary purpose was stated in the abstract as involving patients with long-term conditions in identifying and discussing their needs with HCPs; 2) they involved a clearly defined process carried out with, or by, the patient to identify and address patient need; and 3) they had a holistic focus (incorporated biomedical, psychological and social domains).

Concept of patient need

The use of ‘patient need’ as a search term rather than ‘support need’ was adopted due to the limited use of the term ‘support need’ in the relevant literature based on initial pilot and scoping searches. In contrast, evidence from the pilot searches suggested that focusing more broadly on patient need enabled the identification of studies that could potentially inform understanding of patient involvement in identifying, expressing and addressing their support needs.

Clinical Setting

Studies based in any clinical setting were included.

Types of Studies

The review considered studies reporting on primary research and published in a peer review journal that captured HCP, patient, or a combination of patient/HCP perspectives on participating within an intervention via qualitative or mixed-methods research designs. There were no restrictions on country but only studies written in English were considered for review.

4.3.3 Exclusion criteria

Studies describing the following interventions were excluded from the review:

1). interventions that were designed to support patients identify and express their needs within a single domain of need (e.g. psychological well-being)
2) interventions that were designed to support patients to participate in decisions about treatment choices

3) interventions that were designed to identify patients for referral to a specific service

4) editorials or single case studies

4.3.4 Search strategy

The search terms were developed with an information specialist. These were informed by the review research questions and focused on the following areas: 1) populations with a long-term illness (this included general terms like ‘long-term conditions’ and named chronic conditions that are commonly managed within supportive and palliative care services, e.g. heart disease); 2) interventions used to identify and address patient needs; and 3) the experiences and outcomes from participating in these interventions (patients and HCPs).

The search comprised four steps:

1) Pilot search: an initial search of Medline Ovid was undertaken using keywords and phrases from key articles in the subject area.

2) Extended electronic search informed by the pilot search: search terms used are shown in Box 8. For pragmatic reasons (high number of anticipated studies identified based on the pilot search), search terms were limited to abstract and title only. The search terms were then applied to each of the following electronic databases: Medline (Ovid), EMBASE, PsycINFO, Cochrane Library, and CINAHL. These were identified by IK as key databases for high quality healthcare literature or widely recognised general databases that could potentially incorporate relevant literature. This search covered the period 1946-July 2018.

3) Manual search: reference lists of relevant literature reviews, and papers already identified in steps 1 or 2 of the search process, were checked for further potentially relevant papers against the inclusion/exclusion criteria.

4) Updated electronic search covering the period August 2018- December 2020
Box 8: Thematic synthesis search strategy

Medline (Ovid) search strategy: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)

(chronic* or (long* term care) or (long*term care) or ((persistent or (long* term) or long*term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)) or (heart disease) or (heart failure) or (myocardial isch?em*) or (coronary adj2 disease*) or (myocardial infarct*) or hyperten* or (high blood pressure) or cerebrovascular or (brain isch?em*) or (cerebral infarction) or (carotid artery disease*) or stroke or epilep* or seizure* or neurodegenerative or Huntington* or Parkinson* or (amyotrophic lateral sclerosis) or (multiple sclerosis) or (motor neuron disease) or emphysema or COPD or (obstructive pulmonary dis*) or (obstructive lung disease*) or asthma or bronchitis or osteoporosis* or arthritis or osteoarthritis or rheumati* or fibromyalgia or cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia or hiv or diabet* or multi?morbid* or co?morbid* or (multi adj morbid*) or (co adj morbid*).ti,ab. or exp CHRONIC DISEASE/ or exp Long-Term Care/ or exp lung disease obstructive/ or exp cardiovascular diseases/ or exp stroke/ or exp neoplasm/ or exp hypertension/ or exp Asthma/ or exp pulmonary emphysema/ or exp emphysema/ or exp hiv infections/ or exp nervous system diseases/ or diabetes mellitus/ or exp osteoporosis/ or exp arthritis/ or exp rheumatic diseases/ or exp MULTIMORBIDITY/ or exp Comorbidity/

AND

((mechanism of action) or (problem adj3 solv*) or ((service* or care* or unmet* or assess* or support* or self-care* or healthcare or "health care" or palliative or holistic or) adj5 (need* or requir*)) or barrier* or obstacle*).ti,ab.

AND

(tool* or survey* or (focus group*) or interview* or instrument* or "prom" or "patient reported outcome or intervention**").ti,ab.

AND

((participant* or patient*) adj3 (identif* or self-assess* or clarif* or legitim* or visual* or articulat* or permission or "person?cent*" or experienc* or attitud*)).ti,ab.

Date Limiters:

First search: 1946 – July 2018
Second search: July 2018 –Dec 2020

Translated for Embase via Ovid, CINAHL via Ebsco, PsycINFO via Ebsco, Web of Science Core Collection
4.3.5 Abstract selection process

Titles and abstracts of studies to be considered for retrieval were recorded within the Rayyan systematic review web app, along with details of where the reference was found. Titles and abstracts were screened by the lead reviewer (CG) and those that clearly did not meet the inclusion criteria were excluded by the lead reviewer only. Two reviewers (CG and MF) then independently reviewed the remaining abstracts. Abstracts were assessed for their relevance to the topic, against the inclusion/exclusion criteria. Discrepancies in the selection process were resolved by discussion prior to quality assessment and data extraction.

4.3.6 Assessment of study quality

All studies that met the inclusion criteria and passed the abstract selection were examined in depth. Data regarding the methodological details of each study was extracted onto a designed-for-purpose data extraction sheet. Studies were then assessed against the ten questions on the qualitative CASP Qualitative Studies Checklist, as all studies were either qualitative, or involved data from the qualitative component of mixed methods studies. Each study was therefore assessed according to whether:

- there was a clear statement of the aims of the research
- the qualitative methodology was appropriate
- the research design was appropriate to address the aims of the research
- the recruitment strategy was appropriate to the aims of the research
- the data was collected in a way that addressed the research issue
- the relationship between the researcher and participants had been adequately considered
- ethical issues had been taken into consideration
- the data analysis was sufficiently rigorous
- there was a clear statement of findings
- the research was considered to have value
4.3.7 Data extraction

Data was extracted in two stages. In the first stage, data was extracted onto spreadsheets recording:

1) quality appraisal
2) study characteristics: this included lead author surname, date of publication, the country where the study took place, sample size, participant characteristics, research objective and qualitative methods
3) intervention description

In the second stage, relevant participant quotes and author reported findings were extracted onto an additional spreadsheet for coding and theme development.

4.3.8 Synthesis

A thematic synthesis was undertaken using the three-step method set out by Thomas and Harden (2008) as outlined in Box 9 and reported in detail below.

<table>
<thead>
<tr>
<th>Box 9: Outline of the three analytical steps underpinning thematic synthesis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1:</strong> Line-by-line coding</td>
</tr>
<tr>
<td><strong>Step 2:</strong> Generation of descriptive themes</td>
</tr>
<tr>
<td><strong>Step 3:</strong> Development of analytical themes</td>
</tr>
</tbody>
</table>

For the purpose of this review, undertaking the synthesis involved:

1) *Line-by-line coding*

Each of the papers was read several times and an initial line-by-line coding of the results section within each paper was carried out. Data was extracted onto a table developed in Microsoft Word and assigned to one or more codes. A sub-set
(approximately 20%) of the included studies was additionally coded by the two thesis supervisors (CD and MF) and all three reviewers’ sets of results were compared. Discrepancies were resolved by discussion.

2) **Descriptive themes**

The codes identified in the line-by-line coding were organised into descriptive themes and discussed and confirmed with the thesis supervisors.

3) **Analytical themes**

Central analytical themes, informed by the original research question, were developed by CG, and discussed with the thesis supervisors. These drew on, and were informed by, the descriptive themes identified in Step 2 above.

### 4.4 Results

#### 4.4.1 Included papers

The number of papers identified, included and excluded, together with the reasons for exclusions, are summarised in the PRISMA flow diagram (Figure 3). In total, 16 papers, reporting on 14 interventions were included in this review.

**Quality of included papers**

Most of the studies provided clear aims and outlined a methodology and research design that was appropriate to meet those aims. In six of the studies the sampling process was assessed as limited in terms of fully exploring the study aims (e.g. participants were included who did not take part in the intervention or numbers were very small). Only five of the studies fully described the data collection process (e.g. provided details of interview schedules) and the data analysis process was rarely recorded in detail. All of the studies had obtained ethical approval, although researcher reflection on their role was limited to outlining tasks undertaken. The importance of the findings were consistently discussed and linked to existing or new clinical practice and thinking. All the papers were considered as making a useful contribution to the review.
Identification of studies via databases and registers

Records identified from:
- Databases (n=31,084)
- Registers (n=0)

Records removed before screening:
- Duplicate records removed (n=19,769)
- Records marked as ineligible by automation tools (n=0)
- Records removed for other reasons (n=0)

Records screened (n=11,315)

Records excluded** (n=11,272)

Records sought for retrieval (n=43)

Records not retrieved (n=6)

Reports assessed for eligibility (n=37)

Studies included in review (n=14)
Reports of included studies (n=2)

Identification of studies via other methods

Records identified from:
- Websites (n=0)
- Organisations (n=0)
- Citation searching (n=9)

Records identified from:
- Databases (n=31,084)
- Registers (n=0)

Records removed before screening:
- Duplicate records removed (n=19,769)
- Records marked as ineligible by automation tools (n=0)
- Records removed for other reasons (n=0)

Records screened (n=11,315)

Records excluded** (n=11,272)

Records sought for retrieval (n=43)

Reports assessed for eligibility (n=37)

Reports not retrieved (n=0)

Reports excluded:
- Reason 1 (n=7) incorrect intervention aim
- Reason 2 (n=5) not long-term conditions
- Reason 3 (n=4) qualitative data
- Reason 4 (n=5) incorrect publication e.g. poster
- Reason 5 (n=3) intervention development

Studies included in review (n=14)
Reports of included studies (n=2)
Figure 3: PRISMA flowchart of articles identified in the literature search

Overview of included papers

Table 1 summarises the characteristics of the included papers. Ten of the papers were from the UK, two from Denmark and one each from Ireland, Belgium, Sweden and Australia. The two Danish papers both reported findings from one larger study, as did two of the UK papers. Ten of the papers reported on the qualitative component of a larger study. Most of the papers were set within secondary care out-patient settings, two were linked to post-discharge care, four were based in primary care and one within ‘diverse cancer clinics’. One further paper was based across primary, community and secondary care.

Eight of the papers sought to explore one or more of the following concepts: intervention feasibility, acceptability or usefulness. Five papers were focused on exploring participant experiences of participating in the intervention. One paper described itself as exploring the impact of the intervention, one considered implementation of the intervention and the remaining study was focused on exploring the concept of need in patients with COPD. The papers typically reported on the analysis of findings collected via qualitative interviews or focus groups.

Most of the studies reported on both patient and HCP data, with just three reporting only HCP data and three just patient data. Most of the papers involved patients with cancer, including papers that covered specific cancer sites (lung, melanoma, colorectal, head and neck and gynaecological). In addition, one paper reported on intervention use with patients with heart failure, two with patients with COPD and one with palliative care patients with a range of diagnoses. HCPs in the study were primarily nurses, doctors or radiologists. Three studies also included other health professionals or allied health or social care professionals.
<table>
<thead>
<tr>
<th>Author (year)</th>
<th>Country</th>
<th>Aim (For mixed methods study the aim refers to the qualitative component only)</th>
<th>Sample</th>
<th>Sample size</th>
<th>Participant characteristics</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biddle et al (2016)&lt;sup&gt;18&lt;/sup&gt;</td>
<td>UK</td>
<td>To understand how tools (to support psycho-social needs assessment) are experienced by patients and clinicians in order to optimise use in the future</td>
<td>Sample of patients recruited from a larger study based on two sites offering outpatient chemotherapy and radiotherapy</td>
<td>15 Patients</td>
<td>Female = 66% Within age range 35-75 years Diagnosis of cancer</td>
<td>5 radiotherapists 2 chemotherapy nurses</td>
</tr>
<tr>
<td>Buckingham (2015)&lt;sup&gt;156&lt;/sup&gt;</td>
<td>UK</td>
<td>To assess feasibility, acceptability and potential impact of a nurse-led intervention (HELP-COPD) which sought to identify and address the holistic care needs of people with COPD</td>
<td>Sample of patients from a larger study recruited via secondary care HCPs recruited from services for people with severe COPD including primary,</td>
<td>8 patients 3 carers 28 HCPs</td>
<td>Male = 47.8% Mean age 72.2 years Diagnosis of COPD (recently admitted to hospital with a primary diagnosis of exacerbation of COPD)</td>
<td>Diverse range of professionals from social work, primary care, physiotherapy and nursing teams involved in supporting people with COPD</td>
</tr>
<tr>
<td>Clarke et al (2019)^158</td>
<td>To identify perceived barriers and motivators to implementation and continued use of the prostate cancer-specific Holistic Needs Assessment (sHNA)</td>
<td>Sample of patients recruited from a larger study via five participating primary care practices. Patients had completed an electronic sHNA x2 as part of the larger study</td>
<td>16 patients 11 HCPs</td>
<td>Male = 100%  Age range 61-85 years  Diagnosis of prostate cancer  Completed an electronic HNA x2 as part of the larger study</td>
<td>4 GPs 6 practice nurses 1 clinical nurse specialist</td>
<td>Semi-structured interviews  Inductive thematic analysis</td>
</tr>
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<tr>
<td>Hogberg et al (2019)^168</td>
<td>To explore patient experiences of using the Integrated Palliative Outcome Scale (IPOS) during specialized palliative home care (for person-centred care)</td>
<td>Sample of patients recruited from three palliative home-care units participating in a wider study</td>
<td>10 patients</td>
<td>Female = 3  Age range 46-85 years  Advanced Cancer =9  Stroke = 1  Completed IPOS twice prior to recruitment</td>
<td>N/A</td>
<td>Qualitative interviews  Qualitative interpretive description</td>
</tr>
<tr>
<td>Author(s) and Year</td>
<td>Objective</td>
<td>Sample</td>
<td>Characteristics</td>
<td>Methods</td>
<td>Analysis</td>
<td></td>
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<tr>
<td>Kane et al (2018)</td>
<td>To explore whether and how a palliative care–specific patient-reported outcome intervention involving the Integrated Palliative care Outcome Scale influences patients’ experience of patient-centred care in nurse-led chronic heart failure disease management clinics</td>
<td>Sample of patients from a larger intervention feasibility study recruited from nurse-led chronic heart failure disease management clinics within two tertiary referral centres</td>
<td>18 Patients 4 Nurses  Male = 61% Age range 75 ± 8.5 years Patients diagnosed with chronic heart failure</td>
<td>Semi-structure interviews Analysis informed by framework approach</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kendall et al (2015)</td>
<td>To explore the concept of need in the context of people with COPD</td>
<td>Sample of patients from a larger study recruited via secondary care HCPs recruited from services for people with severe COPD including primary, secondary and intermediate care professionals, social services and other referral agencies</td>
<td>14 patients 3 carers 28 HCPs  Male = 47.8% Mean age 72.2 years COPD (recently admitted to hospital with a primary diagnosis of exacerbation of COPD)</td>
<td>Diverse range of professionals from social work, primary care, physiotherapy and nursing teams involved in supporting people with COPD Semi-structured interviews and field notes Data was analysed thematically using Bradshaw’s classification of need</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Sample description</td>
<td>Participants</td>
<td>Setting</td>
<td>Methodology</td>
<td>Data analysis</td>
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<tr>
<td>Kotronoulas et al (2017a) UK</td>
<td>To explore the feasibility, acceptability and perceived values of a needs assessment intervention for newly diagnosed patients with Stage 1 or Stage II melanoma</td>
<td>Sample of patients from a larger study recruited from out-patient clinics within one NHS board in Scotland</td>
<td>6 patients 1 HCP</td>
<td>Female = 80% Age range 30-70 years Patients newly diagnosed with cancer (melanoma Stage 1 or Stage II)</td>
<td>1 skin cancer nurse specialist</td>
<td>Semi-structured interviews (Patients and carers) Thematic content analysis</td>
</tr>
<tr>
<td>Kotronoulas et al (2017b) UK</td>
<td>To explore the feasibility and acceptability of the use of supportive care needs patient reported outcome measures (PROM)s by colorectal cancer nurse specialists (CNS) in the delivery of supportive care to people with colorectal cancer receiving adjuvant chemotherapy</td>
<td>Sample of patients from a larger study recruited from outpatient clinics of one NHS trust</td>
<td>3 patients 6 HCPs</td>
<td>Male = 9 Mean age 64.1 years Diagnosis of colorectal cancer</td>
<td>6 cancer nurse specialists</td>
<td>Interviews (Patients and HCP) Thematic analysis</td>
</tr>
<tr>
<td>Kotronoulas et al (2018) UK</td>
<td>To examine whether an in-clinic, nurse-led consultation model, which was driven by use of a</td>
<td>Sample of patients from a larger study recruited from out-patient clinics</td>
<td>9 Patients 3 HCPs</td>
<td>Male = 6 Age 51-83 years Diagnosis of lung cancer</td>
<td>3 lung cancer nurse specialists</td>
<td>Open-ended interviews Thematic analysis</td>
</tr>
<tr>
<td>Study</td>
<td>Objective</td>
<td>Sample</td>
<td>Participants</td>
<td>Methods</td>
<td></td>
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<tr>
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<tr>
<td>McIlfatrick and Hasson (2013)</td>
<td>To evaluate a holistic assessment tool for palliative care practice</td>
<td>Sample of HCPs from a larger study recruited from specialist and generalist settings across primary, community and secondary care</td>
<td>10 HCPs</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient-reported outcomes (PRO) measure, was feasible and acceptable in the identification of unmet needs in patients with lung cancer in one NHS board in the UK.

UK

Specialist and generalist palliative care nurses

Focus groups

Content analysis
<table>
<thead>
<tr>
<th>Study</th>
<th>Title &amp; Year</th>
<th>Country</th>
<th>Objective</th>
<th>Methodology</th>
<th>Sample Characteristics</th>
<th>HCPs</th>
<th>Recruitment</th>
<th>Data Collection</th>
<th>Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rogers and Lowe (2014)</td>
<td>To evaluate use of the Head and Neck Cancer Patients Inventory across the Merseyside and Cheshire cancer network</td>
<td>UK</td>
<td>Participants were recruited from review clinics for head and neck oncology within 5 secondary care settings</td>
<td>66 Patients</td>
<td>Male = 68%</td>
<td>8 doctors and 6 nurse specialists</td>
<td>Patients – telephone interviews or written responses</td>
<td>Methods for analysing qualitative data not specified</td>
<td></td>
</tr>
<tr>
<td>Sandsund et al (2020)</td>
<td>To understand the impact of HNA and care planning for people</td>
<td>UK</td>
<td>Sample of patients from a larger study recruited within a tertiary cancer centre</td>
<td>10 Patients</td>
<td>Female = 100%</td>
<td>N/A</td>
<td>Semi-structured Interviews</td>
<td>Thematic analysis</td>
<td></td>
</tr>
<tr>
<td>Schouten et al (2018)</td>
<td>Exploration of patient and nurse’s experiences of using the systematic CARES-assessment in early follow up of patients with digestive cancer</td>
<td>Belgium</td>
<td>HCPs were recruited from two gastroenterology departments in secondary care</td>
<td>2 HCPs</td>
<td>N/A</td>
<td>1 clinical nurse specialist</td>
<td>Semi-structured interviews</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study Reference</td>
<td>Country</td>
<td>Study Purpose</td>
<td>Setting</td>
<td>Participants</td>
<td>Gender</td>
<td>Age</td>
<td>Diagnosis</td>
<td>Topic Area</td>
<td>Data Collection</td>
</tr>
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<tr>
<td>Thayssen et al (2015)</td>
<td>Denmark</td>
<td>Examination of patient experiences of completing a questionnaire prior to needs assessment</td>
<td>GP Practices</td>
<td>16 Patients</td>
<td>Female = 12</td>
<td>Age range 49-83 years</td>
<td>Diagnosis of cancer</td>
<td>N/A</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Thayssen et al (2016)</td>
<td>Denmark</td>
<td>To examine GP experiences of using a short questionnaire when addressing the patients problems and needs as part of clinical cancer care</td>
<td>GP Practices</td>
<td>11 HCPs</td>
<td>N/A</td>
<td></td>
<td></td>
<td>GPs involved in the management of cancer patients</td>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Thewes et al (2016)</td>
<td>Australia</td>
<td>To describe patient and staff attitudes towards the acceptability and feasibility of the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) in routine care</td>
<td>Four geographically diverse cancer clinics</td>
<td>34 Patients</td>
<td>Female = 68%</td>
<td>Mean age 55.4 years</td>
<td>Diagnosis of cancer in people from an Australian Indigenous background</td>
<td>Diverse set of professional backgrounds including social workers, nurse care coordinators and radiation therapist</td>
<td>Brief semi-structured interview</td>
</tr>
</tbody>
</table>
4.4.2 Overview of interventions reported on in the included papers

Table 2 summarises the key features of the 14 interventions reported on in the included papers. These features include: a) purpose, b) materials and resources, and c) processes.

Purpose

Seven of the interventions\textsuperscript{18, 110, 156, 158, 162, 163, 165} were described as supporting a needs assessment, one\textsuperscript{107} as a subjective assessment of patient’s palliative symptoms and concerns, three\textsuperscript{111, 159, 160} focused on assessing (or identifying) and addressing supportive care needs, two\textsuperscript{169} on identifying or screening of unmet needs and two\textsuperscript{161} saw the role of the interventions as either enabling patients raise issues they wished to discuss, or as facilitating a conversation to support a discussion about care needs. In addition, two interventions positioned the intervention in the context of supporting the delivery of patient-centred\textsuperscript{107} and person-centred care.\textsuperscript{168}

Materials and Resources

Across the interventions, four broad types of materials and resources were evident: needs assessment questionnaires/prompts, action planning records, training, and information on available services and resources.

i) Needs assessment questionnaires/prompts

All of the interventions incorporated some form of questionnaire or prompt.

- The DT&PL was used in three interventions\textsuperscript{18, 172 111}
- IPOS and SCNS were each integrated into two interventions\textsuperscript{107, 111, 159, 168}
- In contrast the following questionnaires/prompts formed a component of just one of the interventions: CAREs-SF,\textsuperscript{165} HELP-COPD record sheet,\textsuperscript{156} Brief Holistic Assessment and Referral Screening Tool; SPARC,\textsuperscript{160} PCI H&N,\textsuperscript{161} London Holistic Needs Assessment,\textsuperscript{162} SCNAT–IP\textsuperscript{169} and the s(Holistic Needs Assessment)\textsuperscript{158}
- One intervention incorporated both the DT&PL and SCNS\textsuperscript{111}
<table>
<thead>
<tr>
<th>Studies</th>
<th>Purpose</th>
<th>Materials and Resources</th>
<th>Procedures</th>
<th>Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biddle (2016)</td>
<td>Holistic Needs Assessment</td>
<td>Distress Thermometer and Problems Checklist, Staff Training Session x 1, Resource directory containing information for each problem, possible self-management techniques and support groups</td>
<td>HCPs introduce the DT&amp;PL to patients as a holistic tool to explore aspects of distress during face-to-face meeting. Patients used questionnaire to rate distress and complete checklist. HCP and patient work through the problem list item by item. Action plan derived to identify staff and patient actions. HCPs use training and resource directory to support this process. Patient can request a second DT and PL meeting if required.</td>
<td>DT&amp;PL intervention delivered in cancer out-patients consultation by a radiotherapist or chemotherapy nurse at approximately the second week of radiotherapy or second cycle of chemotherapy. Intervention integrated into, and delivered in addition to, usual care.</td>
</tr>
<tr>
<td>Buckingham et al (2015)</td>
<td>Holistic assessment of patient need</td>
<td>HELP-COPD record sheet, Plastic folder and fridge magnet</td>
<td>Home visit by respiratory nurse arranged 2-6 weeks post patient discharge after admission for exacerbation. During the visit the nurse uses the exemplar open questions on the HELP-COPD record to prompt an informal chat/discussion about any physical, psychological, social or spiritual concerns. A checklist of agreed actions is recorded on the HELP-COPD record to facilitate implementation, and referrals made through the usual channels. The completed one-page record is retained by the patient, with copies for the primary and secondary care records. The respiratory nurse telephones the patient at 1, 3 and 6 months to check progress with action plans.</td>
<td>Delivered (in addition to usual care including discharge planning with appropriate community or hospital follow-up) by a specialist respiratory nurse with palliative care training employed for the purpose of the research project.</td>
</tr>
<tr>
<td>Clarke et al (2019)¹⁵⁸</td>
<td>Holistic needs assessment</td>
<td>s Holistic Needs Assessment (Online prostate specific HNA) The electronic platform also generates a semi-automated care plan</td>
<td>sHNA sent out to patients electronically for patient to complete at home prior to future consultation. HCPs receive completed HNA prior to consultation Completed HNA is discussed within consultation</td>
<td>sHNA is delivered into usual care within a primary care setting</td>
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<tr>
<td>Hogberg et al (2019)¹⁶⁸</td>
<td>Person-centred care</td>
<td>Integrated Palliative Outcome Scale (IPOS) Training focused on using IPOS to support a conversation about needs characterised by presence, genuine curiosity and HCP’s reflecting on their interpretation of patient perceptions</td>
<td>HCP uses IPOS as the basis of a conversation with the patient that is focused on the patient’s need Person-centred use of IPOS was integrated into usual specialist palliative care</td>
<td></td>
</tr>
<tr>
<td>Kane et al (2018)¹⁰⁷</td>
<td>To provide a subjective assessment of patients’ palliative symptoms and concerns to improve their identification and management</td>
<td>Underpinned by a conceptual representation of patient-centred care Integrated Palliative Outcome Scale (IPOS) HCP education and training comprising five components</td>
<td>HCP gives patient IPOS to complete at routine appointment (completion takes place just prior to the appointment) HCPs review each patient with the completed IPOS. If a patient requests assistance to complete IPOS the HCP is not to paraphrase, not to give their own explanations of the questions, to adhere to the questionnaire text and not to prompt patients with potential answers HCPs advised to address individual items with scores ≥3; use their clinical discretion for</td>
<td>Intervention delivered in usual care outpatient nurse-led chronic heart failure disease management clinics</td>
</tr>
<tr>
<td>Study</td>
<td>To assess and address patient supportive care needs</td>
<td>Supportive Care Needs Survey (SCNS)</td>
<td>Patient is given the tool at the setting and completed prior to consultation</td>
<td>The intervention was delivered by specialist cancer nurse to patients with colorectal cancer</td>
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<td>-------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
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<tr>
<td>Kotronoulas et al. (2017)</td>
<td></td>
<td>Case report forms for documenting needs and resulting interventions</td>
<td>The completed tool is given to the nurse prior to consultation</td>
<td>Consultations focused on the intervention took place in addition to usual care</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Consultation directed by information on the tool to identify the patients supportive care needs, direct consultation and intervene accordingly</td>
<td>Patients participated in 3 consultation over three, equally spaced (monthly) time-points: penultimate chemotherapy cycle (T1); last chemotherapy cycle (T2); and approximately one month after the last chemotherapy cycle (T3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HCP uses clinical expertise to assess and respond to needs</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>HCP documents any needs identified and resulting interventions on case report forms</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>Timing of the intervention is selected in consultation with CNS participants</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Enhance the identification and management of the supportive care needs of people with</th>
<th>Distress Thermometer Problem List</th>
<th>Participants are asked to complete the questionnaires in the hospital immediately prior to their consultation with the nurse specialist</th>
<th>Delivered to patients with new diagnosis of melanoma by a skin cancer specialist nurse.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kotronoulas et al. (2017)</td>
<td>Supportive Care Needs Survey</td>
<td></td>
<td>Completed questionnaires are passed on to the nurse specialist for review</td>
<td>The intervention was delivered via three consultations in line with chemotherapy cycle, additional to usual care</td>
</tr>
<tr>
<td></td>
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<td>The subsequent consultation is based on information collected on priority supportive care</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Description</td>
<td>Intervention</td>
<td>Outcome</td>
<td></td>
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<tr>
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<tr>
<td>Kotronoulas et al. (2018)</td>
<td>Delivery of enhanced supportive care via the identification of unmet needs in patients</td>
<td>SPARC tool</td>
<td>Patients complete the questionnaire in a quiet room immediately prior to the consultation. The lung CNS documented any identified needs and clinical interventions/advice</td>
<td></td>
</tr>
<tr>
<td>McIlfatrick and Hasson (2013)</td>
<td>Holistic Assessment of patient needs</td>
<td>Brief Holistic Assessment and Referral screening Tool including record of actions</td>
<td>Tool prompts HCP to consider a range of response and services</td>
<td></td>
</tr>
<tr>
<td>Rogers and Lowe (2014)</td>
<td>A prompt for patients to raise issues they wish to discuss in a consultation and early indication of need for support</td>
<td>Head and Neck Cancer Patients Inventory Resource material on website including instructional videos about how to interpret the responses, and an information leaflet for patients</td>
<td>Patient complete the PCI-H&amp;N in the clinic prior to consultation (electronically) HCP uses tool to identify issues they wish to discuss/other members of the clinical team they wish to see and addresses them in the consultation</td>
<td></td>
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</tbody>
</table>

Lung nurse specialists delivered the intervention to patient with lung cancer Three consecutive nurse-clinician consultations at monthly intervals in hospital setting in addition to usual care.
| Sandsund et al (2020)\textsuperscript{162} | Holistic needs assessment and collaborative care planning | London Holistic Needs Assessment (incorporating template for highlighting issues, a summary of the discussion and actions required) | Patients offered face-to-face or telephone consultation
Patients receive the questionnaire in the post and are asked to complete and bring it to the consultation where it provides the basis for a discussion and development of a collaborative care plan
The HNA and care plan are reviewed after 3 months | The intervention was delivered to women with gynaecological cancer
The intervention was delivered in addition to usual outpatient care by an AHP experienced in multi-professional rehabilitation and familiar with behavioural change principles |
| Schouten et al (2018)\textsuperscript{165} | Systematic assessment of Quality Of Life and care needs to support cancer care for the whole patient. | Cancer Rehabilitation Evaluation System – Short Form (CARES-SF)\textsuperscript{173} | Patients asked to complete CARES at home either electronically or using a paper version
Where patients completed the paper version an SAE was supplied, and patients were asked to return the completed questionnaire in the post.
A researcher processed the returned CARES data, wrote an output report, and sent it to the reference nurse for use in patient follow up | Integrated into the routine follow up of patients with digestive cancer |
| Thayssen et al (2016)\textsuperscript{163} Thayssen et al. (2017)\textsuperscript{164} | Needs Assessment | Distress Thermometer Impact Thermometer Problem List (DT and PC) | DT and PC is posted to patients at home prior to pre-existing appointment with GP
Patients bring the completed DT and PC to the consultation
Based on the answers in the questionnaire the consultation focuses on addressing patients distress and problems and clarifying their possible needs for rehabilitation | Delivered by GPs to patients with cancer
The consultation was in addition to usual care |
<table>
<thead>
<tr>
<th>Thewes et al (2016)</th>
<th>Routine screening of unmet support needs</th>
<th>The Supportive Care Needs Assessment Tool for Indigenous People</th>
<th>HCP completes the tool with the patient (HCP reads out the questions)</th>
<th>Intervention is delivered to indigenous Australians with cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3 hour training session for HCPs</td>
<td></td>
<td>Items scoring 4/5 are discussed further and patients were offered assistance in line with usual care</td>
<td>Consultation is additional to usual care. Intervention delivered by social workers, nurses and clinical trial coordinators</td>
</tr>
</tbody>
</table>
In addition Table 3 outlines how the above questionnaires differed in relation to their underlying purpose, format, content, focus and psychometric properties.

In the first instance the questionnaires varied in relation to the purposes that were ascribed to them both within the study and more generally. These included: assessment of quality of life; assessment of holistic needs; assessment or identification of care needs/supportive care needs; subjective assessment of palliative symptoms and concerns; prompting a conversation about need; acting as a Patient Reported Outcome Measure (PROM) and screening for supportive and palliative care. Only one questionnaire was designed as an integral feature of a specific intervention rather than as a standalone questionnaire/prompt.

The majority of interventions incorporated questionnaires whilst just two used prompts. One questionnaire was designed to be read out to the patient, and one supported completion by either the patient or the HCP. In contrast the majority of questionnaires were designed to be completed by the patient.

The format adopted by eight of the questionnaires included a list of narrowly focused questions requiring patients to answer on a Likert scale. Seven incorporated, or were based around, a checklist or tick box which typically required patients to select a yes/no answer. Two questionnaires also included open questions. The two prompts provided a list of questions HCPs could use to directly ask questions of the patients.

Typically, the questions across all the questionnaires/prompts sat within broad domains that encompassed physical, psychological, social and spiritual issues, although in many cases the majority of questions sat within the physical domains.
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Purpose</th>
<th>Format</th>
<th>Content Domains (plus number of questions in each domain).</th>
<th>Focus</th>
<th>Development and Validation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Rehabilitation Evaluation System – Short Form (CARES-SF)</td>
<td>Measurement of quality of life and care needs</td>
<td>Questionnaire 59 items Each item consists of a problem statement. For each statement patients are asked to answer ‘How much does this apply to you?’ Patient replies on a 5-point ordinal scale with following answer-options ‘does not apply’ to ‘applies very much’ For any problem experienced, patients are asked to answer yes/no to the question ‘Do you want help?’</td>
<td>Physical (n=10) Psycho-social (n=17) Medical interaction (n=4) Marital (n=6) Sexual (n=3) Miscellaneous (n=19)</td>
<td>All items ask about: 1) potential problems and 2) need for help with that problem</td>
<td>Development and validation process informed by psychometric theory The developers concluded that CARES had robust psychometric properties including: excellent test-retest reliability; concurrent validity; an acceptable internal consistency of summary scales; was sensitive to change and is highly related to the Functional Living Index-Cancer (FLIC), an existing quality of life instrument</td>
</tr>
<tr>
<td>Distress Thermometer and Problem List (DT&amp;PC)</td>
<td>Designed to support routine screening for distress and identification of associated problems and concerns</td>
<td>Questionnaire Two components 1. Distress Thermometer 1 item Comprises visual aid to support patients’ rate the level of distress experienced in the past week. Patient rates distress on a scale on a Likert scale of 0-10.</td>
<td>Distress (n=1) Practical problems (n=5) Family problems (n=3) Emotional problems (n=6) Spiritual/religious concerns (n=1) Physical problems (n=21)</td>
<td>All questions ask about symptoms and problems.</td>
<td>DT developed in response to understanding that distress is an unpleasant experience that impacts on an individual ability to cope with cancer Content for the problem tool identified via the literature, expert review</td>
</tr>
</tbody>
</table>
2. Problem list
36 items. Items address areas where the patient could be experiencing problems. Patient ticks boxes (yes/no) to indicate areas where they have been experiencing problems in the past week.

Further clinical assessment recommended if the patient shows clinical evidence of moderate to severe distress or has a score of 4 or more on the problem tool.

