Development of a core set of clinical care provision indicators for non-specialist palliative care in hospitals

A thesis submitted to the University of Dublin, Trinity College, in fulfilment of the requirements for the Degree of Doctor of Philosophy

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Declaration

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Summary

Background: Ageing populations with associated chronic illnesses and multi-morbidity will lead to a rapidly escalating need for all levels of palliative care provision. This will place significant pressures on health systems to optimise the utilisation of all resources, including hospital-based care. For most patients presenting to hospital with palliative care needs, these needs can be met by healthcare providers who do not work within specialist palliative care services. However, integrating non-specialist palliative care (NSPC) within acute care delivery in hospitals is challenging and requires multi-level organisational support. Therefore, this study seeks to explore NSPC, to understand the issues associated with the delivery of NSPC in hospitals, and to use the knowledge gained to develop core clinical care provision indicators for NSPC in hospitals. These can provide a basis to support multi-level integration of NSPC in the hospital care setting.

Aim: To develop a core set of clinical care provision indicators (CCPIs) for non-specialist palliative care in hospitals.

Methods: This study had three distinct, yet complimentary phases;

- Phase I: A principle-based concept analysis; to analyse terminology associated with this care, how the concept of NSPC is currently understood, and key attributes of NSPC from multiple philosophical perspectives;
- Phase II: A qualitative systematic review; to explore the experiences, barriers and facilitators of NSPC from the views of healthcare providers engaged in NSPC provision in hospitals to understand relevant contextual issues for the provision of NSPC in hospitals;
- Phase III: A Delphi study to identify, through International consensus, core CCPIs for NSPC in hospitals, and to make recommendations for future policy, practice, research and education.

Findings: A total of 124 papers were included in the concept analysis of NSPC. Findings from this phase uncovered diverse meanings and definitions employed to describe NSPC reflecting the ambiguous nature of the concept. Attributes of NSPC were identified with various degrees of operationalization/abstractness but were generally poorly measured and understood in practice. NSPC was found to be strongly associated with quality of life, holism and patient-centred care. While there was some consistency in meaning across healthcare disciplines, there was blurring of boundaries particularly with specialist palliative care and a lack of clear roles and boundaries within NSPC provision.

Phase II included a total of thirty-nine papers (reporting on thirty-seven studies). Thematic synthesis produced four dominant themes relating to inadequate knowledge and competency in NSPC, poor communication between healthcare providers, and with patients, particularly in relation to worsening prognosis, differing perspectives of nurses and doctors relating to their perceived role in NSPC provision, and several environment issues that impacted on providers ability to provide adequate NSPC.

The findings from phases I and II were used to inform an initial list of 34 CCPIs which were presented to participants in round one of the Delphi study (phase III). A further 12 indicators, based on participants' suggestions, were added following round 1. A total of seventy-two of 97 experts (e.g. healthcare providers, patients, researchers) from twelve countries participated in the final Delphi round (74% overall response rate). Consensus was achieved on 32 core CCPIs for hospital-based NSPC with: five structural indicators (relating to infrastructure and governance), 21 organisational indicators (relating to clinical care processes) and six staff indicators (relating to training and support for healthcare providers).

Discussion and Conclusion: This study presents an advancement of the conceptual basis of NSPC and a greater understanding of the contextual issues associated with NSPC practice in hospitals. The core set of 32 CCPIs for NSPC in hospitals developed in this study reflect the fundamental palliative perspective of total pain and whole person care, highlighting the importance of a multidisciplinary approach for the provision of NSPC in hospitals, the interface between NSPC and specialist palliative care, and the essential training needs for NSPC providers. These core CCPIs incorporate multi-level guidance for clinical practice, policy and research for NSPC in hospitals. They provide a means to assess, review, and communicate the essential elements required to integrate NSPC within hospitals, thereby setting a benchmark for informing policy and practice.

Publications and Presentations Relating to this Thesis

Peer-Reviewed Publications

Nevin M., Hynes G., Smith V. (2020). Healthcare Providers' Views and Experiences of Non-Specialist Palliative Care in Hospitals: A Qualitative Systematic Review and Thematic Synthesis. *Palliative Medicine.* Vol. 34(5) 605-618 (Impact Factor 4.956)

Nevin M., Smith V., Hynes G. (2019). Non-Specialist Palliative Care. A Principle-Based Concept Analysis. *Palliative Medicine*. Vol. 33(6) 634-649 (Impact Factor 4.956)

Nevin M., Hynes G., Smith V. (2019). Development of Core Indicators for Non-Specialist Palliative Care in Hospitals – An International Modified Delphi Study. *Annals of Oncology 30* (Supplement 5)

Nevin M., Smith V., Hynes G. (2018). Non-Specialist Palliative Care: A Concept Analysis. 10th World Research Congress of the European Association for Palliative Care. Bern, Switzerland, 24-26 May 2018. *Palliative Medicine* 32 (IS) 3-330

Oral Presentations

Nevin M., Smith V., Hynes G. (2020). Integrating Non-Specialist Palliative Care in Hospitals – An International Modified Delphi Study. Irish Association of Palliative Care, Annual Educational and Research Seminar, Richmond Education and Event Centre, Dublin, Ireland. 6 February 2020

Nevin M., Smith V., Hynes G. (2019). *Development of Core Indicators of Non-Specialist Palliative Care in Hospitals – An International Modified Delphi Study.* EONS12 the European Oncology Nursing Society Congress at ESMO 2019 Congress, Barcelona, Spain. 28 September 2019

Nevin M., Smith V., Hynes G. (2019). *Non-Specialist Palliative Care: Current state of play: A Concept Analysis*. Trinity Health and Education International Research Conference, Dublin, Ireland. 6 March 2019

Nevin M., Smith V., Hynes G. (2018). *Palliative Care is Part of Everyone's Job - The Education and Training Needs of Non-Specialist Palliative Care (NSPC) Practitioners; Findings from a Concept Analysis.* 22nd International Congress on Palliative Care, Palais des Congrès, Montréal, Canada, October 2-5, 2018