<table>
<thead>
<tr>
<th>Distress Thermometer Impact Thermometer and Problem Checklist^{75}</th>
<th>To detect adjustment orders and depression</th>
<th>Questionnaire</th>
<th>As above</th>
<th>As above</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>As above</td>
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<td></td>
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<td>As above</td>
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<td></td>
<td></td>
<td>The questionnaire was assessed for found to have sensitivity and specificity and criterion validity</td>
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<tr>
<td></td>
<td></td>
<td>Comparison of performance in detecting distress with the Hospital Anxiety and Depression Scale suggest that the Distress and Impact Thermometer is an effective tool for routine screening of depression etc. in clinical oncology settings</td>
<td></td>
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</tr>
</tbody>
</table>
### Head and Neck Cancer Patients Inventory (PCI-H&N)\(^{161}\)

<table>
<thead>
<tr>
<th>To identify concerns that patients would like to discuss during their consultation</th>
<th>Questionnaire</th>
<th>Cause of cancer (3) Treatment (17) What Will I be like? (2) Social Care and social Well-being (10) Psychological, emotional and spiritual wellbeing. (13) Physical and functional well-being (30)</th>
<th>All questions ask about symptoms and problems</th>
<th>Domains based on the validated University of Washington Quality of Life Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>57 items</td>
<td>The PCI-H&amp;N is completed using a touch-screen computer immediately before the consultation. Responses are networked into the consultation room. Patient ticks a box (electronically) if they want to discuss an particular item further. The inventory also lists potential members of the professional team that the patients could see or be referred on to.</td>
<td></td>
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</tr>
</tbody>
</table>

### HELP-COPD record sheet\(^{156}\)

<table>
<thead>
<tr>
<th>To support holistic needs assessment, together with an action planning record to document agreed action plans</th>
<th>Prompt</th>
<th>Social (n=2) Psychological (n=3) Spiritual (n=3) Physical (n=1) General (n=3)</th>
<th>9x questions about the impact of living with COPD 1 x question about current support (spiritual) 1 x open question about support need 1 x question about carer</th>
<th>Designed-for-purpose (information on design process not found)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 exemplar open questions HCP can use to start a discussion about impact of COPD and current support for HCP to draw on</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Brief holistic assessment and referral screening tool</td>
<td>HCP prompt/aide memoire to support holistic needs assessment</td>
<td>Questionnaire</td>
<td>Physical health; Social and occupational well-being; Mental health and emotional well-being; Family and close relationships; Spiritual well-being; Awareness and decision making; Prognostic clinical indicators</td>
<td>Six of the domains underpinned by suggested questions about impact and symptoms</td>
</tr>
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<tr>
<td></td>
<td></td>
<td>Questions that prompt HCP to ensure they assess domains; identify risk factors; measure impact; make themselves aware of interventions tried to date + suggestions of actions to be considered and record outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>S (Holistic Needs Assessment)</td>
<td>For use with patients with prostate cancer</td>
<td>Electronic Questionnaire Information not available</td>
<td>Information not available</td>
<td>Information not available</td>
</tr>
<tr>
<td>Integrated Palliative care Outcome Scale (IPOS)</td>
<td>Patient Reported outcome measure (PROM) Subjective assessment of patients' palliative symptoms and concerns</td>
<td>Questionnaire 10 primary questions incorporating 11 sub questions 2 x open questions 8 x questions based around a 5-point Likert scale (0–4) 1 x question on questionnaire completion</td>
<td>Domains cover: Symptoms (11) Family distress (1) Existential well-being (1) Sharing feelings with family (1) Practical concerns (1) Information available (1)</td>
<td>Symptoms/impact (16) Satisfied with services (2) General/open (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HCP can completed the IPOS for patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>London Holistic Needs Assessment(^{162,176})</td>
<td>Adaption of the Distress Thermometer and Problem checklist, Questionnaire</td>
<td>Distress (n=1) Practical problems (n=10) Family problems (n=3) Emotional problems (n=7) Spiritual/religious concerns (n=3) Physical problems (n=21)</td>
<td>Symptoms and impact (49)</td>
<td>Information not identified</td>
</tr>
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</tr>
<tr>
<td></td>
<td>Two components 1. <em>Distress Thermometer</em> Format as detailed above. 2. <em>Problem list</em> Adapted to incorporate 48 areas where patient could be experiencing problems or concerning symptoms. Patient ticks yes/no to indicate areas where they have been experiencing problems in the past week and a further box if they wish to discuss that issue. Patients also have the option to say they chose not to complete the assessment today. The questionnaire also incorporates a care plan template detailing issues identified, a summary of the discussion and actions required.</td>
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</tr>
<tr>
<td>Sheffield Profile for Assessment and Referral to Care (SPARC)(^{2,178})</td>
<td>Assessment/measurement tool Designed to identify patients who may benefit Questionnaire 45 Items (plus sub questions) 4x = (Yes/No)</td>
<td>Communication and information (1) Physical symptoms (21) Psychological issues (9)</td>
<td>Satisfaction with services and support (13) Symptoms and impact (40)</td>
<td>Content and convergent validity demonstrated</td>
</tr>
</tbody>
</table>
from additional supportive or palliative care, regardless of diagnosis or stage of disease via a comprehensive early holistic needs assessment

<table>
<thead>
<tr>
<th>Supportive Care Needs Survey (SCNS)</th>
<th>Assessment /measurement tool</th>
<th>Questionnaire</th>
<th>SCNS-35 Psychological needs (n=10) Health system &amp; information needs (n=11) Sexuality needs (n=3) Physical &amp; daily living needs (n=5) Patient care &amp; support needs n=(5)</th>
<th>Support needs (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCNS-Short Form (SF)</td>
<td>Questionnaire</td>
<td>SCNS-SF 34 items Individual items Questions on a Likert scale Questionnaire</td>
<td>17 questions ask about symptoms/problems 17 questions ask about desired interactions with supportive input (SCNS also includes items relating to skin soreness, recurrence and information treatment protection and kin protection) All questions ask about need for support</td>
<td>Content validity undertaken on CNQ which underpinned development of the SCNS tools Construct validity of SCNS-34 determined using factor analysis Internal consistency determined using Cronbach alpha</td>
</tr>
<tr>
<td>SCNS-Melanoma</td>
<td>SCNS-Melanoma This is used in conjunction with the SCNS-34 and comprising 12 additional items</td>
<td></td>
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</tr>
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</table>

Two versions
1. SCNS-Short Form (SF)
2. SCNS-Melanoma

41x 4-point rating scale (0-3); "Not at all" to "Very much Open questions x2

Religious and spiritual issues (2) Independence and activity (3) Treatment issues (5) Family and social issues (4)
| The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)\(^{177,182}\) | A culturally-specific assessment tool that captures the unique unmet supportive care needs of Indigenous people with cancer. | Questionnaire  
27 items delivered verbally  
Each item consists of a problem/interaction with supportive care and items are asked to choose from a yes/no reply. If this was the case in the past month they were asked to choose the degree to which they required help on a scale ranging from ‘satisfied because my needs were met’ (scored as one) to ‘a lot more help needed’ (scored as five) | Physical (n=11)  
Psychological (n=4)  
Treatment issues (n=6)  
Social (n=5)  

Each item focuses on impact and patient need for help in that area  
20 questions ask about impact  
6 questions ask about desired interactions with supportive input | Construct validity undertaken via factor analysis  
Convergent validity supported by significant correlations between the SCNAT-IP with the Distress Thermometer and the Cancer Worry Chart |
The focus of the majority of the questionnaires/prompts was on identifying disease impact through questions that asked the respondent about symptoms and problems.\textsuperscript{107, 110, 156, 161, 174-176, 178} In three cases, the use of these questions was also interwoven with a smaller number of questions about satisfaction with services, general questions about the patient priorities or the patient's need for support.\textsuperscript{107, 110, 178} Three questionnaires contained questions that asked predominately about potential problems and experience of service use, together with the need for help with these issues.\textsuperscript{173} \textsuperscript{101, 177}

The psychometric validity of eight of these questionnaires\textsuperscript{2, 101, 161, 173, 175, 178, 181, 182} had also been considered and established, or partially established.

ii) Action planning records

Five of the interventions incorporated a template for recording agreed actions.\textsuperscript{111, 156, 158, 160, 162, 170}

iii) Training

Four of the interventions included training sessions for the HCPs involved in delivering the interventions.\textsuperscript{18, 107, 110, 168, 169} Two included content on how to deliver the intervention in a patient/person centred approach.\textsuperscript{107, 168}

iv) Information on available service and resources

One of the interventions included a resource pack for HCPs including information about local services.\textsuperscript{18} One intervention was supported by a website concerning information on how to deliver the intervention and an information sheet for patients outlining what to expect.\textsuperscript{161}

Procedures

The interventions also involved a number of differing procedures based around i) Introduction to and completing the questionnaire, ii) Integrating the questionnaire into the conversation, iii) identifying and addressing need iv) reviewing the action plan
i) Introduction to and completing the questionnaire.

Most of the interventions required the patient to complete the questionnaire prior to a consultation with the HCP either at home or immediately before a consultation. In one case, the expectation was that HCP would read out the questions and fill in the patients’ responses. Patients were expected to use the questionnaires to identify and, where appropriate, rate their symptoms, concerns or needs.

ii) Integrating the questionnaire into the conversation

Across the interventions the role of the completed questionnaires was to inform the conversation. Two interventions emphasized going through the list one by one. However, typically, the interventions guided HCPs to base the conversation more generally around the questionnaire. In one intervention the patients' responses were initially seen and summarised by a ‘reference nurse’ who subsequently summarised these and sent the summary to the HCP who would be involved in the conversation.

iii) Identifying and addressing need

Two interventions indicated that the HCPs should note the scores provided by the patients and identify these as priorities for action. Three interventions outlined a collaborative approach to identifying need and developing an action plan. Most of the other interventions appeared to operate on the assumption that the participating HCPs would draw on their professional knowledge and skills (this was specifically outlined in three of the interventions).

iv) Reviewing the action plan

Five interventions incorporated a review of identified needs and actions. One further intervention gave patients the option of requesting a review.
Eight of the interventions\textsuperscript{18, 107, 110, 158, 161, 164, 165, 168} were delivered within routine clinical appointments. In contrast, the remainder were delivered in addition to routine care.

4.4.3 Qualitative data synthesis

The synthesis identified a range of descriptive themes which are summarised in Table 4. Further analysis of the descriptive themes based on the research questions led to the emergence of seven analytical themes:

1) Opportunities for patient participation in directly identifying, expressing and addressing their support needs
2) The dominance of traditional HCP-led approaches to identifying and addressing support needs
3) Process-orientated, rather than holistic and tailored outcomes
4) Strategies supporting direct expression of need by patients
5) Questionnaires as enablers of patient reflection and communication
6) The incorporation of processes to support patients in discussing and addressing their support needs beyond the questionnaires
7) A person-centred framework.

Themes 1-3 are linked to RQ 1 and Themes 4-7 are linked to RQ 2.

RQ 1: What can the current research tell us about patient and HCP experiences of identifying, expressing and addressing patient support need within existing interventions?

In response to this question three broad sub-themes emerged from the synthesis of eligible studies namely:

1) Opportunities for patient participation in directly identifying, expressing and addressing their support needs
2) The dominance of traditional HCP-led approaches to identifying and addressing support needs
3) Process-orientated, rather than holistic and tailored outcomes.

Each is outlined below with supporting quotes.
1) **Opportunities for patient participation in directly identifying, expressing and addressing their support needs.**

Within this review, a number of examples were found of patients who had been able to consider and identify their support needs to HCPs whilst receiving the interventions.\(^{107,111,156-158,160,165}\) For example, patients attending a melanoma clinic were able to reflect on their support needs prior to the consultation and then express to the specialist nurse that they needed more support. This primarily involved patients identifying needing help with understanding the nature of their condition and managing the symptoms they were experiencing.\(^{111}\)

Patients also described being able to consider their need for help more broadly than had previously been the case.\(^{111,156,168-170}\) One participant reflected that in response to the question: “...‘Do you feel anxious or panicky?’ In general I would have said ‘no’ but I suddenly realised that ‘Yes I do get breathless’...I hadn’t really thought about that before, so I could put that down and we could actually address that” [Buckingham 2019, p. 5].\(^{156}\) Attention was also drawn to the way participating in the intervention had led to an increased understanding of the legitimacy of asking for help beyond immediate disease control: “...to be fair, obviously there was things in there that, I mean I did’nae know you could o’ got help for...” [Kotronoulas et al, 2017, p. 63].\(^{111}\)

When encountering patients who had identified and expressed a need for support, some of the patients and HCPs described how they used these needs to shape the agenda of the patient-HCP conversation, and involve patients in developing a shared response to those needs.\(^{18,157,158,162}\)

“If you’ve had a patient like that who you may have seen a couple of weeks on the trot and they’re still not doing what you’ve advised them to do with the pain medication... instead of them sat there saying ‘yeah okay’ listening to me spiel on about taking pain killers, they’ve actually said, ‘oh well, I suppose really what I need to do is...’ and get them to come to this decision that they’re going to put a timetable up on the fridge about when they’re going to do their pain medication.
I mean, I’ve even drawn it out for them when I’ve done [DT&PL action plan]…then they’ve made that decision that that’s what they’re going to do.” [Biddle et al 2016, Supplementary Material p. 4]18

Some of these HCPs also recognised that facilitating patient involvement in expressing and addressing their support needs required them to change their approach to identifying where support was needed and determining the response to that need.107,111 Typically, they acknowledged that their traditional practice was ‘paternalistic’ and that they now needed “to do something with that (insights from the CARES) in collaboration with them…in the end it’s all about them” [Schouten 2019, p. 2722].35 This was a particular challenge when patients raised (but refused help with) issues that the HCPs felt warranted a response.157,158 However, as exemplified by this HCP’s interaction with one such patient, some were able to accept, and work with, this discrepancy: “Solutions offered, but declines. No ‘definite’ actions decided, just ‘if I decide to’ actions.” [Kendall et al, 2015 p. 4].157

2) The dominance of HCP-led care in identifying and addressing support needs

In contrast to directly identifying, expressing and addressing their support need with an HCP, many patients described participating in the interventions in a way that mirrored the assessment of their support needs in traditional care (i.e. led by the HCP). In practice this meant that patients typically described: 1) reflecting on, identifying and assessing their symptoms and concerns via the needs assessment questionnaire;107,168 2) describing their symptoms and concerns to the HCP;107,168 and 3) accessing and deferring to professional knowledge, expertise and solutions111,168,170

“I need to think a bit more carefully when I complete the form [IPOS]. I am a bit more thoughtful about how I am feeling when I grade whether it’s good, better or not at all. So yes that’s important, and I can fill in any other symptoms that I have, which I have done, that I bruise easily and that I feel a little dizzy when I have taken my medication” [Hogberg et al 2019, p. 69]168
“and for them to take time out to sit and talk to you and explain what’s all going to happen, what to worry about, what not to worry about you know … the nurses were great” [Kotronoulas et al 2017, p. 118]

Despite this many patients perceived that participating in the interventions enhanced their experience of undertaking these familiar roles. Some patients recounted how the questionnaires gave them more opportunity to reflect on their condition and increased their awareness of how it affected their day-to-day lives. One noted:

“I had a lot of these things and I didn’t realise, you know, ‘Constipation, poor appetite, nausea, weakness, lack of energy’. But I would surprise myself that they would be relevant to the way I am feeling sometimes. … I would tick quite a few of them” [Kane et al 2018, p. 147].

Other patients were pleased that the presence of symptoms on the questionnaires/prompts made them ‘legitimate’ and ‘allowed’ them to raise issues previously seen as trivial. Many of the patients also valued the way the questions enabled them to think about their situation more comprehensively, or, as one patient put it, to focus “a little bit more in terms of the detailed things… that weren’t necessarily specifically to do with the condition itself.” [Clarke et al 2019, p. 8].

The interventions also provided opportunities for patients to play a more active role in the patient-HCP conversations. For example, patients described how the questions acted as a useful aide memoire, enabled them to communicate difficult symptoms and issues without having to actually verbalise them, and made them feel more confident about describing, and asking questions, about their symptoms and problems.
However, a number of patients also perceived limitations to their involvement.\textsuperscript{107} Some were reluctant to discuss their responses to the questions with HCPs for fear of compromising the expert input they currently received.\textsuperscript{107} Others felt reluctant to discuss non-medical subjects “\textit{because you’re always aware that you’re taking up precious time}.” [Biddle et al 2016, p. 62].\textsuperscript{18}

The dominance of an HCP-led approach to identifying and addressing patient support needs was also evident in HCP descriptions of how they used the interventions.\textsuperscript{107, 110, 164} In particular, many clinicians outlined how they saw the intervention as providing a useful source of information that could enhance their own assessment of need.\textsuperscript{107, 160, 164} Many perceived this as a process that could raise ‘red flags’,\textsuperscript{158, 164} help make their assessment more holistic,\textsuperscript{107, 160, 164, 170, 18, 110} facilitate a focus on patient priorities,\textsuperscript{164} and enable discussion and consideration of difficult or sensitive issues that were often avoided.\textsuperscript{164} Some commented that it also raised their awareness of issues that they thought they had already addressed or had previously failed to consider.\textsuperscript{107, 110}

“\textit{I think it does help you to consider new areas that are not usually considered....the psychological care bit, it would help you to consider this and especially preferred place of care which is not normally or routinely discussed or considered}” [McIlfatrick and Hasson 2013, p. 1070]\textsuperscript{110}

“\textit{Like some of them came in, and they’d have shortness of breath as ‘severe’ [graded on IPOS]. But they’d be just as they always are ... So it just showed that’s a really big problem for that person, even though we’ve got them to their baseline, or as good as they can be, ... that we felt ... we had got under control, but it was still a big problem for them.....it really led the conversation ...but where the patient wanted to lead it}” [Kane 2018, p. 174]\textsuperscript{107}

As a result, many HCPs perceived themselves to be working in a way that was personalised or person-led.\textsuperscript{107, 111, 158, 160, 164, 165} However, this seemed to be based
on the patients’ role as contributor to the HCP assessment rather than one in which they were supported to share, or take responsibility for identifying needs:

“I think it’s a really good idea…it gives the patient a little bit of not power as such but good involvement, so it’s you know, very much patient-centred care” [Clarke et al 2019, p. 4].

Others however perceived the move to involve patients in this way as ‘tokenistic,’ and potentially weakening their clinical judgement. One HCP noted “you can ask does it add anything to my knowledge about the patient and I don’t think it does, compared to how I usually do things” [Thayssen et al 2017, p. 116].

In addition to the assessment process, HCPs also described playing a large role in determining and organising supportive input. Participant accounts describe HCP involvement in signposting to services, and liaising with multi-disciplinary colleagues: “I think it’s given me an opportunity to signpost to Maggie’s or signpost to The Haven, or even MASScot as well” [Kotronoulas et al, 2017 p. 63]. Some also described providing input themselves (e.g. dealing with medical issues or providing a therapeutic context within which to talk about issues).

3) **Process-orientated, rather than holistic and tailored outcomes.**

Patients and HCPs were generally positive about intervention use. However, much of this feedback was focused on issues relating to improvements in process-orientated outcomes rather than the supportive input received in response to these processes.

Patients commented on the way the intervention enabled them to feel more connected to services, spend more time with an HCP, the enhanced quality of the meeting, and the opportunity this gave for an instant response to concerns, as one noted “the most useful thing I’ve found is actually the
“one to one...” [Kotronoulas et al, 2018, p. 3733]. Only a small number of patients felt that taking part in the intervention had made no discernible difference to the nature of the care they received.107

Similarly, HCPs generally felt that the intervention enabled them to be more focused and prepared.158,160 In addition to accessing more holistic information, many liked the structure the questionnaire could give to the conversation,164, 170 whilst other felt more connected to patients158 or that the intervention contributed to the development of a warm and empathic relationship with the patient.164,167,170 In one study HCPs who were working with the indigenous population in Australia felt that the intervention enabled better engagement with patients and colleagues in this population.169 Typically, HCP concerns about the intervention were also focused around process, including the time available to deliver the intervention,169 the availability of resources to address unmet needs18 and conflict with their other professional roles.18

In contrast, there was more uncertainty with the participants’ comments concerning how far the interventions delivered supportive input that was holistic. Some participants reported the supportive input offered and received was more comprehensive than usual care.160,168,169 However, many of the descriptions of care received, or delivered, focused on physical concerns: an emphasis that was also noted by some of the HCPs.110,111,183

In addition there were mixed perceptions as to how the supportive input they received in response to taking part in the interventions was tailored to their situation.18 Some patients described feeling happy with what they had received.162,165 Others noted the therapeutic value in being able to talk and have concerns validated.18,162,169 However others were less clear: “She put me in touch with all sorts of different things, actually, and er, gave me some leaflets and all sorts, so er, yes it did help. Certain things helped, some things didn’t” [Sandsund et al 2020, p. 11].162 HCPs also felt they often failed to provide patients with anything useful,
which they attributed to a lack of skills, resources or time to respond to the patient’s specific needs. \(^{18}\)

**RQ 2: What features within these interventions enable or hinder patient involvement in identifying, expressing and addressing their support needs?**

Four further analytical themes emerged in response to Research Question 2:

4) Strategies supporting direct expression of need by patients

5) Questionnaires as enablers of patient reflection and communication

6) The incorporation of processes to support patients in discussing and addressing their support needs beyond the questionnaires

7) A person-centred framework

**4) Strategies supporting direct expression of need by patients**

In cases where patients described being supported to identify and express where they needed more help they often recounted participating in strategies that enabled them to directly formulate and articulate their support needs. This could involve being asked specifically by HCPs: “you know, how did I feel about this, or did I need any more help...” [Kotronoulas et al 2017, p63]. Alternatively, some had received interventions that used tools, such as the SCNS, containing questions that were worded to support direct expression of need.\(^{111, 159, 169}\)

In contrast, patients who participated in interventions that used the tools or prompts designed to support the identification of problems and symptoms reported more mixed experiences.\(^{18, 160, 168}\) Some described how this “made you think about what was going on and how your body was reacting and made you think more about what you wanted” [Kotronoulas et al 2018, p. 3733].\(^{160}\) Others, however, reflected on how this process could leave them more vulnerable to HCP interpretations of how these issues should be managed. This was exemplified by one patient who, having identified feelings of distress on one of the questionnaires,
commented: “am I going to be labelled as mad or barmy, are they going to put me on medication? It's one of those things you think, do I answer this how I actually feel or is it going to end up with me in trouble” [Biddle et al 2016, p.62]. Participants also described how the patients’ responses could also be used for purposes outside identifying and addressing support need, such as self-management or symptom monitoring.107

5) Questionnaires as enablers of patient reflection and communication

Patients’ sense of visibility and legitimacy in raising issues and support needs was enabled when they recognised their experiences in the tool and were able to use the tools to express these.107,111 One patient observed how “maybe I wouldn’t have thought about it if I hadn’t had those questionnaires [...] but when you see it written down on paper you think oh no I, I do need more information on that” [Kotronoulas et al 2017 p. 63]111 Some patients also commented on the value of open questions that enabled them to individualise their responses.107,111

However, the process of identifying and expressing support need (or indicators of support need) could be limited by features that were common to many of the tools in these interventions.18,107,158,160,163,168 Some patients reflected on how the content did not always capture their lived experiences, for example, by not directly addressing emotional issues or concerns about the future.18,107,158,163 Reconciling the complexity of their experience within the narrowly focused questions was also perceived to be a challenge particularly when they wanted to describe complex feelings such as loneliness. Others struggled to describe the transient nature of their symptoms:18,168,169 “You would have got different results from me if I was having chemo when I was filling it out ... and now it's different again. So it does change as you go through” [Biddle 2016, p. 63].18 Some experienced further difficulties in quantifying their experiences as a numerical score163,169: “you know, answering whether you feel extremely distressed or not distressed ” (interviewer: “was that difficult?”) “Yes, because at first I ticked 1, because I don’t think I am particularly distressed, but still I felt pretty annoyed with my stomach” [Thaysson
Together these provided barriers to some patients being able to accurately express their problems and needs. In other cases the questions raised issues that patients perceived were no longer applicable, or were issues the patients were not ready to face, further inhibiting participation.\textsuperscript{111, 158}

6) \textit{The incorporation of processes to support patients in discussing and addressing their support needs beyond the questionnaires}

Patients who took part in interventions that specifically incorporated aspects of care planning were more likely to be involved in decisions about the nature of supportive-input they received in response to identified support needs.\textsuperscript{157, 162} Typically, these interventions incorporated features/strategies that looked beyond the assessment or identification of support need and instead incorporated strategies or resources, such as templates for documenting patient and HCP actions and/or HCP training. For example, patients in one intervention emphasised the value of being encouraged by the HCPs to set, and enact, their own goals: \textit{“It sort of made me...do some target setting......and then she (the HCP) rang me to see if I had done them.”} [Sandsund et al 2020, p.11]\textsuperscript{162}.

However, patient participation in collaborative care planning seemed to be vulnerable in interventions where this was not the case, and where the process was directed by the professionals’ expertise. This was evident even in interventions where patients had previously been supported to directly identify their support needs to HCPs.\textsuperscript{159, 160} For example, one HCP described how she reviewed the patient’s responses relating to their support needs prior to the consultation in order to be able to consider her response and the necessary resources in advance.\textsuperscript{160}

7) \textit{A person-centred framework}

Further support for patients across the process of identifying, expressing and addressing their needs was also evidenced in interventions underpinned by elements of person-centred theories or concepts.\textsuperscript{107, 111, 157} Here HCPs described
proactively drawing on these person-centred principles to re-evaluate and modify their usual HCP-led response and instead support patients to take a lead in determining where they needed support and what that should look like:

“I think as healthcare professionals we are a bit paternalistic and we think this is what they [the patients] need to know, or what we think they need to know, so for me, it [the intervention] directed to be relevant to the patient”[Kotronoulas et al 2017, p. 63].111

However, in interventions where this was not the case HCPs appeared to more readily embrace the idea of “doing a thorough assessment with the patient.” [Thewes 2016, p 8].169 There was also evidence that they drew on features in the intervention in such a way that it supported their ‘assessor’ role, e.g. using patient scores to identify priorities for action18,107 or using the headings on the questionnaires to structure the patient-HCP conversations rather than the patients responses.164
### Table 4: Analytical and descriptive themes

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<tr>
<th>Analytical Themes</th>
<th>Descriptive Themes</th>
<th>Exemplifying quotes</th>
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<tr>
<td>1. Opportunities for patient participation in directly identifying, expressing and addressing their support needs</td>
<td>Help-seeking&lt;br&gt;A small number of examples were provided in which patients were able to identify and express to HCPs areas where they identified needing more help managing their condition, or where they didn’t want help. Patients also felt that participating in the intervention had made them more aware of areas where they could ask for help, and their role in raising these issues.</td>
<td>“It started me thinking it did....Yeah ... I need to know these things (understanding heart disease) and it’s no good blaming them if I’m not asking .. “ [Kane et al 2018, p. 148]&lt;sup&gt;107&lt;/sup&gt;&lt;br&gt;“...it’s very good for, I mean uhm, identifying actually what you don’t want.” [Sandsund 2020, p. 11]&lt;sup&gt;162&lt;/sup&gt;</td>
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<td>Patient focused and collaborative responses&lt;br&gt;A small number of HCPs described becoming aware of the kind of help or support that the patient felt they did, or did not, need. They also described working with patients to develop a response or accepting the patients’ wishes even when they did not align with their views.</td>
<td>“So it’s—it’s you know just being very pragmatic and honest about what you can offer these patients, what you think is realistic as well, so you know, not setting the bar too high, and finding some common ground that you can work on together.” (Kendall et al 2015, p. 4)&lt;sup&gt;157&lt;/sup&gt;&lt;br&gt;“If they refuse things or do not want it, well...it’s their way” [Schouten 2019, p. 2722]&lt;sup&gt;165&lt;/sup&gt;</td>
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<td>2. The on-going influence of the biomedical approach</td>
<td>Identifying and discussing symptoms and problems&lt;br&gt;Patients described reflecting on and identifying symptoms and problems. They also noted on how taking part in the intervention led to them to have a better understanding of the nature and impact of their condition, and more confidence about discussing these issues and asking questions. Some however preferred not to take an enhanced role for fear of wasting the HCPs time or compromising their expertise</td>
<td>“.It’s just the normal things I do ask ... I suppose you would find it intimidating ... you’ll be saying, Maybe you shouldn’t ask that question at all. ... It [IPOS] would be helpful ... the words is there, that you’re going through that. All, the whole lot of them [symptoms/concerns on IPOS].” [Kane 2018, p.48]&lt;sup&gt;107&lt;/sup&gt;&lt;br&gt;‘Well, because (without the questionnaire) I probably would have thought, well just because I experience pain from time to time, is it something to talk about?’ [Thayssen 2016, p. 226]&lt;sup&gt;163&lt;/sup&gt;</td>
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<td>Traditional patient and HCPs interactions</td>
<td>“and for them to take time out to sit and talk to you and explain what's all going to happen, what to worry about, what not to worry about you know ... the nurses were great” [Kotronoulas et al 2017a, p. 118]</td>
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<td>Patients described taking part in patient-HCP conversations in which HCPs took time to address a range of issues. Patient discussions of these conversations focused around the HCPs professional response and patient appreciation of this input.</td>
<td>“Meeting the nurse was [...] really very helpful, cause she was able to identify straightway what I was thinking and feeling [...] and I felt really happy once I left [her] and I think the questionnaire opened out to enable that” [Kotronoulas et al 2017a, p. 6]</td>
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<td>Needs assessment</td>
<td>“It’s [IPOS] patient centred, ... it’s the patient being allowed to voice their symptoms and their experiences, and how they feel ... and it’ll also help with the interview afterwards ..., we can discuss things, and it means we don’t miss out on anything either. It covers everything.” [Kane et al 2018, p. 149]</td>
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<td>HCP assessments of need often focused around exploring the extent to which symptoms and problems were bothersome/burdensome for the patient, and the rationale this provided for organising supportive input. HCPs often felt the intervention enhanced patient participation in this process, and supported them to carry out these assessments in a way that was more comprehensive and focused on the patients’ priorities. Some HCPs felt that patient involvement compromised their professional assessment.</td>
<td>“You've got the Distress Thermometer in front of you with seven, eight, nine in a number of areas saying ‘High distress’ then you can say, ‘Look, would you think that perhaps seeing somebody else might be a good idea because you’re showing me that you’re distressed?’ sort of almost like the evidence” [Biddle et al 2016, Supplementary Material]</td>
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<td>“Then you can ask; well does it add anything to my knowledge about the patient, and I don’t think it does, compared to how I usually do things” [Thayssen et al 2017, p. 116]</td>
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<td>3. Process-orientated, rather than holistic and tailored outcomes</td>
<td>Improved processes</td>
<td>“I’ve found this [DT&amp;PL] quite useful … very satisfying. Especially when there are small, [physical] issues that I’ve very easily been able to rectify myself. (...) One interview, the lady had [social problem], it was probably the longest interview I did. I wasn’t able to give her any advice. I mean I said I’d get her information and stuff. So, I kind of left thinking poor lady, you know. Sometimes it’s better to offload and try and share it with somebody but ultimately has that improved things for her?” [Biddle et al 2016, p.61]18</td>
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<td></td>
<td>Mixed experiences of receiving and delivering holistic and tailored care</td>
<td>“The thing I liked was that she was able to speak to me immediately” [Kotronoulas et ala 2017a, p. 63]</td>
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<td>“I’ve never had anything like this before. Not in-depth. You get asked basic questions at the surgery” [Buckingham et al 2015, p.3]156</td>
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<td>“I think it’s also a good opportunity for staff who may not be as experienced or, you know, trained for working with people of Indigenous background to have this sort of specific tools to use. It can make some people a little bit more comfortable being able to ask some of these questions otherwise they may not know where to start or the right language to use.” [Thewes et al 2016, p. 7]169</td>
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| Care planning | HCPs frequently described taking responsibility for delivering supportive input. They often worried about their inability to access an adequate response outside of their medical expertise. | “I’ve found this [DT&PL] quite useful … very satisfying. Especially when there are small, [physical] issues that I’ve very easily been able to rectify myself. (...) One interview, the lady had [social problem], it was probably the longest interview I did. I wasn’t able to give her any advice. I mean I said I’d get her information and stuff. So, I kind of left thinking poor lady, you know. Sometimes it’s better to offload and try and share it with somebody but ultimately has that improved things for her?” [Biddle et al 2016, p.61]18 |

<p>| Mixed experiences of receiving and delivering holistic and tailored care | The participants described a mixed picture in relation to how far care was holistic and tailored to the individual. Some patients were happy because the response was more comprehensive and effective - others less so. Some | “It’s a nursing profession thing; we can fix a physical problem... that’s where we are comfortable. ... We think we are holistic but maybe they are not practising holistically (resulting in a focus on delivering responses to physical problems)” [McIlfattrick and Hasson 2013, p. 1070]110 |</p>
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<th>4. Strategies supporting direct expression of need by patients</th>
<th>Questions enabling consideration and expression of support need</th>
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<td>HCPs felt the supportive input they delivered was better – whilst others felt they still focused on medical inputs and struggled to deliver more holistic approach. Little evidence of follow up to see if supportive care made a difference.</td>
<td>“Do you remember what the outcome of doing this was? P4: No, other than that I did think actually I should probably do something and I went and bought the [recommended] relaxation tape. There were some booklets that went with it, and I stuffed them on the study floor at home and they stayed there for months ... I: Did it [DT&amp;PL] help you in any way?: I ‘spouse if I’m honest it probably hasn’t, has it” [Biddle et al 2016, p. 63]¹⁸</td>
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<td>“I have now been referred to psychology and what I said is, “I wish this had have happened two years ago.”” [Thewes et al 2016, p.6]¹⁶⁹</td>
<td>“It [IPOS] started me thinking it did. Yeah ... I need to know these things ... and it’s no good blaming them if I’m not asking. It’s up to me for to do it” [Kane 2018, p.48]¹⁰⁷</td>
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<td>Participants described how the process of asking for help was facilitated either through answering questions that asked specifically about the support they needed or being prompted to think about where they needed help after reflecting on symptoms and problems and raise those support needs.</td>
<td>“it’s [IPOS] patient centred, ... it’s the patient being allowed to voice their symptoms and their experiences, and how they feel ... and it’ll also help with the interview afterwards ..., we can discuss things, and it means we don’t miss out on anything either. It covers everything.” [Kane et al 2018, p.49]¹⁰⁷</td>
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<td>Focus on symptoms and problems</td>
<td>Patient responses about symptoms and questions were often used by HCPs in their own assessment of need. HCPs also had their own views on symptoms and needs. Here patient identification of where they needed support could be vulnerable to HCP rather than patient interpretation.</td>
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### 5. Questionnaires as enablers of patient reflection and communication

**Questionnaires as enablers of patient-HCP communication**
Patients described how the questionnaires/prompts enabled them to think about the impact of their condition/support needs more broadly, and gave them permission and opportunities to discuss these issues with HCP.

*“Because now it’s on paper that I have to relate to it, and then I’m allowed to put a tick against: yes, I have been in pain, yes I have had… and then it is legitimate and is, well, okay, even though perhaps it’s a trivial matter”* [Thayssen 2016, p. 227]^{163}

*“If I hadn’t had this questionnaire … I am not sure I would have gotten around all these things, I am not certain I would have mentioned it all”* [Thayssen 2016, p. 226]^{163}

**Barriers to expression within the questionnaires**
Patients described how many features on the needs assessment questionnaires (content/format) hindered their ability to express their particular perspective and experiences in relation to symptoms, issues and needs.

*“You would have got different results from me if I was having chemo when I was filling it out … and now it’s different again. So it does change as you go through.”* [Biddle 2016, p.63]^{18}

*I think even if the questionnaire would say just plain simple terms, ‘how did you cope with it in your mind?’* [Kotronoulas et al 2018, p. 3733]^{160}

### 6. The incorporation of processes to support patients in discussing and addressing their support needs beyond the questionnaires

**Integrated approach to identifying and addressing need.**
In some interventions patients were supported in an approach that enabled them to identify issues/need on the needs assessment questionnaire/prompts and then decide further how to address these needs.

*This should be available to everybody …I think if other people could have just, I mean even one or two appointments of the sitting down making their own targets for what they are going to do, to deal with the situation from here on, then I think that it shows that someone else is interested, and puts you in control which is great.”* [Sandsund et al 2020, p.11]^{162}

**Separation of identifying and addressing needs.**
Some participants discussed patient involvement primarily in terms of identifying and discussing their response on the questionnaires. HCPs positioned their role in assessing need/organising supportive input in terms of professional roles and skills.