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Poster Presentations

Nevin M., Hynes G., Smith V. (2019). *Healthcare Providers' Views and Experiences of Non-specialist Palliative Care (NSPC) in the Acute Care Hospital Setting: A Systematic Review.* 16th World Congress of the European Association for Palliative Care, Berlin, Germany, May 23-25, 2019

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Nevin M., Hynes G., Smith V. (2019). *Healthcare providers' views and experiences of Non-Specialist Palliative Care (NSPC) in the acute care hospital setting: A Systematic Review.* Trinity Health and Education International Research Conference, Dublin, Ireland. 6 March 2019

Nevin M., Hynes G., Smith V. (2018). *Non-specialist Palliative Care (NSPC) in the Acute Care Hospital Setting: A Systematic Review***.** 22nd International Congress on Palliative Care, Palais des Congrès, Montréal, Canada, October 2-5, 2018

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Glossary

AIIHPC	All Ireland Institute for Hospice and Palliative Care
CCPIs	Clinical Care Provision Indicators
CDC	Consensus Development Conference
DET	Data Extraction Tool
EAPC	European Association for Palliative Care
GP	General Practitioner
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IAHPC	International Association for Hospice and Palliative Care
NACPC	National Advisory Committee on Palliative Care
NGT	Nominal Group Technique
NICE	National Institute for Health and Care Excellence
NSPC	Non-Specialist Palliative Care
PIL	Patient Information Leaflet
SPC	Specialist Palliative Care
WHA	World Health Assembly
WHO	World Health Organisation

Definitions of Key Concepts

Palliative Care

Palliative care is considered an approach to care that *'improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual problems'* (World Health Organisation 2002, p. 84). It is the responsibility of all healthcare providers working with people with life-threatening conditions to provide palliative care.

Palliative Care Need

A palliative care need is considered a physical, social, psychological or spiritual need of someone with a life-limiting or life-threatening illness.

Non-Specialist Palliative Care

Palliative care that is provided by healthcare providers who do not work within specialist palliative care services. For many people with life-limiting conditions, palliative care delivered by their usual treating team can be sufficient to meet their needs.

Specialist Palliative Care

Some people with life-threatening illness who experience complex physical, psychological, social or spiritual problems will require referral to a specialist palliative care service. These services have palliative care as their core speciality and are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

Clinical Care Provision Indicator

For the purposes of this study an indicator of NSPC is considered a statement that describes an aspect of NSPC which is relevant within the hospital care environment.

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Chapter 1 Introduction to thesis

1.1 Introduction to topic

Palliative care, synonymous traditionally with a cancer diagnosis (Milligan 2018) has evolved to include patients with complex multiple problems, who need care over a lengthy period of time, and not just in their last days and weeks of life (Temel *et al.* 2010, Ferrell *et al.* 2017, Gärtner *et al.* 2019, National Clinical Programme for Palliative Care 2019). Palliative care is thus diffuse throughout everyday healthcare practice and everyone working in healthcare who has direct contact with patients should have, at a minimum, basic knowledge of palliative care (World Health Organisation 2002, Radbruch & Payne 2009, World Health Assembly 2014). In addition, as a result of the rising burden of chronic diseases and ageing populations the global need for palliative care will increase (Connor & Sepulveda Bermedo 2014, Morin *et al.* 2016). This is very pertinent within an Irish context where annually, 80% of deaths are from conditions considered to have palliative care needs (National Clinical Programme for Palliative Care 2019). This necessitates optimal utilisation of all facets of the health system, including hospitals (Gott & Robinson 2018). Healthcare providers working in hospitals have substantial exposure to patients with palliative care needs, with many of these patients dying in hospital. For example, in exploring place of death, half of the 45 included populations reported that 54% or more of all deaths in their population occurred in hospitals (Broad *et al.* 2013). Other research has identified that people in their last year of life are high users of inpatient hospital services (Clark *et al.* 2014), and for most of these patients, their palliative care needs can be met without necessarily requiring a referral to Specialist Palliative Care services (Clark *et al.* 2014).

In the context of hospital care, however there is strong evidence to support the view that many patient groups such as those with chronic illnesses have unmet palliative care needs (Murray & Boyd 2011, Gardiner *et al.* 2013a, Hynes *et al.* 2015). Studies of healthcare providers in hospitals working outside of specialist palliative care services have highlighted difficulties such as engaging in conversations with patients regarding poor prognosis, complex and uncertain disease trajectories, role uncertainty, and integrating palliative care within an acute care workload, as issues which contribute to difficulties in providing palliative care in this setting (Gott *et al.* 2012, Kirby *et al.* 2014, Hynes *et al.* 2015, Bergenholtz *et al.* 2016, Chan *et al.* 2018). Increasing the capacity to support palliative care within everyday hospital practice to meet the future needs of the patients it serves necessitates a major change in core assumptions about the organisation and delivery of acute care, requiring a multi-level approach to change (Ingram 2014, Hynes *et al.* 2015).

In acknowledging the bodies of knowledge surrounding the global developments of palliative care in a variety of care settings, for example the community, for clarity, the focus of this thesis relates to palliative care for adults within the general hospital care setting only. Also, while arguably palliative care provision in the context of maternity, paediatric and mental health hospitals may be similar to that of adult general hospitals (Department of Health and Children 2009, Van Hoover & Holt 2016, Sheridan *et al.* 2017), it is likely that many differences also exist. For this reason, and to optimise homogenous contextual enquiry, it was decided that exploring palliative care provision within these respective settings was beyond the scope of this thesis.

1.2 Background

While this thesis relates to the topic of palliative care, conceptual understandings of palliative care can differ. For example, the earliest conceptualisation of palliative care focused on terminal care or care associated with the last days and weeks of life (Saunders 1978, World Health Organisation 1990). In this thesis, the contemporary, broader conceptualisation of palliative care, such as that provided by the World Health Organisation (WHO) 2002 as an approach to care that *'improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual problems'* (World Health Organisation 2002, p. 84) is adopted.