*“It depends on your experience whether you would use these prompts or not, really. If you were quite well experienced, I don’t think you would need them.”* [McIlpatrick and Hasson 2013, p. 1070]^{110}

*“We did this thermometer, which she sort of talked me through it and I sort of done it … and then after that I never seen her again”* [Biddle 2016, p.63]^{18}
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<th>7. A person-centred framework</th>
<th>Moving towards person centred working</th>
<th>“Sometimes I feel that I am ‘clutching at straws’ to find an action, as it feels awkward when there are none, even although patient is adamant that there is nothing they wish to change/improve. Sometimes feel myself almost trying to create a problem when there isn’t one in order to have at least one action!” [Kendall 2015, p.4]^{157}</th>
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<td>In interventions with a person-centred focus HCPs recognised the pull of traditional ways of working, noted how this hindered patient participation in the process of identifying and addressing their needs, and described being prompted to change their practice to support increased patient involvement in this role</td>
<td>it’s all about empowering the patient really to take ownership in the consultation. I think it really does make a difference and whether it just makes a difference for that day for them and they feel like they have been listened to” [Rogers and Lowe 2014, p. 622]^{161}</td>
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<td>An assessment context</td>
<td>HCPs discussions and practice often reflected the influence of key ideas associated with assessment. They adapted features in the intervention to support their role as ‘assessor’ and positioned patient involvement in terms of being a contributor to the assessment</td>
<td>“I just tried to remember the headings (in the questionnaire) that is how I chose to handle it” [Thayssen et al 2016, p. 116].</td>
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4.5 Discussion

This review sought to consider patient experiences of identifying, expressing and addressing their support needs within existing clinical interventions (designed to support patient participation in identifying and addressing their needs). A further focus was on how far the format and delivery of these interventions enabled or hindered this process.

The review found that most of the identified interventions comprised post-hoc practitioner orientated questionnaires integrated into a standard patient-HCP conversation. This suggested they were largely informed by the concept of Systematic Needs Assessment. However, variation in the exact nature of the interventions was identified including: how far the questionnaire/prompts emphasised support needs versus symptoms and problems; how far they incorporated design features traditionally associated with measurement questionnaires or had more open questions; and whether the response to identified needs was supported by traditional approaches to care or a structured process designed to support an integrated shared response between the patient and HCP.

The results suggest, firstly, that within some of the interventions patients were able to take a leading role in identifying, expressing and addressing their support needs. Evidence was found of patients being able to identify and express to HCPs where they needed more support, and work alongside HCPs to develop an appropriate solution. However, the patients rarely described fully participating in all the different stages of identifying, expressing and addressing their support needs within any one intervention.

In contrast, it was found that patient support needs were more typically identified and assessed by HCPs. Here patients perceived themselves as playing an enhanced role in identifying symptoms and problems via the needs assessment questionnaires. However, HCPs often described taking the lead in the identification of unmet support needs and the care planning process. Patients experienced greater involvement but the process was predominantly HCP-led.
Overall patients and HCPs reported many benefits from taking part in the interventions. However their descriptions were often focused on enhanced access to care (e.g. more one-to-one contact with an HCP) rather than a significant move towards a more person-centred approach. It was also unclear how far the interventions facilitated input that was holistic and tailored to individual needs.

The review also found that these mixed experiences were supported by intervention characteristics that variously helped or hindered patient involvement in identifying, expressing and addressing their support needs. Findings suggest firstly patients were enabled to identify and express their support needs when assisted by a strategy that supported them to identify their support needs directly by answering questionnaires/questions designed for this purpose. Patients were also helped when the intervention looked beyond patient involvement with the questionnaire and incorporated a broader strategy to support their involvement in developing a shared response. Framing the intervention as person-centred also encouraged HCPs to work in ways that supported a patient-led rather than HCP-led approach. These features can therefore be understood as operationalising person-centred processes.

In contrast, patient involvement in identifying, expressing and addressing their support needs appeared more vulnerable when the interventions involved patients in the identification of symptoms and problems. Whilst the findings suggest that patients could use these questions to identify their support needs, these responses were also used to inform HCP assessments of need - they therefore served as indicators of a potential need for support rather than a direct expression of support need. Patient involvement could also be hindered by the use of questionnaires with lists of narrowly focused items and Likert scales inhibiting consideration and expression of need. In addition, the failure of many interventions to incorporate a broader strategy for supporting patient involvement beyond completing and describing their answers on the questionnaire, together with positioning the intervention in a framework that supported the HCP ‘assessment’ role over person-centred care, appeared to act to restrict patient involvement in addressing their support need.
The presence of many of the latter characteristics within the majority of the interventions (as detailed within Tables 2 and 3) suggests that the majority of interventions contained either a combination of strategies to enable both a patient and HCP-led approach or were primarily orientated towards an HCP-led approach. At best the format adopted by these interventions appeared to partially enable a patient-led approach to identifying, expressing and addressing their support needs.

Within a wider context these results draw attention to the value of exploring how patient-HCP power relationships play out within interventions rather than assuming (as appears to be the case in the policy and clinical literature) that they automatically facilitate a move towards a more person-centred approach. The value of this type of investigation is supported by a strong tradition, outside of intervention use, that has drawn on sociological theory to explore dynamics underpinning patient-HCP relations. In particular work by Barry et al (2001) and Greenhalgh et al (2006) has applied theoretical work by Habermas and Scambler to explore whether and how the patient perspective is privileged within patient-HCP consultations. Together both the findings from the review, and the broader exploration of patient-HCP power relationships through a sociological lens, highlight the potential value of adopting a similar approach to the evaluation of future interventions.

In addition, findings from the thematic synthesis also lend support to wider concerns about specific intervention characteristics commonly associated with the Systematic Needs Assessment model. Firstly the results endorse observations by Osse et al (2000) and McElduff et al (2004) that many of the questionnaires focus on patient identification of symptoms and problems leaving patients vulnerable to HCP assumptions about what a need is and where help is required. Similarly concerns expressed by Rimmer et al (2021) regarding the lack of clarity about how unmet need is operationalised within validated scales, are lent further support by the difficulties some patients in the review experienced in responding to these scales. The problems some patients encounter when faced with long lists of narrowly focused questions are also highlighted by work reported by Doyle and Henry (2014). Together these findings serve to question the emphasis placed within the Systematic Needs Assessment intervention model on the use of questionnaires that are developed around, and validated, using psychometric principles, evidenced by the vast
literature in this area. Findings from the review also lend support to the view of Johnston et al (2019) that many Systematic Need Assessment interventions tend to be ‘tool centric’ rather than focused on enabling patients to take responsibility throughout the process of identifying, expressing and addressing their support needs and support her call for the need for interventions to focus on supporting holistic processes.

However, in contrast to the limitation highlighted above, the results in this review also lend support to the wider case for an alternative person-centred approach to intervention format and delivery. Features within these interventions, identified as being orientated towards a patient led approach, can also be understood as operationalising key outcomes associated more widely with person-centred care (e.g. acknowledging the need to pay attention to the patient’s understanding of the support they need and how that support is enacted). Similarly these features also reflect characteristics within CSNAT-I which, as noted in Chapter 3, provides an evidence-based example of a successful person-centred intervention. Together these highlight the potential of exploring an intervention, based around a similarly person-centred approach to format and delivery, with patients with long term conditions.

4.5.1 Limitations

A number of challenges were identified in undertaking this review that may indicate potential limitations in relation to the findings. Many of the definitions and concepts in this area are often ill defined, and vary in how they are applied in practice (e.g. ‘need’, ‘interventions’, ‘person-centred care’). The search strategy may therefore have failed to identify relevant studies. In addition, only papers in English were included which may also have compromised the identification of studies. Further limitations can also be identified in relation to the analysis. Firstly, some of the data was drawn from author conclusions about the data. As above the authors often used terms such as ‘need’ or ‘person-centred’ without defining these terms, leading again to a lack of clarity about the specific nature of patient involvement in these studies. Data was also drawn from patient quotes, which was typically only a small proportion of the data collected and lacked the contextual understanding that can be gained from analysing interview transcripts.
4.5.2 Summary

This chapter presented a thematic synthesis of literature, investigating the role of existing interventions in supporting patients with long-term conditions identify, express and address their support needs. The review found that patients could experience identifying, expressing and addressing their support needs within these interventions, but that patient support needs were more typically identified and assessed by HCPs. It also highlighted features in the format and delivery of the interventions that both enabled and hindered this process. Together these limitations expose a weakness in the evidence base of existing interventions, and lend support for the case for an alternative person-centred approach to intervention format and delivery. The next part of the thesis explores this further by outlining and investigating an ’exemplar person-centred intervention’— the Support Needs Approach for Patients (SNAP)
Chapter 5: An alternative person-centred intervention – the Support Needs Approach for Patients (SNAP)

5.1 Introduction

In the light of previous findings, Chapter 5 considers an alternative person-centred approach to intervention format via consideration of an exemplar intervention – the Support Needs Approach for Patients (SNAP). I start by outlining the background leading to the development of SNAP, go on to describe SNAP in more detail and then explore the rationale for SNAP as a person-centred intervention.

5.2 Background to SNAP

In the previous chapter it was argued that, despite strong support for the Systematic Needs Assessment intervention model, such interventions can fall short of enabling a patient-led approach to identifying, expressing and addressing patients’ support needs. It was also proposed that this failure is a result of characteristics within the intervention format that orientate the interventions towards an HCP-led, rather than patient-led, approach. These findings resonate with earlier concerns within the wider literature about potential limitations within this intervention model, and related calls for a more person-centred approach to intervention format.1, 2, 188, 189

These conclusions are further supported by work undertaken at the University of Cambridge that pre-dates this thesis. Here, initial considerations about the need for a person-centred intervention were informed by key findings from the Living with Breathlessness (LwB) study,190 a prospective mixed-method multiple-perspective longitudinal programme of work that sought to improve care and support for patients and informal carers living with advanced COPD – a long-term, life-limiting respiratory disease associated with high levels of morbidity and mortality. The study involved mixed-method interviews conducted with a population-based cohort of 235 well-characterised patients with advanced COPD (meeting at least two of six clinician-defined criteria) and their informal carers (n=115; family and friends who supported them in an unpaid role). In addition, qualitative interviews were
undertaken with purposively sampled patient-identified clinicians (n=45; primary, community and secondary care). Findings from these interviews indicated that patients with advanced COPD had a range of unmet support needs that they rarely identified and expressed to HCPs, nor expressed to researchers in response to direct questioning. Further, patients’ descriptions of care received suggested that decisions about their needs in clinical practice were often reactive, and driven by organisational or medical agendas, with little evidence of the resulting supportive input being holistic or person-centred. These findings resonated with pre-existing evidence suggesting that: 1) patients with COPD often are not asked about their support needs due to HCP concerns about time, resources and institutional or medical needs, and 2) patients with COPD may not raise their concerns due to guilt around the sometimes self-inflicted nature of COPD from smoking, a desire to stay independent, or a lack of awareness of potential support needs due to the slow, insidious decline of COPD leading them to normalize their experience as old age.

Together these findings suggested the potential for some form of intervention to address the challenges faced by this patient group in identifying, expressing and addressing their needs with clinicians in a person-centred way. In the latter stages of the LwB study, exploratory work was conducted on a prototype tool to help patients identify their unmet support needs. The tool was based on the Carer Support Needs Assessment Tool (CSNAT) a component of CSNAT-I that was already being used successfully as a research tool within LwB to identify broad areas of unmet support need in these patients’ informal carers. It was therefore anticipated that an adapted version may similarly enable patients to identify and express their support needs. Formal permission to adapt CSNAT to develop a patient prototype was obtained from the CSNAT developers (Dr Gail Ewing [University of Cambridge] and Professor Gunn Grande [The University of Manchester]). The resulting prototype patient tool (“Your Support Needs Now”, shown in Fig. 4) was integrated into the remaining LwB Study interviews and found to enable patients to consider and identify a range of unmet support needs within the context of a research study.
**Your support needs now (for patients)**

We would like to know what support you need. Please tick the box that best represents your needs now, for each statement below.

<table>
<thead>
<tr>
<th>Do you need more support with ...</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
<th>Very much more</th>
</tr>
</thead>
<tbody>
<tr>
<td>understanding your illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>managing your symptoms, including medicine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your financial, legal or work issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your personal care (e.g. dressing, washing, toileting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dealing with your feelings and worries</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>knowing who to contact if you are concerned (for a range of needs, including at night)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>looking after any other health problems you may have (physical problems)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>equipment to help you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your beliefs or spiritual concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>talking with your relatives about your illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>practical help in the home</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>knowing what to expect in the future</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>anything else (please write in)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted with permission from the rights owners of the Carer Support Needs Assessment Tool (CSNAT) Copyright © 2009 University of Cambridge (Centre for Family Research) / The University of Manchester (School of Nursing, Midwifery and Social Work). All rights reserved. Gail Ewing (Cambridge) and Gunn Grande (Manchester) have asserted their moral right to be identified as authors of the CSNAT.

**Figure 4: The prototype tool used in the LwB**
The success of the prototype suggested the potential for using such a tool to facilitate patient identification and expression of their support needs to HCPs as a component of a clinical intervention. Subsequent exploration of the literature found no pre-existing tools, questionnaires or interventions specifically designed to enable the identification, expression and addressing of support needs in patients with advanced COPD. Further, exploratory consideration of the use of interventions employed with patients with other long-term conditions (typically based on the systematic needs-assessment intervention model) failed to demonstrate that this approach offered an intervention format that could enable patients to overcome the known challenges they faced in expressing their needs within a traditional medically-driven assessment. In response, a decision was made to: 1) formally develop the tool (which, in its prototype form, was not formally grounded in evidence from patients) and 2) incorporate this into a person-centred intervention for patients modelled on the evidence-based CSNAT-I but which would be known as the Support Needs Approach for Patients (SNAP).

5.3 The Developed SNAP Intervention

The SNAP intervention comprises two core components:

1. A concise set of 15 evidence-based questions to help patients identify and express areas of unmet support need (Fig. 5. provides an extract of the copyrighted SNAP Tool; a licence is required for its use in clinical or research practice).

2. A five-stage process in which the patient-completed tool helps start a needs-led conversation with an HCP about their unmet support needs (Fig. 6 shows the graphic used to illustrate the five-stage process).
### How are you?

We would like to know what support you need. Please tick the box that best represents your needs now, for each statement below.

<table>
<thead>
<tr>
<th>Do you need more support with...</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
<th>Do you need support with...</th>
</tr>
</thead>
<tbody>
<tr>
<td>...understanding your illness</td>
<td></td>
<td></td>
<td></td>
<td>...practical help</td>
</tr>
<tr>
<td>...managing your symptoms (including medication and oxygen)</td>
<td></td>
<td></td>
<td></td>
<td>...your personal care (washing)</td>
</tr>
<tr>
<td>...dealing with your feelings and worries</td>
<td></td>
<td></td>
<td></td>
<td>...aids or equipment</td>
</tr>
<tr>
<td>...looking after any other physical health problems you may have</td>
<td></td>
<td></td>
<td></td>
<td>...family related to your relationship</td>
</tr>
<tr>
<td>...having a healthier lifestyle (e.g. keeping active or eating well)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...getting out and about</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 5: The SNAP Tool**

**Figure 6: The Five Stages of SNAP**
5.4 The SNAP Tool

The SNAP Tool\textsuperscript{30} consists of 15 questions each relating to a different broad domain of support need identified in COPD. The first 14 questions adopt the format of a stem question ‘Do you need more support with…’ followed by a domain of support need \textit{e.g.} ‘Do you need more support with overcoming boredom and loneliness?’ The 15\textsuperscript{th} question enables patients to identify any concerns they may have about those who support them informally (i.e. ‘Does a family member or friend who helps you need more support?’). An additional question captures “anything else” that the patient identifies, but which they feel they cannot fit under the formulated questions. Box 10 provides a list of all 15 of the tool’s questions.

<table>
<thead>
<tr>
<th>Box 10: SNAP Tool Support Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Do you need more support with ...</strong></td>
</tr>
<tr>
<td>... understanding your illness</td>
</tr>
<tr>
<td>... managing your symptoms (including medication and oxygen)</td>
</tr>
<tr>
<td>... dealing with your feelings and worries</td>
</tr>
<tr>
<td>... looking after any other physical health problem you may have</td>
</tr>
<tr>
<td>... having a healthier lifestyle (e.g. keeping active or eating well)</td>
</tr>
<tr>
<td>... getting out and about</td>
</tr>
<tr>
<td>... overcoming boredom or loneliness</td>
</tr>
<tr>
<td>... financial, legal, work or housing issues</td>
</tr>
<tr>
<td>... practical help in the home or garden</td>
</tr>
<tr>
<td>... your personal care (e.g. dressing, washing)</td>
</tr>
<tr>
<td>... aids or equipment to help you</td>
</tr>
<tr>
<td>... family relationships (including talking to your relatives about your illness)</td>
</tr>
<tr>
<td>... knowing what to expect in the future</td>
</tr>
<tr>
<td>... accessing or using services</td>
</tr>
<tr>
<td>... anything else</td>
</tr>
</tbody>
</table>

Does a family member or friend who helps you need more support?
The SNAP Tool’s questions are set into the rows of a grid layout with three response categories forming the columns (No/A little more/Quite a bit more). The tool starts with a set of brief instructions for tool completion. The tool is currently available in two print versions: (i) a coloured (or black and white) version designed by an NHS Trust media studio in an A5 booklet format (Fig. 7 shows the front page) recommended for use in clinical practice and (ii) an alternative black and white version on one side of A4 which may suit the needs of researchers seeking to identify patients’ broad areas of unmet support need (i.e. not for clinical practice use). A time-limited inspection copy of the SNAP Tool is available via the SNAP website: https://thesnap.org.uk/use-snap/licensing/

Figure 7: Front page of the SNAP Tool ‘How are you?’ booklet
5.4.1 The Five Stages of SNAP

Informed by CSNAT-I, a structured five-stage approach was formulated to enable patient engagement and integration of the patient’s responses on the SNAP Tool into a needs-led conversation with the HCP to identify and address the patient’s particular support need(s). The five stages are as follows:

**Stage 1:** Introduction of the SNAP Tool: patients are introduced to the SNAP Tool by the practitioner

**Stage 2:** Consideration of needs: using the SNAP Tool, the patient considers their needs and then completes the tool

**Stage 3:** Needs-led conversation between the patient and practitioner: this is a conversation between the patient and practitioner to prioritise their support needs using the patient’s self-completed tool

**Stage 4:** Shared response: the patient and practitioner together tailor responses to the patient-prioritised need

**Stage 5:** Shared review: the patient and practitioner, together, review the outcome of the shared response(s) and consider when the five-stage approach might commence again.

5.4.2 Additional resources

In addition, SNAP is supported by the following resources and materials:

- SNAP Tool licence: the SNAP Tool is protected by copyright, and a licence required for its use (free for not-for-profit organisations). This can be requested via the SNAP website at https://thesnap.org.uk/use-snap/licensing/ once SNAP training has been completed.

- SNAP Training: all practitioners who deliver SNAP must complete SNAP training. Training is currently available in two formats: (1) online via the SNAP website at https://thesnap.org.uk/use-snap/training/ (narrated PowerPoint with downloadable workbook; 90 minutes to complete; no cost) or (2) bespoke face-to-
face training which can be delivered as a train-the-trainer model (typically a one-day workshop bringing together a small group of practitioners plus three post-workshop discussion sessions to share experiences and problem-solve; price depends on the agreed training package).

- SNAP Support Plan: this optional document/framework can be used for recording SNAP activity and outcomes in clinical records as the SNAP Tool itself cannot be reproduced in clinical records (as per the licence). Further, the Support Plan is more meaningful in terms of reporting SNAP actions and outcomes than the tool itself (the tool is just the conversation starter). The SNAP Support Plan is provided with the SNAP Tool once a licence is in place.

- SNAP Website: the SNAP website is the portal for accessing information about SNAP including SNAP training, licencing, and resources (including SNAP publications): https://thesnap.org.uk/

5.4.3 SNAP: A person-centred intervention

Within this thesis, a distinction has been made between interventions based on a Systematic Needs Assessment intervention model and an alternative person-centred approach. The former has taken the traditional practitioner-led approach to identifying need as its starting point, then adapted it in an attempt to include the patient’s voice and perspective within a systematic assessment and decision-making process (typically via the use of a needs assessment questionnaire/promt and a conversation). In contrast, a person-centred intervention can be understood as one that is purposively developed to operationalise and safeguard person-centred values in supporting the identification and discussion of patient need.

SNAP may, at first, appear to sit within the Systematic Needs Assessment intervention model given that it is structured around a comprehensive patient-completed tool that is then used to support a conversation focused around patient responses on the tool. However, the discussion below highlights the key ways in which the development, structure and format of SNAP differs from the Systematic Needs Assessment model and can therefore be understood as an alternative person-centred approach.
To be clear, although the development of SNAP began in 2016, understanding of it as an alternative person-centred approach has been an evolving process. This has moved from initial observations about the lack of adequate tools and questionnaires that can support conversations about patient needs in clinical practice with COPD patients, to a broader understanding of the literature concerning existing interventions and the more detailed analysis of these interventions via the thematic synthesis of the relevant literature (Chapter 4). The discussion below therefore draws on each of these areas.

5.4.4 Evidencing SNAP as person-centred

Unlike the interventions reviewed in Chapter 4, which are post-hoc adaptations of practitioner-led tools in order to enable patient involvement, the development of SNAP was proactively person-centred and thus is different to existing interventions. SNAP is formally underpinned by person-centred theory that it operationalises as a patient-led approach to identifying expressing and addressing support needs. The key concepts of person-centred care and support need are highlighted and used consistently within SNAP, and its supporting materials. The language used in its operationalisation is consistently used in the intervention materials, on the website and in the training resources. In contrast, terms such as ‘assessment’ and ‘assessor’ (which is associated primarily with an HCP-led approach) are actively avoided in order to keep the focus on the patient-led (rather than HCP-led) nature of the intervention.

The nature of SNAP’s person-centred approach is further exemplified within the design of The SNAP Tool itself and the format of the 5 person-centred Stages of SNAP, which are discussed more fully below.
Design of the SNAP Tool

In contrast to many questionnaires and prompts discussed in this thesis, the SNAP Tool was purposively designed to support patients to directly identify and express their support needs. In order to facilitate this patient-led approach, the tool was designed around two key features: questions focused directly on patient support needs and the purposeful move of the SNAP Tool away from a psychometric to a facilitative format.

a. Questions focused directly on patient support needs

In many of the questionnaires and prompts identified in this thesis, patient expression of need can be understood in terms of expression of ‘symptoms’ which aligns with a medical or practitioner-led approach. Symptoms are not the same as support needs and such a focus is vulnerable to HCP assumptions about where help is needed as it is frequently the HCP who is perceived as being ‘in charge’ of symptoms. Within this approach (or paradigm) the patients’ role is therefore often reduced to one in which they, implicitly, contribute to an HCP-led process of identifying their needs.

In contrast, a core feature of the SNAP Tool is that it is based around questions that allow patients to consider and identify directly where they need more support, not just symptom relief. As noted earlier, 14 of the 15 questions on the SNAP Tool specifically adopt the format of a stem question ‘Do you need more support with…’ followed by each of the domains of support need e.g. ‘Do you need more support with knowing what to expect in the future?’ Furthermore, each of the questions describe domains of support need identified by patients themselves.

Evidence from the thematic synthesis, and the use of CSNAT with carers, highlights how adoption of this approach enables the person completing the tool to take responsibility themselves for considering and identifying where they need more help to manage their particular situation. The adoption of this approach within the SNAP Tool can therefore be understood as operationalising a patient-
led, rather than HCP-led, approach to the identification and expression of support need.

b. **Purposeful move of The SNAP Tool away from a psychometric to a facilitative format.**

The prevalence of pre-determined narrow questions and measurement scales within the needs assessment questionnaires reviewed in the previous chapter suggest the influence of psychometric theory that has dominated questionnaire development in healthcare, a trend reflected in the wealth of literature assessing the psychometric properties of needs assessment questionnaires.\(^\text{17, 112, 113, 195}\)

Alongside observations by Rimmer et al (2021)\(^\text{17}\) and Doyle and Henry (2014)\(^\text{188}\) the thematic synthesis has further highlighted how these psychometric characteristics can be problematic for patients as they can limit how far a patient is able to use the answers on the questionnaire to highlight their actual experiences.

More broadly, the psychometric approach is concerned with the development of questionnaires designed for **objective** measurement of theoretical constructs such as IQ, psychological traits and support needs (as in the CARES\(^\text{173}\) and SCNS\(^\text{101}\)).\(^\text{196}\) This is underpinned by a clear methodology based around stakeholder involvement and statistical analysis e.g. factorisation and item response theory which together support: 1) the summary of stakeholder data into individual items that combine to identify the overarching theoretical construct of interest, and 2) the structuring of these items into internally consistent measurement scales. The resulting questionnaires typically comprise a list of questions based on these measurement scales, in which each question is underpinned by a single factor, each of which is numerically rated by the respondent. In turn, these ratings combine to produce an overall score enabling the individual performance of the respondent to be compared to the overarching theoretical construct.

SNAP has addressed the problems identified in relation to use of this approach, or the incorporation of features adapted from this approach, by purposefully moving away from the influence of psychometric theory. More specifically the rationale for SNAP’s approach is twofold: 1) the incompatibility between psychometric theory
and a person-centred approach and 2) the rejection of the idea that psychometric tools can be re-purposed as a prompt.

As noted, it is argued firstly that there is a fundamental incompatibility between psychometric theory and a person-centred approach. In a healthcare context, the idea that a concept such as support needs can be universally defined and measured sits within a bio-medical model rather than a person-centred approach. Further, the psychometric approach fails to acknowledge that an individual’s support needs should take into account their subjective experience of need. As a result, psychometrically designed need assessment tools can be understood as supporting an objective HCP-led assessment of need in which the role of the patient is limited to supplying information to assist the HCP in a professionally led assessment process.

Secondly, the idea is rejected, implicit in the majority of Systematic Needs Assessment interventions, that psychometric tools can be ‘re-purposed’ as a prompt, or framework, for patients to comprehensively think about and articulate their support needs. In particular, the shortcomings in those design features outlined above (that are intrinsically linked to psychometric methodology) require patients to: 1) consider there is legitimacy in discussing their issues and support needs with HCPs, 2) understand the holistic nature of supportive care and, 3) have the opportunity and confidence to contribute to discussions on what they require to manage life with their illness rather than perceiving the HCP in their traditional role as the expert assessor. An alternative is for the questionnaires to contain a long lists of questions to ensure comprehensive coverage - however this is often too lengthy to be feasible in busy generalist settings where most people with long-term conditions are seen (e.g. the SCNS-LF has 59 items). In contrast to the psychometric approach, the SNAP Tool was developed using an inductive, iterative approach focused on information from patients themselves on what matters to them and areas where they commonly say they have support needs (both met and unmet) through systematic review methods, the analysis of
patient-/carer-derived qualitative data, and patient/stakeholder involvement at every stage of the process. This approach was adopted to enable the identification and incorporation of features into the SNAP Tool that were identified as pro-actively enabling a patient-led approach to identifying and expressing their support needs.

In practice, this approach involved two stages. The first involved the identification of a comprehensive set of domains of patient support need that directly underpin the questions of the tool. In order to ensure the domains were based on a deep understanding of patient support needs, this included three sources of evidence: 1) a systematic review of the qualitative literature, 2) further analysis of purposively sampled qualitative patient and informal carer data from the LwB Study, and 3) focus groups involving patients with advanced COPD and their carers recruited from primary care and Breathe Easy patient peer-support groups. This analysis resulted in a typology of patient support needs comprising broad domains of need. The second stage involved formulation of tool items based on the identified typology (converting the domains of need into questions), and the development of the tool format (instructions and layout), informed initially by the CSNAT, but developed via a process of review and refinement involving patient focus groups, stakeholder workshops (patients, carers and HCPs), and consultation with PPI and clinical experts. Members of these groups were involved in influencing the final number of domains (and, therefore, questions on the tool) and key wording in some of the domains. This work further highlighted the need to involve professional graphic designers in production of a patient-friendly design for the tool.

In response to the above, key features of SNAP can be considered as having been incorporated into the SNAP Tool on the basis that they facilitated operationalisation of a patient-led approach to identifying and expressing support need.
These are:

- fifteen questions underpinned by the comprehensive evidence-based set of domains to support visualisation of potential support needs, and legitimising the raising of these needs (in contrast with questionnaires that may emphasise one type of support need over others and fail to provide visibility/legitimacy to the holistic nature of support need)
- questions based around the broad domains of support in order to gain information from patients themselves on what matters to them and areas where they commonly say they have support needs within these domains (both met and unmet). The broad domains are purposively designed to encourage patients to explore their specific needs within these domains (in contrast to pre-determined narrow questions that cover specific needs).
- the use of three (non-numerical) response categories to encourage any expression of need (e.g., rather than a dichotomous yes/no or a numerical measurement scale)
- the use of simple non-medical language in the wording of the instructions and questions
- an attractive booklet design entitled ‘How are you?’ designed to invite patient engagement and distinguish the tool as something person-centred rather than assessment orientated.

Together these features combine to create a facilitative format that further supports the focus of the Tool in enabling patient expression of their direct support needs.

c. The person-centred processes underpinning the Five Stages of SNAP

In their review of the literature, Johnston et al 2019\textsuperscript{16} highlighted a potential distinction between interventions that were tool-centric (e.g. positioned patient involvement primarily in relation to the tool) and those that involved patients
throughout the whole process of identifying and addressing need. They further noted that the majority of studies identified by their review fell into the former camp. Similarly, the thematic synthesis in this thesis found that interventions rarely incorporated processes beyond the use of a questionnaire that could be easily distinguished from usual care. In contrast, where interventions in the thematic synthesis incorporated features that supported patient involvement beyond the tool (e.g. goal setting or the development of a shared action plan) there was evidence of patients and HCPs moving beyond completing and describing their responses to the questionnaire and taking a further role in determining the support they needed. In relation to CSNAT-I, Ewing et al. (2015)28 also identified the benefits of a formally outlined approach to support HCPs to deliver the intervention in a way that was HCP-facilitated but carer-led across the whole process of identifying, expressing, and addressing carer support need. For example, this involved documenting the need for an ‘assessment conversation’ and a ‘shared action plan’.

In parallel with these findings, the SNAP intervention involves the delivery of five stages outlined earlier in this chapter in section 5.4.4 (2) – each of which was specifically included to facilitate, and safeguard, the patient’s role throughout the process of identifying, expressing and addressing their needs. The person-centred processes underpinning each of these stages is outlined below.

- Stage 1 seeks to support this process by ensuring patients are introduced to SNAP and the SNAP Tool in a way that highlights the person-centred focus of SNAP. Here the HCP invites them to participate in SNAP and explains the purpose of completing the SNAP Tool and how it enables a subsequent conversation based on their needs. In addition, this process is designed to facilitate patient perceptions of legitimacy in relation to expressing their support needs to the HCP and the comprehensive focus of the intervention aims – thereby acknowledging and addressing the challenges outlined in Chapter 3 that patients could face in considering what is appropriate to raise with HCPs.
• Stage 2 further supports the process of patient identification and expression of support need by enabling patients to actively consider and express their support needs via completion the SNAP Tool. (the processes underpinning this have already been described above).

• In Stage 3, patients and HCPs participate in a needs-led conversation. Here the conversation is structured around the completed tool to enable patients to express, and further explore, their individual support needs within their prioritised support domain. This process is in contrast to interventions within the Systematic Needs Assessment model that simply conceptualise this process as a conversation – thereby providing opportunities (as evidenced in the review) for HCPs to diminish the patients’ contribution and take the lead in prioritising areas for discussion and assessing need.

• Stage 4 is designed to actively involve patients in identifying and enacting the support they need via the development of a shared response with the HCP. Here the aim is that the patient and HCP together tailor responses to the patient-prioritised need(s). The goal is to provide an opportunity for the patient and HCP to identify what supportive input would be valuable and is accessible and create a shared action plan, drawing on the resources available to both the patient and the HCP. Conceptualising this as a shared response differentiates this approach with processes such as shared decision making where patients are included in (and can even lead) decisions focused around consumer choice in relation to available services. In addition, it provides an alternative to those interventions identified in the thematic synthesis in which decisions about supportive input were guided by the HCP’s professional expertise.

• Stage 5 incorporates a shared review by the patient and HCP, together, to review the outcome of the shared response(s) and consider when the five-stage approach might commence again. The rationale for recommencing the five stages again is that patients’ support needs change. There may be times when a full revisiting of the patient’s support needs is beneficial (e.g.
deterioration in their condition, change in their care plan or informal support arrangements); the prompt for a review may therefore come from the patient or HCP.

Together the 5 stages aim to provide a structure that supports HCPs deliver person centred care and provides a means of supporting and safeguarding the patient’s voice throughout the process of identifying, expressing and addressing their needs.

5.5 **SNAP in clinical practice**

Although SNAP has been purposively designed for use in a clinical context, there is still need to explore how it supports patients with long term conditions identify, express and address their support needs to HCPs. In particular, the validity of the SNAP Tool needs to be established, together with an exploration of whether and how SNAP supports a patient-led approach to identifying, expressing and addressing their support needs within clinical practice.

5.6 **Summary**

This chapter has sought to demonstrate how SNAP can be understood as a person-centred intervention through considering the features within it that directly operationalise a patient-led approach to identification, expression and patient involvement in addressing their support needs. It did so by outlining: 1) the key person-centred characteristics of the SNAP Tool and 2) the person-centred processes underpinning the Five Stages of SNAP. The following chapters (chapters 6-8) seek to expand on this further by exploring how this plays out in a clinical context – firstly by assessing the validity of the SNAP Tool in order to demonstrate suitability of purpose and enhance clinical confidence in the tool (Chapter 6), and secondly by considering whether and how the intervention supports a patient-led approach when implemented in practice (Chapter 8; the methodology for this is explored in Chapter 7).
Chapter 6: SNAP Tool Validation Study

RQ 5: Is the evidence-based support needs tool, integral to the Support Needs Approach for Patients (SNAP), valid for patients with advanced COPD?

6.1 Introduction

Chapter 5 outlined the role of the SNAP Tool as one of two key components of SNAP. It was further noted that there remained a need to test aspects of the tool’s validity in order to demonstrate suitability of purpose and enhance clinical confidence in the tool. However the previous chapter also highlighted that the SNAP Tool was not developed within a psychometric framework (as it is not a psychometric questionnaire), and therefore it is argued below that the application of traditional psychometric theory to the assessment of validity for the SNAP Tool is inappropriate. In response I present the argument for a pragmatic approach to testing aspects of the tool’s validity testing through a mixed method study design. I then go on to detail the study design and methods chosen to implement this approach. I conclude by presenting and discussing the results, and argue that they demonstrate that the SNAP Tool is valid for use in clinical practice.


CG, MF and GE all contributed to drafting and critically revising the paper. SM provided statistical expertise.

6.2 Background

As outlined in chapters 3 and 4, existing reviews of patient needs assessment questionnaires have focused on assessing their suitability for clinical practice via consideration of their psychometric properties e.g. reliability and validity. Although the SNAP Tool is not a psychometric tool there is, however, a similar need to demonstrate suitability of
purpose in order to support clinical confidence in the tool. As the SNAP Tool was developed to be patient-friendly, cover the range of support need domains experienced by patients with COPD and enable patients to identify issues relevant to their condition, this requires consideration of whether the tool is acceptable to patients, and whether the content is relevant to COPD.

However, whilst there is a wealth of literature outlining the theory and methodology that can be used to assess the characteristics of psychometric measurement questionnaires to ensure their suitability\textsuperscript{196,199-202} there is a dearth of literature on the assessment of the acceptability and suitability of tools developed outside this framework. In practice, this appears to have resulted in a ‘one size fits all’ approach in which the default position is that the psychometric approach is used without a clear rationale. In the section below I argue that a psychometric theory-driven approach is inappropriate for the SNAP Tool and therefore does not provide an appropriate philosophical or methodological approach to evaluating the tool’s suitability of purpose. In contrast I make the case that the properties of the SNAP Tool can be better described and evaluated using a pragmatic multi-methods approach. Previous work undertaken by Ewing et al (2013)\textsuperscript{193} in relation to the CSNAT is drawn upon to support this approach and provides a blueprint for the methods outlined below.