This study further focuses on palliative care provision outside of the role of Specialist Palliative Care services, that is Non-Specialist Palliative Care, as defined in the context of this research study. Palliative care can be delivered within different levels of expertise. For example, in some national policies a two-step ladder of care is advocated (Ministry of Health 2015, Palliative Care Australia 2018), while in other literature, and in Irish palliative care policy a three-step ladder of palliative care provision is described (Figure 1) (Radbruch & Payne 2009, Northern Ireland Practice and Education Council 2011, African Palliative Care Association 2012, National Clinical Programme for Palliative Care 2019).

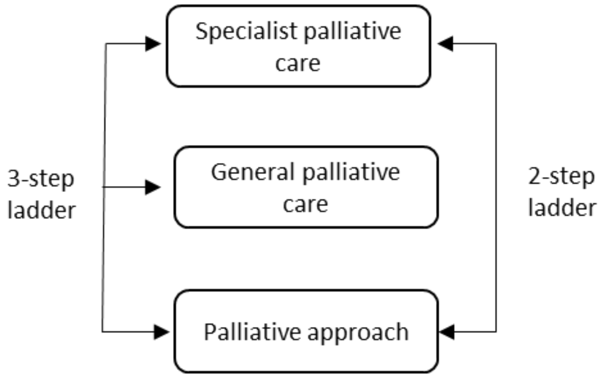


Figure 1 Two and three-step ladders of palliative care provision

In a 3-step ladder of care, level 1 (a palliative care approach) should be used by healthcare providers to integrate palliative care principles in settings and services that only occasionally treat patients with palliative care needs. Level 2 (general palliative care) is provided by healthcare providers more frequently involved in palliative care, who may have acquired special education and training in palliative care but do not provide palliative care as the main focus of their work (Radbruch & Payne 2009). Lastly, level 3, Specialist Palliative Care (SPC), is provided by a multidisciplinary specialist palliative care service whose sole activity is the provision of palliative care, for patients with complex palliative care needs. Inconsistencies relating to terminology which describes the role of healthcare providers who do not work within SPC provision exist, for example, 'generalist palliative care', 'a palliative care approach', 'primary palliative care', and 'basic palliative care' have been identified in the literature, and are discussed in greater detail in Chapter 4 of the thesis. For the purposes of this thesis, the term Non-Specialist Palliative Care (NSPC) is used, specifically, to describe the palliative care role of healthcare providers who do not work solely within SPC provision.

Palliative care has an important role to play in the management of non-malignant life limiting illnesses (Mitchell *et al.* 2010, Afshar *et al.* 2015, Gadoud & Johnson 2015, Hynes *et al.* 2015). Its benefits are well supported in the literature as an early intervention in a wide range of illnesses (Dalgaard *et al.* 2014, Johnston *et al.* 2015, Ferrell *et al.* 2017, Gärtner *et al.* 2017), or for anyone experiencing 'serious health related suffering' (Knaul *et al.* 2018). However, the body of evidence pointing to the integration of palliative care early in hospitals largely emanates from intervention studies relating to integration of SPC services (Temel *et al.* 2010, Gaertner *et al.* 2017, Groenvold *et al.* 2017). Furthermore, although there have been calls to measure and evaluate the effectiveness of NSPC provision (Shadd *et al.* 2013, Grubbs *et al.* 2014, Bergenholtz *et al.* 2015a), in principle it is very difficult to evaluate quality of care without clear understanding and guidance as to what that care entails. Terminology associated with NSPC is inconsistent (Ministry of Health 2015, Gärtner *et al.* 2019) and no framework exists as to how NSPC specifically should be operationalised throughout all organisational levels within the hospital care setting to support NSPC integration.

Palliative care policy in Ireland (discussed in greater detail in Chapter 2) since 2001 has supported the need to increase the capacity of all healthcare providers to deliver palliative care (Dept of Health and Children 2001, National Clinical Programme for Palliative Care 2019). Although practitioner competencies, as required by disciplines for everyday practice of NSPC, are available (Ryan *et al.* 2014), guidance for the provision of hospital based NSPC beyond healthcare provider competencies, that reflect organisational support for its integration are not provided. Thus, clarity of how NSPC may be understood, and establishing core clinical care provision indicators for NSPC that reflect organisation support for the adoption, and implementation of NSPC is required. This would provide hospitals with a means to establish their degree of NSPC integration and monitor their progress towards meaningful, relevant NSPC provision and support current policy.

1.3 Purpose of thesis

The purpose of this thesis is to describe the development of and to present a core set of Clinical Care Provision Indicators (CCPIs) for NSPC in hospitals. In achieving this, the study was conducted in three distinct, yet complimentary phases as follows:

- Phase I: A concept analysis; to analyse how the concept of NSPC is currently understood from multiple philosophical perspectives;
- Phase II: A systematic review; to explore the experiences, barriers and facilitators of NSPC from the views of healthcare providers delivering NSPC in hospitals;
- Phase III: A Delphi study to identify, through International consensus, core CCPIs for NSPC in hospitals, and to make recommendations for future policy, practice, research and education.

1.4 Personal background to the topic

The origins of my interest in palliative care emanated from my experiences of working as a nurse with patients in a busy surgical ward of an acute hospital, where I often witnessed intense suffering. I conscientiously undertook my clinical duties in providing patient care, but often felt despondent at the end of my shift, frustrated that I could not fully meet the needs of many of the patients I cared for. I did not fully understand the reasons for this at the time, but this changed for me when I began working with the Irish Cancer Society as a night nurse caring for dying patients and their families in their own homes. I was asked to contribute a piece to a national newspaper about this work (Appendix 1). It was through this process of reflection, and writing this article, that I began to compare my experiences of working in hospitals as opposed to caring for patients in their own homes. Working alongside patients and families in their homes triggered a seismic shift in how I understood the nature of my relationship with patients, and of the influence that the hospital environment had on me as a practitioner. Working in people’s own homes, being able to spend time, to really listen to their needs, having more freedom to make decisions, and influence their care caused me to realise how constrained I felt in providing hospital-based care, particularly in relation to my inability to provide the level of attention beyond their physical needs that I felt those who were most sick really needed from me. What these patients and families in their own homes taught me was that impending death did not have to mean defeat, or that a ‘battle’ was lost, nor that there was little I could offer, which was something I had always struggled with working in the hospital environment. Hope can not only remain in the face of a life limiting illness and impending death, but people still had an incredible amount of very important wishes even in their last days and hours; to die surrounded by loved ones, to be free of pain and suffering, not to be a burden, and to be remembered.

Around this time I also read a journal paper titled *'That's part of everybody's job': the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care* (Gott *et al.* 2012) which impacted on me greatly. Reading this study, which was based on hospitalists' perspectives of palliative care was the first time I realised that I actually had a role in palliative care provision while working as a general nurse in the hospital setting. The issues with embedding palliative care in routine acute hospital care as identified in this paper, such as lack of understanding and unclear boundaries with SPC, resonated with many of the frustrations I had personally experienced and held, perhaps somewhat sub-consciously. The result for me was a genuine desire to understand this problem and through intellectual pursuits, attempt to uncover and offer solutions that ultimately might result in, or at a minimum, contribute to improved palliative care for patients in hospital. In 2015, I was successfully awarded a HRB Research Training Fellowship for Healthcare Professionals to undertake my study, which I commenced in 2016. This provided me with the privileged opportunity to focus exclusively on my research and has led to this PhD thesis.

1.5 Format of thesis

This thesis is presented in nine chapters. In Chapter **two** the context to this study is provided. This addresses the broader topics of the modern hospice movement, a philosophy of palliative care, the development of palliative care globally, and within the hospital care setting. Addressing these areas were critical, I believed, in providing context to the literature regarding NSPC.

Chapter **three** introduces the study and describes the philosophical and methodological issues associated with this research project. It includes a discussion of the ontological and epistemological perspectives that underpin the study. The methodological approaches that framed the development of the three phases of the study are then presented.

Chapters' **four to seven** present the findings of the study. In chapter **four**, the methods and findings of phase I of the study, a concept analysis of NSPC are presented. Chapter **five** describes phase II of the study and presents the methods and findings of a qualitative systematic review of the experiences of healthcare providers of NSPC in hospitals. Chapter **six** describes the work undertaken to prepare an initial list of CCPIs of NSPC extracted from phases I and II. While chapter **seven** details the methods, ethical issues and findings of phase III of the study; a Delphi study, which sought to achieve international consensus on a core set of CCPIs for NSPC for hospitals.

Chapter **eight** discusses the main findings of the study with reference to the existing body of knowledge. This chapter also addresses the strengths and limitations of the study.

Chapter **nine** concludes the thesis and presents directions for future research in light of the findings. This includes recommendations for practice, education, palliative care policy, and future research, and also includes a national and international dissemination plan and personal reflection.

Chapter 2 The study in context

2.1 Introduction

This chapter presents an exploration of the literature to provide context and rationale for this study of NSPC in hospitals. To understand the complexities of NSPC it was first necessary to explore the origins and philosophy of palliative care and the emergence of the modern hospice movement. How palliative care has evolved at various levels of care provision, and global trends are then discussed including the evolution of palliative care internationally and within an Irish healthcare context. Palliative care in hospitals is then examined. The chapter concludes with a discussion of current clinical guidance for palliative care provision in hospitals.

2.2 Origins of Palliative care and development of the modern hospice movement

To understand the origins of palliative care and the modern hospice movement, it is necessary to explore the origins of western medicine in the Greek world. Two general traditions of healthcare have been described; Asclepius and Hippocrates (Savel & Munro 2014). The focus of medicine, according to Asclepius tradition, was both mythical and spiritual. This tradition stressed healing from within oneself, in the context of accepting our mortality. People with incurable illnesses who sought relief of suffering, through a process of acceptance and meaning-making, invoked Asclepius' name in prayer in healing ceremonies in temples. The second, newer tradition of medicine (Hippocrates) assumes a very different perspective which is rooted in the scientific approach. Diseases were thought to follow patterns, treatments are developed to cure, knowledge is generalizable, the emphasis is on external intervention, and, in a sense, the individualism of the patient experience is lost (Radall & Downie 2006). Originally, although these traditions of 'cure' and 'heal' were polarised approaches to health and illness, they thrived in coexistence, and patients benefited from both approaches. However, through the developments of modern medicine, and healthcare, it is arguably the Hippocratic 'cure' tradition, and evidenced based medicine that has come to dominate (Savel & Munro 2014, Gamble *et al.* 2019). This resulted in an approach that viewed death as the enemy, whereby diseases always had to be 'fought', and patient's dignity and quality of life in the face of this fight was of lesser concern.

Modern palliative care has its origins in hospice care. Hospices were originally places of rest for travellers in the 4th century (Bradshaw 1996). These early hospices evolved, and the concept of hospice developed through the middle ages and into the 18th and 19th century, becoming associated with places for the dying run by religious orders in both Ireland and London (Clarke 2016). The ideas of acceptance, fulfilment and meaning in illness, central to the Asclepius tradition, mirror that of the early religious influence on the care of the dying. These were the forerunner for what has become known as the modern hospice movement.

One of the founders of the modern hospice movement was Dame Cicely Saunders (1918-2005), a nurse, social worker and doctor. Her introduction was through her work with the dying in St. Joseph's Hospice for the Dying Poor, which was run by the Irish Sisters of Charity in London since 1905. Saunders and colleagues, responding to the perceived neglect of dying patients by physicians established St. Christopher's Hospice in England in 1967 (Clark 2018). The hospice movement focused on the quality, rather than length of life during the course of a disease. The widely lauded success of St Christopher's hospice led to the rapid development of the hospice movement in the USA, Canada and Australia through the 1970s and onwards. Other pioneers who were considered instrumental in laying the groundwork for the hospice movement in the USA included Elizabeth Kubler-Ross' work with dying patients (Kubler-Ross 1975). Also, Florence Wald, who amongst others were responding to the perceived excessive use of life-prolonging advances in medical technology, which led to the founding of Connecticut Hospice, the first hospice program in the United States. Canadian Professor Balfour Mount was also instrumental in spreading the hospice movement throughout North America. Mount subsequently coined the term 'palliative care' in place of the term 'hospice', which had custodial connotations in French speaking parts of Canada (Saunders 2006).