6.2.1 The Psychometric Approach to describing and evaluating questionnaires’ properties

Psychometric Theory

As noted in the previous chapter, psychometric theory is concerned with the development of questionnaires designed to facilitate the objective measurement of theoretical constructs such as IQ, psychological traits and patient experiences.\textsuperscript{196} It was also noted that questionnaire development is based around the identification of a set of empirical indicators that represent individual components of, and facilitate the measurement of, the theoretical construct of interest (e.g. IQ). As such psychometric questionnaires typically comprise a set of single items, or questions which together comprise a test or measurement
scale against which individual performance, or characteristics, can be quantified in relation to the overarching theoretical construct.

Alongside questionnaire development, psychometric theory also seeks to describe and explain the extent to which a given psychometric instrument actually represents, and measures, the theoretical concept it is designed to assess. To this end psychometricians have identified two essential properties of empirical measurement, reliability and validity. Within the field of psychometrics it is now widely accepted that these two properties form the basis of understanding the quality of the data provided by a particular psychometric instrument. This, in turn, has led to the development of a number of psychometric methods that are widely used to assess the nature and extent of these two properties within individual psychometric tools.

Instrument Reliability

Reliability can be understood as the ability of an instrument to consistently measure a given attribute across time or application. As such it is considered an indicator of the stability of the score, or data, produced by a given instrument when that instrument is re-administered within the same context or completed by different users across settings. However reliability is not a single fixed property but instead ‘relies on the function of the instrument, of the population in which it is used, on the circumstances [and] on the context’ [Souza et al 2017, p2]. Commentators have therefore established different types of reliability indicators which enable evaluations of an instrument’s consistency from these differing perspectives. As a result a range of statistical techniques have been developed enabling an assessment of reliability in relation to each of these indicators: these are outlined below in Box 11.
Instrument Validity

Validity is seen as ‘the extent to which the test is measuring what it is purported to measure’ (Rust and Golombok 2009, p72). As such, validity testing emphasises the importance of establishing the meaning or interpretation of a measurement scale in order to assess how far it is measuring the stated underpinning theoretical concept and not a differing concept. As in the case of reliability, the validity of an instrument is not considered a fixed property but one that varies between populations and circumstances. Similarly,
validity is normally considered in relation to a range of validity types which can in turn be investigated via a range of methods: these are outlined below in Box 12. Increasingly validity has been something that cannot be definitively proven but instead involves ‘the ongoing accumulation and evaluation of sources of validity evidence to provide supportive arguments for the intended interpretations and use of test scores in each new context’ [Hawkins et al 2018, p1696]200.

<table>
<thead>
<tr>
<th>Key aspects of validity</th>
<th>Definition</th>
<th>Examples of Validity Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Construct</td>
<td>The extent to which an instrument measures the construct it is intended to measure</td>
<td>Contrasted groups, Hypothesis testing, Exploratory factor analysis, Multitrait-multimethod (MT-MM)</td>
</tr>
<tr>
<td>Content</td>
<td>The extent to which the range of instrument items completely represent the theoretical construct</td>
<td>Computation of Content Validity Ratio Expert review of scale items</td>
</tr>
<tr>
<td>Criterion (predictive and concurrent)</td>
<td>The extent to which the items on the instrument correlate with scores from another instrument assessing the same construct. Predictive - the degree to which test scores predict performance on some future criterion Concurrent - the extent to which scores on a tool are correlated to a related criterion at the same point in time</td>
<td>Correlation with scores on gold standard measurement instruments measuring the same construct,</td>
</tr>
<tr>
<td>Face</td>
<td>The relationship between the instrument and the thought processes of subjects or observers</td>
<td>Expert or lay person review of instrument for grammar, syntax, organisation, appropriateness, and confirmation that the questionnaire appears to flow</td>
</tr>
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</table>

6.2.2 Psychometric testing and the SNAP Tool

As psychometric questionnaires are increasingly used in clinical practice the concepts of reliability and validity are widely considered by clinicians as key to ensuring that the data
generated by the questionnaires they are using are objectively sound.\textsuperscript{199, 200} As a result, the application of a psychometric theory-driven approach to testing new questionnaires is extensively reported within the medical literature.\textsuperscript{199, 200} Despite this, I will argue below that this approach does not provide a useful framework for evaluating the suitability of the SNAP Tool for clinical practice.

The key argument for this arises primarily from fundamental differences in the underpinning philosophy and structure of the SNAP Tool versus a psychometric questionnaire, as outlined in Chapter 5 and summarised in Box 13. This is highlighted by the following key points:

- The SNAP Tool was not developed to identify and measure an overarching, quantifiable, theoretical construct of ‘support need.’ Instead the aim was to develop a framework to enable patients to start a conversation about their individual support needs.
- The SNAP Tool does not seek to measure a theoretical construct. Therefore, the questions on the tool do not comprise a range of individual components that combine to create a definitive empirical scale for measuring that construct. Instead, they consist of broad evidence-based domains of support need that may be overlapping, multi-layered and open to individual interpretation.
- The response categories on the SNAP Tool are not measurement scales that allow individual experiences to be measured and compared, but instead are designed to act as conversation starters.
### Box 13: Comparison of the characteristics of psychometric questionnaires and the SNAP Tool

<table>
<thead>
<tr>
<th></th>
<th>Psychometric questionnaires</th>
<th>SNAP Tool</th>
</tr>
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<tbody>
<tr>
<td><strong>Primary purpose</strong></td>
<td>Designed to measure individual attributes in relation to an overarching theoretical construct (e.g. patient need)</td>
<td>Designed to enable patients to consider, identify and express their support needs</td>
</tr>
<tr>
<td><strong>Development</strong></td>
<td>Psychometric theory incorporating a number of statistical approaches and models designed to develop assessment tests to achieve the above, e.g. classic test theory, Exploratory Factorisation</td>
<td>Iterative development of questions and tool structure supported by literature review, collection and analysis of qualitative data, patient and carer focus groups and stakeholder involvement</td>
</tr>
<tr>
<td><strong>Structure</strong></td>
<td>A set of items that when combined will measure an overarching theoretical construct (e.g. need). Items are structured into internally consistent scales/dimensions</td>
<td>Tool consists of a set of 15 questions, each underpinned by a broad domain of support need, that ask patients to consider whether they need more support in each domain. Organised to support ease of completion and understanding</td>
</tr>
<tr>
<td><strong>Items/Questions</strong></td>
<td>Each item captures a single (summary) aspect of the overarching theoretical construct. Respondents provide a rating for each item (usually numerical). Assessment of individual attribute in relation to the construct (e.g. individual levels of need) is represented in a single score (for each scale/dimension in the tool)</td>
<td>Each question is overlapping, multi-layered and open to individual interpretation. Respondents indicate whether they need support in each domain by ticking a box that enables them to note whether they need a little bit more support, quite a bit more support, or no support</td>
</tr>
<tr>
<td><strong>Outcome</strong></td>
<td>Score indicates level of patient need as defined by the overarching construct. This enables comparison, generalisation and prioritisation</td>
<td>Together the SNAP questions provide visibility of common support domains and acts as a screening tool which enables patients to narrow down and identify which of the domains they need more support with, and prioritise those most important to them which can be discussed with a practitioner</td>
</tr>
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</table>

As a result of these differences an argument can be made for not conducting reliability testing on the SNAP Tool. Firstly, the fact that the SNAP Tool is not linked to a specific theoretical construction of patient support need negates the requirement to test for internal consistency (which is typically used to assess the consistency of the relationship between the questionnaire items and the overarching construct it purports to measure).
Secondly, as the SNAP Tool is designed to support an individual patient’s identification and interpretation of their support need, rather than produce a measurement score, it is inappropriate to assess the other aspects of reliability: stability, equivalence, agreement and generalisability. This is because when completing the SNAP Tool:

1) two patients may tick the same domain (question) but identify two very different types of support need in response to that domain, and

2) an individual patient may highlight the same domain at two different time points but for two different reasons.

This again means that the psychometric methods designed to assess these aspects of reliability, such as test-retest, are inappropriate for the SNAP Tool and would produce scores that would be meaningless in terms of individual support needs.

Similarly, as with reliability, an argument can also be made that a psychometric-theory driven approach to validity testing lacks relevance in relation to evidencing the characteristics of the SNAP Tool. As noted earlier, the fundamental aim of validity testing within psychometric theory is to consider how far a questionnaire can be understood as measuring the stated overarching concept. For example within psychometric theory the assessment of criterion validity considers the extent to which the scores on an instrument actually measure the overarching concept by testing it against a ‘gold standard’ instrument measuring the same construct. Similarly content validity is investigated to identify how far the range of items on the instrument completely represent the construct. As SNAP is not designed to measure an overarching concept these tests have no relevance to the SNAP tool these approaches to testing validity are inappropriate for the SNAP Tool.

There are, however, aspects of validity that are relevant to the SNAP Tool. An important exception is face validity. Face validity is not solely concerned with consideration of the theoretical construct but instead establishes user perceptions of a tool’s usability and usefulness, and generally employs qualitative techniques to achieve this. As a tool designed to be patient-friendly it is clear that this aspect of validity could, and should, be investigated for the SNAP Tool. However, as noted in Section 6.2.1 the validity of a tool requires an accumulation of evidence and therefore the establishment of face validity would
not be enough in itself to demonstrate the validity of the whole tool – some further exploration of the validity of the SNAP Tool’s characteristics is required.

6.2.3. A ‘pragmatic’ approach to assessing the characteristics of the SNAP Tool

In response to the factors outlined above a pragmatic approach to assessing the characteristics of the SNAP Tool was adopted, modelled on the validation of the CSNAT which, as was outlined earlier, shares similar properties to the SNAP Tool.

The validation of the CSNAT

The CSNAT validation is unique in that it provides the only identified example of work exploring the characteristics of a tool with similar properties to the SNAP Tool.\textsuperscript{193} Despite the fact that the CSNAT was not designed as a quantitative measurement scale (and therefore did not require reliability testing) Ewing et al (2013)\textsuperscript{193} argued that there was still a need to test whether the tool performed ‘sufficiently well in terms of face, content and criterion validity’[Ewing et al 2013, p.46]. More specifically this was to establish whether the CSNAT covered the right domains and whether those domains resonated with carers, clinicians and well-established indicators of carer burden. The authors were therefore not assessing these validity types in relation to an overarching construct but instead in relation to how well comprehensive coverage and domain resonance were operationalised within the developed tool. As such the validation process focused on investigating:

1) the comprehensive coverage of domains of carer support needs (content validity),

2) the relationship with clinically-relevant measures of how the carer, and patient who is being care for, are feeling (criterion validity), and

3) comprehension and ease of completion (face validity)

Furthermore, as many of the methods used within a psychometric theory-driven approach are specifically designed to explore the statistical relationship between questionnaire items and a theoretical construct, Ewing et al (2013)\textsuperscript{193} had to draw on a range of alternative methods as outlined in Box 14. These included both the selective use of relevant psychometric techniques (e.g. carer and peer consultation) and the adoption of methods
that are not traditionally associated with this approach (e.g. a carer completed postal survey). Together these indicated a shift from methods informed by psychometric theory to a mixed methods approach.

<table>
<thead>
<tr>
<th>Box 14: Carer Support Needs Assessment Tool Validation: Outline of validation types tested and methods employed</th>
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<tbody>
<tr>
<td><strong>Validity Type</strong></td>
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<tr>
<td>Face</td>
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<tr>
<td>Content</td>
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<tr>
<td></td>
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<tr>
<td>Criterion</td>
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</tbody>
</table>

Overall the authors argued that the above study enabled them to demonstrate that the CSNAT “combines comprehensiveness of content with feasibility of administration and has utility both as a research tool and a tool for everyday palliative care practice”[Ewing et al (2013) pg. 395]. This enabled them to conclude that the evidence collected by the validation work suggested the CSNAT was valid for use with informal carers in an end of life caring context.
The validation of the SNAP Tool

The CSNAT’s validation approach was identified as the blueprint for the validation of the SNAP Tool for the following reasons:

1) The similarities in the purpose and design of the CSNAT and SNAP Tool are such that the SNAP Tool properties are similar to those of the CSNAT.

2) Ewing et al (2013) demonstrated how existing concepts of validity can be pragmatically applied in relation to the CSNAT. Thus, whilst there are no established definitions or frameworks informing the validity testing of non-psychometric tools (with the exception of face validity), the CSNAT validation study suggests that existing concepts of validity can be applied more broadly to consider how a concept is translated or operationalised into a tool. More specifically, Ewing et al demonstrated how this could be achieved with face, content and criterion validity. Using a similar process with the SNAP Tool: 1) the establishment of face validity could demonstrate acceptability to patients, 2) content validity could establish that tool questions reflect patient support needs and 3) criterion validity could provide evidence of a relationship between questions on the SNAP Tool and commonly used indirect clinical indicators of patient need (disease impact).

6.3 Aim

The aim of this validation study was therefore to assess the face, content and criterion validity of the SNAP Tool with an exemplar population of patients with advanced COPD.

6.4 Method

6.4.1 Study design

The design adopted in the validation study was a sequential mixed methods study comprising two steps:
Step 1: Assessment of face validity and initial assessment of content validity via two focus groups with patients living with advanced COPD, and their informal carers.

Step 2: Assessment of content and criterion validity via a patient-completed postal survey administering the SNAP Tool alongside standard measures of disease impact to patients with advanced COPD.

Mixed methods

As noted in Chapter 1 the analytical framework for this thesis is a pragmatically informed ‘multiple study’ mixed-method approach enabling different studies to be conducted separately using different methodology (e.g. quantitative, qualitative or mixed methods)\textsuperscript{32} – and more specifically via the method identified as being the most suitable to answer any given research question.\textsuperscript{203-205}

In line with the above framework, and the arguments made in the previous sections of this chapter, the study outlined below in this chapter was also informed by similar mixed-methods approach. More specifically the rationale for the adoption of a mixed-methods framework in this study is as follows:

- Two of the validity types being investigated are most suitably addressed by different methods.\textsuperscript{196, 199} Face validity focuses on obtaining the views of patient and experts and can be understood as being best explored using qualitative methods. In contrast criterion validity is typically investigated using statistical techniques to identify the strength of the relationships between tools.
- The work by Ewing et al\textsuperscript{193} suggested that an effective way of exploring content validity was via a combination of both qualitative and quantitative approaches in order to benefit from both an in-depth qualitative exploration together with the comprehensive coverage afforded by a postal survey.
- Use of one method across each of the three validity types would limit the findings of those aspects of validity testing that are best served by the alternative approach.
- The shift away from the emphasis placed on quantitative methodology employed in psychometric testing (where the purpose of the qualitative data is to confirm rather
than develop the overall findings) enables equal weight to be given to any qualitative findings.

Mixed methods not only enables the researcher to draw from both quantitative and qualitative methods, but as Greene (2007) has noted it also requires consideration of: 1) the conceptual lens through which to integrate the different types of data (e.g. triangulation, complementarity, development, initiation and expansion), 2) the relative weight given to qualitative and quantitative methods, 3) the importance of addressing divergence arising from the different types of methods and 4) the order in which data is collected. The SNAP Tool’s validation study was run in two sequential stages. The qualitative and quantitative data were given equal weight, and collected and analysed independently. The findings from each stage were considered together in the discussion.

6.4.2 Ethics

Ethical approval was obtained from the East of England Essex Research Ethics Committee (REC reference 17/EE/1092).

6.4.3 Research governance

The University of East Anglia (UEA) was the SNAP2 study sponsor.

6.4.4 Research management and support

In addition to supervision provided by my PhD supervisor (CD), co-supervisor (MF) and advisor (GE), the validation study benefited from study management processes set in place to support the overarching Marie Curie-funded SNAP 2 Study (which sought to validate the SNAP Tool and pilot its use in clinical practice) including a:

- Study Management Group (SMG):
  The SMG was comprised of myself, MF and GE. The group met monthly to oversee, plan and execute all aspects of operationalising the SNAP2 Study. My particular role was to organise the meetings, help plan the agenda, and contribute to reporting on study progress.
• Study Advisory Group (SAG):
The SAG comprised of clinical experts in COPD and long-term conditions and academics with methodological expertise and/or an interest in COPD or long-term conditions, in addition to the members of the SMG. The group met bi-annually to review study progress, troubleshoot, and advise on data analysis and dissemination. My role was to co-ordinate the meetings, contribute to reporting on study progress and meeting reporting (minutes).

• Patient and Carer Advisory Group (PCAG)
The PCAG group comprised patients with COPD, carers of people with COPD and members of the public with an interest in COPD. In total the PCAG involved eight members. They were recruited from a larger PPI forum within the University of Cambridge Clinical School, local Breathe Easy peer support groups and former study participants who had contacted the study team and expressed an interest in further involvement. Background data about the PPI members was not formally collected but they all had experience of COPD, or other long term conditions, either directly or in a caring capacity. Member involvement was via bi-annual meetings and email. PCAG members were consulted on recruitment, data analysis and two members of the PCAG also attended the SAG, acting as a point of liaison between the PCAG and SMG. Throughout I acted as the key contact for the PCAG, providing guidance and information as well as organising meetings and PCAG involvement via email. During the meetings, I took a role in presenting information to the group and led key discussions pertinent to the study.

6.4.5 Step 1: Assessment of face and initial content validity
Focus groups were used to obtain patient and carer feedback on face validity and to give an initial indication of content validity.

In her discussion of focus group methodology, Kitzinger (1995) defines this approach as ‘a form of group interview that capitalises on communication between research participants in
order to generate data’ [Kitzinger (1995) p.299]. Here she has argued that the key strength of this approach is the potential of the inter-group dynamic to generate and facilitate the expression of a wider range of ideas and experiences than those obtained via surveys or individual interviews. In particular she notes that focus groups also give participants the opportunity to express criticism in a way that might feel more comfortable than if they are in an individual one-to-one conversation with an interviewer.

In the context of the SNAP Tool validation study, focus groups were therefore identified as a way of facilitating discussion of the SNAP Tool with participants who had not had prior exposure to the tool, but who shared the common experience of living with, or caring for someone with, advanced COPD. It was therefore anticipated that comments, questions and reflections of individual members would generate thoughts and further discussion in relation to the tool amongst the wider group. This in turn would potentially enable responses that might have been left undeveloped or unconsidered within an individual interview or survey. In particular this approach was seen as a means of enabling participants to express criticism in a context where they were being asked to give feedback to the SNAP tool developers.

Recruitment of focus group participants

Two primary care practices, recruited via the NIHR Clinical Research Network: Eastern, searched their databases to identify eligible patients against the inclusion and exclusion criteria. Patients were eligible if they met two or more of six well-established clinician-developed inclusion criteria for patients with advanced COPD (and none of the exclusion criteria), shown in Box 15, which have been successfully applied in previous research studies with this population.
Eligible patients were sent a recruitment pack by their practice comprising a letter of invitation printed on the practice’s headed paper, Participant Information Sheet, reply slip, and freepost envelope for direct-return to the study team. Patients were also invited to bring along a friend or family member who supported them (their informal carer) to the focus group. On receipt of a reply form from patients interested in taking part, I contacted the respondents by telephone to answer any questions they had about the study and to make arrangements for the focus groups.

As recruitment of patients with a long-term, life-limiting condition such as COPD can be difficult (both initial recruitment and the ability to attend “on the day”), the decision was made to run the focus groups in a way that made attending easy, comfortable and enjoyable. As such the focus groups were planned around the provision of the following practical arrangements:

- hotels with meeting rooms that were local to the recruiting primary care practices
- dedicated venue parking
- ease of access to the room where the focus group would take place, e.g. ground floor
- afternoon tea

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with COPD meeting two or more of the following:</td>
<td>Patients with any of the following:</td>
</tr>
<tr>
<td>• FEV1 &lt; 30%</td>
<td>• Serious mental health problem</td>
</tr>
<tr>
<td>• Long-term oxygen therapy</td>
<td>• Serious learning difficulty</td>
</tr>
<tr>
<td>• Cor pulmonale</td>
<td>• Unable to give informed consent</td>
</tr>
<tr>
<td>• MRC dyspnoea scale 4+</td>
<td></td>
</tr>
<tr>
<td>• Admission for COPD in previous year</td>
<td></td>
</tr>
<tr>
<td>• 2+ exacerbations requiring both prednisolone and antibiotics in the previous year</td>
<td></td>
</tr>
</tbody>
</table>
• an ‘unhurried’ approach
• transport where necessary (e.g. taxi) and reimbursement of travel costs.

This practical information was given to all patients who returned the reply slip, building on preliminary information in the Participant Information Sheet on likely venue and reimbursement of travel costs.

Setting

Two focus groups were held, in two different geographical areas in East Anglia, in hotel meeting rooms that were situated near to the recruiting primary care practices.

Consent

On arrival, patients and their carers were welcomed and made comfortable, then provided with an additional copy of the Participant Information Sheet and a consent form (see Appendix 1). There was an opportunity for them to discuss the Participant Information Sheet and have any questions answered. The patients and carers were also asked to read the consent form and indicate if they agreed to six points (including consent to being audio-taped and their right to withdraw without giving a reason) by initialling each and providing a signature at the end of the form, witnessed by one of the research team. Each participant was given a carbon copy of the signed consent form to keep for their own records. Participants were allocated a study ID number which was added to their completed consent forms. The participants were also provided with an expenses claim form for reimbursement of any travel costs.

Data Collection

A topic guide was developed by CG, MF and GE covering the SNAP Tool format, relevance of the SNAP Tool questions, the booklet design and the applicability of the SNAP Tool across a range of settings (see Appendix 2). Prior to the focus group discussion, participating patients and carers were each asked to complete a brief questionnaire to capture background details.
Each group was facilitated by myself, CG (acting in the role of moderator), and MF. The groups lasted approximately 90 minutes and were audio-recorded with participant permission.

At the start of the discussion the participants were formally welcomed and introductions were made. As confidentiality is a key issue in focus groups, not just between the researcher and focus group attendees, but also between the attendees, this was also discussed. Group members were: 1) given assurances that any of their views that were subsequently reported by the study team, either orally or written, would be anonymised and 2) asked not to discuss the views and experiences of the other group members outside the focus group. This was followed by a short presentation on the SNAP Tool made by MF in order to set the scene for the participants.

During the course of the discussion the groups were shown the SNAP Tool in different formats:

1) A black and white version of the professionally designed A5 booklet
2) A colour version of the professionally designed A5 booklet format
3) A second colour version of the professional designed A5 booklet format in a different colour scheme to the above

In the first part of the focus group discussion, the participants were shown the black and white version of the professionally designed A5 booklet format and asked to consider the range of questions, clarity of the instructions, ease of completion, relevance of tool questions and suitability for purpose. In the second part, they were asked to review the two coloured versions of the A5 booklet format and asked to comment on the colours and overall design. Prior to closing the focus group, participants were also asked whether there was anything else they would like to say about patient support needs in COPD or how patients with advanced COPD could be better supported. The next steps of the study were also outlined.
A key issue in focus groups is keeping the participants focused and on topic. However, as moderator of the focus group I was mindful that people with a chronic illness often: 1) overcome a range of physical difficulties to get to a focus group, and 2) have little opportunity to share their illness experiences with others undergoing the same experience. Thus, in order to ensure that the participants also felt some benefit from having participated in the group, there was some leeway in the group for discussions that weren’t always relevant to the assessment of face validity in the SNAP Tool. Once the focus group had finished, the participants were also encouraged to stay on to enjoy the refreshments and chat to each other.

In line with good practice, the Study Management Team (SMT) were also keen to make the results of the study available to the participants. However, we were also mindful of the fact that the participants were living with an advanced, progressive and unpredictable condition and that their health status could change rapidly following participation. As a result, instead of sending the results to the participants once the study had finished, the participants were informed that the study findings would be disseminated on the SNAP website. The participants were also given details about how to request the information in a different format if required.

As discussing the SNAP Tool domains also had the potential to raise sensitive or difficult issues for people with COPD, a supportive contact (an experienced community respiratory nurse) had previously been identified as someone who was available to talk to any patients, or carers, who may have found aspects of the discussion upsetting. The participants had already been provided with these details in the Participant Information Sheet but were reminded that that this was available to them and they were encouraged to use this contact if they felt they would benefit from talking to someone as a result of participating in their focus group.

Data Management

Participant data was collected and stored in line with University of Cambridge policies, including restricted and secured access, password protection and anonymization of data.
The link between participant ID numbers and participant details was recorded on a hard copy only and kept in a locked cabinet. Participant consent forms and data was kept in separate secure filing cabinets. Qualitative data was audio-recorded using a password protected digital recorder. Audio-recordings were transcribed by a professional transcription company, which I then checked for accuracy and anonymised. The anonymised quantitative participant database was kept on a password secured computer.

Data Analysis

Qualitative data was analysed using conventional content analysis. Conventional content analysis has been identified as a useful approach to describing, rather than interpreting qualitative data, enabling the researcher to represent the findings without imposing preconceived theoretical perspectives. It is typically applied to data that has been collected through interviews or focus groups that seek to explore accounts of an experience or event through open-ended questions and prompts. Whilst the relevance of a more interpretive approach to analysis was identified earlier in this PhD the exploration of face validity should aim to represent patient views in a way that stays as close to the data as possible. As such, conventional content analysis was chosen to describe patient views of the SNAP Tool.

In order to achieve this, I coded the interview transcriptions, grouped the codes into categories and explored the categories for variation. Despite the focus on staying close to the data, a key discussion within content analysis has been how far the analysis can ever be free of researcher interpretation. In order to address this, MF and GE also read the focus group transcripts and the transcripts, codes and categories were discussed until there was agreement about the key findings.

6.4.6 Step 2: Assessment of content and criterion validity

To assess the content and criterion validity of the SNAP Tool, quantitative data was required. This was collected through a postal survey. In contrast to focus groups, which (as noted above) support dialogue and debate, surveys typically support the collection of data from individual participants via a ‘decontextualized choice of tick boxes’ (Meetoo et al
A key strength of this approach is that, in contrast to individual interviews, it overcomes known recruitment difficulties in people with advanced disease (if appropriately designed) by reducing respondent burden. In addition, it enables researchers to easily collect quantifiable data from a large sample. 210

Survey Recruitment

A further twenty-eight primary care practices, recruited via the NIHR Clinical Research Network, invited patients to participate in the postal survey using the same inclusion and exclusion criteria shown in Box 15, until a minimum sample size of two hundred patients was achieved. The justification for this sample size (established with a statistician) was that it had sufficient power (>80%) to detect a Spearman’s correlation of 0.3 between SNAP Tool questions and the disease impact measures.

Study recruitment packs were sent by each practice to eligible patients and comprised a letter of invitation, participant information sheet, postal survey booklet (see Appendix 3) and freepost envelope for direct return to the study team. A follow-up procedure was employed of a phone call from the practice to non-responding participants within two weeks of their recruitment pack being sent. This enabled practice staff to establish if the patient had received and understood the pack, and whether they would like to be sent a new pack, thereby giving every eligible patient the opportunity to participate if they wished. This approach was used successfully within the LwB Study (referred to in Chapter 5) and was mentioned in the letters of invitation to potential participants.

Patient Consent

The postal survey booklet included a consent form. The consent form was on the second page (following an introduction on how to complete the booklet) and asked participants to consent to five items. In the focus groups, participants were asked to initial each of the items and provide a signature at the end of the form to confirm consent. Upon return of the survey booklet the consent form was removed from the booklet and stored in a separate locked filing cabinet.
Data Collection

The survey booklet contained the original A4 black and white version of the SNAP Tool, basic demographic questions to assess sample representativeness (final page), and (with the appropriate permissions) three standard measures of disease impact for COPD: the Chronic Respiratory Questionnaire (CRQ)\textsuperscript{211} the COPD Assessment Test (CAT),\textsuperscript{212} and the Hospital Depression and Anxiety Scale (HADS).\textsuperscript{213}

- The CRQ measures quality of life in chronic lung disease: the 20-question self-report version (CRQ-SR) covers four dimensions (dyspnoea, fatigue, emotional-functioning and mastery) which in turn form two subscales for physical and emotional functioning (CRQ-Emotional and CRQ-Physical).

- The CAT (eight questions) assesses COPD impact e.g. shortness of breath, ease of living at home.

- The HADS (14 questions) consist of two subscales (seven items each) to screen for anxiety (HADS-A) and depression (HADS-D).

These standard measures are commonly used in clinical practice to assess patients with advanced COPD and are thus considered as indicators of patient clinical need, providing appropriate comparators to the SNAP Tool in the absence of a gold standard direct measure of patient support need in COPD. As they were familiar to patients it was also anticipated that patients would be unlikely to find them a burden to complete: a view supported by members of the SMG having previous experience of successfully using the questionnaires in a similar postal survey.

Data Management

Completed survey booklets were anonymised on receipt by removal of the completed consent form page. Data from returned postal surveys were entered into SPSSv24 by myself.
Double data entry was performed on a 10% sample (MF) and showed a high level of data entry accuracy. Missing data was handled as follows:

- **HADS:** No information is provided on how to score missing data for the HADS. An example of how missing data had been managed was therefore identified from a previous study. The appropriateness of this approach was discussed and agreed with the validation survey statistician (SM). The decision was taken that missing data be replaced by the mean value of the patient’s responses within the respective subscale, provided that the patient had answered at least four of the questions in that subscale.

- **CRQ:** Missing data for the CRQ was handled in line with the CRQ scoring system outlined in the accompanying manual. The manual states that in order to score the CRQ, ‘the scores for each dimension are added together and divided by the number of completed questions in each domain’ and that ‘questions not answered or missed should be excluded’ [Guyatt and Schunemann 2001, p.9]. Whilst this guidance is specifically aimed at those using the CRQ in a longitudinal context, an assumption was made that this approach could also be used in cases where the patient was asked to complete the tool on a single occasion.

- **CAT:** No guidelines for missing data are provided in relation to the CAT and no examples were identified of how missing data was addressed in existing studies. Where data was missing the final CAT score for the patient was not calculated.

- **SNAP Tool:** Missing data on the SNAP Tool was left as missing. The rationale for this approach was the lack of relationship between the tool domains suggesting that a composite score could not act as a reliable indicator for a missing response.

**Statistical Analysis**

Content validity of the SNAP Tool was assessed by the percentage of patients indicating a need for more support with each tool question, to identify any redundant questions. In
order to achieve this, the responses were recoded into a dichotomy: yes/no. Thus, where a respondent indicated no need for support in relation to an item this was recoded as a 0 to indicate ‘No’. Similarly where a respondent ticked either a need for a little more support or quite a bit more support, either response was recoded as 1 to indicate ‘Yes’.

Where patients had commented in the ‘Anything else – please write in’ section, these comments were reviewed to assess whether they could be allocated to existing tool questions. To do this, each member of the Study Management Group (CG, GE, MF) independently mapped the ‘anything else’ comments to existing tool questions; this mapping was then compared, and differences of opinion resolved through team discussion until consensus was achieved.

Criterion validity was tested by investigating the relationship between the SNAP Tool questions and each of the standard measures of disease impact. We hypothesised that greater need for support (indicated by a greater need for support on a SNAP domain and represented numerically purely for the purpose of this test) would correlate with lower health-related quality of life, lower levels of patient functioning and higher indicators of anxiety and depression. As the questions on the standard measures of disease impact acted as indicators of patient need for support, but could not act as indicators of patient perceptions of carer need, the final carer-related question on the SNAP Tool (‘Does a family member or friend who helps you need more support?’) was omitted from this stage of validity testing.

The potential problem of how to undertake criterion analysis with a tool that does not employ an empirical measurement scale was overcome by initially assigning a score to each of the SNAP Tool response categories (e.g. no (0), a little more (1), quite a bit more (2)). Whilst the underlying philosophy of SNAP rejects the idea that patient support needs are best measured in relation to a construct, and the related idea that priorities for addressing patient need can be identified by the highest score, the rationale for assigning a score to the patient responses in the above context is twofold:
1) The responses provided by patients in response to the SNAP Tool questions do involve patients making an evaluation of how much support they would need within each domain and, as such, their responses can be represented along a numerical linear scale.

2) Whilst the purpose of the evaluative process within a clinical context is purely to prompt consideration of individual needs (which does not require a numerical scale) this does not rule out the usefulness of such a scale in a non-clinical research context.

The nature of the tool questions indicated the need for non-parametric testing. Spearman’s rank ($r_s$) correlation was therefore used. Correlations of 0.10 were considered weak, 0.3 moderate, 0.5 strong and 0.7 very strong. Missing values were handled by pairwise deletion in the correlation table.

6.4.7 Patient and Public Involvement

PPI members were involved firstly in reviewing participant recruitment documents for appropriateness and clarity prior to submitting an application for ethics approval. In particular they were asked to consider whether the postal survey could be considered burdensome for the target patient group. All PPI members were happy with the original documents and no changes were requested. Secondly the members of the group were involved in reviewing, and commenting on, findings from the data analysis. The group were given a brief presentation of the findings from both stage 1 and stage 2 of the validation and given the opportunity to discuss these conclusions and implications. More specifically they considered feedback from the focus groups and were given the opportunity to comment on whether there should be changes to the wording and layout of the SNAP tool based on these findings. Overall the PPI members endorsed the results outlined below.

6.4.8 Integration of Stage 1 and Stage 2 data

The findings from the Step 1 content analysis were combined to consider tool comprehensiveness. The overall findings from Step 1 and Step 2 were considered together in the discussion to assess whether all three components suggested there was evidence of
validity, whether there was divergence between the different components or whether all three suggested a lack of validity in the SNAP tool.

6.5 Results

6.5.1 Sample characteristics

Step 1: Focus Groups

In total, 27 eligible patients were invited to participate in the focus groups: eight patients and four carers agreed to take part. Seven participants were female (58.3%) and they ranged in age from 51 to 90 years. Participating carers were two spouses, a daughter and a friend. The level of recruitment reflected protocol targets (i.e. two focus groups comprising 12-16 patients and carers).

Step 2: Postal Survey

Recruiting practices identified 503 eligible patients who were invited to take part in the postal survey. Of these, 167 (33%) responded to the first mail out and a further 61 (12%) responded to the re-mail resulting from the follow up phone call from the practice (confirming its usefulness as a methodological approach with this patient group); in total, 228 patients participated (45%). There were 126 male participants (58%) and participants’ ages ranged from 49 to 94 years.

6.5.2 Face and content validity

Focus Groups

The patient and carer focus groups were unanimous in identifying key features of the SNAP Tool. In particular the felt the tool was easy to understand, straightforward to complete and patient-friendly. For example, one participant described that SNAP Tool as “all quite clear and straightforward” [FG1-S4].
The focus group participants felt that the questions on the tool were relevant and that the range of questions was comprehensive for people with advanced COPD. When considering the list of questions one carer commented on how it reflected particular concerns she had:

“I find there’s quite a few things on here that we don’t know... about what’s going to happen in the future and, you know, what equipment we might need and, you know, just in general. So, we would like to know more about that, but they don’t seem to tell you at the doctors.” [FG2-P5]

None of the focus group participants identified additional questions (domains of need) they felt were missing from the SNAP Tool.

Feedback was also provided on the wording of the questions. Participants endorsed, in particular, the use of plain English and non-medical language. One patient noted positively: “It’s in layman’s terms as opposed to medical terms” (FG1-P4). Another participant described how use of the term ‘feelings and worries’ within one of the questions was far less threatening than standard medical terminology. Participants also commented favourably on the tool’s format: “I think the layout is particularly good... It’s the clarity of it... it’s not threatening in any way” [FG1-P6]. They appreciated, in particular, the concise nature of the tool, the clarity of the instructions and overall ease of completion. They also liked the welcoming title ‘How Are You?’

There was further positive response to the use of colour, and the potential for clinical service providers to customise the tool’s front and back covers (e.g. by adding service logos, notes sections etc.). It was felt that both the use of colour and the adaptive properties of the cover would enhance patient and HCP engagement with the tool. Only one participant felt that the current design would not attract their attention.

Participants also highlighted a number of ways in which patients might find the SNAP Tool useful:

“at a glance you can see where the problem is and then you can think about it rather than asking questions to find out” [FG1-P2]
They discussed the experience of arriving at a consultation with questions but then forgetting to raise these issues. In contrast it was felt that the completed tool might act as a reminder with one participant suggesting that “if you write it down at least someone will look at it” [FG1-P2].

There were, however, concerns about whether HCPs had the time, resources or interest to discuss and address issues that might be raised by the tool. A couple of participants discussed how the level and nature of need changes over time and suggested SNAP Tool was potentially useful at different stages of the disease trajectory.

“In the early stages …. they might say, ‘Oh you’ve got this’.…. it [the SNAP Tool] might make them think … ‘Actually, yeah, I do want some more help’, but [they] might not want to say it” [FG2-P4]

Postal Survey
Data from the postal survey established that the tool questions reflected the domains of support needs of patients with advanced COPD. Figure 8 shows the 15 SNAP Tool questions ordered according to the percentage of patients who expressed a need for more support with each (i.e. any indication of need for more support other than ‘No’).
Figure 8: Percentage of patients with advanced COPD expressing need for more support with each SNAP Tool question. [Sample size ranged from 218 to 225 patients across questions except for “Does a family member or friend who helps you need support?” (n=157)]

Over 50% of patients wanted more support with ‘knowing what to expect in the future’ and ‘looking after any other physical health problems’. In addition, over 40% identified a need for support with ‘practical help in the home or garden’, ‘getting out and about’, ‘dealing with feelings and worries’, ‘accessing or using services’ and ‘having a healthier lifestyle’. Only one question was identified by less than 20% of patients (‘family relationships’) but this was nevertheless relevant to 39 people who took part. In total, 3% identified other needs in the ‘anything else’ section, but all could be consensus-mapped to existing tool questions e.g. ‘Access to a GP that does not judge’ could be mapped to the question ‘Support accessing and
using services.’ Across the sample, patients responded to all tool questions indicating that none was redundant for this population.

6.5.3 Content and criterion validity

Clear correlations were found between tool questions and the majority of questions on the impact measures. This analysis focused on correlations showing statistical significance with $p \leq 0.05$. All SNAP Tool questions were positively correlated with both HADS-D (depression) and HADS-A (anxiety) scores. That is, the greater the unmet need for support, the higher the likelihood of depression or anxiety. All the SNAP Tool questions were negatively correlated with the CRQ-Emotional subscale and all but one question were negatively correlated with the CRQ-Physical subscale. That is, the greater the unmet need for support, the lower health-related quality of life reported. All but two of the SNAP Tool questions were positively correlated with the CAT scores: that is, the greater the unmet need for support, the greater the impact of COPD as reported.

Stronger associations between questions on the SNAP Tool and the measures of disease impact are highlighted in Table 5: the strength of associations ranged between $r_s = 0.15$ and $r_s = 0.44$ for questions that were positively correlated and between $r_s = -0.13$ and $r_s = -0.48$ for questions that were negatively correlated. Whilst the overall picture is mixed, moderate correlations were primarily identified between psychological indicators (CRQ-Emotional, HADS-D) and SNAP Tool questions, whereas there were weaker correlations with indicators assessing physical aspects of the disease (CRQ-Physical and CAT). With the exception of three questions, each of the SNAP Tool questions was moderately correlated with at least one of the standard measures of disease impact. The exceptions were: ‘aids and equipment to help you,’ ‘financial, legal, work and housing issues’ and ‘family relationships.’
<table>
<thead>
<tr>
<th>SNAP Tool questions</th>
<th>HADS-A (Anxiety)</th>
<th>HADS-D (Depression)</th>
<th>CAT</th>
<th>CRQ (Physical)</th>
<th>CRQ (Emotional)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing what to expect in the future</td>
<td>0.24 (&lt;0.01)</td>
<td>0.25 (&lt;0.01)</td>
<td>0.15 (0.04)</td>
<td>-0.15 (0.03)</td>
<td>-0.32 (&lt;0.01)</td>
</tr>
<tr>
<td>Looking after any other physical health problems</td>
<td>0.29 (&lt;0.01)</td>
<td>0.24 (&lt;0.01)</td>
<td>0.21 (&lt;0.01)</td>
<td>-0.19 (&lt;0.01)</td>
<td>-0.36 (&lt;0.01)</td>
</tr>
<tr>
<td>Practical help in the home or garden</td>
<td>0.24 (&lt;0.01)</td>
<td>0.31 (&lt;0.01)</td>
<td>0.32 (&lt;0.01)</td>
<td>-0.34 (&lt;0.01)</td>
<td>-0.32 (&lt;0.01)</td>
</tr>
<tr>
<td>Getting out and about</td>
<td>0.22 (&lt;0.01)</td>
<td>0.41 (&lt;0.01)</td>
<td>0.32 (&lt;0.01)</td>
<td>-0.31 (&lt;0.01)</td>
<td>-0.38 (&lt;0.01)</td>
</tr>
<tr>
<td>Dealing with your feelings and worries</td>
<td>0.44 (&lt;0.01)</td>
<td>0.35 (&lt;0.01)</td>
<td>0.22 (&lt;0.01)</td>
<td>-0.18 (0.01)</td>
<td>-0.48 (&lt;0.01)</td>
</tr>
<tr>
<td>Accessing or using services</td>
<td>0.27 (&lt;0.01)</td>
<td>0.28 (&lt;0.01)</td>
<td>0.25 (&lt;0.01)</td>
<td>-0.21 (&lt;0.01)</td>
<td>-0.38 (&lt;0.01)</td>
</tr>
<tr>
<td>Having a healthier lifestyle</td>
<td>0.22 (&lt;0.01)</td>
<td>0.29 (&lt;0.01)</td>
<td>0.12 (0.09)</td>
<td>-0.23 (&lt;0.01)</td>
<td>-0.30 (&lt;0.01)</td>
</tr>
<tr>
<td>Understanding your illness</td>
<td>0.22 (&lt;0.01)</td>
<td>0.24 (&lt;0.01)</td>
<td>0.16 (0.03)</td>
<td>-0.13 (0.05)</td>
<td>-0.32 (&lt;0.01)</td>
</tr>
<tr>
<td>Managing your symptoms</td>
<td>0.34 (&lt;0.01)</td>
<td>0.32 (&lt;0.01)</td>
<td>0.25 (&lt;0.01)</td>
<td>-0.28 (&lt;0.01)</td>
<td>-0.46 (&lt;0.01)</td>
</tr>
<tr>
<td>Overcoming boredom and loneliness</td>
<td>0.36 (&lt;0.01)</td>
<td>0.39 (&lt;0.01)</td>
<td>0.30 (&lt;0.01)</td>
<td>-0.30 (&lt;0.01)</td>
<td>-0.47 (&lt;0.01)</td>
</tr>
<tr>
<td>Aids or equipment to help you</td>
<td>0.25 (&lt;0.01)</td>
<td>0.24 (&lt;0.01)</td>
<td>0.26 (&lt;0.01)</td>
<td>-0.25 (&lt;0.01)</td>
<td>-0.28 (&lt;0.01)</td>
</tr>
<tr>
<td>Financial, legal, work or housing issues</td>
<td>0.15 (0.03)</td>
<td>0.17 (0.01)</td>
<td>0.15 (0.04)</td>
<td>-0.08 (0.24)</td>
<td>-0.24 (&lt;0.01)</td>
</tr>
<tr>
<td>Your personal care</td>
<td>0.35 (&lt;0.01)</td>
<td>0.41 (&lt;0.01)</td>
<td>0.43 (&lt;0.01)</td>
<td>-0.45 (&lt;0.01)</td>
<td>-0.43 (&lt;0.01)</td>
</tr>
<tr>
<td>Family relationships</td>
<td>0.27 (&lt;0.01)</td>
<td>0.21 (&lt;0.01)</td>
<td>0.09 (0.20)</td>
<td>-0.14 (0.03)</td>
<td>-0.29 (&lt;0.01)</td>
</tr>
</tbody>
</table>

The table shows Spearman’s rank correlation (and p-values for the two-tailed test). SNAP Tool questions are sorted in descending order of expressed need (per Fig. 8). Cells are coloured depending on the strength of the correlation: blue cells show associations with worse disease burden. Worse disease burden is associated with higher HADS and CAT scores and lower CRQ scores. The number of patients in each cell ranged from 189 to 225.
6.6  Discussion

This chapter reports the validation of the SNAP Tool in patients with advanced COPD. The findings suggest that the SNAP Tool has face, content and criterion validity for patients within this population.

Face validity has been identified as particularly important for tools as it enables acceptability of the tool to potential users. Qualitative feedback on the format and acceptability of the tool came directly from patients with advanced COPD, and their carers, recruited from primary care.

Content validity was demonstrated via two sources: qualitatively through focus groups (which established patient and carer acceptability of the range of questions and their comprehensiveness), and quantitatively through the postal survey. The postal survey found that cross-sample identification of need for more support through the SNAP Tool established that none of the questions was redundant and that the existing questions comprehensively reflected patient support needs.

If the SNAP Tool is identifying something meaningful and relevant within the context of advanced COPD it should also be significantly related to standard measures of disease impact in advanced COPD. Criterion validity was used to test this within the postal survey and identified significant correlations in the right direction between the tool questions and the standard measures, with low to moderate strengths of association. If the SNAP Tool was a psychometric measure, stronger associations would be more desirable: traditional psychometric testing of criterion validity seeks to assess how far a measurement tool can be used to predict outcomes on a ‘gold standard.’ Here stronger levels of association indicate higher levels of predictive ability, suggesting in turn that the two tools are performing the same function. However, as the SNAP Tool is intended to facilitate a conversation rather than ‘measure’ anything in the psychometric sense, the approach was fundamentally different. The aim was not to assess the predicative ability of the SNAP Tool against a gold standard (no such gold standard of need exists), and the SNAP Tool is not a measurement.
instrument. Instead the aim was to look for evidence of an underlying relationship between the tool and the standard measures of disease impact (that clinicians are familiar with), in order to enhance clinician confidence in the tool. Importantly, the strengths of association found suggest the SNAP Tool is related to, but different from, the standard measures. These results support the view that, as a tool that has been specifically designed to directly identify broad areas of unmet patient support need, the SNAP Tool is distinct from the standard measures of disease burden currently used in the assessment of patient needs.

Together the different approaches used to explore validity allowed for the different characteristics of the SNAP Tool to be explored. However this approach also highlighted tensions between the qualitative data (which demonstrated content validity) and the quantitative data (which showed low correlations between the SNAP tool and standard measures of the impact of COPD), suggesting that the content of the tool did not reflect standard clinical ways of measuring disease impact. However the exploration of this tension highlighted the validity of the SNAP Tool as a tool designed to support patients identify and express their view on their support needs rather than endorse the medical perspective of need.

The SNAP Tool was not subject to traditional validity or reliability testing because the tool was not developed to define, or measure, any internal psychometric construct. Rather the tool consists of a set of questions intended to help patients identify and express individual unmet support needs within a range of broad, evidence-based domains of support need relevant to their situation. The domains taken together are comprehensive in terms of the range of areas they address, yet they remain ‘standalone’ individual broad areas of support need rather contributing to an overarching construct of support need. Assessing reliability or construct validity is therefore neither feasible nor warranted. However, the lack of applicability of psychometric testing to the SNAP Tool also highlights the lack of alternative approaches that are currently available to test the suitability of non-psychometric tools. The approach outlined here builds on the work started by Ewing and Grande (2013) to address this issue.
Similarly the validation was not directly informed by the more recent, and influential, body of work known as the Cosmin taxonomy of measurement properties.\textsuperscript{219} Identified via international consensus the taxonomy outlines those properties considered necessary for the evaluation of all measurement tools used in any health related application. In line with the arguments made above in relation to psychometric theory many of the properties identified in the taxonomy are not directly relevant to the evaluation of the SNAP tool in line with the focus on the evaluation of measurement tools. However the inclusion of content, face and criterion validity within this internationally endorsed piece of work lends an important legitimacy to the decision to demonstrate these properties within SNAP.

A key strength of this study is the central role of patients. Patients with advanced COPD were involved in each stage of the study, and recruitment via primary care was undertaken to ensure representation of all patients with advanced COPD (rather than just those referred to specialist or secondary care). PPI members also contributed to study recruitment processes and reviewed the study findings. Whilst it is standard practice to include patients in the assessment of face and criterion validity\textsuperscript{199}, Osse et al (2000)\textsuperscript{1} and Richardson et al (2007)\textsuperscript{2} both noted that not all studies involve patients in validation of tool content. Osse et al argue that failure to use patient data in this respect can result in tools that give precedence to needs that are seen as important from a professional, rather than patient, perspective. Luyt (2011)\textsuperscript{220} has also argued that when patients are involved within psychometric testing, their data is primarily used to confirm, rather than inform, the validity of the theoretical construct. In contrast the mixed methods framework adopted enabled equal value to be given to the patient data. The use of qualitative patient and carer data from focus groups, combined with quantitative patient data from completed SNAP Tools within the postal survey, therefore ensures that each question on the tool has been identified as relevant by patients with advanced COPD.

A potential limitation of this study was that data came only from patients from the East of England. However, the 30 GP practices involved in the study were spread across the region serving a diverse population in terms of low, moderate and high deprivation across both rural and urban areas. In addition, the age and sex of the study population reflects known national patterns for patients with COPD.\textsuperscript{221}
A further potential limitation may be that only two focus groups were undertaken in the assessment of face and initial content validity, involving 12 patients and carers in total. However, this reflects the peer-reviewed recruitment targets in the protocol, that were in turn established in response to known difficulties of recruiting patients with advanced disease. Furthermore, the findings suggest that the number of focus groups was sufficient and the recruitment of further participants would have been unwarranted, and thus unethical.

In conclusion, this study establishes the SNAP Tool as valid for identifying the broad areas of unmet support needs of patients with advanced COPD. As the SNAP Tool is not a psychometric tool further psychometric testing is not appropriate.

As a validated tool the SNAP Tool has clear usefulness as a research tool in studies examining patients’ experience of living with COPD. However, crucially, it is also potentially useful in clinical practice to identify and enable person-centred discussion of patients’ unmet support needs. This validation study has shown the tool’s suitability and acceptability to patients with its relevant content and simple and attractive format. It could therefore provide HCPs with a way of engaging with patients, enabling patients themselves to identify and discuss their unmet support needs, thus ensuring more tailored support to self-manage their condition.

Finally, this work drew attention to current lack of alternatives to psychometric theory or methods for the testing of non-psychometric tools and highlights the need for further work in this area.
Chapter 7: Understanding how the Support Needs Approach for Patients (SNAP) enables identification, expression, and discussion of patient support needs: a qualitative study (methods)

7.1 Introduction

This chapter describes the methods for a qualitative study exploring how SNAP enables identification, expression, and discussion of patient support needs. This piece of work sits within the Marie Curie SNAP pilot study (which as detailed in Chapter 1 section 1.8 aimed to examine the feasibility of SNAP within clinical practice) but forms an additional piece of analysis that is my unique contribution as part of this thesis. The chapter below outlines the background to this additional analysis, together with the recruitment processes, data collection and data analysis within the pilot that supported this particular piece of work.

7.2 Background

In Chapters 3 and 4 it was argued that a key focus of intervention evaluation should be to consider in more detail whether, and how, interventions such as SNAP facilitate patient-led expression and identification of support need. In particular, attention was drawn to the socially constructed nature of need, and the role of social factors (e.g. patient-HCP power dynamics) in influencing the way patient need is identified and managed within a clinical context. It was also highlighted that existing research in this area has lacked a critical, in depth analysis of these social relationships.

More broadly, however, there has been a strong tradition of analysing patient-HCP communication specifically through the application of biomedical, psychological, psychoanalytical and sociological theories (Greenhalgh 2007). Sociological theories, in particular, have supported qualitative investigations of communication and power relations between patients and HCPs. For example work by Scambler (2013), Barry et al (2001) and Greenhalgh et al (2006) has drawn on Habermas’ Theory of Communicative Action.
to understand and explore the distinction between the patient’s perspective of their needs and concerns (their lifeworld) and the medical system represented by the HCPs.

The methods outlined below draw on this tradition. Greenhalgh (2007)\(^{222}\) and Sandelowski (1993)\(^{223}\) have both argued that theory can be usefully applied in qualitative research within a healthcare context. Sandelowski (1993) has further outlined how the use of theory enables a researcher to draw on:

> ‘The disciplinary paradigms in the arts, sciences, and humanities that direct or inform both the enquiry process, including the presentation of findings, and the abstract schemas (including what is commonly referred to as concepts, conceptual models, and frameworks) describing, organizing, and interpreting the target phenomena that constitute the subjects/objects of individual research projects in substantive area’ [Sandelowski 1993, p. 214].\(^{223}\)

As there was already an argument for, and focus on, exploring patient-HCP dynamics within SNAP it was anticipated that existing theory in this area could provide a useful way of conceptualising and understanding the nature of these relationships. However, the choice of a specific theory to inform this process was not straightforward. In the early stages of the pilot, it was anticipated that Normalisation Process Theory (NPT),\(^ {224}\) which was identified as useful for considering intervention feasibility in line with the original aims of the SNAP pilot, could also support a more in-depth understanding of participant experiences within SNAP. However, the patient data did not fit easily within the core theoretical concepts of NPT. Consideration was also given to Cognitive Authority Theory\(^ {225}\) which conceptualises how individuals negotiate expectations in a context in which there are inequalities in power and expertise. Although Hunt and May (2017)\(^ {225}\) have described how this theory has been successfully applied to exploring power relations between HCPs and patients in relation to self-management tasks, again it did not seem to provide a useful way of making sense of the data within the SNAP pilot. However, in contrast, clear parallels began to emerge with the work of Barry (2001)\(^ {184}\) and Greenhalgh (2006)\(^ {185}\) who, as noted above, have each drawn on Habermas’ Theory of Communicative Action\(^ {186}\) to identify the tensions within patient-HCP interactions, and the social and communicative processes that underpin these dynamics. An
initial application of this approach to patient data from the SNAP pilot suggested that Habermas’ theoretical concepts could also potentially help with understanding and conceptualising patient-HCP interactions taking place within SNAP.

Habermas’ Theory of Communicative Action

The work described in the following chapter is therefore informed by Habermas’ Theory of Communicative Action.\(^{185-187}\) Habermas’ work does not directly address the use of interventions within the patient consultation relationship, but instead seeks to consider society more broadly from a dialectical perspective. More generally, he argues that there are two different types of rationality leading to a split within society between the ‘lifeworld’ and the ‘system’. The lifeworld represents community, family and social interaction and is supported by patterns of communication that enable understanding (e.g. consensus building and understanding of another’s perspective). In contrast, ‘the system’ can be understood in relation to scientific, organisational and economic factors in which communication can be considered as strategic and orientated to success. Habermas also argued that the ‘system’ can intrude into the ‘lifeworld’ in inappropriate ways, resulting in a form of ‘colonisation’. These concepts are further outlined in Box 16.
Box 16: Key concepts within Habermas’ Theory of Communicative Action

<table>
<thead>
<tr>
<th>Communicative Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>This form of communication is orientated to understanding another person’s perspective via communication. This typically involves seeking out another’s view and is orientated to agreement.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purposive/strategic communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>This form of communication is orientated to producing an effect on another or particular outcome. It can take a number of forms. Open strategic action occurs when a speaker openly seeks to influence another person. Concealed strategic action involves the speaker creating confusion between actions orientated to understanding and actions orientated to success. This can be either conscious or unconscious. Communicative action is typically achieved via money or power.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifeworld</th>
</tr>
</thead>
<tbody>
<tr>
<td>This represents the social world in which individuals interact, organise themselves and make decisions with family, friends and the wider community. It is characterised by communicative action.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>System</th>
</tr>
</thead>
<tbody>
<tr>
<td>This comprises the economy, state, and other administrative structures that are characterised by strategic action.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Colonisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colonisation occurs when the system uses its resources (e.g. power) to intrude in inappropriate ways into the lifeworld.</td>
</tr>
</tbody>
</table>

Scambler (2013)\textsuperscript{187} and Mishler (1984)\textsuperscript{226} have both argued that key concepts from Habermas’ theory can be applied in the context of healthcare, and in particular in relation to patient-clinician interactions. Mishler (1984) has argued that the system can be understood as the medical world in which strategic action is used to maintain dominance over patients and achieve medically orientated outcomes. In contrast, the ‘lifeworld’ represents the patient’s voice within the consultation and is supported by a search for mutual
understanding and shared responses. Mishler has also suggested that, in reality, patient-HCP consultations involve elements of each of these constructs, but draws attention to ways in which the dominance of the medical system can result in patients’ accounts of their health and health needs being suppressed. Scambler has also highlighted the role of interpersonal and macro processes in exacerbating these tensions.

The section below therefore outlines the methods for a qualitative study, that draws on the work of Habermas, in order to facilitate understanding of how the Support Needs Approach for Patients (SNAP) enables identification, expression, and discussion of patient support needs.

7.3 Aim

The aim of the additional analysis described here was to consider whether, and how, SNAP support patients to identify, express and address their support needs.

7.4 Methods

A qualitative approach was taken, addressing two research questions:

1. How do patients and HCPs engage with SNAP to identify and manage their unmet support needs?
2. What factors enable, or hinder, patient-led identification and expression of support needs through delivery of SNAP?

7.4.1 Methodology

Again as noted in Chapter 1, the pragmatic-paradigm informed framework of this thesis enables the choice of methods to be informed by the research question. Qualitative methodology and qualitative methods are widely acknowledged as being the most suitable way of exploring and interrogating participant experiences, perceptions and interactions. As such the approach outlined below was informed by a qualitative methodology.
7.4.2 Ethics

Ethical approval for the SNAP pilot, including additional work that supported the data analysis for this thesis, was obtained from the North West-Preston Research Ethics Committee (REC reference 18/NW/0234). Letters of Access were issued by the relevant trusts and clinical settings. The University of East Anglia was the study sponsor.

7.4.3 Research governance

The research governance process is outlined in the Stage 1 Validation study (Chapter 6, Section 6.4.3).

7.4.4 Research management and support

The research management and support process are outlined in the Stage 1 Validation study (Chapter 6, Section 6.4.4). SNAP Tool licences were issued to participating clinical sites.

7.4.5 Pilot site recruitment and training

Site recruitment

Site recruitment was undertaken via research engagement events (Academic Respiratory Conference and Study-specific Research Roadshow – both of which involved contact with at least some of the HCPs who would be delivering the intervention) and liaison with a clinician in a leadership role who had previously shown an interest in SNAP (which therefore did not directly involve the HCPs who would be delivering SNAP). In response, sites representing three key care settings (primary, community and secondary), based in the East of England, were recruited to participate in the SNAP pilot. Participating sites included one GP practice, two community specialist respiratory teams and one secondary care respiratory team. One of the community specialist teams did not go on to deliver SNAP in practice and therefore is not included in this analysis.
**HCP recruitment**

In the remaining sites, HCPs and support staff linked to the care of patients with COPD were sent a study recruitment pack (directly or via the team lead). This included a letter of invitation, a participant information sheet and details for replying to the research team (reply slip and pre-paid envelope, email and contact telephone number). HCPs who responded positively were contacted by the research team, given the opportunity to ask further questions and provided with details about the first activity (the pre-pilot workshop) in terms of its timing and location.

**HCP training workshops**

Five setting-specific pre-pilot workshops took place within the teams’ administrative bases and involved 20 participants: 15 HCPs, two nursing students, and three support/administrative staff.

Immediately prior to the commencement of the workshop, participants were provided with an additional copy of the Participant Information Sheet and given the option to ask any further questions. Each participant was then asked to complete and sign a consent form (see Appendix 4) asking them to agree to participation in the workshop, together with further participation in the mid-pilot interviews and end-of-pilot focus groups (detailed below).

During the consent process, participants were required to indicate if they agreed to six points (including consent to being audiotaped and their right to withdraw without giving a reason) by initialling each of the points and providing a signature at the end of the form, witnessed by one of the research team. Each participant was given a carbon copy of the signed consent form to keep for their own records.

Once they had completed the consent form, participants were asked to complete a brief questionnaire covering their demographic and professional backgrounds.
Each participant was allocated a participant ID number to enable anonymity and facilitate research team identification of data origin. These were applied to the original consent forms and demographic questionnaires, which were subsequently stored separately in two locked filing cabinets, in swipe card protected premises at the University of Cambridge in order to ensure separation of personal details and research data in line with ethical approvals.

At the start of the workshop the participants were formally welcomed, and introductions made. The participants were made aware that their contributions would be treated as confidential and were solely to be used for the purposes of the research study. They were also given assurances that any of their views that were subsequently reported by the study team, either orally or written, would be anonymised.

The workshops were dual purpose:

1) they delivered SNAP training
2) they were data-generating (regarding the participants’ understanding of person-centred care and existing approaches to identifying and responding to patient support needs).

Each workshop was co-facilitated by me and MF, lasted approximately two hours, and was audio-recorded (with permission). The data collection was informed by a topic guide developed by myself, MF and GE (see Appendix 5). The training component covered the principles of person-centred care, why and how SNAP was developed, SNAP’s five stages and how SNAP could be implemented in the given clinical setting. Training certificates were given to participants at the end.

7.4.6 Four-month pilot implementation

The occurrence of the four-month pilot implementation period varied by setting (between July 2018 and January 2019) and involved thirteen of the 15 SNAP-trained HCPs who had participated in the pre-pilot workshops.
Patient recruitment

To facilitate delivery, patient inclusion/exclusion criteria were suitably pragmatic: the target population was adults diagnosed with COPD and only those unable to provide informed consent were excluded. As SNAP is designed with flexibility to fit with existing practice, SNAP-trained HCPs could determine three delivery factors for their respective settings:

1) the service delivery context(s),
2) targeted patient sub-groups (within the pilot’s inclusion criterion), and
3) patient approach method (SNAP Stage 1).

Box 17 shows the outcomes of these determinations.

<table>
<thead>
<tr>
<th>Participating site</th>
<th>Delivery context</th>
<th>Target patient group</th>
<th>Patient approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care:</td>
<td>Delivered within usual care i.e. COPD annual reviews</td>
<td>Patients due for COPD annual review delivered by the practice’s specialist respiratory nurse</td>
<td>Recruitment packs (including the SNAP Tool) were sent out with usual postal invitation to attend for COPD annual review</td>
</tr>
<tr>
<td>Community:</td>
<td>Deliveried within usual care i.e. home visits</td>
<td>Patients with COPD due to receive a home visit from a member of the community specialist respiratory team</td>
<td>Recruitment packs (including the SNAP Tool) were given to patients by HCP during a home visit</td>
</tr>
<tr>
<td>Specialist Respiratory Team 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary Care:</td>
<td>Delivered in pilot-specific consultation with specialist respiratory nurse or within usual care (i.e. secondary care outpatient appointment)</td>
<td>Patients with COPD due to attend an outpatients’ appointment with specialist respiratory nurses</td>
<td>Patients were first phoned by a research nurse to ascertain whether the patient was willing to consider taking part – those agreeing were then sent a recruitment pack (including the SNAP Tool) by post</td>
</tr>
<tr>
<td>Respiratory Department</td>
<td>Delivered within usual care</td>
<td>In-patients with COPD identified for discharge via the Early Supported Discharge Service (ESDS)</td>
<td>Patients were given a recruitment pack (including the SNAP Tool) by an ESDS HCP prior to discharge</td>
</tr>
</tbody>
</table>

Box 17: Site-determined pilot delivery factors for their specific settings
The pilot sample size was similarly pragmatic: as SNAP was first delivered in clinical practice the learning gained could then inform any required future formal SNAP sample size calculation. Patient recruitment was undertaken by the HCPs who were provided with patient recruitment packs for distribution ahead of pre-planned consultations. Individual patients within the target patient groups identified by the SNAP-trained HCPs were invited to participate in the SNAP pilot. The recruitment packs included a letter of invitation (printed on each clinical team’s headed paper), participant information sheet, consent form (for patient self-consenting), and the SNAP Tool (for self-completion by the patient as part of the intervention). An envelope was provided in which the patient could store the completed consent form and SNAP Tool in order to facilitate ease of return directly to the HCP at their consultation. The consent form asked the patient to agree to up to eight points (including understanding that participation was voluntary and that their name and address would be shared with the research team) by initialling each point, signing and dating the form. The latter was checked and signed by the HCP who received the consent form from the patient. The invitation letter represented Stage 1 of the five-stage SNAP intervention: it introduced the tool (as the ‘How are you?’ booklet) explained its purpose and how it would be used in the follow-on appointment.

The exact method of patient recruitment pack distribution varied by setting, as outlined above in Box 17 enabling the HCPs to integrate recruitment into their current practices in a manner that was compatible with their clinical context, and likely to be comparable with future distribution of the SNAP Tool outside of a research study. Across the clinical settings, there were differences in ease of integration. Both primary and secondary care found it straightforward to incorporate the SNAP recruitment packs within their existing appointment-making processes, as they already sent materials by post ahead of these appointments. Within the community teams this proved to be more complex. Initially the team chose to give patients the recruitment pack by hand at the start of the SNAP conversation, however the appointment structure did not allow time for the patient to consider and complete the SNAP Tool prior to delivery of stages 3-5 of the intervention. This approach was subsequently amended, and recruitment packs were left with the patients at the end of one appointment and, where appropriate, SNAP stages 3-5 delivered at a subsequent appointment. In addition, challenges arose in response to delivering the
recruitment packs face-to-face, specifically in relation to how to introduce SNAP and the SNAP Tool, despite this being covered in the SNAP training. A conversational prompt was therefore provided to the HCPs by the research team to facilitate this process.

Patients who agreed to participate in SNAP brought their completed consent form and self-completed SNAP Tool with them to the consultation, or (if forgotten) completed them within the consultation (representing Stage 2 of SNAP). HCPs held spare copies of both documents in case patients forgot to bring them. The remaining stages of the intervention (stages 3-5) were then delivered by the HCPs to 56/58 consenting patients. Intervention non-delivery to two patients (who had consented) was due to a patient death and a time constraint. Box 18 presents patient response rates.

Patient data collected within the intervention (i.e. the completed SNAP Tools) were securely stored in the clinical settings in line with normal clinical practice.

### Box 18: Patient recruitment to SNAP by site

<table>
<thead>
<tr>
<th>Activity</th>
<th>Primary</th>
<th>Community</th>
<th>Secondary</th>
<th>Total</th>
<th>Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot start</td>
<td>Mid July 2018</td>
<td>1st September 2018</td>
<td>1st October 2018</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Pilot end</td>
<td>Mid December 2018*</td>
<td>31st December 2018</td>
<td>31st January 2019</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of packs distributed to sites</td>
<td>67</td>
<td>100</td>
<td>60</td>
<td>227</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of packs given to patients</td>
<td>67</td>
<td>64</td>
<td>41</td>
<td>172</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of patients consenting to receive SNAP</td>
<td>13</td>
<td>20</td>
<td>25</td>
<td>58</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of patients who received SNAP</td>
<td>13</td>
<td>20</td>
<td>23</td>
<td>56</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of mid pilot HCP interviews</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>8</td>
<td>n/a</td>
</tr>
<tr>
<td>No. of patients interviewed</td>
<td>9</td>
<td>5</td>
<td>6</td>
<td>20</td>
<td>18-24</td>
</tr>
</tbody>
</table>

*Five months due to one-month annual leave by HCP
7.4.7 Healthcare professional interviews and pilot-end focus groups

Mid-pilot interviews

Up to two HCPs who were delivering SNAP from each site were contacted to participate in a mid-pilot topic-guided individual or group interview, conducted either in-person or by telephone (Appendix 6 provides the topic guide). The aim of the interviews was to monitor and discuss SNAP use and identify (and address) any barriers to the SNAP pilot recruitment and SNAP delivery. HCPs were also asked to provide examples of using SNAP with patients. The topic guide was informed by Normalisation Process Theory (NPT), a theory of social action addressing the gap between research and adoption into clinical practice, providing a structure to investigate implementation processes in order to support the original aims of the pilot but also included broader questions to support the additional analysis. Questions asking patients to reflect on their more general experiences of taking part in SNAP were also incorporated into the interview schedule.

Semi-structured interviews were used, as they have been recognised in the literature as a means of enabling participants to reflect in-depth on their perceptions and behaviours in response to a particular situation. The conversational format enables participants to open up about their experiences. However the use of an interview guide ensures all participants are prompted to consider particular aspects of the topic under discussion. This approach has been widely used to investigate patients’ and HCPs’ perceptions of participating in clinical interventions and to explore the nature of patient-clinician consultations. In each case this style of interview has been shown to be useful, not just as a means of obtaining accounts of what happened, but also in supporting reflection on events surrounding the phenomena of interest, although the quality of data can be compromised by the participants’ ability to recall events and to make sense of what has occurred. In addition, this approach was seen as preferable to alternative forms of qualitative interviews such as surveys with their limited focus or the much broader unstructured explorations within a narrative approach, which may not necessarily remain focused on intervention use.

The initial aim was to interview at least one HCP per month, from each site (therefore four interviews per site). However, this was not always possible due to the busy clinical settings.
and so three interviews were conducted per site, across the four month pilot period. The interviews were brief, but focused, ranging from 5 to 30 minutes. Face-to-face interviews took place at the interviewees’ place of work, in line with HCP preferences and ethical and governance approvals. As a result, the context for the interviews varied between the settings. Within primary care the interviews were conducted in a quiet, private office for a protected period of 20 minutes. In one of the community teams, they took place in an open plan office at a relatively quiet time and at the secondary care site they took place within a busy open plan office. In the latter two cases, there was a need for flexibility (when the conversation was interrupted by a phone call or colleague) and an awareness of issues of confidentiality e.g. the interview was halted when someone in the office was involved in a phone call or when someone who was not a participant in the SNAP pilot entered the room.

**End of study focus groups**

All HCPs who consented to participate in the pilot were also invited to participate in end of study focus groups. As in the SNAP Tool Validation Study (Chapter 6) the use of focus groups was identified as a useful way to generate ideas and discussion around the topic and provide a forum in which participants may find it is easier to be critical of the issue under consideration (again something identified as important given that the HCPs were being asked to discuss SNAP with the developers). In the context of a busy clinical service, they also provide a pragmatic way of collecting data that is not too disruptive for the service. However, as with qualitative interviews, the quality of data collected can be limited by a number of factors. In focus groups these include an unwillingness to discuss personal reflections in a group and difficulties in differentiating individual experiences in the data analysis. However, it was anticipated that this would be complemented by data from mid-pilot interviews in which HCPs had the opportunity to reflect in more detail on individual cases.

As with the HCP workshops, the focus groups took place at the site where the HCPs were based and lunch was provided. The focus groups were shorter, however, lasting no more than one hour to facilitate clinician engagement and reflected their focused content. As part of the consenting process in the pre-pilot workshops, all participating HCPs had given
consent for the end-of-study focus groups. However, due to the time lapse between the workshops and the end-of-study focus groups, further verbal consent was taken immediately prior to commencement of the focus groups. As part of this process the participants were provided with the opportunity to re-read the Participant Information Sheet and given the option to ask any further questions.

A topic guide was developed by the research team which, as above, was informed by Normalisation Process Theory to support the original aims of the pilot and broader questions to support the additional analysis. The topic guide covered their experiences of the SNAP training, preparation for delivering SNAP within their clinical setting, and using SNAP in their clinical practice (see Appendix 7).

### 7.4.8 Patient interviews

*Recruitment*

All 56 patients who had received the SNAP intervention during the four-month pilot implementation period were invited to take part in an interview about their experiences of SNAP. With the patients’ written consent, each clinical setting provided the research team with eligible patients’ names and addresses, copies of their consent forms and patient-completed SNAP Tools. This was either collected by a member of the SNAP research team (me) directly from the sites or delivered to me by hand from a member of the site team. Each site was asked to make the relevant documentation available within two weeks of the SNAP intervention being delivered, although in practice this ranged between 1-8 weeks.