These early pioneers of the modern hospice movement, often religiously motivated, were responding to concerns about the dignity and care of the dying. For those who pioneered the hospice movement, many medical interventions were believed to merely slow the process of dying and led to much suffering. Jaspers *et al.* (2010) describes how this increasing unease about modern medicine is set within the cultural context of the 1960s-1970s and a general backlash against the established political environment. Saunders and her fellow pioneers were reacting in a sense, to the perception that death was medical failure and something to be hidden away (Bradshaw 1996). The common goal for all the early pioneers of palliative care was to provide care for people who were dying, while also developing increasing specialist pain management skills and knowledge (Mount 2013). Saunders was adamant that her intention to develop hospice care outside the National Health Service (NHS), was in order to have the freedom to develop and realise her vision which could then be applied within the NHS (Clark 2018). This voluntary banding together of concerned people, and the momentum at which the early hospices spread internationally, has resulted in some likening it to a social movement (Greer 1986, Elsey 1998). The modern hospice movement represented a separation from mainstream medicine; a counter movement from care directed at disease or patho-physiological cure, to one of healing. As to whether modern day palliative care bears any relationship to this social movement is explored further in section 2.4.

2.3 A philosophy of palliative care

While differences exist as to how a philosophy of care is articulated, ranging from less interventionist to more technical approaches, for the purpose of this thesis, a philosophy of palliative care is described in terms of the core assumptions, values and beliefs that underpin palliative care (Bruce *et al.* 2014). For the early pioneers of the hospice movement, their philosophy of palliative care was underpinned by the concept of a 'good death' (Floriani & Schramm 2012). Death was not something to be feared, rather the dying and their families should be embraced, and death could be peaceful and meaningful with close observation and the appropriate interventions. Saunders adopted a multidimensional view of the person (Clark 2018). A dominant feature of Saunders's papers was her description of the nature of the relationship between physical and mental suffering (Saunders 1960, 1967). She articulated this most comprehensively within the concept of 'total pain' which she identified through her multidisciplinary experiences as a nurse, social worker and doctor. Total pain was understood as the totality of patients suffering to include physical symptoms, mental, social and spiritual pain (Saunders & Baines 1983, Saunders *et al.* 1995). Frequently, Saunders simply referred to total pain as 'all of me is wrong', which was reportedly said by one of her patients (Saunders & Clark 2006). This approach to the care of dying people and those close to them focussed on the inter-related aspects of human suffering that can occur in the experience of terminal illness.

Saunders views and beliefs about pain and suffering were heavily influenced by both her strong Christian religious faith and the work of Victor Frankl (Frankl 1975). Frankl, a prisoner, in Nazi concentration camps experienced transcendence, and believed that if a person could find meaning in their suffering, this ceases to be suffering in some way. In this sense, in all situations where suffering comes about, the meaning of the occurrence to the person and the person's perception of the future are crucial. Since palliative care implies a certain engagement with mortality, then any discussion about palliative care occurs on the basis of the fundamental nature of the meaning of life, what makes life worthwhile, or what constitutes a good life and death for an individual. Although not specifically referencing 'total pain', this multidimensionality of the pain experience has also been explored in the wider healthcare literature (Cassell 1982, Fricchione 2011, Hutchinson 2011).

The professional mandate to relieve suffering as a goal of medicine and nursing has been articulated by several researchers (Cassell 1982, Ferrell & Coyle 2008, Cassell 2011, Hutchinson 2011). In 1982 Eric Cassell published a seminal paper on suffering. The essence of Cassells description is that suffering is a specific distress, involving self-conflict, that occurs when one feels that their integrity, or intactness as a person is threatened, and will continue until the threat is resolved or integrity is restored (Cassell 1982, 1991). In this sense suffering is always individual. For example, even in two people suffering from identical sources for example, an above knee amputation, they will suffer the way they do because of the particulars of *who they are* (Mehta & Chan 2008). Furthermore, people with no physical symptoms may suffer, such as the family member witnessing the pain of a loved one who is ill, while others many deny suffering even while in extreme physical pain, for example during childbirth. Frankl also makes this distinction between sickness and suffering (Frankl 1975, Frankl 1984). Cassell aligned his views on the relief of suffering to that of whole person care, whereby whole person care means focusing scientific knowledge and clinical expertise on the main obligation in medicine – the relief of suffering in sick patients (Cassell 2011, Hutchinson 2011). To do this requires the person to be viewed as a whole, and not just a collection of symptoms or disease. With treatment, there is always hope for cure, but one also hopes to be healed during the process. If a cure is not possible, the patient can still die healed. What is important is having a sense of wholeness as a person, at any stage of the disease.

Revisiting the Asclepios healing tradition of medicine, the word ''heal' originates from the Anglo-Saxon word 'haelon', which means 'to make whole'. Therefore, terms such as 'whole person care' and 'holism' became terms synonymous with palliative care philosophy (Radall & Downie 2006). Mount (2013) describes this as a paradigm shift in health care from the diagnostic and therapeutic models to a model of care that also embraces whole person care. Similarly, Saunders concept of total pain and suffering imbues the notion of total care, a central constituent of palliative care (Clark & Seymour 1999). To this end Saunders, in 1978 presented an early list of components for palliative care (Saunders 1978), which included;

- An emphasis on management by an experienced team, with recognition of the inter-professional dynamics which valued the contribution of all staff involved;
- Recognition of the significance and complexity of total pain and the need for expert symptom control;
- Recognition of the family as the unit of care;
- The need for skilled and experienced staff, recognising the importance of additional training;
- The importance of the physical space for patients and families;
- Bereavement support, acknowledging the loss and grief experiences of families;
- The need to mix patient groups such as long-term care and hospice care to provide a sense of community, and avoid 'death labelling';
- Effective central administration to support easy access to the service.

Saunders made it clear in later writings that these components for palliative care could be applied to all those who cared for patients with terminal illness. These components do not presuppose that the patient should be in a hospice, rather they can be interpreted and developed anywhere, and the skills of a special team may never be needed (Saunders & Baines 1983, Saunders *et al.* 1995). In this sense the original articulation of Saunders philosophy of palliative care was conceived for all healthcare providers and as such represents the very first articulation of NSPC. Although the components for palliative care, and the ideas provided by Saunders (1978) informed the development of palliative care internationally, major variations exist, and the concept of 'hospice' has been embraced differently across various countries and health systems depending on the local context. For example, in the USA a separate trajectory emerged of 'hospice' based on homecare and a federal reimbursement of hospice costs via Medicaid and Medicare (welfare systems for older people and the very poor in the USA). Hospice care has been defined bureaucratically in terms of a statutory set of reimbursable clinical events, with the focus on home-based specialist nursing (Osterweis & Champagne 1979, Connor 2007, Buck 2009, 2011). As a consequence, in the USA, the term palliative care tends to be restricted more to hospital-based specialist care (Morrison 2013).

2.4 Palliative care – becoming mainstream

Several innovations occurred within the period of 1948-1967 in the UK, which constituted an emerging specialised focus of palliative care within medicine and healthcare. There was a shift in focus from anecdotal writings to the systematic observations of the dying in the professional literature, and a growing recognition of an interdependency between physical and mental distress (Clarke 2016). Ideas about the dying process emerged which sought to foster concepts of meaning and dignity, and to examine the extent to which patients should know about their fate (Saunders 1965, Saunders 1967, Clark 2018). There was also a move towards an active rather than passive medical approach to the care of the dying, which constituted a response to perceptions of the medical neglect of the dying, and potentially an expansion of medical dominance (Clark 2007, Clarke 2016). Since the 1960's the focus of knowledge development in pain and symptom control has resulted in the evolution of palliative care into a recognised sub-speciality of medicine, first registered in the UK in 1987. Since then many other countries have followed suit, such as New Zealand, Australia and the USA, and over sixteen countries in Europe (Clark 2007, Bolognesi *et al.* 2014). Ireland, in 1995 became the second country in Europe to recognise this distinct medical speciality (Bolognesi *et al.* 2014). Albeit in much more recent terms, the development of specialist palliative nursing has also gained momentum, however the numbers of advanced nurse practitioners providing SPC internationally are relatively unknown (Kennedy & Connolly 2018).

Since palliative care as a medical speciality ‘arrived’ on the global stage in 1990, much palliative care research activity has produced studies which have described the development, role and impact of SPC services, and environments of care. Areas of further palliative care specialisation, beyond cancer, the disease that had defined the approach of the hospice pioneers, slowly began to appear – for example in cardiology, renal medicine, stroke, respiratory disease and neurological conditions (Afshar *et al.* 2015, Gadoud & Johnson 2015, Braun *et al.* 2016). The medical model of palliative care was gathering strength, with studies demonstrating that SPC benefits patients with malignant and non-malignant chronic health conditions, providing relief from their symptoms, improving their quality of life, reducing aggressive end of life treatments, and healthcare costs (Ahmedzai *et al.* 2004, Dickens 2004, Downing 2005, Hupcey *et al.* 2009, De Lima *et al.* 2012, Toye *et al.* 2012, Linnemann *et al.* 2016, Isenberg *et al.* 2017, Triplett *et al.* 2017). Various social circumstances have also been explored in relation to palliative care needs such as the homeless (Klop *et al.* 2018), migrants (Jansky *et al.* 2019), and prison inmates (Maschi 2014) to name a few.

The discourse around why palliative care should only be initiated when a disease is no longer responding to treatment and a person is dying also gained significant traction. This earlier initiation of palliative care, and a move away from its association solely as ‘terminal’ or ‘end of life’ which implies a relatively short time-line, where death is imminent, was possibly fuelled by a need for this new medical specialty to claim its own clinical territory, skills and evidence base. There was a proliferation of studies evaluating the involvement of SPC services alongside acute care treatments (Higginson *et al.* 2014, Davis *et al.* 2015, Vanbutsele *et al.* 2018), and the term ‘early palliative care’ is often synonymous in clinical practice, solely with SPC interventions (Gärtner *et al.* 2019). The evidence base for early referral to SPC intervention emerged which argued that early SPC care not only improved quality of life for patients but also reduced unnecessary hospitalizations and use of health-care services (Bakitas *et al.* 2009, Gaertner *et al.* 2013, Zimmermann *et al.* 2014).

Some studies, however, applied vague definitions of ‘specialist’ palliative care or did not distinguish between support by a specialist team or NSPC, such as in two meta-analyses which reported higher quality of life associated with early palliative care (Kavalieratos *et al.* 2016, Haun *et al.* 2017). Also, in a review of randomised trials (Davis *et al.* 2015) which examined early integration of outpatient (n=15 studies) and home palliative care (n=13 studies), the authors concluded that definitions of ‘early’ palliative care differed vastly. Furthermore, ‘usual’ care was poorly described, and study designs and procedures were frequently flawed. Evidence that early SPC intervention can increase life expectancy has also emerged from the USA (Temel *et al.* 2010, Hoerger *et al.* 2018). Although this was actually an incidental finding of the Temel (2010) study, whose intention was to measure the effect of early SPC on quality of life and mood, findings which have not been replicated in

Europe (Groenvold *et al.* 2017). Prolonging life was never the goal of the original pioneers of the modern hospice movement, and any future palliative care interventions with the aim of doing so, I would argue, constitutes a major reorientation of the fundamental philosophy and goal of palliative care. Simply put, while there is a body of evidence to support the early involvement of SPC, the nature and extent of the professional working relationship between SPC and NSPC providers is not clearly articulated in these studies. A systematic review conducted by Firn *et al.* (2016) found that NSPC providers reported benefits to the clinical care they provide when a supportive and collaborative relationship with SPC services is fostered. Therefore, reported improvements in the quality of life of the patients in those early SPC studies could potentially also be attributed to better NSPC, although this effect is not known.