All participant details (names, ages, addresses) were securely stored in a locked cabinet in swipe-card protected premises at the University of Cambridge. The completed SNAP Tools were securely stored in a second locked cabinet in the same location to ensure separation between data and patient details.

All patients who had received the SNAP intervention were sent a second recruitment pack comprising a letter of invitation, participant information sheet and details for replying to the research team (reply slip and pre-paid envelope, email and contact telephone number).
Those who responded positively were then telephoned to answer any questions and, if happy to proceed, arrangements were made for the interview to take place at their chosen location. Twenty patients agreed to take part. Their demographic profile highlighted that they comprised 10 men and 10 women whose ages ranged 53-87 years (this is within the typical demographic profile of people with COPD). HCPs reported that patients were from across the range of COPD stages and had a number of co-morbidities. Purposive sampling was applied to ensure that patient participants were recruited from across the three sites.

Location

The participants were given the option of being interviewed either at home or in an alternative setting convenient for them. All but one interview was held in the participant’s home. The interview that was not conducted in a home setting was undertaken in a café at the request of the participant.

Consent

Prior to the interview start, participants were provided with an additional copy of the Participant Information Sheet and asked if they had any further questions. Attention was also drawn to the confidential nature of the interview and each participant was made aware that any of their views that were subsequently reported by the study team, either orally or written, would be anonymised. The participants were then asked to complete a consent form (see Appendix 8), which asked them to indicate agreement to seven points (including consent to be audio-taped and understanding that they could withdraw, at any point, without providing a reason). Each participant was given a carbon copy of their signed consent form for their personal records. Once the consent process had been completed participants were asked if they were happy for the digital recorder to be switched on and for the interview to start. At this point they were also reminded that they had the option to refuse to answer a question and that they could terminate the interview at any point without providing a reason.
Semi-structured interviews

Open semi-structured interviews were conducted with each of the participants. As above this was identified as an appropriate method for collecting patient data. Similarly, the topic guide (see Appendix 9) was developed by the study team and covered the participant’s experience of living with COPD, their usual care, their impressions of the SNAP Tool (e.g. ease of use and relevance to people with COPD), their rationale for identifying areas of support need on the SNAP Tool and their experience of participating in SNAP within their appointment. The participants were also asked whether there was anything they wished to discuss in relation to SNAP that had not been covered in the interviews and about the experience of participating in the research study.

Participating Patient Support

Discussion of an existing life-limiting condition, combined with the potentially sensitive nature of topics covered within the SNAP Tool’s domains, had the potential to uncover pre-existing or new concerns about the impact of COPD and symptom management. In acknowledgement of this the Patient Information Sheet provided details of an experienced respiratory nurse (SH) who had agreed to act as a point of contact for patients who wished to discuss any issues that arose from the interview process. In addition, time was taken after each interview to assess the impact of taking part and remind participants of the option to contact SH. This offer was not taken up by any of the participating patients.

Lone working protocol

A lone working protocol was developed and employed during fieldwork collection involving a buddy system and mobile phone contact.

Timeline

The interviews were carried out between August 2018 and February 2019.
7.4.9 Data processing and analysis

Data processing

All patient and HCP interviews/focus groups were audio-recorded (with permission), transcribed by a professional transcription service, checked for accuracy and anonymised. Patients were ascribed an alternative name for reference purposes within the analysis. The audio files and transcripts were stored in locked filing cabinets in a university office with swipe-card access or on password protected computers backed up on university servers.

Data analysis

A deductive approach to data analysis\textsuperscript{231} was adopted supported by the Framework Method.\textsuperscript{232,233} Use of a Framework Model has been identified by Gale et al (2013\textsuperscript{233}) as providing a useful way of conducting the deductive analysis of qualitative data together with facilitating:
1) a structured, transparent approach to data management
2) ease of comparison between participants.\textsuperscript{233}

In line with the recommended stages of the Framework Method this involved the following:

1) The development of an initial coding framework based on the key theoretical concepts identified by Habermas (1984)\textsuperscript{186} and Mishler (1984).\textsuperscript{226} Additional codes were also created for contextual data.

2) Initial reading and re-reading of the transcripts to identify key issues emerging from the data which were further discussed with the study management team. The original framework was adjusted as new areas of interest were identified based on the application of Habermas’ and Mishler’s concepts in the context of SNAP – and a new working framework was created. Separate framework matrices were created for HCPs and patients. In each matrix, rows were assigned to each of the participants and columns to the different codes within the working framework. Data from patients and HCPs was used across the data. A separate row was created in each framework for data that couldn't be attributed to a particular participant (e.g. from the focus group data).
3) Data from the transcripts was summarised and transferred onto the appropriate cells in the matrices (charting). The summarised data was linked to relevant quotes within the transcripts.

4) Notes and memos were written throughout the process to support conceptualisation of emerging ideas. This activity focused on 1) comparing and contrasting the cases in order to form groups of cases and 2) the use of a grid format to consider how these differing groups interacted.

5) Emergent findings were discussed and refined with the thesis supervisors and PPI group.

7.4.10 Contribution to recruitment, data collection and analysis.

During the pilot site recruitment and training process, I was involved in preparing materials, co-ordinating all aspects of the HCP recruitment, facilitating the set-up of the workshops, consenting participants, acting as a co-facilitator in the workshops and carrying out appropriate data management. Within the pilot implementation stage, I co-ordinated distribution of the recruitment packs, carried out all the mid-pilot interviews and was responsible for data management and data analysis. In addition, I was fully responsible for organising the patient interviews including: production of materials; liaison with the clinical sites to facilitate collection of paperwork relating to patients who had participated in SNAP; sending out patient recruitment packs; acting as a liaison point with patients in order to answer questions and organise interviews; conducting all the patient interviews; data management and storage, and taking the lead on data analysis.

7.4.11 PPI Involvement

As in the validation study PPI members: 1) provided input into reviewing participant recruitment documents for appropriateness and clarity prior to submitting an application for ethics approval and 2) reviewed the findings from the data analysis. In the first stage members primarily considered the wording and layout of the documents. Key feedback from this process was that instead of one generic Patient Information Sheet (PIS) there should be different versions orientated towards each of the three settings in the study. This, it was felt, would better orientate and engage potential participants. This suggestion was
adopted in the final versions of the PIS. In the second stage of their involvement the PPI members were asked to review and comment on the themes emerging from the analysis. The PPI members were provided with portions of the data and asked to discuss whether or not they felt they supported the emerging themes or brought different insights. Overall the PPI members felt that the data supported the initial analysis.

7.5 Summary

In this chapter I have outlined the methods for a qualitative study exploring how SNAP enables identification, expression, and discussion of patient support needs, highlighting in particular the choice to use Habermas’ Theory of Communicative Action to inform the analysis. The next chapter (Chapter 8) presents the results of this analysis.
Chapter 8: Understanding how the Support Needs Approach for Patients (SNAP) enables identification, expression, and discussion of patient support needs: a qualitative study (results)

8.1 Overview

Chapter 8 describes the results of the qualitative investigation (outlined in Chapter 7) into whether and how the experience of participating in SNAP enabled patients to identify, express and address their support needs with HCPs within clinical practice. Participant experiences were considered in the context of Habermas’ Theory of Communicative Action. This, as noted in the previous chapter, provides a framework for conceptualising, and comparing, patient and HCP expressions of need, and the communication and behaviours associated with these differing expressions of need. More specifically this is achieved via the concepts of lifeworld (which can be understood as representing a patient-led approach) or system-world (an HCP-led approach).

8.2 Participants

The sample included 20 patients (10 men and 10 women) who were aged from 53 to 87 years, with a mean age of 71 years. Patients were recruited from across each of the participating clinical settings (primary=9; community=5; secondary=6) and all had received SNAP.

Thirteen HCPs were involved in delivering the intervention, of which five took part in the mid-pilot interviews and 11 took part in the end of pilot focus groups. This included 11 respiratory nurses, 2 nursing assistants and 1 community physiotherapist.
8.3 Findings from the data analysis

The findings revealed a picture of complex social actions, influences and outcomes. These have been organised around three major themes: 1) HCP approaches to intervention delivery of SNAP, 2) patient engagement with SNAP, and 3) patient-HCP interactions within SNAP.

- The first theme identified two distinct approaches to delivering SNAP by HCPs that can be aligned to Habermas’ ‘systems’ and ‘lifeworld’ respectively.
- The second theme can be understood as a continuum of patient engagement in SNAP, from an active lifeworld-orientated engagement to a passive response aligned to the medical system.
- The third theme explores the different types of patient-HCP interactions and outcomes that occur between patients and HCPs as a result of those different approaches to intervention delivery and range of patient engagement with SNAP.

In the first theme participating HCPs integrated elements of the differing approaches in their work with SNAP but each clearly emphasised either a lifeworld or systems way of working. Each of these responses were evenly distributed across the participating HCPs. In the second theme the participants were also fairly evenly distributed between the three key points on the continuum (active engagement, limited engagement and passive). Approximately 6-7 patients were clustered around each point, with 1-2 of the patients in each cluster also sharing characteristics with those attributed to a different category. The third theme can also be understood as a continuum from patient-led to hcp-led care in which interactions within the middle of the continuum contained elements of both approaches. As above these interaction types were evenly distributed across the continuum.

8.3.1 Theme 1. HCP approaches to intervention delivery

The analysis suggested that HCPs employed different approaches to integrating SNAP into their clinical practice. This was characterised by how far they valued and enabled an approach to identifying and responding to patient support needs. Specifically this was demonstrated either by an approach that focused on understanding and facilitating the patient’s view of their support needs (Habermas’ lifeworld) or an approach in which a
greater emphasis was placed on supporting an existing HCP-led bio-psycho-social approach (Habermas’ systems). Differences were also identified in how far the HCPs integrated their approach to SNAP with strategies characteristic of either communicative or strategic action. Whilst the results highlighted areas of overlap and tension between these competing spheres, two clear overarching approaches emerged: one in which HCPs emphasised and facilitated a lifeworld approach and one in which system-based priorities predominated. These approaches are presented below as two sub-themes: 1) lifeworld approach and 2) systems approach.

**Lifeworld approach**

HCPs whose intervention delivery was aligned to the lifeworld approach typically recognised that SNAP provided a framework designed to facilitate the identification, expression and discussion of patient support need in a way that was patient-led and contextually grounded within the patient’s everyday social world (*lifeworld-focused*). Furthermore, they identified the role SNAP could play in enhancing their lifeworld-focused practice. The primary care nurse, who was an enthusiastic adopter of SNAP, commented:

“*(when I first encountered SNAP) I could see the value it would add and the difference it would make to our appointments... because we were looking at what was important to the patient particularly around whether or not there were non-medical needs ... which we weren’t looking at or addressing, but I could see how it (SNAP) could help.*”  [HCP 11 Primary Care]

As such, lifeworld-focused HCPs were happy to work within the advised structure and content of SNAP and described themselves as delivering SNAP in line with the five stages of the intervention. They illustrated this with examples of ways in which they introduced the SNAP Tool to their patients, enabled patient rather than HCP consideration of need via
discussion of their completed SNAP Tools, and used the patient-identified support needs to structure the SNAP conversation:

“…. and then later in the SNAP conversation he did say ‘I’m worried about the future’ so it was quite a useful point to think about what his plans were, what he would like, what he wouldn’t like, what. …and then I think we are not, I suppose we’re not at Stage 5 yet. The shared response part of it is that he needs to work out (what would be helpful) and think about it a bit more. He’s on our ongoing caseload so it’s something that..that can then be brought up again and (we can) look at priorities for care and that sort of thing.” [HCP 21 Community Respiratory Team]

Many of the patients encountering these lifeworld-focused HCPs also provided coherent descriptions of ways in which the HCPs had involved them across the different stages of SNAP. For example, Bob, a patient in the primary care setting, provided a detailed account of how the HCP had fully integrated the intervention into his COPD annual review:

“I saw her (the practice nurse) ....and then she explained what would happen. And then it (the SNAP tool) came in the post......And I thought when I first opened it oh you know da da da but I didn’t I sat and read it and thought about it and those are the things I came up with (understanding your illness, dealing with feelings and worries and knowing what to expect in the future) ...(In the SNAP conversation) she (the practice nurse) opened it (the SNAP tool) and looked at it and said ‘what do you mean by this?’....She listened and we discussed it round...talking about it did help”
[Bob, Primary Care patient]

Participant accounts also described ways in which these lifeworld-focused HCPs worked to further support and enhance the lifeworld focus of SNAP. In particular, their narratives highlighted how the HCPs integrated delivery of SNAP with strategies and actions that attended to 1) emphasising the inter-personal context within which SNAP was delivered and 2) the adoption of a communication style aimed at understanding and consensus – strategies that in turn resonate with Habermas’ related concept of communicative action.
In the first instance many patients noted how the HCPs had sought to emphasise to them the interpersonal context of SNAP. In particular they commented on how these HCPs drew attention to the value and legitimacy of their role within SNAP through actively situating, and supporting, delivery of SNAP in a way that was meaningful for them as individuals. As in the quotes above, many recalled HCPs taking the time to explain how SNAP would be integrated into their particular relationship and care context. Barbara, a primary care patient, noted:

“she (the nurse) said would you be interested, and I said yes I would. Yeah so and then I think she sent me home with it, that was it. She sent me home with it, ‘fill it in your own time and come back next week with it and we’ll go through it’....” [Barbara, Primary Care patient].

Others highlighted the readiness with which these HCPs had supported them to overcome any particular difficulties they had experienced in taking part (e.g. lost copies of the SNAP Tool were replaced, appointments rescheduled if required and any uncertainty about the questions). A further example was provided by Susan, who was being supported by the community respiratory team and described one of the team members providing much needed help to complete the SNAP Tool:

“she (the HCP) went through the questions with me because I was, I had a chest infection at the time.., we went through it together and she kind of read the questions and then I read the questions and she said to me do you understand the questions and I said yeah..” [Susan, Community Respiratory Team patient]

An additional approach involved HCPs outlining to patients the legitimacy SNAP afforded to the patient’s particular view on their support needs. This was exemplified by the primary care nurse who described how she communicated to patients the value of considering and addressing their need for support outside the traditional medical focus:

“I have tried to explain the difference between this one (the SNAP Tool) and the COPD Assessment Test (CAT). The CAT test that we send out .. is very much (focused on) the
kind of medical type thing that we might be thinking about and this one (the SNAP tool) is more thinking about some of the things that you might be worried about that we may not have asked you about” [HCP 11 Primary Care]

Further importance was placed by these HCPs on reassuring patients that their identified needs would focus the subsequent patient-HCP conversation, for example one HCP described explaining to a patient: “you can look at what your priorities are...the idea being that I can then focus my visit a bit more” [HCP 21 Community Respiratory Team].

Secondly, In addition to highlighting the interpersonal context of SNAP, the narratives also described HCP use of a communication style, aligned with communicative action, that directly supported understanding and negotiation of patient support needs. Patients gave many examples of these HCPs using open questions, displaying empathy, responding positively to patient queries and providing patients with relevant information. In their accounts, these HCPs also described employing similar strategies, as well as additional techniques such as using verbal prompts or creating opportunities for patients to further their consideration and expression of their support needs:

“He (the patient) said ‘I’ve no idea why I ticked that, everything’s fine.’...and I said ‘Oh well, at the time you ticked it you were thinking that there’s something ‘..’Well I can’t think why that was’ and I said ‘Oh perhaps you can just spend a moment and think about it’.” [HCP 11 Primary Care].

Similar techniques were also detailed in relation to facilitating the shared response to need (Stage 4 of SNAP), for example the primary care nurse noted that she approached this by: “helping people to think of other things they could do...offering suggestions of things they (the patients) could try” [HCP 11 Primary Care].

Although the strategies above highlighted a commitment from these HCPs to putting the patient’s voice in the foreground with respect to their support needs, the HCPs also recognised that delivery of SNAP was set in a context in which they had wider system-based
responsibilities and constraints. In particular, tensions were identified between delivering SNAP and issues relating to time, the need to deliver standard medical care and risk.

Already working within time constraints, HCPs felt under pressure to limit the time available for SNAP but, equally, they recognised that this could potentially compromise patient engagement. One community nurse recalled: “I had the nightmare where he (the patient) - I told him how he should do it but literally he went through every single thing and I couldn’t – because it was the first time I’d met him, it felt wrong to go ‘right, stop now’” (HCP 22 Community Respiratory Team). The HCP wasn’t able to manage this situation but it did cause her to reflect on how to support future patients to identify their priorities for discussion.

HCPs also felt responsible for ensuring patients didn’t get overburdened within consultations, noting that, in situations in which they had to combine their usual medical assessments with SNAP, patients could get potentially ‘tired’ and ‘breathless’ if the session went on for too long. In these cases they described making a specific appointment in which to discuss SNAP. The primary care nurse also drew attention to the difficulties of negotiating the limited available time with discussing some of the more sensitive issues that SNAP could raise, for example, she noted:

“one person, who has been specifically worried about the future….., I didn’t want to open the Pandora’s Box, and then know that we hadn’t got time (to address the issue). Because generally speaking, by the time we get to the last three or four minutes, before the end of the appointment, that’s the point at which I’m definitely making sure we’ve moved to this (SNAP), and we’re asking people if they have any other concerns or worries, and I don’t want to open that one and then have, me having to shut it down, because I know that we need to close the appointment” [HCP 11 Primary Care]

Nonetheless, despite these tensions, these HCPs characterised themselves as applying an approach that was aligned to striving to maintain, rather than suppress, the lifeworld focus. Typically they described how they focused on maintaining a balance between SNAP and
their wider responsibilities, for example, by offering: “reassurance that we’ll talk about this (SNAP item) today, but the next time we’ll be able to talk about other stuff.... and actually if there’s reassurance that I’m coming back, so the next time think about something else, then that might also reduce the time” [HCP 21 Community Respiratory Team].

The primary care nurse also described how she used protected, but limited, time for SNAP, with the offer of an additional session if necessary:

“What I say to them when we open the booklet to have a look at it, we try and explain, would be towards the end of the appointment, which I do deliberately, is ...., as I’m opening it, I say, ‘We’re going to have a look and see the things you’re asking about, and then we’ll have a look and see if there are maybe one or maybe two of those things we can look at with today, but we may plan that you’ll come back so that we can look at them properly for another time’” [HCP 11 Primary Care].

However, there were also times when SNAP had to be blended with the use of strategic actions (in response to biomedical concerns), particularly in relation to managing risk or the impact of potentially distressing conversations. Expanding on the need to respond to any distress experienced by a patient as a result of identifying and discussing their support needs, the primary care nurse noted: “some of it has been handled at the time, to make some reassurances, but with a couple of them we have had to get them back” [HCP 11 Primary Care]. On one particular occasion she also recounted how SNAP enabled her to identify someone who was potentially suicidal. This therefore prompted her to adopt a more proactive approach to monitoring the patient and ensuring he was picked up by the appropriate support services.

In summary, these HCPs and their patients provided coherent and complementary accounts of these HCPs delivering SNAP as planned and interacting with SNAP in a way that was characterised by communicative action: through highlighting the interpersonal context within which SNAP was delivered and the adoption of a communication style orientated towards understanding and consensus. On the occasions in which HCPs needed to employ
strategic, rather than communicative, actions in relation to SNAP, they nevertheless approached this in a way that strove to minimise disruption to the lifeworld focus of SNAP.

*Systems Approach*

HCPs whose intervention delivery was aligned to the system approach were much more sceptical about what SNAP could add to their practice and the need for mechanisms to support lifeworld conversations about the patient support needs. Nevertheless they did describe delivering SNAP across the five stages, e.g. examples were provided in which patients were given the tool, encouraged to complete the tool prior to the appointment and their responses were discussed in a SNAP conversation. Some also outlined ways in which they had integrated SNAP with strategies compatible with communicative action. For example, one of the HCPs described her use of open questions to facilitate a conversation about a patient’s answers on the SNAP Tool:

"I think it was all ‘Explain to me why you have put what you’ve put. Why do you feel that’s more important than that?’ Why have you ticked quite a bit more there but not there?...yeah I kind of said how did you get on filling the form out and then I went through each and clarified, if you like, that they’d put that one, that one and then I tried to get them to pinpoint the most pertinent” [HCP 31 Secondary Care]

Despite this, these HCPs were less likely to perceive any additional value in further exploring the patients’ perceptions about their support needs. Typically, they stated that they ‘did this anyway’, emphasising how they integrated this approach into their usual practice with an HCP-led bio-psycho-social approach. One of the respiratory nurses in secondary care commented:

“We all work as clinicians slightly differently. We all have our own consultation skills, you know, and there’s nothing to say one’s better than another. But I think for a lot of our patients, when they come through, especially in clinic, we’ll see them maybe alongside (the doctor) in the first instance, and then we may have subsequent follow-ups, so we’re unpicking a lot of issues as we’re going along. So we might not do it all
in one sitting but we will certainly go through their disease, we’ll go through their symptoms, their medications, you know and we’ll discuss how they are feeling about it and we’ll put it stage by stage. I think this (SNAP) is all in one step whereas we might do to over two, three, four processes” [HCP 32 Secondary Care].

Furthermore, despite the accounts provided by the HCPs, the patients who encountered these HCPs rarely articulated HCP use of lifeworld actions and strategies (e.g. listening, using open questions, negotiating) or faithfully delivering SNAP. In particular, patients rarely mentioned HCP facilitation of a needs-led conversation or shared response, with some not able to recall taking part, whilst others briefly commented on how the HCP had “a look at a few bits” or “did go through a few things.”

Instead participants emphasised three clear ways in which the HCPs seemed to use strategic actions to limit the lifeworld focus of SNAP and maintain the existing HCP-led bio-psycho-social approach (systems approach). Here, strategic action took the form of:

1) de-personalising SNAP
2) limiting lifeworld conversations within SNAP
3) emphasising the professional context of need.

Each is explored below.

i) De-personalising SNAP

In the first instance many of the participants described how SNAP was introduced to them in a way that was de-personalised and decontextualized. HCPs described firstly how the process of introducing and engaging patients (Stage 1 of SNAP) was frequently undertaken by someone from outside of the clinical team and, as such, this process was by-passed by the HCPs who would actually be involved in delivering SNAP. One recounted:

“X (a research nurse) would ring them in the first instance and ask them if they would be willing to participate in the study. So she would give them a brief
synopsis of the ..what the study’s about and then put the paperwork in the post and they’d read about it and then if they came to clinic we knew they were willing to engage” [HCP 35 Secondary Care].

Patients’ descriptions suggest that limited attention was paid to ensuring patients understood the details of the SNAP Tool. Some like Audrey (below) found themselves having to navigate the larger institutional context in order to work out where, when and with whom discussion of the completed SNAP Tool would take place:

“...one of the nurses rang me up and said, would I mind taking part in the survey, study thing, I said, yes not at all and then that (the SNAP Tool) arrived in the post. I’d had two appointments up at the hospital and the first lot were like ‘no, no we don’t want that’. ‘Right ho Audrey, alright then’ and the second appointments I went to the first guy was like ‘no I don’t want that, you need to give that to someone else, give that to the consultant’. I saw the consultant, ‘no I don’t want that, give that to the nurse’ and eventually I saw the right nurse” [Audrey, Secondary Care patient]

Others described how SNAP was presented to them in a way that actively misrepresented the purpose and nature of the intervention. As in the case of Audrey, many recalled that the SNAP Tool was introduced to them as a ‘survey’ or ‘questionnaire’ rather than as part of an intervention. One or two patients also described being given the impression that their role was simply to complete the tool rather than participate in a clinical conversation. Roger, a patient in secondary care, noted: “(The nurse) just said, ‘Fill it in and then we’ll send it off. Do you mind filling it in?’ and I said ‘yeah I’ll fill it in’” [Roger, Secondary Care patient].

ii) Limiting lifeworld conversations within SNAP

Patients' descriptions of the SNAP conversation also highlighted ways in which these HCPs sometimes sought to limit the lifeworld focus of SNAP in this context.
As highlighted above, the patients who encountered these HCPs rarely noted taking part in a needs-led conversation or contributing to a shared response. Instead, descriptions were provided of ways HCPs appeared to focus on limiting the content and shape of the patient’s involvement, in particular, by the use of closed or rhetorical questions. This was again exemplified by Audrey who, on finally finding the right nurse, described how: “I handed it (the SNAP Tool) over to her and she opened it up and looked at it and went, ‘oh right, Audrey, so there’s not really much you want to talk about then?’ and I said ‘no, not really’” [Audrey, Secondary Care patient]

These HCPs themselves also provided similar scenarios without seeming to recognise that these descriptions were at odds with the intervention design. For example, one secondary care nurse outlined how she went through the SNAP Tool with a patient and asked the patient: “you understand your medicines, because we do that anyway, don’t we? But yeah And you’re okay at home. You don’t need any help?” [HCP 33 Secondary Care]. This was further reflected in the views of these HCPs which suggested they saw little need to prioritise SNAP, or the patients’ support needs as identified through SNAP, over their usual approach to identifying and responding to need and delivering care.

“Patients have come into the clinic sometimes with a set agenda of what they want to do and why they’re there, they’ve come in for hyperinflation or what have you, but they have come in for a specific reason and want specific answers...” [HCP 31 Secondary Care]

iii) Emphasising the professional context of need

In contrast to exploring and opening up conversations about their support needs, these patients described how these system-focused HCPs orientated the discussion to one in which need was primarily considered in relation to professional opinion. This was illustrated by Julie who described her interaction as one in which her
support need, and the response to that need, were discussed by the HCP entirely in the context of service provision and the HCP role:

“So I gave the (SNAP Tool) to (the respiratory nurse) and she took a copy of it and, you know, yeah, she was ever so helpful and nice because we were talking and she said ‘what are you claiming?’ and I said ‘PIP but I’d been reassessed again…’. She said ‘phone me’, she said ‘let me know and I will deal with things’…so it’s nice to know if I do get a letter I can phone her up” [Julie Secondary Care patient]

To summarise, these HCPs characterised themselves as using SNAP to give structure to the process of identifying and expressing patients support needs. Furthermore they also described enabling this process by employing actions associated with communicative action which, at first, suggests Habermas’ lifeworld. However, some patients provided alternative accounts in which the lifeworld and communicative action were rarely visible from these HCPs. Instead, their accounts suggested a greater emphasis among these HCPs of using strategic action, orientated towards limiting the use and application of SNAP in a lifeworld context, and instead focused on identifying and addressing need in a way that was more closely aligned with professional perceptions of need (the systems approach).

8.3.2 Theme 2. Patient engagement with SNAP

Differences were also identified in how patients described engaging with SNAP to consider and express their support needs. The results suggested these differences could be understood in relation to patient perceptions of the purpose and relevance of SNAP, and how they prepared for the SNAP conversation. Together patient accounts of these areas suggest that ‘engagement’ in this context can be understood as occurring along a continuum from active (recognising that SNAP was a mechanism to articulating support need in the context of their lifeworld) to passive (perceiving SNAP to be part of the system). Three key types of engagement along this continuum are discussed below: 1) active, 2) limited, and 3) passive.
Active engagement

On encountering SNAP, patients at the ‘active engagement’ end of the spectrum recognised the potential of the intervention to enable patients with COPD identify and express their support needs with HCPs (and thereby express their lifeworld perspective on these issues). Many highlighted an awareness of the barriers both they, and the wider COPD population, experienced in this area and recognised that the purpose of SNAP was to address these issues through giving visibility to the comprehensive range of support needs experienced by people with COPD, and in assisting people to raise those needs with HCPs:

“...asks all the right questions and some that are never asked ... If I was with the guys at pulmonary rehab and I got this out they would all answer it without question ... there are things on here, and I know guys on permeant oxygen and we talk about it, and they would tick these quite honestly as no one probably asked and some of these things are probably not asked in general. I mean if they go and see the doctor you know relationships? Does a family member need support? These are probably things that never come up but in a perfect world, they would. But they don’t” [Bob, primary care patient]

“Well, I presume or I would think if someone is bad or starting to get worse that this (the SNAP Tool) is really good because it asks the questions that you might not ask, so you know (my health) is not too bad but I didn’t know where to get any of this information (about the future) from, other than going to the doctor and asking, but people don’t do they, that’s the thing” [Dave, Primary Care patient]

As such, these patients were willing to actively prepare for the SNAP conversation, through demonstrating their willingness to use the tool to reflect on where they needed help to manage their lives with COPD, and to think in more detail about what exactly they wanted to raise in the SNAP conversation.

In the first instance these patients typically emphasised their readiness to invest time in considering and completing the domain questions. For example, Brenda described how her
reaction had been to “take my time and fill that in because you know, the questions on there I thought well you know, you need to think about them and that’s what I did” [Brenda, Community Respiratory Team patient].

Furthermore, this group of patients also described how they engaged with the SNAP Tool as a prompt – using it to facilitate consideration of the comprehensive range of support needs and demonstrating, in particular, a willingness to consider areas of support need that they had not previously been aware of or seen as relevant to their situation or their clinical conversations. For example, in relation to the SNAP domain ‘knowing what to expect in the future’, David reported that he “had never thought about it, but seeing it on there you think ‘yeah, let’s see what my future will hold’” [David, Secondary Care patient].

In addition, these patients also described how they used questions on the SNAP Tool to consider their needs outside of the medical context and focus instead on identifying their support needs within the context of their lifeworld experiences. Many, therefore, gave examples of evaluating, not just the symptoms and impact they experienced in relation to their COPD, but also (1) how they managed their disease, (2) the supportive input offered by family, community and professional support services, and (3) those gaps where they prioritised needing more support. Robert and Susan reflected:

“Oh (the impact of COPD) it’s immense it...it prevents me from doing lots of things. I can walk, well I can’t walk reasonably, this time last year I would walk, go out and walk two miles, today I have I can just make about 250 yards to the pub .....but I thought (when I looked at the SNAP Tool) it doesn’t look like I have actually got a problem. But I suddenly realised that what I have got is a limitation, but I am still able to drive and ...well and I can walk. If I couldn’t drive I can live in this village. I’ve got a butcher who has everything there like fish, bread, milk I get everything from there. And I have got a cafe...I can manage in this village.. I’ve also got lots of friends ...I don’t have family near but they will come at the drop of the hat....and the landlord and landlady of the pub they hold the keys to the house. If I’m not seen for two or three days they ring me ...so I’m looked after. “ I have a support network....Honestly the only thing I thought was, I read through them [the SNAP Tool items]) before I
started ticking them, and I just thought I can cope with all of this, and then (I identified needing) a little bit more help in the home and garden ...you know it takes me a long time to dust and you get a lot of dust in the houses this old” [Robert, Primary Care patient]

“The understanding of my illness, I would like to know a little more because like before, I used to take no notice if you know what I mean. I used to go in but you know, sometimes I think to myself well you know, if I understood myself a little bit more, perhaps I wouldn’t push myself too hard then I wouldn’t struggle if you know what I mean. I overdo it sometimes.” (Susan, Community Respiratory Team patient)

Having completed the tool, patients at this end of the spectrum typically went on to describe considering their responses in the context of the future SNAP conversation. For example, Peter and Fiona both understood that SNAP created an opportunity for them to raise lifeworld issues that they would not normally have seen as appropriate within a respiratory conversation and were keen to take advantage of this situation:

“it was such a relief to know I could talk about the anxiety and depression” [Fiona, Primary Care patient]

“(Normally) I wouldn’t have thought about that (feelings and worries) or I wouldn’t have put that down because when I see the nurse she might do a breath test and you know... you know ‘how are you’ but it doesn’t go any deeper than that. She can’t ask everybody about their psychological problems.” [Bob, Primary Care patient].

In addition, for many, the process also involved going beyond the identification of relevant domains of support need to thinking further about the specific nature of the support need they wished to raise with the HCP. For example having identified needing more support with ‘knowing what to expect in the future’, Dave explained that: “All I wanted to really know (from the HCP) was that as I get older and things are probably going to get worse, then I wanted to know where either I or my good lady could find out information or places that I can get respite” [Dave, Primary Care patient]. Others also had more concrete ideas about
the type of supportive input they would find useful, e.g. having the opportunity to talk or requesting a befriender.

**Limited engagement**

Patients in the middle of the continuum also understood and acknowledged the potential benefits of SNAP for the wider COPD population in relation to supporting lifeworld considerations and conversation. Reflecting on the SNAP Tool, Rose commented “*I think it’s an excellent booklet because people can see where they need help*” (Rose, Community Respiratory Team patient) and Isabel noted “*I think it’s very useful (if for some reason you don’t have) the ability to know your way around (services) and be forceful or argumentative*” [Isabel, Community Respiratory Team patient].

However, in contrast to the patients in the active engagement group, these patients differed with regard to how far they perceived the SNAP Tool to be applicable to them, as individuals, at that point in time. John commented: “*I think to me, because I have had it for so long now, a lot of things (on the tool) are common sense, you know*” [John, Primary Care patient]. Susan noted: *I feel sometimes it doesn’t apply to me because, as I say, I don’t realise I’ve got COPD”* [Susan, Primary Care patient]. In contrast, Linda acknowledged that she needed support but felt that she was currently able to manage the situation independently. She also felt uncertain about how far she could discuss lifeworld needs.: “*I’m not sure if it was relevant really because I think a lot of the help that we have, let’s say for example in the garden, is because …X (husband) is very severely sight impaired and because we’re perfectly happy doing it independently at the moment*” [Linda, Primary Care patient].

These patients also demonstrated some hesitancies about the tool in terms of how far they wanted, or needed help, raising issues with HCPs. Isabel did not really see the tool as useful as she was very comfortable with HCPs taking charge of her care. Others argued that, whilst the tool could be useful for those who might find it difficult to talk to HCPs, they were fully confident in their ability to raise any support needs in a consultation without the SNAP Tool. Despite these reservations the majority of this group complied with completing the tool prior to the SNAP conversation and, like those patients at the active end of the spectrum,
their accounts suggest that the tool guided them to consider and identify their support needs across the comprehensive range of domains.

However, in contrast to the patients in the previous group, these patients rarely described engaging with the SNAP Tool as a prompt to think more broadly and deeply about their support needs. Instead, their accounts suggest that they were more likely to fill in the SNAP Tool quickly “it arrived in the post and I just quickly ticked it off” [Audrey, secondary patient]. This process often led them to identify simple requests that they felt were appropriate to the HCPs role that typically they had planned to raise anyway (e.g. a letter of support for re-housing).

In some cases they were also less likely to reflect on what was important to them and appeared more focused on providing the ‘right’ answer:

“I mean like ‘understanding your illness’ I understand it, you know, it just gets worse and worse. ‘Managing your medication’ is fine, I do that. ‘Dealing with feelings and worries’ well you just talk to the doctor or somebody... ‘Looking after other physical health problems you may have’? Well I did not know what to put down really for that. It says a little more, I mean what do they mean by a little more support? I deal with it.” [Julie, Secondary Care patient]

Although this group of patients were aware that they would be discussing their responses with an HCP, they also rarely reflected on their needs in the context of the SNAP conversation. For some this was because they did not identify any current needs that they wanted to discuss within SNAP, for others because they felt some uncertainty about raising lifeworld issues or more typically because they saw the SNAP Tool as useful for negotiating the traditional medical patient-HCP context.

*Passive*

For the remaining patients, completing the SNAP Tool and preparing for the SNAP conversation was a process about which they had little understanding and in which they had
no investment. Instead, their interaction with SNAP suggested that their perception and participation in SNAP was something required by the system. Commenting on the patients more widely, one HCP noted: “they will happily partake in anything we give them, they are that sort of patient group... that they will say ‘Oh the nurses have just asked me to fill it in so I will fill it in for them’” [HCP secondary care].

Typically, this group did not understand that the SNAP Tool was designed to support them to identify their own support needs, or that it sat within a wider intervention that was intended to be directly integrated into their care. Instead, their accounts suggest that they perceived they were participating in a wider organisational process such as completing a survey or filling in the tool to help out the HCPs. For example, Geoffrey described how the HCP: “presented the forms to me and asked if I could have a look at them and asked if I was happy to fill them in, and I have done that” [Geoffrey, Primary Care patient].