After initially occupying a somewhat outcast position in mainstream healthcare provision (Clark 2007), the hospice movement arguably now operates very much within the main systems of care, operationalised for example through increasingly more hospices and SPC services in hospitals (Floriani & Schramm 2012). The effect of this ‘social legitimation’ of the hospice movement (Clark & Seymour 2002), and mainstreaming of palliative care has given rise to criticism about the increasing ‘routinization and bureaucratisation’ of the original hospice ethos (Bradshaw 1996). Also, from Saunders’ early description of palliative care, there had always been a strong emphasis on multidisciplinary care. Authors in the 1990’s began to argue that palliative care had become increasingly medicalised, with medicine dominant over other health professionals working within palliative care provision, and an emphasis away from care of the dying person towards symptom control (James & Field 1992, Field 1994, Corner & Dunlop 1999). Dangers of this increasing medical specialisation of palliative care have been expressed in terms of the creation of a reductionist and rigid service whereby the prevailing medical voice subsumes others, and the elements of total pain that are most amenable to measurable parameters, such as physical pain, prevail (Radall & Downie 2006, Royal College of Physicians of London 2007, Floriani & Schramm 2012, Hynes *et al.* 2015).

2.5 Palliative care in Ireland – origin and policy context

Palliative care in Ireland originated in the voluntary sector with the establishment, by religious orders, of St. Patrick’s Hospital in Cork and Our Lady’s Hospice in Dublin as centres for the dying in the late 19th century. Similar to other services such as intellectual disability, palliative care continues to be associated with volunteering, advocacy, community and not-for profit organisations (May *et al.* 2014). From the late 1980’s provision of palliative care services expanded beyond the hospices and into hospital and community/homecare settings. Two key organisations working in the area of palliative care were formed in the 1980s and the early 1990s. The Irish

Hospice Foundation (IHF) was founded in 1986 and the Irish Association for Palliative Care (IAPC) was established in the early 1990s. Since Ireland registered palliative care as a medical speciality in 1995, development of services has tended to be uneven, and there was wide variation in the availability of SPC throughout the 1990's (Health Service Executive 2017). The social and political influence of palliative care in Ireland continued to grow however (May *et al.* 2014), and Ireland, in 2001 became one of the first countries in the world to publish a dedicated national palliative care policy titled *Report of the National Advisory Committee on Palliative Care (NACPC)* (Dept of Health and Children 2001). It is this document that has formed the basis of many national reports, guidelines and strategic frameworks that have emerged in Ireland since its original publication.

The NACPC comprehensive policy mapped out a strategy for the development of palliative care services, and explicitly stipulated for the development of services beyond specialist-centred care. Three distinct levels of palliative care were identified (Figure 2), and it was proposed in this policy that all palliative care services needed to be structured in a manner that provided for these levels of specialisation. This supports the requirement that palliative care be embedded in everyday practice and that everyone working in healthcare who has direct contact with patients should have, at a minimum, basic knowledge of palliative care.

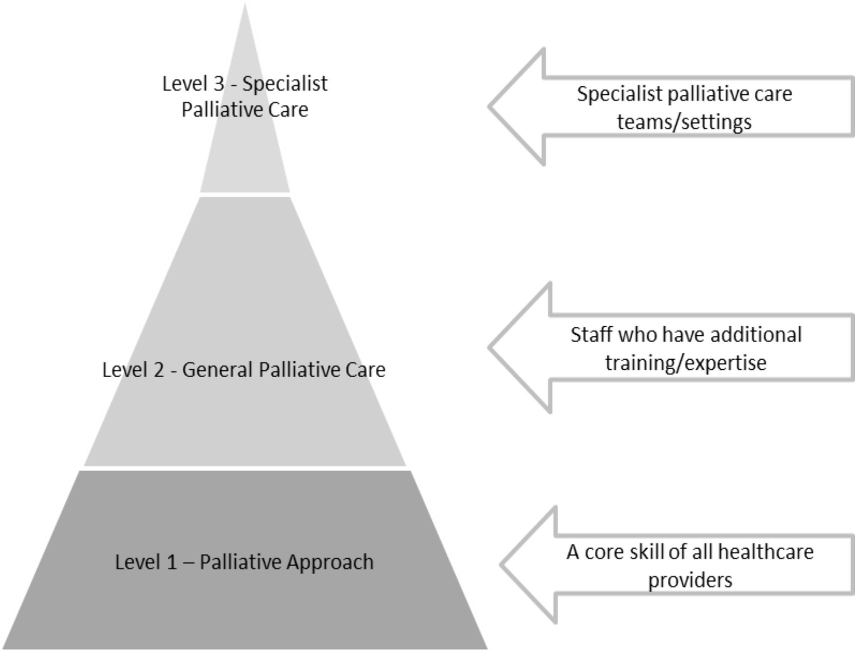


Figure 2 Levels of palliative care in ascending order from Level 1-3

Many recommendations relating to all three levels of palliative care provision arose from the NACPC report (Dept of Health and Children 2001). Subsequent reports that reviewed the progress of this policy however, and provided direction for future palliative care services, focused heavily on identifying gaps within, and prioritising current and future service needs solely in the provision of hospice/SPC (Irish Hospice Foundation 2006, Health Service Executive 2008). Little attention was initially given to the development of level 1 and 2 palliative care provision (NSPC) which could serve as a basis to develop future work at these levels. The National Clinical Programme for Palliative Care, which was established in 2010 as a joint initiative of the HSE Clinical Strategy and Programmes Division and the Royal College of Physicians (Health Service Executive 2011), once again emphasised the need to develop palliative care beyond the provision of SPC services. Work began to support this, and subsequently a palliative care needs assessment guidance (National Clinical Programme for Palliative Care 2014a), and palliative care competency framework was published in 2014 (Ryan *et al.* 2014). This framework outlined core competencies and competencies specific to 12 health and social care disciplines for all three levels of palliative care provision. The purpose of this framework was to inform academic curricula and professional development programmes and to encourage inter-professional and inter-organisational collaboration in palliative care provision at all levels. This once again firmly placed NSPC on the national agenda.