Not surprisingly, the engagement of this group was manifest by the lack of time, thought or consideration they gave to completing the tool. Describing his approach to filling in the tool Geoffrey reported: “I ticked it off and I thought, ‘Right I’ll tick it, tick it’ ...I didn’t think about nothing when I was doing it..just ticked it off... Is red black? Black, white? And stuff like that...just like a tax form” [Geoff, Secondary Care Patient].

This lack of engagement also led to further confusion, with some patients interpreting the purpose as one in which they were required to provide information about supportive input already received rather than indicating where they needed more support. Shirley, a Secondary Care patient, described firstly how she was asked if she would take part in a survey and her subsequent confusion about how she was meant to respond: “I mean, I made a mistake thinking you wanted to know what help I had instead of what – it just says ‘practical help’ and I was, ‘Yes, I’ve got it’ ..” [Shirley, Secondary Care patient].

Further indication of the passive response was the lack of acknowledgement from these patients that SNAP was part of a process that involved preparing for a conversation, or that a healthcare professional would look at or respond to any identified domains.
To summarise Theme 2, the patients’ accounts suggest that they show different levels of engagement in SNAP, and the process of identifying and expressing their needs. These differences were further highlighted by how far patients understood that SNAP facilitated: 1) consideration and expression of their support needs within a lifeworld context; 2) support to use strategic action in relation to their needs or 3) a system based response from them as requested by the HCP.

8.3.3 Theme 3: patient-HCP interactions within SNAP

By exploring the interaction between the HCPs’ orientation towards the lifeworld or systems (Theme 1 above) and the three types of patient engagement (Theme 2 above), a continuum of care was identified as enacted within SNAP, from patient-led care to HCP-led care.

*Patient-led care*

Where HCP engagement with SNAP was characterised by communicative action, HCPs delivered SNAP as planned, facilitating an understanding that the patient-HCP interaction within SNAP that was based around exploring and responding to the patient’s lifeworld. This enabled a patient-led approach to identifying and expressing those areas where they needed more support and the development of a shared patient-HCP response to their prioritised support need. For example, Brenda, a Community Respiratory Team patient who had identified needing more support with getting out and about, was able to describe to her HCP her embarrassment at having to wear an oxygen mask, how this was stopping her from accessing social activities and her need for strategies to overcome this problem.

Typically, these HCPs identified that developing a shared response (Stage 4 of SNAP) could sometimes be difficult and felt that the patients wanted more direction or a traditional biomedical response:

“patients would be interested to hear the things that they might be able to do but unfortunately, as can happen with an older population who are also used to a very medically-led way, they just sort of sit there and think who’s going to sort it out for
them ...so that was a little bit more tricky – to help people to think of other things that maybe they could do” [HCP 11 Primary Care].

In contrast, patients described this as an interactive life-world focused process that provided them with the opportunity to outline the kind of response they would like and, on occasion, position those responses outside the medical system. Fiona, a community team patient who experienced severe anxiety and rarely left the house, recounted: “I think she said what I’d most like help with...and I said I just felt I needed somebody to talk to more than anything” [Fiona, Primary Care patient].

Many of these patients also described being comfortable with considering, and rejecting, the suggestions put forward by the HCPs, even those that could be considered as standard medical (system) responses. Brian, a Primary Care patient, noted: “well she did say I can put you on... prescribe you tablets, but, no, I didn’t really want that”. He also compared this encounter to previous medically-based consultations and described how he was able to move beyond a more passive patient role concluding: “The SNAP Tool prompted me to ask some more questions with [the nurse]. That was something that I hadn’t understood in the past – that I should have asked more relevant questions” [Brian, Primary Care patient]

In contrast to the engaged patient group who enthusiastically participated in SNAP, when the lifeworld focused HCPs encountered patients who were limited-engagers, to encourage patient involvement they typically described employing communicative action strategies to “check there wasn’t anything else [the patient] wanted to talk about” [HCP 21 Community Respiratory Team]. Some of these patients recounted how this led to them to engage fully with SNAP and explore their particular support needs. For example, Susan, who had not initially filled in the tool because she didn’t see the domains as relevant to her situation, described how she and the nurse went through the SNAP tool and “talked about each question as it came up. That was it and then I spoke to her about what to expect in the future” [Susan Primary Care patient]. For others, reviewing their completed SNAP Tool with the HCP confirmed that they currently had no unmet support needs. However, passive patients could not recall taking part in SNAP beyond completing the tool. Overall, however, these HCPs were delivering person-centred care.
Benefits were also identified by HCPs in relation to the way SNAP enabled new lifeworld-focused conversations, with one HCP reflecting: “people have come in with questions that it wouldn’t have occurred to me to ask” [HCP 11 Primary Care]. In addition, the HCPs role as the medical ‘expert’ was challenged by patients highlighting needing more support with understanding their illness or dealing with their feelings, which the HCPs felt they had already addressed. Both HCPs and patients noted that SNAP was “definitely really helpful with end-of-life conversations” allowing patients to raise these issues when they were ready and to focus on the things that were important to them. Isobel, a Community Care Patient who was extremely confident, nonetheless used the SNAP Tool to start a conversation about the likely deterioration in her condition and her prognosis, mindful that her husband was also unwell and that she might become a burden. The HCPs who had this conversation with Isabel reflected that they would not have raised this issue at this point in time as she was relatively newly diagnosed.

As a result of these person-centred lifeworld conversations, facilitated by SNAP, most of these patients described receiving a tailored response to their need. For some patients SNAP facilitated the opportunity to talk to the HCP, find out more about their condition or discuss its management. For others, SNAP enabled access to supportive input beyond traditional medical responses, e.g. referral to befriender schemes, peer support or community groups.

HCP-led care

Where HCPs’ actions suggested a more strategic medically-focused approach, patient-HCP interactions within SNAP were more aligned with a traditional HCP-led bio-medical response.

With those patients who had actively engaged with the SNAP Tool, and identified that they needed more support, these HCPs frequently reframed this into a medical context by undertaking an HCP-led needs assessment and responding with HCP-determined supportive input. For example, one patient described using the SNAP Tool to express that he needed
more support in “knowing what to expect in the future” [David, Secondary Care patient], whereas his HCP concluded his “primary need was actually to understand his condition” and so “went through education on COPD [with him]” [HCP 32 Secondary Care]. David’s overall assessment was that the conversation was reassuring and helpful although he acknowledged he had had a similar conversation in the past: “In that respect I got from her the knowledge I’d already had in previous conversations. Yeah, it helped.” However the HCP saw less value “I’m sure at any stage of the clinic that conversation would still come up” [HCP 32 Secondary care].

When these HCPs encountered limited or passively-engaged patients, their narratives suggested that they used their power to take the patients’ responses at face value: patients were not encouraged to become engaged with SNAP. This was justified by the HCPs as patients wanting to make the most of ‘medical conversations’. One such HCP commented that, as the patients had attended for a specific medical purpose, they “don’t want to be there even longer discussing... things that have already been discussed” [HCP 32 Secondary Care]. In particular, passive patients of these HCPs reported either not having a conversation about the SNAP Tool or, like this patient, that they couldn’t “remember if [the HCP] did go through that [the SNAP Tool] with me or not” [Jim Community Team patient].

Nonetheless some patients used the opportunity the SNAP Tool provided to make simple requests traditionally associated with HCPs’ professional role (e.g. requesting a letter of support for a benefit claim or checking inhaler technique). Apart from patients who had no engagement with SNAP, most patients receiving HCP-led care were still pleased to have had an opportunity to highlight their support needs through the SNAP Tool and access supportive input. For example, one patient reflected positively on how the HCP had said that the team “would back me up [with her housing claim]” [Rose, Secondary Care patient]. In contrast, HCPs delivering HCP-led care felt that SNAP (as they delivered it) did not add value to their practice concluding “we’ve been covering those issues anyway” [HCP 31 Secondary Care] and “at any stage in the clinic that conversation would still come up” [HCP 32 Secondary Care].
A continuum of care

The analysis in Theme 1 highlighted how patients interacted with SNAP in range of differing ways along a continuum of engagement, suggesting that some patients adopted characteristics associated with more than one of the key points along the continuum. Similarly, in Theme 2 the HCPs often described integrating elements of the systems and lifeworld approach in their work. As a result the care enacted within SNAP was also not classifiable into a distinct dichotomy: patient-led care or HCP-led care also occurred along a continuum, reflecting the fact that HCPs’ and the three types of patient engagement, did not form discrete categories.

8.4 Discussion

This chapter explored patient and HCP experiences of SNAP to establish how patients engage with SNAP to identify, express and address their unmet support needs. In addition the study sought to identify factors that enable or hinder a patient-led approach. Participant experiences were considered in the context of Habermas’ Theory of Communicative Action186 which provided a framework for conceptualising and identifying patient and HCP expressions of need and the communication and behaviours that were associated with either a patient-led approach (lifeworld) or an HCP-led approach (system world). The findings identified that there were differences in how HCPs delivered SNAP and how patients engaged with it; analysing the interaction of these identified a continuum of care (from patient-led to HCP-led) which impacted on patient identification and expression of need and resulting responses. This in turn highlighted the role of intervention fidelity in supporting these experiences.

The findings revealed, firstly, differences in how HCPs interacted with SNAP. Two separate groups were identified - those whose interactions were lifeworld focused (e.g. they acknowledged the patient’s subjective experiences of support need and the response required) and those whose interactions were system focused (e.g. they emphasised traditional institutional/biomedical ways of understanding and managing need). The former group recognised the lifeworld focus of SNAP and how it was distinct from more biomedical
ways of working. In addition they interacted with SNAP in a way that was characterised by communicative action (e.g. seeking out understanding of the patient’s perspective and negotiating a shared response to need based around this perspective). In contrast, the system-focused HCPs perceived SNAP as having limited value within the medical system and therefore looked to limit their engagement with, or adapt their use of SNAP towards more system-orientated goals (e.g. by depersonalising SNAP or asking rhetorical questions about the patient’s responses).

Differences were also identified in how patients engaged with SNAP. Those who were identified as being ‘actively engaged’ in SNAP typically recognised that SNAP was a mechanism designed to support the visibility and legitimacy of their lifeworld in a medical context. As such they used their role of considering and completing the SNAP Tool as a means of actively engaging in this process. In contrast a second group of ‘limited engagers’ recognised the potential of the SNAP Tool to support patients engage with and express their lifeworld. However in the main they did not see either the SNAP Tool or SNAP as relevant to them at that time – although the SNAP Tool was identified as something that could assist them make traditional medically-focused or system based requests. Finally, the patients in the ‘passive’ group adopted a view that completion of the SNAP Tool was something that benefited the system rather than themselves, and therefore their engagement was minimal and based on misunderstandings.

Where HCP engagement with SNAP was characterised by communicative action, HCPs delivered SNAP as planned, facilitating an understanding that the patient-HCP interaction within SNAP was based around exploring and responding to the patient’s lifeworld. Patient-completion of the tool legitimised raising their support needs with HCPs, enabled patients to articulate directly to HCPs where they needed more help, and made the process visible. The SNAP conversation was then centred on lifeworld conversations characterised by patient-identified and prioritised areas of support need: it enabled exploration of the specific support needs and a co-developed response. As a result, these patients received a range of supportive inputs including the opportunity to talk, reassurance, future care planning and access to medical and non-medical services. Some limited or passive patients were initially reluctant, unsure about some of the questions, or identified no current need for support,
but the opportunity to review this with an HCP ensured this remained a person-centred lifeworld focused consideration of their current circumstances, rather than reflecting a lack of understanding of SNAP’s purpose.

Where SNAP was delivered by system focused HCPs it was rarely delivered as intended and patients were far less likely to identify and express their support needs: fewer patients fully engaged with the SNAP Tool or understood SNAP’s potential usefulness. Critically, both passive and limited-engagers indicating no support needs appeared less likely to be encouraged to re-consider the SNAP Tool and truly consider their support needs. This may represent missed opportunities by these HCPs to identify and address unmet support needs as there was uncertainty about whether this was a patient-led choice not to engage. Where patients did express their support needs to HCPs who deviated from SNAP, the follow-on discussion was more akin to usual care (or an enhanced experience of usual care) in terms of content and outcome e.g. traditional bio-medical, rather than holistic, tailored responses. However, apart from patients who had no engagement with SNAP, most patients receiving HCP-led care were still pleased to have had an opportunity to highlight their support needs through the SNAP Tool and access supportive input.

In addition to the above, the understanding that many of the individual experiences underpinning the above findings are characterised by differing (and overlapping) levels of engagement in the identified core concepts, makes the case for further exploration of this variation. In particular a birds eye view of both the identified continuums, and different ways in which HCPs engaged in the process, indicates a potentially broader range of patient-HCP experiences and interactions than those outlined above. Future work could therefore explore in more detail how the themes identified in this PhD interact within clinical practice. This in turn may further inform implementation issues and the identification of person-centred outcomes.

Overall the above data supports the case for the adoption of a person-centred approach to intervention format and delivery (as exemplified by SNAP) as an alternative to a Systematic Needs Assessment Intervention model. In particular the findings demonstrated that, when implemented as planned, SNAP can facilitate a patient led approach across each stage of
identifying, expressing and addressing their support needs. The application of Habermas’ theory further enabled a clear understanding that this process involved patients in engaging with, and enacting a response to, their lifeworld concerns rather than a medical or organisational agenda.

More specifically the data demonstrated that, in contrast to the limitations identified in relation to the post hoc tools currently used within the Systematic Needs Assessment Intervention model, the SNAP Tool easily and actively engages patients to consider support need in the context of their lifeworld. Where this was not the case this was found to be due to the dominance of a system based approach to the implementation of SNAP, suggesting the issue is one of delivery rather than the tool format itself.

In addition SNAP addressed concerns raised by Johnston et al (2019) about the tool-centric nature of many interventions, which appears to compromise a patient-led approach beyond completion of the tool or questionnaire. The above findings underline the understanding of SNAP as more than just the SNAP Tool, but instead as a structured process that supports patients to highlight and engage with their lifeworld concerns that encompasses identifying, expressing and being involved in addressing their support needs. In addition, the structured process further supports HCPs to deliver SNAP in a way that enables, and safeguards, this patient-led approach. As such, SNAP provides an enhanced alternative, not just to post-hoc problem based questionnaires, but also to questionnaires such as the Supportive Care Needs Survey9 which, like the SNAP Tool, enables patients to direct identify their support needs, but, unlike SNAP (the intervention), doesn’t support HCPs to subsequently involve patients in a needs-led process beyond the survey responses. As above, the data suggest that where patients were not engaged across the 5 stages of SNAP this was due to failure by system-focused HCPs to deliver SNAP as intended.

Overall the results suggest that when delivered in a lifeworld context SNAP was able to address issues within the wider literature relating to the well-documented challenges and ways of working that patients can face in identifying and discussing their needs with HCPs.10 The findings highlight how SNAP addresses these barriers by making visible, and legitimising, the support needs patients can discuss with their HCP, and by providing a
mechanism for HCPs to deliver person-centred care. In addition the results suggest that, in response to facilitating a patient led-approach, patients were also able to access supportive input that was holistic and tailored to their particular needs.

Consideration of the complex interactions between system and lifeworld has also been discussed within the wider literature and highlighted further areas for potential exploration. In their work on interpretive consultations, Greenhalgh et al (2006) argued that Habermas’ concepts of unconscious deception or systematically distorted communication may be relevant to understanding consultations where the HCP role is dominant but everyone is happy with the outcome. Here the authors argue that this can arise from what Habermas has described as an unconscious deception which takes place when both patients and HCPs believe they are engaging in communicative action whilst, in fact, the medical agenda continues to be enacted at the expense of the lifeworld. This, they suggest, is supported by patients being willing to recognise and accept common features of patient-HCP interactions such as the HCPs’ expertise, and the busy context in which they work, thereby enabling strategic actions to be incorporated into the discussion. Clear parallels can be observed in the data presented in this thesis in relation to patient interactions with system focused HCPs. Firstly there is evidence of these HCPs engaging with the SNAP Tool to identify issues raised by the patients and employing behaviours aligned with communicative action, and then combining this with a strategic response based around their professional roles. Here patients were pleased to have their particular concerns acknowledged and addressed, but were also happy to defer to the expert input of the HCP. It was also clear that these patients, although less so the HCPs, left the conversation feeling positive about SNAP and the nature of the patient-HCP interaction that SNAP has supported. As above exploration in this area has potential implications for enhanced understanding of the interactions underpinning SNAP which in turn could inform HCP training in order to better support SNAP implementation.

In addition, the above application of Habermas’ theory by Greenhalgh et al (2006) may also provide a broader explanation as to why the Systemic Needs Assessment intervention model continues to be popular with policy makers, practitioners and patients, even when
there are limitations in delivery and format that appear to compromise person-centred care and a holistic, tailored response. Drawing on their observations above, Greenhalgh et al further emphasised that unconscious deception or systematically distorted communication can occur even when all parties are acting in good faith and that this kind of interaction “represents a considerable advance over old-style portrayals of medical imperialism and intransigence. It is not that open strategic action and manipulation, especially on the part of doctor, does not occur, but that lifeworld agendas and motifs can also go missing by default” [Greenhalgh et al 2006, pp. 1184-1185]. Considered within this context, Systematic Needs Assessment can be understood as delivering care that is an improvement on an approach characterised by a more overtly dominant medical agenda. However this in turn also emphasises the need for policy makers, practitioners and researchers to fully engage with the on-going complexity of delivering person-centred care. These conclusions, together with the findings outlined above, suggest that this should include exploring the use of person-centred interventions, such as SNAP, that has been specifically designed to address the rhetoric within policy, good practice guidance and the person-centred care literature.  

*Limitations*

A potential limitation was that all clinical settings were in the East of England. Also, this analysis included only one site per setting (primary, community and secondary care), limiting our ability to explore the influence of settings on different approaches to delivering SNAP; further, only one HCP delivered SNAP in primary care.

In addition, patient engagement with SNAP may have been limited by the study itself: HCPs reported that some patients declined to complete the SNAP Tool (and therefore receive SNAP) due to reluctance to participate in research. As a result, our findings may not fully reflect intervention engagement in a non-experimental setting.

Furthermore the research context may have directly influenced participant actions. For example the ‘passive’ patients above may have been introduced to the SNAP Tool as a
survey or ‘something to be sent off’ because of the research context, something which may not have been the case if the decision to use SNAP was a clinical one.

8.5 Summary

The use of Habermas theory provided a lens through which to explore whether and how SNAP is able to deliver a patient-led approach to identifying, expressing and addressing support need (a lifeworld focused approach). The findings suggest that, when delivered as intended, SNAP enables identification, expression, and discussion of support need and is able to operationalise delivery of holistic person-centred care, providing an alternative to HCP-led approaches to identifying and addressing patient support needs. When delivered as intended, SNAP also addresses the rhetoric within clinical strategy documents and person-centred care literature, emphasising the need to involve patients in identifying their needs, goals and preferences.
Chapter 9: Discussion

9.1 Introduction

The aim of this thesis was to critically analyse the nature and usefulness of the Systematic Needs Assessment intervention model in enabling a patient-led approach to identifying, expressing and addressing patients’ unmet support need, whilst making the case for an alternative person-centred approach to intervention format and delivery. In addition, the thesis aimed to investigate whether, and how, this alternative approach can enable patient-led identification and expression of their unmet support needs in practice through the exploration of an ‘exemplar’ – the Support Needs Approach for Patients (SNAP). Together, it is argued here that these critical analyses combine to highlight the value of a person-centred approach to intervention format and delivery in facilitating patient-led identification, expression and the addressing of unmet support needs in patients with long-term conditions.

In this concluding chapter the main findings of the thesis as a whole are outlined, together with the methodological strengths and weaknesses and the implications of this work for clinical practice, policy and research.

9.2 Main findings

The findings within this thesis suggest firstly that the Systematic Needs Assessment intervention model (which was found to primarily consist of post-hoc practitioner-orientated questionnaires integrated into a standard patient-HCP consultation) is limited in how far it encourages a patient-led approach to identifying, expressing and addressing patient support needs. Results from the thematic synthesis indicated that, whilst use of these interventions can support patient-led ways of working, this was not consistently described either within, or across, the identified interventions. In contrast, in most of the studies, patients and HCPs described participating in processes more typically associated
with a traditional HCP-led approach. Here, the participants perceived that patient participation was greater than without the interventions, but decisions about their needs, and supportive input to address these needs, often appeared to be made by the HCPs. In addition, there was little clear evidence that the care they received was consistently holistic and individually tailored.

The format and characteristics of these interventions were identified as key factors in shaping the above findings. Some of these interventions were found to incorporate features that enabled a patient-led approach to identifying, expressing and addressing their support needs. These included underpinning the intervention with a person-centred philosophy, the use of questions that enabled patients to directly identify their support needs and the inclusion of a clear strategy to support patients in the development of a shared response to their unmet support needs. However, it was also found that many of the characteristics within these interventions served to limit patient involvement and instead supported an HCP-led process to identifying and addressing patients’ needs. This was linked to: 1) questionnaires that asked patients primarily about their symptoms and problems, 2) the use of questionnaires with lists of narrowly focused items and Likert scales, and 3) an emphasis on professional expertise beyond questionnaire completion. Typically, the interventions contained either a combination of strategies to enable both a patient-led and HCP led approach, or just those orientated towards enabling an HCP-led process. At best, the format adopted by these interventions was orientated towards partially enabling a patient-led approach to identifying, expressing and addressing their needs.

In contrast, this thesis outlined an alternative person-centred approach to intervention format to enable patients to fully participate in a patient-led approach to identifying, expressing and addressing their support needs. Drawing on an exemplar person-centred approach (SNAP) this thesis considered firstly why SNAP could be considered a person-centred intervention, and therefore distinct from the Systematic Needs Assessment intervention model. Attention was drawn to the way the development of SNAP was proactively person-centred, evidenced by 1) the key person-centred characteristics of the SNAP Tool (supporting direct expression of need and a facilitative rather than psychometric framework) and 2) the person-centred processes underpinning the Five Stages of SNAP.
Secondly the specific value of SNAP as a person-centred intervention in practice was evidenced within the tool validation and qualitative study. The validation study found that the SNAP Tool has good face, content and criterion validity and was therefore suitable for use in clinical practice with the exemplar population. This highlighted further the potential to facilitate the delivery of holistic, supportive, person-centred care by enabling patients to identify and express their unmet support needs to HCPs. The qualitative study also found that SNAP operationalised person-centred care by enabling patient-led identification, expression, and discussion of support needs. However, differences were found both in how HCPs delivered SNAP and how patients engaged with it. These differences were in turn focused around how far the individual participants engaged with, and enacted, what Habermas\textsuperscript{186} has described as the ‘lifeworld’ (which in this context can be understood as the patients’ subjective experiences of support need). An analysis of patient-HCP interactions, informed by the above differences, identified a continuum of care (from person-centred to HCP-led), highlighting in turn the role of intervention fidelity.

When delivered as intended (evidenced by lifeworld focused HCPs) SNAP operationalised person-centred care by enabling patient-led identification, expression, and discussion of support needs. In particular, the format facilitated this process by enhancing the visibility of support needs, and the legitimacy of raising those needs with HCPs. More specifically the 5 stages of SNAP created and safeguarded opportunities for a patient-led approach throughout the intervention. Where SNAP was less successful, this was linked to HCPs delivering SNAP in a way that suited their traditional system-focused biomedical ways of working. Together these drew further attention to the role of implementation issues, suggesting this should be the focus of future work.

More broadly these findings support wider observations about the need to challenge the usefulness of the Systematic Needs Assessment intervention model. As noted earlier, Osse et al (1999),\textsuperscript{1} McElduff et al (2004)\textsuperscript{101} Richardson et al (2005),\textsuperscript{2} Johnston et al (2019)\textsuperscript{16} and Rimmer et al (2021)\textsuperscript{17} have each highlighted potential limitations of this approach arising from: 1) the use of post hoc professional tools,\textsuperscript{1,2,17} 2) the resulting focus in many interventions on using symptom/problem-based tools to identify support needs rather than
enabling their direct expression of support need, 1, 17, 101 and 3) the lack of a formal structure to facilitate patient involvement beyond completion of the questionnaire. 16 Each of these, it was argued, orientated the process of identifying and addressing need towards the professional, rather than a patient-led approach. Support for these observations was further identified within the thematic synthesis in Chapter 4 of this thesis. In contrast, SNAP pro-actively supports a patient–led approach via a purposively designed tool which underpins a five-stage person-centred process. As noted earlier this is further evidenced by both the validation and the qualitative study. As such, SNAP also provides an alternative to those interventions that use problem-based questionnaires, and those that use questionnaires such as the Supportive Care Needs Survey 101 (which don’t support HCPs to involve patients in a needs-led process beyond completing the questionnaire).

It is however important to note that the qualitative study also found that when SNAP was delivered by system-focused HCPs many of the participant descriptions of intervention use, and outcomes, were similar to those found in relation to Systematic Needs Assessment. However, unlike the interventions in the review, there is clear evidence that, when implemented appropriately, SNAP delivers an integrated approach to this process.

Work within this thesis has also drawn attention to the need to reconsider empirical methodology in relation to the validation for clinical use of non-psychometric tools. Traditionally, questionnaires associated with the Systematic Needs Assessment approach have taken the psychometric approach to development and testing. The observations by Osse et al (1999) 1 and Richardson et al (2004) 2 sit within a large body of work that has focused on reviewing and assessing the psychometric properties of clinical tools highlighted as being useful for identifying and assessing needs. 17, 108, 112, 113, 115 The thematic synthesis also found that many of the questionnaires identified in the review were influenced by psychometric design features and had been assessed for reliability and validity. However, in their work on the CSNAT, Ewing et al (2013) 193 recognised a need to move away from this approach, highlighting the inappropriateness of testing for reliability in a non-measurement tool. Work in this thesis has built on the work by Ewing et al (2013) by formally outlining why psychometric testing lacks relevance for assessing the characteristics of tools developed to support patient identification and expression of (rather than measurement of) support
The use of an alternative mixed methods approach to validation outlined in Chapter 6 further supports understanding about how this alternative approach can be utilized for validation of non-psychometric tools like the SNAP Tool.

Finally, the findings from the evaluation of SNAP in practice also illustrate ways in which a person-centred intervention can address wider concerns within the literature. Firstly, the results suggest that a person-centred approach to intervention format and delivery can enable patients to overcome the well-established personal, institutional and organisational barriers to identifying and expressing need highlighted in Chapter 3. For example work by Beernaert et al (2014)\textsuperscript{12} and Coventry et al (2011)\textsuperscript{11} highlighted patient hesitancy in relation to raising their support needs due to concerns about legitimacy, a desire for independence, or a limited awareness of their potential support needs. Chew-Graham et al (2013)\textsuperscript{10} and Chatwin et al (2014)\textsuperscript{191} further observed that, even when raised, patient concerns and expressions of need can be curtailed by institutional or medical concerns. However, the findings from the qualitative study suggested that SNAP was able to address these barriers by providing visibility to patient support needs, legitimising the raising of support needs with an HCP, and through the provision of a mechanism for HCPs to deliver person-centred care. Secondly, the findings from the qualitative study also highlight how a person-centred approach to intervention format and delivery, as embodied by SNAP, operationalises aspirations, both within supportive care and the wider healthcare context, to move away from a biomedical approach to delivery of care to one in line with person-centred principles.\textsuperscript{8,82} Evidence was found that SNAP enables patients to identify and express their needs in a way that takes into account their subjective experiences of support need; empowers and enables patients to take, and share responsibility, in identifying and developing a response to need; and facilitates care and support that is holistic and tailored towards the individual. As such, when delivered as intended, SNAP addresses the rhetoric within policy, good practice guidance and the person-centred care literature espousing the need to involve patients in identifying their needs, goals and preferences.\textsuperscript{8,234}
9.3 Methodology – strengths and limitations

The work reported in this thesis was informed by an analytical framework that Burt (2015), Fetters and Molina-Azorin (2016) have described as a ‘multiple study’ mixed-method approach enabling different studies (using different methods) to be conducted separately, but which together have the potential to contribute to an overall understanding of a programme of work – in this case the exploration of the value of a person-centred approach to intervention format via consideration of SNAP.

The work in this thesis involved:

1) A thematic systematic review of qualitative studies considering interventions that aim to involve patients with long-term conditions in the process of identifying, expressing and addressing their support needs
2) A mixed-method validation study of the SNAP Tool
3) A qualitative study of HCP and patient experiences of using SNAP in clinical settings

9.3.1 Strengths

The methods employed in this thesis had a number of strengths. These included: 1) use of a mixed methods design combining both qualitative and quantitative methods, 2) a critical focus, and 3) the involvement of the patients’ voice. These are discussed further below.

The use of mixed methods is common in the context of interventions in healthcare where it is seen as being able to “enable a better understanding of whether and how an intervention works (or does not work) and inform the design of subsequent studies [Farquhar et al 2011, p. 748]. The choice of this approach within this thesis was not straightforward due to differences in the literature about how mixed and multi-methods are defined, and questions about their respective suitability for a programme of work containing two separate studies linked to one intervention. In particular, the literature raises questions about whether
multi-methods can include both qualitative and quantitative methods or whether it can only include different methods within one methodology.\textsuperscript{205, 235} In addition, questions have also been raised as to whether the use of both qualitative and quantitative methods necessitates data integration taking place within the analysis (and therefore within a single study) or whether it also lends itself to a cross-study narrative.\textsuperscript{235} However, this thesis adopted an approach in which the integration of separate studies, informed by different methods (qualitative and quantitative), took place via a narrative within an overall discussion of the study programme in order to best support the wider objectives of exploring the usefulness of SNAP as an intervention for use in clinical practice. This enabled the choice of method that most suitably addressed each research question (i.e. mixed methods in the validation study and qualitative methods in the SNAP pilot), and the ability to draw on a combination of methods in the validation study (enabling, in particular, a greater use and consideration of qualitative patient data than in traditional validation studies).

A second strength was the adoption of methods that supported a more critical approach to exploring the value of the different intervention models. This approach was driven by the descriptive focus identified within the existing literature identified in Chapter 3. In this thesis, a thematic synthesis\textsuperscript{149} of the qualitative literature was therefore undertaken in order to ask new questions of these existing studies concerning how far they involved patients in identifying and addressing their support needs and the factors that enabled or hinder this involvement. This supported an approach to the literature that was more interrogative enabling, for example, an understanding of the different patient-HCP power relations that take place within these interventions and the way these in turn can be supported by factors such as language and the format of a questionnaire. In addition the critical approach, supported by the use of Habermas’ Theory of Communicative Action\textsuperscript{186} in Chapter 8 enabled the use of a theoretical lens within the qualitative data analysis that facilitated the ability to conceptualise and explore dynamics underpinning patient and HCP interactions within SNAP.

A final strength of the thesis was that its component studies accessed the accounts of patients with long-term conditions across a range of clinical settings, enabling exploration of a range of perspectives. The thematic synthesis incorporated the exploration of direct
quotes from patients about their experiences of participating in existing interventions. The SNAP Tool validation study involved patients recruited from primary care within focus groups and a postal survey, and the qualitative study involved patients from primary, community and secondary care, each of whom participated in an in-depth qualitative interview. In addition, both the validation and qualitative studies benefitted from the active involvement of PPI members. Together these facilitated an approach that ensured patient voices informed understanding of: 1) their direct experience of support needs, 2) using the interventions, and 3) those features within the interventions that enabled these experiences.

9.3.2 Limitations

One of the major challenges in this thesis was the lack of discussion within the wider literature regarding many of the key concepts. In particular there was an absence of consideration about how to conceptualise interventions designed to support patient involvement in identifying and addressing their needs. Terms such as ‘needs assessment’ and ‘holistic needs assessment’ were widely used but rarely defined. In the end the decision was made to adopt my own term ‘Systematic Needs Assessment’ in order to be able to define and contrast different interventions. However, this may not have fully captured the essence of these interventions or taken full account of any variation.

Many of the other concepts within this subject area are also often ill-defined (e.g. ‘need’\textsuperscript{1, 90} ‘holistic’,\textsuperscript{16} ‘person-centred’\textsuperscript{25}) and sit alongside other terms that are seen as overlapping (e.g. ‘person-centred care’ is often used interchangeably with ‘patient-centred care,’ ‘personalisation’ and patient empowerment).\textsuperscript{25} This caused problems in exploring the background literature as it could often be unclear exactly how far the authors were discussing issues that were compatible with the definitions outlined at the beginning of this thesis. Similar difficulties were also encountered in the thematic synthesis. Thus even though the search strategy applied in the thematic synthesis was broad (e.g. it incorporated a large number of search terms) it may be that the complexities associated with terms such as need, person-centred and interventions etc. led to relevant studies not being identified.
A further limitation, both in terms of the background literature and in the thematic synthesis, was the preponderance of literature on interventions designed for people with cancer, probably due to the dominance of research in this area in comparison to other long-term conditions.\textsuperscript{236} For example, of the 14 interventions identified within the thematic synthesis, only three were used with patients who had long term conditions other than cancer. This may have implications concerning the relevance of findings for patients with other conditions who may experience different symptoms or a different disease trajectory.

Some of the data used in the thematic synthesis was drawn from author interpretation of the qualitative data. As above, the authors often used terms such as ‘need’ or ‘person-centred’ without defining these terms, leading to a lack of clarity about the specific implications for patients. For example, when authors were talking about unmet need it was sometimes unclear whether they were referring to a patient’s symptoms or whether they were discussing the assistance the patient needed to manage their condition. This could have therefore led to some misunderstanding by the reviewer as to how their comments related to the concepts of support need and patient-led care. To some extent this was overcome by the availability of direct quotes from participants across the different studies. However, the latter represented only a small proportion of the data collected within these studies and lacked the contextual understanding that could be gained from an interview transcript.

Protocol recruitment targets were achieved within both of the empirical studies reported in this thesis. However, a number of factors may have impacted on how far these participants were a representative sample. Firstly, within the validation study, only two focus groups were undertaken to assess face and initial content validity, involving 12 patients and carers in total. However, these peer-reviewed targets were established in response to known difficulties of recruiting patients with advanced disease\textsuperscript{208} and the findings suggest that the number of focus groups was sufficient; the recruitment of further participants was therefore unwarranted and would thus have been unethical. Secondly, within the qualitative study, the range of people invited to interview may also have been limited by the study itself: HCPs reported that some patients declined to complete the SNAP Tool (and therefore receive SNAP) due to a reluctance to participate in research. Finally, the use of people with COPD as
an exemplar population across both studies may limit generalisability to people with other conditions. In line with the initial development work the empirical work in this PhD was focused around the use of this exemplar population. The rationale was that focusing on one patient group would enable their experiences (and those of relevant stakeholders) to be understood in-depth, but that the presence of shared key characteristics and experiences could also support the application of SNAP to those with other long term conditions. In addition many people with COPD are known to have multi-morbidities (e.g. they have more than one long-term condition) and the SNAP development work with stakeholders (patients, carers and HCPs) spontaneously identified SNAP’s relevance to people with long-term conditions beyond COPD. A case can therefore be made that the empirical work in the PhD can inform work with the wider population of people with long term conditions. However, the focus on one patient group also has potential disadvantages. For example, the engagement and experience of other patient groups may be influenced by how well the SNAP tool reflects their particular support needs, or the type of settings within which they typically receive support. There is therefore a need for on-going work to explore further the usefulness of SNAP with people with other long term conditions.

A further potential limitation across both studies was their location only in the East of England. In addition, the qualitative study included only one site per setting (primary, community and secondary care) limiting the ability to explore the influence of settings on delivery of SNAP. Further, only one HCP delivered SNAP in primary care.

An additional limitation within the qualitative analysis is that the research context may have directly influenced participant actions. For example, the ‘passive’ patients identified in this study may have been introduced to the SNAP Tool as a survey or ‘something to be sent off’ because of the research context, something which may not have been the case if the decision to use SNAP had been a clinical one. Furthermore, the findings from this analysis may also have been limited by the decision to use qualitative interviews. Thus whilst the in-depth nature of these interviews enabled a rich picture to emerge concerning the participants experience of taking part in SNAP, the reliability of these accounts may have been compromised by known difficulties experienced by interviewees in fully, or accurately, recounting what took place.
Finally, my own work on the development of SNAP meant that I was already sensitised to key concepts about interventions, and the likely value of SNAP, prior to starting the thesis, with potential for bias in interpreting the results across the reviews and empirical studies. This was counterbalanced by having a primary PhD supervisor (CD) who was not part of the SNAP development team.

9.4 Implications for practice, policy and research

9.4.1 Implications for practice

The results of this thesis highlight that a person-centred approach to intervention format and delivery, embodied in the Support Needs Approach for Patients (SNAP), operationalises delivery of holistic person-centred care in clinical practice, by providing an alternative to HCP-led approaches to identifying and addressing patients’ support needs. When delivered as intended, SNAP enables identification, expression, and discussion of support needs by legitimising support need expression and making the process of involving patients in discussing and addressing these needs visible. SNAP addresses the rhetoric within policy, good practice guidance and the person-centred care literature espousing the need to involve patients in identifying their needs, goals and preferences. Further it demonstrates how this can be achieved by providing HCPs with a mechanism for how a truly holistic person-centred approach can be achieved in everyday practice, facilitating the delivery of a tailored response. SNAP is therefore suitable for use in clinical practice to enable patients with long-term conditions to identify, express and address their support needs.

9.4.2 Implications for policy

Current UK policy emphasises the role of Holistic Needs Assessment (an approach that sits within the Systematic Needs Assessment model) in supporting patients with long-term conditions to express their needs. Findings in this thesis suggest that this should be re-evaluated as they appear to contradict the assumption that this approach addresses the rhetoric around person-centred care by facilitating a patient-led approach to expressing need and planning care. In contrast, the findings reported here indicate there is a role for
policy in actively discussing, and highlighting, the contribution that a person-centred approach to intervention format and delivery (e.g. SNAP) can make in supporting a patient-led approach to identifying, expressing and addressing need.

Even when the policy focus is less on person-centred care, and is instead focused on addressing issues such as self-management and personalisation, there is an often an implicit assumption that these processes are underpinned by patient expression of need.\textsuperscript{84-86} There is therefore a further role for policy in highlighting these gaps and drawing attention to the role person centred interventions, such as SNAP, can play in underpinning these processes.

The successful use of SNAP in an exemplar population with a long-term condition also highlights the need for a further shift within policy discussion and policy recommendations away from primarily considering patients with cancer to one that actively addresses the delivery of person-centred care to patients with long-term conditions.

Finally a further potential policy role is in supporting the implementation of SNAP in clinical practice. The findings suggest that, when implemented as planned, patients and HCPs are willing to engage with SNAP. However the thesis found that implementation is influenced by the resistance of some HCPs to person-centred ways of working and not all patients were given the opportunity to participate in a patient-led process. In order to support more equitable delivery, incentivisation for HCPs through a framework such as QOF should be considered.

9.4.3 Implications for research

This thesis has highlighted how, on a general level, there is a case for further theoretical critical work to understand the distinction between Systematic Needs Assessment versus person-centred care and the development of person-centred interventions – both in relation to people with long-term conditions and more generally. In addition, this includes further work on understanding and identifying the best methods for developing and validating interventions in this area.
In particular relation to SNAP, there is also a need for further research on the application and effectiveness of SNAP in practice. The findings from the evaluation study highlighted implementation as a key area of investigation, which in turn can be used to inform future training materials: to date SNAP training has focused on the individual practitioner level – however organisational-level implementation training is also needed. In addition, there is a need to explore the use of SNAP in wider populations, such as people with other long-term conditions and multi-morbidity, and to develop ways of working with SNAP in populations that face additional barriers to taking part in interventions (e.g. language, structural vulnerabilities, visual problems, and learning difficulties). There is also a need to test SNAP within a quantitative study, requiring additional work to identify relevant outcomes. Finally, there is on-going work in relation to making the SNAP Tool available to non-English speakers. On-going translation work of the SNAP into Swedish suggests that this requires time, investment and investigation as it involves not just a straight language translation but also a cultural translation.

9.5 Current applications of learning from the PhD

The work presented in this PhD has led to new understandings about how to deliver SNAP in clinical practice – in particular the benefits of introducing SNAP to patients as a conversation starter rather than a ‘form’ or a ‘questionnaire.’ This learning has in turn led to changes in the SNAP training and has informed the support offered to HCPs in a study currently exploring the use of SNAP by district nurses. In addition, work has begun to address some of the limitations in the PHD. The study involving district nurses is exploring the use of SNAP with people experiencing a range of conditions. A further proposal is also being developed to explore SNAP for people in prisons experiencing different chronic progressive conditions. The PhD has also informed consideration of how to conduct future work in this area, in particular by addressing the limitations of qualitative interview data. Future studies will therefore look to incorporate observations of clinical consultations where SNAP is delivered.
9.6 Summary

This thesis found that interventions based on a Systematic Needs Assessment intervention model are orientated to supporting enhanced patient involvement in an HCP-led approach to identifying and addressing support need in patients with long-term conditions.

In contrast, an alternative person-centred approach to intervention format and delivery (explored in this thesis via SNAP), was found to have value in clinical practice. The evidence found in this thesis highlights that SNAP can directly enable patient-led identification, expression, and involvement in addressing of their unmet support need, This in turn can also facilitate a response to support need that is both holistic and tailored to the individual needs. Where SNAP was less successful, this was identified as related to implementation rather than format, highlighting a focus for future research and policy initiatives.
Title of project: Support Needs Study – focus group
Lead Investigator: Dr Morag Farquhar

Consent (patients & carers)

1. I confirm that I have read the information leaflet for the above study (version 2 13/05/2017). I have had the opportunity to consider the information, to ask questions and to have these answered satisfactorily.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my legal rights being affected.

3. I give my consent for audio-recording and typing up of the recordings made. I am aware that if I decide to withdraw from the study after taking part in a group discussion it will not be possible to withdraw my data.

4. I understand that any information I provide will be treated as confidential. However, the research team have a duty to report any safeguarding concerns disclosed in the focus group. I confirm that anonymous quotations from audio recordings may be used in research publications.

5. I understand relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

6. I agree to take part in the above study.

Signed …………………………………………………………… Date…………………………

Please write your name and address below:

Name: ……………………………………………………………………………………………

Address: ………………………………………………………………………………………
……………………………………………………………………………………………………

Post code: ………………………

One copy for participant; one for researcher  IRAS project ID: 223429  SNAP2 St1 Tk1-1 FG consent v2: 13/05/2017
Appendix 2: SNAP Tool Validation Study – Focus Group Topic Guide

GUIDE for SUPPORT NEEDS STUDY (SNAP 2) STAGE 1 TASK 1.1
– PATIENT FOCUS GROUPS

On ARRIVAL:

- Welcome, refreshments
- Consent process – information sheets available for all, answer any questions
- Expenses forms (where applicable)
- Name badges

STEP 1 - WELCOME:

- Formal welcome, thank you and introductions
- Ground rules to cover: keeping confidential the discussion within the group
- Short presentation of SNAP tool to set the scene

STEP 2 - TOPICS TO COVER:

1) Ask participants to read through the tool so that they can get a sense of how it works: (some may wish to complete it - stress confidential and that they do not need to share their answers)
   a) How did they find it?
   b) Were the instructions easy to understand?
   c) Was anything unclear?

2) For each tool item:
   a) Does the topic feel relevant for people with COPD?
   b) Is the wording ok?
   c) If you were to tick this item what sort of things might you expect to discuss with a HCP?

3) Show participants differently formatted versions of the tool:
   a) Which version do they like and why?
   b) What do they think of the name of the tool?

4) Which health care settings, and with which health care professionals, could you imagine sharing your completed tool, and why? (ask first as open question, then use the below prompts to facilitate discussion)
   a) Settings:
      i. primary care?
      ii. community care (at home / community clinic)?
      iii. hospital (outpatient / inpatient)?
   b) Health care professionals (by settings):
      i. primary care nurses?
      ii. GPs?
      iii. community respiratory team?
      iv. hospital respiratory nurses (outpatients)?
      v. hospital respiratory doctors (outpatients)?
      vi. hospital respiratory nurses (inpatients)?
      vii. hospital respiratory doctors (inpatients)?
      viii. other? Who?
STEP 3 - CLOSE:

- Exit question: Is there anything else you would like to say about support needs in COPD or how patients can be better supported?
- Close focus group and thank participants
- Remind all participants that a supportive contact is available – contact details on information sheet
- Outline next steps for the study
- Let participants know how the study findings will be disseminated and how they can access them
- Collect name badges

NOTE: if support required or requested on the day ask participant for permission to pass on their details to supportive contact and highlight supportive contact’s details on the information sheet
Appendix 3: SNAP Tool Validation Study - Postal Survey (including Patient Consent Form)

Support Needs Study
Postal Survey

Blank pages omitted
How to complete this booklet

This survey asks about your health, your concerns and areas where you feel you need more support.

Please complete the Consent Form on the next page, then complete the survey.

The survey is in five sections:

- Section 1 asks what support you might need
- Section 2 asks how your lung problem has been over the last two weeks
- Section 3 asks how you have been feeling over the past week
- Section 4 asks how your lung problem is now
- Section 5 asks for some general information

Each section has instructions on how to complete it. There are no right or wrong answers. We are just interested in your views.

When you have completed the survey and consent form, please return the whole booklet to the Support Needs Study team in the FREEPOST envelope provided (no stamp needed).

Please turn over.
Title of Project: **Support Needs Study – Postal Survey**

Lead Investigator: **Dr Morag Farquhar**

1. I confirm that I have read and understand the information sheet for the above study [version 1: 19/03/2017] I have had the opportunity to consider the information and ask any questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.

3. I understand that any information I provide will be treated as confidential.

4. I understand relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

5. I agree to take part in this study.

Signed ................................................................. Date.................................

Please write your name and address below:

Name: ..............................................................................................................

Address: ...........................................................................................................

..............................................................................................................

Post code: .....................................................................................................

*We will remove this page from your returned survey booklet so that your responses are anonymous.*
## Section 1. Your support needs now

We would like to know what support you need. Please tick the box that best represents your needs now, for each statement below.

<table>
<thead>
<tr>
<th>Do you need more support with ...........</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
</tr>
</thead>
<tbody>
<tr>
<td>understanding your illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>managing your symptoms (including medication and oxygen)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dealing with your feelings and worries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>looking after any other physical health problems you may have</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>having a healthier lifestyle (e.g. keeping active or eating well)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>getting out and about</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>overcoming boredom or loneliness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>financial, legal, work or housing issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>practical help in the home or garden</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your personal care (e.g. dressing, washing)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>equipment to help you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family relationships (including talking to your relatives about your illness)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>knowing what to expect in the future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>accessing or using services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>anything else - please write in:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Does your carer (family member or friend who helps you) need more support?

---

*Copyright © 2016 University of Cambridge. Morag Farquhar, Carole Gardener and Gail Ewing have asserted their moral right to be identified as authors of the SNAP tool. Please do not remove this notice from this or any copies. Copying and use of the SNAP tool is subject to agreement to the SNAP Licence Agreement Terms and Conditions. SNAP v1*
Section 2. Respiratory Questionnaire

These questions are designed to find out how you have been feeling during the last 2 weeks. On this page you will be asked about activities which make some people feel short of breath. Then you will be asked about how you have been feeling.

- Please read each question carefully and then place an "x" in the box beside the answer that best describes you.
- If you are unsure about how to answer a question, please give the best answer you can.
- If you would like to change an answer, put a line through the box you want to change. Place an "x" in the box beside the option you would like to choose instead.
- There are no right or wrong answers.

Below is a list of activities which make some people with lung problems feel short of breath. For each of the activities, put an "x" in the box that best describes how much shortness of breath you have had while doing that activity during the LAST 2 WEEKS.

The last column has been provided for you to tell us if you have NOT DONE an activity during the last two weeks. Place an "x" in one box on each line.

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>Extramey short of breath</th>
<th>Very short of breath</th>
<th>Quite a bit short of breath</th>
<th>Moderate shortness of breath</th>
<th>Some shortness of breath</th>
<th>A little shortness of breath</th>
<th>Not at all short of breath</th>
<th>Not done</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling emotional such as angry or upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Taking care of your basic needs (bathing, showering, eating or dressing)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Performing chores (such as housework, shopping for groceries)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Participating in social activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
These next questions ask you about your energy in general and how your mood has been during the LAST 2 WEEKS. Please put an "x" in a box, which best describes how you have felt.

6. In general, how much of the time during the LAST 2 WEEKS have you felt frustrated or impatient?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time  (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

7. How often during the LAST 2 WEEKS did you have a feeling of fear or panic when you had difficulty getting your breath?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time  (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

8. What about fatigue? How tired have you felt over the LAST 2 WEEKS?

1. Extremely tired
2. Very tired
3. Quite a bit of tiredness
4. Moderately tired  (Place an "x" in one box only)
5. Somewhat tired
6. A little tired
7. Not at all tired
9. How often during the **LAST 2 WEEKS** have you felt embarrassed by your coughing or heavy breathing?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

10. In the **LAST 2 WEEKS**, how much of the time did you feel very confident and sure that you could deal with your illness?

1. None of the time
2. A little of the time
3. Some of the time
4. A good bit of the time (Place an "x" in one box only)
5. Most of the time
6. Almost all of the time
7. All of the time

11. How much energy have you had in the **LAST 2 WEEKS**?

1. No energy at all
2. A little energy
3. Some energy
4. Moderately energetic (Place an "x" in one box only)
5. Quite a bit of energy
6. Very energetic
7. Full of energy
12. In general, how much of the time did you feel upset, worried, or depressed during the **LAST 2 WEEKS**?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

13. How often during the **LAST 2 WEEKS** did you feel you had complete control of your breathing problems?

1. None of the time
2. A little of the time
3. Some of the time
4. A good bit of the time (Place an "x" in one box only)
5. Most of the time
6. Almost all of the time
7. All of the time

14. How much of the time during the **LAST 2 WEEKS** did you feel relaxed and free of tension?

1. None of the time
2. A little bit of the time
3. Some of the time
4. A good bit of the time (Place an "x" in one box only)
5. Most of the time
6. Almost all of the time
7. All of the time

Please turn over
15. How often during the **LAST 2 WEEKS** have you felt low in energy?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

16. In general, how often during the **LAST 2 WEEKS** have you felt discouraged or down in the dumps?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time

17. How often during the **LAST 2 WEEKS** have you felt worn out or sluggish?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time (Place an "x" in one box only)
5. A little of the time
6. Hardly any of the time
7. None of the time
18. How happy, satisfied, or pleased have you been with your personal life during the **LAST 2 WEEKS**?

1. Very dissatisfied, unhappy most of the time  
2. Generally dissatisfied, unhappy  
3. Somewhat dissatisfied, unhappy  
4. Generally satisfied, pleased  (Place an "x" in one box only)  
5. Happy most of the time  
6. Very happy most of the time  
7. Extremely happy, could not be more satisfied or pleased  

19. How often during the **LAST 2 WEEKS** did you feel upset or scared when you had difficulty getting your breath?

1. All of the time  
2. Most of the time  
3. A good bit of the time  
4. Some of the time  (Place an "x" in one box only)  
5. A little of the time  
6. Hardly any of the time  
7. None of the time  

20. In general, how often during the **LAST 2 WEEKS** have you felt restless, tense, or uptight?

1. All of the time  
2. Most of the time  
3. A good bit of the time  
4. Some of the time  (Place an "x" in one box only)  
5. A little of the time  
6. Hardly any of the time  
7. None of the time  

Please turn over
Section 3. How you feel

This questionnaire is designed to help us know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week.

Don’t take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought-out response.

<table>
<thead>
<tr>
<th>I feel tense or ‘wound up’</th>
<th>I feel as if I am slowed down</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most of the time</td>
<td>Nearly all the time</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Very often</td>
</tr>
<tr>
<td>From time to time, occasionally</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I still enjoy the things I used to enjoy</th>
<th>I get a sort of frightened feeling like ‘butterflies’ in the stomach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely as much</td>
<td>Not at all</td>
</tr>
<tr>
<td>Not quite so much</td>
<td>Occasionally</td>
</tr>
<tr>
<td>Only a little</td>
<td>Quite often</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>Very often</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I get a sort of frightened feeling as if something awful is about to happen</th>
<th>I have lost interest in my appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very definitely and quite badly</td>
<td>Definitely</td>
</tr>
<tr>
<td>Yes, but not too badly</td>
<td>I don’t take as much care as I should</td>
</tr>
<tr>
<td>A little, but it doesn’t worry me</td>
<td>I may not take quite as much care</td>
</tr>
<tr>
<td>Not at all</td>
<td>I take just as much care as ever</td>
</tr>
</tbody>
</table>

[Please turn over]
<table>
<thead>
<tr>
<th>I can laugh and see the funny side of things</th>
<th>I feel restless as if I have to be on the move</th>
</tr>
</thead>
<tbody>
<tr>
<td>As much as I always could</td>
<td>Very much indeed</td>
</tr>
<tr>
<td>Not quite so much now</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Definitely not so much now</td>
<td>Not very much</td>
</tr>
<tr>
<td>Not at all</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worrying thoughts go through my mind</th>
<th>I look forward with enjoyment to things</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal of the time</td>
<td>As much as I ever did</td>
</tr>
<tr>
<td>A lot of the time</td>
<td>Rather less than I used to</td>
</tr>
<tr>
<td>Not too often</td>
<td>Definitely less than I used to</td>
</tr>
<tr>
<td>Very little</td>
<td>Hardly at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I feel cheerful</th>
<th>I get sudden feelings of panic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Very often indeed</td>
</tr>
<tr>
<td>Not often</td>
<td>Quite often</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Not very often</td>
</tr>
<tr>
<td>Most of the time</td>
<td>Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I can sit at ease and feel relaxed</th>
<th>I can enjoy a good book or radio or television programme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely</td>
<td>Often</td>
</tr>
<tr>
<td>Usually</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Not often</td>
<td>Not often</td>
</tr>
<tr>
<td>Not at all</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>
Section 4: How is your COPD?

Take the COPD Assessment Test™ (CAT)

This questionnaire will help measure the impact COPD (Chronic Obstructive Pulmonary Disease) is having on your wellbeing and daily life.

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy 0 0 2 3 4 5 I am very sad

I never cough 0 1 2 3 4 5 I cough all the time

I have no phlegm (mucus) in my chest at all 0 1 2 3 4 5 My chest is completely full of phlegm (mucus)

My chest does not feel tight at all 0 1 2 3 4 5 My chest feels very tight

When I walk up a hill or one flight of stairs I am not breathless 0 1 2 3 4 5 When I walk up a hill or one flight of stairs I am very breathless

I am not limited doing any activities at home 0 1 2 3 4 5 I am very limited doing activities at home

I am confident leaving my home despite my lung condition 0 1 2 3 4 5 I am not at all confident leaving my home because of my lung condition

I sleep soundly 0 1 2 3 4 5 I don’t sleep soundly because of my lung condition

I have lots of energy 0 1 2 3 4 5 I have no energy at all
Section 5: About you

This last section asks for general information about you. This will help us to understand more about you and your answers to the questions so far. Please tick or write your answer in the boxes provided.

1. Are you ....?

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
</table>

2. How old are you?

Age in years: ______

3. How long have you had your lung problem?

<table>
<thead>
<tr>
<th>Less than 5 years</th>
<th>5-10 years</th>
<th>More than 10 years</th>
</tr>
</thead>
</table>

4. Which health care professional gives you the most support with your lung problem? (please tick one box only)

<table>
<thead>
<tr>
<th>GP / family doctor</th>
<th>Practice nurse</th>
<th>Community respiratory nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital doctor</td>
<td>Hospital nurse</td>
<td>Other (please specify):</td>
</tr>
<tr>
<td></td>
<td></td>
<td>None</td>
</tr>
</tbody>
</table>

5. Is there someone who gives you help and support other than a care professional? (a family member or friend)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

6. If you answered “Yes” to question 5, is that person....?

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
</table>

7. If you answered “Yes” to question 5, is that person your....? (please tick one box only)

<table>
<thead>
<tr>
<th>Wife / husband / partner</th>
<th>Daughter / son</th>
<th>Daughter-in-law / son-in-law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other family member</td>
<td>Friend / neighbour</td>
<td>Other (please specify):</td>
</tr>
</tbody>
</table>

Please turn over 17
8. Do you live on your own?

Yes [ ] No [ ]

9. Is there a car or a van available to your household?

Yes [ ] No [ ]

10. How old were you when you left full time education?

Age left full time education (in years): [ ]

11. What has been your main occupation during your working life?

Main occupation during working life: [ ]

12. How would you describe your ethnicity?
   (please tick one box only)

White [ ] Chinese [ ]
Black or Black British [ ] Mixed [ ]
Asian or Asian British [ ] Other ethnic group (specify): [ ]

THANK YOU

Please check that you have completed the consent form on page 4, then return the whole booklet to the Support Needs Study team in the FREEPPOST envelope provided
(no stamp needed)
Appendix 4: SNAP Pilot Qualitative Study - Healthcare Professional Consent Form

Title of project: SNAP2 Study (Stage 2) – Health care professionals
Lead Investigator: Dr Morag Farquhar

Consent (health care professionals)    ID number: ......................

Please initial box

1. I confirm that I have read the information leaflet for the above study (version 2 30/04/2018). I have had the opportunity to consider the information, to ask questions and to have these answered satisfactorily.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my legal rights being affected.

3. I consent to participating in the SNAP training workshop, as outlined in the above information leaflet.

4. I consent to participating in the SNAP pilot, as outlined in the above information leaflet.

5. I consent to participating in the SNAP end of pilot focus group, as outlined in the above information leaflet.

6. I give my consent for audio-recording and typing up of the recordings made. I am aware that if I decide to withdraw from the study after taking part in a group discussion it will not be possible to withdraw my data.

7. I confirm that anonymous quotations from audio recordings may be used in research publications and health care professional training.

8. I understand that the information collected may be used to support other research in the future, and may be shared anonymously with other researchers (secondary analysis).

9. I understand that any information I provide will be treated as confidential. However, the research team have a duty to report any safeguarding concerns disclosed.

10. I agree to take part in the above study.

Signature of participant: .................................................. Date: ............... 

Signature of person taking consent: ........................................... Date: ...............
Appendix 5: SNAP Pilot Qualitative Study - Healthcare Professional Workshop Topic Guide

Note to REC: This topic guide is designed to explore the views of health care professionals within a training workshop – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise. The workshop will involve additional SNAP training material interwoven with the topic area questions.

TOPICS for SNAP2 STAGE 2 TASK 2.2
HEALTH CARE PROFESSIONAL WORKSHOPS

On ARRIVAL:
- Welcome, refreshments
- Consent process – information sheets available for all, answer any questions
- Name badges

STEP 1 - WELCOME:
- Formal welcome and thank you
- Ground rules to cover: keeping confidential the discussion within the workshop

TOPICS TO COVER DURING THE TRAINING WORKSHOP:

Current practice
1. Thinking about your current practice, how do you identify the support needs of patients with Chronic Obstructive Pulmonary Disease (COPD)?
   - Are there any barriers to identifying their support needs?
   - What are the positives?
   - What are the limitations?

2. And how do currently support patients with COPD? How do you respond to those needs?

Person-centred care
3. What does the term person-centred care mean to you?

4. Is person-centred care something you manage to integrate into your current practice?
   - If so, how?
   - Are there any barriers to delivering person-centred care?

SNAP tool
5. What do you think of the SNAP tool?
   - Relevance of domains?
   - Reactions to domains [do HCPs see them as domains or needs?]
Note to REC: This topic guide is designed to explore the views of health care professionals within a training workshop – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise. The workshop will involve additional SNAP training material interwoven with the topic area questions.

**Delivering SNAP**

6. How do you see SNAP working within your setting?
   - Do you see any potential benefits to using SNAP?
   - Or any disadvantages?

7. What aspects of your current practice will support the delivery of SNAP?
   - Or make the delivery of SNAP difficult?

8. What might need to change to support the integration of SNAP into your practice?

**STEP 3 - CLOSE:**

- Close workshop and thank participants
- Remind all participants of monthly contacts with study team (as a minimum)
- Remind all participants that an issues contact is available – contact details on information sheet
- Collect name badge
Appendix 6: SNAP Pilot Qualitative Study - Healthcare Professional Monthly Contacts

Note to Reader: This is a guide for monthly telephone interviews – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise.

**Monthly Follow-up Contact with Health Care Professionals**

<table>
<thead>
<tr>
<th>HCF ID. No.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Today’s date &amp; type of contact (phone / in-person)</td>
<td></td>
</tr>
<tr>
<td>Date &amp; type of last contact</td>
<td></td>
</tr>
<tr>
<td>Consent verbally confirmed?</td>
<td></td>
</tr>
<tr>
<td>Audio-recording no.</td>
<td></td>
</tr>
</tbody>
</table>

1. How is it going? How have you got on with working with SNAP? (listen for barriers & facilitators)
2. Are there any immediate issues with working with SNAP that we should talk through?
3. How many patients with COPO have you seen since last contact/call? (Log introduced at training)
4. How many patients have you used SNAP with since the last contact/call? (Log introduced at training)

Note to Reader: This is a guide for monthly telephone interviews – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise.

5. Which domains (items) do you find are coming up/being prioritised?
6. What sort of needs come up in this domain?
7. How have you responded?
8. Were patients able to suggest support they might find helpful?
9. Talk through an example of working with SNAP
10. Roughly how much additional time is it taking to work with SNAP within consultations? (Range & estimate of average per patient – in minute(s)
11. How is the mail out of recruitment packs going?
12. Do you need any more consent forms? SNAP tools?
13. Anything else?
Appendix 7: SNAP Pilot Study HCP Focus Group – Topic Guide

Note to REC: This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise. The topic guide covers the four broad topics within Normalisation Process Theory (Coherence, Cognitive Participation, Collective Action and Reflexive Monitoring) but the questions will be iteratively refined through Tasks 2.2-2.4.

GUIDE for SNAP2 STAGE 2 TASK 2.5
HEALTH CARE PROFESSIONAL FOCUS GROUPS

On ARRIVAL:

- Welcome, refreshments
- Consent process – information sheets available for all, answer any questions
- Completion of background details and NoMAD ice-breaker questionnaire
- Name badges

STEP 1 - WELCOME:

- Formal welcome, thank you and introductions
- Ground rules to cover: keeping confidential the discussion within the group
- Focus is on SNAP, rather than the process of running the study
- Short recap of SNAP

STEP 2 - TOPICS / QUESTIONS TO COVER:

1. Introduction
   - What was your first reaction when you heard about SNAP, or saw the SNAP tool?

2. Training
   - After the training how confident were you that you understood what SNAP involved?
     - How confident were you that you understood SNAP? i.e. the approach
     - After the training was what you had to do to enable SNAP clearly defined in your mind?
     - How long after the training did you start using SNAP?
   - How was the training for you?
     - Too short/too long
     - Style

3. Preparation for SNAP within the clinical setting
   - Who were the key people driving the use of SNAP in your organisation?
     - Who was keen to get involved and why?
     - What did they do?
   - Did you, or anyone else, have any reservations? What were they?
     - Tool itself?
     - The approach?
     - Using it in a particular context/ with a particular patient?
Note to REC: This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users [PPI], clinicians, and research team expertise. The topic guide covers the four broad topics within Normalisation Process Theory (Coherence, Cognitive Participation, Collective Action and Reflexive Monitoring) but the questions will be iteratively refined through Tasks 2.2-2.4.

- In addition to the training, what work needed to be done to support SNAP being used in your organisation?
  - Planning? Management? Administration?
  - Record systems?
- Who took on these tasks/roles?
  - Team effort or one person?
- Were people happy to be involved with this?
- Have you had sufficient resources to support the use of SNAP?
  - What else might have helped? Management support?

4. Using SNAP in your clinical practice

- Talk us through an exemplar of working through the SNAP steps:
  - Domain > need > action
  - How easy is it to follow the different steps for SNAP?
  - How easy is it to integrate SNAP into your existing work?
- How long does it take to deliver SNAP?
  - Shortest / longest / average per patient
- As a team/practice how far do you think you share similar ideas about the aims, processes and outcomes of SNAP?
  - Do you have different ideas about how to use it in clinical practice?
  - Are there differences between professional groups in the team?
    - e.g. doctors, nurses, admin staff, HCAs
- Are you the right HCPs to be using it? Or would other professional groups/settings be more appropriate? Why?

5. Evaluation

Your evaluation

- How is SNAP different to your previous approach to identifying patients’ needs?
- Has SNAP identified anything unexpected? Or had any unexpected effects?
- Have you made any changes to the processes that support SNAP?
- Do you feel using SNAP has been worthwhile?

Patients’ evaluation

- Have you had feedback from patients on SNAP?
  - How have you responded?
- Has it had an impact, positive or negative, on patients and their care?
  - Does it allow you to tailor your support to the individual needs of patients?

Team evaluation

- Have you appraised SNAP as a team? How?
  - Discussed at team meetings? Shared examples with colleagues?
- Has it had an impact, positive or negative, on other staff?
  - Does it support, or disrupt, the wider work of the team?
Note to REC: This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise. The topic guide covers the four broad topics within Normalisation Process Theory (Coherence, Cognitive Participation, Collective Action and Reflexive Monitoring) but the questions will be iteratively refined through Tasks 2.2-2.4.

6. Going forward

- Will you continue to use SNAP?
  - As an individual?
  - As a team?
- If Yes - what do you need to make that happen?
  - Senior management support
  - Peer support [within team? SNAP champions network?]
  - Resources
  - Training
- If No – why not? What would encourage you to give it another go?

- Is there anything else you’d like to share about taking part in the SNAP pilot? (e.g. anything about the study itself)

STEP 3 - CLOSE:

- Close focus group and thank participants
- Remind all participants that an issues contact is available – contact details on information sheet
- Collect name badge
Appendix 8: SNAP Pilot - Patient Interview Consent Form

Title of project: Support Needs Study (patient interviews)
Lead Investigator: Dr Morag Farquhar

Consent (patient interviews)                   ID number: .........................

1 I confirm that I have read the information leaflet for the above study (version 2 30/04/2018). I have had the opportunity to consider the information, to ask questions and to have these answered satisfactorily.

2 I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my legal rights being affected.

3 I give my consent for audio-recording and typing up of the recordings made. I confirm that anonymous quotations from audio recordings may be used in research publications and health care professional training.

4 I understand that the information collected may be used to support other research in the future, and may be shared anonymously with other researchers (secondary analysis).

5 I understand that any information I provide will be treated as confidential. However, the research team have a duty to report any safeguarding concerns disclosed.

6 I understand that relevant sections of data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.

7 I agree to take part in the above study.

Signature of participant: ................................................................. Date: ................

Signature of person taking consent: .................................................. Date: ................
Appendix 9: SNAP Pilot - Patient Interview Topic Guide

**Note to REC:** This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise.

**SNAP2 STAGE 2 TASK 2.4**

**Patient Interview Topic Guide**

Questions are a guide only

**Topic 1: Background**

- Can you tell me a little bit about your lung problem: how long you have had it and how it affects you?
- Which health care professionals do you see on a regular basis in relation to your lung problem?

**Topic 2: Usual care**

- Does [your HCP] usually take the lead at your appointments, or do you?
  - And how is that for you? Is that what you prefer?
- Does [your HCP] usually take the lead in decision-making or planning your care, or do you?
  - And how is that for you? Is that what you prefer?

We are interested in talking to you about the *How are you?* booklet which was sent to you by your [setting] and which you filled in and discussed with your [HCP]. The following questions are about your experience using the booklet.

**Topic 3: Completing the booklet [give patient a blank SNAP tool as reminder]**

- How did you get the *How are you?* booklet?
  - In the post? At an appointment?
  - Was it OK getting it that way?
  - Would you prefer to get it another way?
- What did you think when you first saw it?
- Did the instructions make sense? Did you understand what you needed to do with it?
- Did the questions make sense?
Note to REC: This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise.

- **THINK ALOUD**: Can we look through the booklet together and talk about what each of the questions means to you?

- Did the questions on it feel relevant for people with lung problems?
  - Anything missing?

- Tell me about your experience of filling it in:
  - Did you get help from anyone else to fill in the booklet?
  - Or discuss it with someone else?
  - Why did you tick the things you did? [Individual needs within domains]
  - Were there any (other) difficulties with filling it in? If so, what would make it easier?

**Topic 4: At the appointment**

- Did you bring your 'How are you?' booklet with you to your appointment with your [HCP]? If not, what happened? (Where completed? Time to fill it in?)

- Tell me about your appointment with your [HCP]
  - How did you find sharing your filled-in booklet with your [HCP]?
  - What did you discuss?
  - Did your [HCP] focus on the things you highlighted on the booklet?
  - If you ticked more than one question, did your [HCP] ask which one was the most important to you? Did they find out what was your priority?

- How, if at all, was the appointment different from previous appointments?
  - Do you think you talked about things you might not have otherwise?
  - Did the booklet help? In what way?
  - What prevented you raising these concerns before?

- Can you tell me about a particular concern you identified, and what happened as a result?
  - Do you feel you had any part in deciding what should happen?

- Did anything stop you discussing things that you would like to have raised at your appointment?
  - Barriers to highlighting them on the booklet
  - Barriers to discussing within the appointment

- Overall what did you feel about your appointment? How did it go? (just the same as others?)

Topic guide SNAP2 SII Tsk2 4 Patient v1 24/02/2018
Note to REC: This is a guide for a focus group – it acts as a guide to the operational steps and topic areas to be covered, informed by preparatory work with users (PPI), clinicians, and research team expertise.

**Topic 5: Future appointments**

- Do you think the booklet might be useful in future appointments with your [HCP]?  
  - In what way?  
  - Probe: how often/when?

- Do you think the booklet might be useful with different health care professionals/ settings/ types of appointments? [probe – who/ where/ when]

- Do you have any thoughts on what we should call the booklet?

**Closing Question**

- Is there anything else you’d like to tell me about the booklet, your appointment, or about taking part in the study?

Remind patient about supportive contact – contact details on information sheet
References


78. Cramp F and Bennett MI. Development of a generic working definition of ‘supportive care’. *BMJ Supportive &amp;amp; Palliative Care* 2013; 3: 53. DOI: 10.1136/bmjspcare-2012-000222.
79. NICE guideline: Supportive and palliative care draft scope for consultation 31 December 2015 2016. NICE.
95. Cordingley L, Hughes J and Challis D. *Unmet need and older people: towards a synthesis of user and provider views*. 2001. PSSRU, Faculty of Medicine, Dentistry, Nursing and Pharmacy, University of Manchester.


106. Kane RA. Goals of home care: Therapeutic, compensatory, either or both? *Journal of Aging and Health* 1999; 11.


*CASP Qualitative Studies Checklist*, https://casp-uk.net/casp-tools-checklists/ (accessed 04/05/2021).


166. Högberg KM, Stockelberg D, Sandman L, et al. The meaning of web-based communication for support: from the patients’ perspective within a hematological healthcare setting.


183. McIlfatrick S. Assessing palliative care needs: views of patients, informal carers and healthcare professionals.


215. Guyatt G and Schünemann H. The self-administered Chronic Respiratory Questionnaire Standardized (CRQ-SAS) and Individualized version (CRQ-SAI) – Background Information and Interviewing Suggestions. . 2001. McMaster University, Canada.


221. British Lung Foundation. [https://statistics.blf.org.uk/copd?gclid=Cj0KCQiA-onjBRDSARisAEZXckbLpL5qROE1fkEoPy9ko7CoEZkWECkYn0loml7FFv_dQde0PjKmisaAiBKEALw_wcB](https://statistics.blf.org.uk/copd?gclid=Cj0KCQiA-onjBRDSARisAEZXckbLpL5qROE1fkEoPy9ko7CoEZkWECkYn0loml7FFv_dQde0PjKmisaAiBKEALw_wcB) (accessed 12/02/2019).