Since 2014, however, a similar pattern of solely level 3, SPC service development and evaluation publications has emerged (National Clinical Programme for Palliative Care 2014b, Health Service Executive 2015, 2017). Most recently, an adult palliative care services model for care in Ireland has been published to support the provision of 'best practice' (National Clinical Programme for Palliative Care 2019). However, guidance for the provision of hospital based NSPC beyond healthcare provider competencies, that reflects organisational support for its integration is not provided. Furthermore, while International comparisons indicate that palliative care in Ireland is rated highly (Arias-Casais *et al.* 2019), many inequities in the provision and access to these level 3 SPC services in Ireland have also been reported (Irish Hospice Foundation 2013, Lolich & Lynch 2017).

2.6 Embedding palliative care principles in everyday practice - NSPC

Cassell (2011) criticised advances in modern medicine for not only failing to relieve suffering, but for often intensifying suffering. Cicely Saunders warned that new technologies and more effective specific treatments of diseases has still left much suffering unaddressed (Saunders 2001). Although advocated by the early pioneers of the hospice movement, by the World Health Organisation (WHO) and in government policies (Saunders *et al.* 1995, Dept of Health and Children 2001, World Health Organisation 2002), the palliative care role of healthcare providers who do not work within SPC services has not received much attention in the literature. Some early academic commentators warned that the consequences of not nurturing and harnessing the concurrent contribution of 'generalists', in palliative care provision, would lead to future unsustainable and ineffective palliative care provision (Higginson 1999, McLaren *et al.* 1999). The lack of investment in the development of the role of NSPC, is evidenced from many perspectives. Studies have highlighted concerns among healthcare providers on how to engage in end of life related conversations with patients (Gott *et al.* 2012, Lewis *et al.* 2017, Thorn & Uhrenfeldt 2017), and in responding to the notion of suffering and loss that are common features associated with living with chronic illness (Lewis *et al.* 2017). Other work has also highlighted the fundamental conflict between the disease-oriented language of acute care and that of palliative care, contributing to difficulties in realising palliative approaches to care of patients with advanced chronic illness (Hynes 2011, Hynes *et al.* 2015, Cooper *et al.* 2018). In short, the concept of total pain which underpins that of palliative care, conflicts with the more disease-oriented focus of acute care.

Similar issues regarding early initiation of palliative care concurrent with acute care arose within a sample of SPC clinicians in a study from Australia within a SPC unit of an acute hospital (Michael *et al.* 2016). These authors sought to implement a model of early SPC integration, as opposed to the existing end of life model. These staff providing SPC found managing patients' concurrent palliative and acute care needs stressful, it required a faster-paced work-life, which detracted from emotional care and challenged their reported fundamental palliative care principles (Michael *et al.* 2016). Uncertain and complex disease trajectories are also viewed as important factors in research studies examining why NSPC provision is proving to be problematic (Murray *et al.* 2005, Murray & Boyd 2011, Gott *et al.* 2013, Gomes 2015, Rosenwax *et al.* 2016). Conflation of palliative and end of life care remains a persistent challenge, resulting in late referral of patients to SPC services and less focus on palliative care in the early phase following a life-limiting diagnosis (Hupcey *et al.* 2009, Gaertner *et al.* 2013, Merel *et al.* 2014). Also, where palliative care delivered by healthcare providers working outside of SPC features in the published literature, variability in terminology such as 'a palliative approach', 'generalist palliative care', 'basic palliative care', or 'NSPC' exists (discussed in greater detail in Chapter 4). This, consequently, has a direct impact on how palliative care delivered by those outside of the SPC sphere is understood and operationalized in policy and practice.

Although embedding palliative care principles in everyday practice requires competence and commitment at an individual practitioner level, to optimise palliative care provision, integration within care structures and care environments is also required (Taylor *et al.* 2015, Curry *et al.* 2018). The term 'integrated palliative care' is described as bringing together aspects such as organisational, clinical and service elements to provide continuity of care between all those involved in the care network of patients receiving palliative care (Hasselaar & Payne 2016). Based on a systematic review, existing integrated palliative care models in Europe were found to be lacking and considerably varied in their design; the interface between SPC and NSPC was not clear, and direct comparisons between palliative care models could not be made (Siouta *et al.* 2016). A taxonomy of integrated palliative care initiatives has been developed by Ewert *et al.* (2016). This taxonomy provides a useful conceptual basis to develop future integrated palliative care. However, to fully embrace palliative care provision, the role of NSPC providers should be prominent and clearly described in any future integrated palliative care model if the global demands for palliative care are to be met.

2.7 Palliative care as a global concern

Paradoxically, although the original hospice movement was conceived and developed outside of mainstream healthcare delivery systems, palliative care has evolved as an agenda for all healthcare systems, and Saunder's 'total pain' approach to relieve suffering is embedded within the WHO (1990) definition of palliative care. This document produced by the WHO was viewed as the first major international endorsement of palliative care, where the WHO urged policy makers and care providers to see palliative care as a major global health challenge. The concept of total pain remains a central theme within the most recent definition of palliative care provided by the WHO, which references the; *"impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual"* (World Health Organisation 2002, p. 84).

In view of the expanding definition of the patient with palliative care needs, and based on estimates of future palliative care need, there is a need for palliative care to rediscover its origins and develop the capacity of NSPC providers to meet future demands. The World Health Assembly (the governing body of the WHO) issued a resolution in 2014 calling on all governments to integrate palliative care into their health plans (World Health Assembly 2014). This has reaffirmed palliative care's place on the international public health agenda. This was followed by the Lancet Commission Report on Pain and Palliative Care (Knaul *et al.* 2018). This report recommended that palliative care was suitable for anyone with 'serious health related suffering' and highlighted an 'access abyss' in relation to available palliative care and pain relief. The Commission estimated that nearly half of all deaths worldwide in 2015 involved people dying with serious health related suffering. In addition to this, another 35.5 million people experienced serious health-related suffering but did not die. Several other authors have articulated population-based demand for palliative care describing how the global need for palliative care will rise as a result of the rising burden of non-communicable diseases and ageing populations (Lynch *et al.* 2013, Connor & Sepulveda Bermedo 2014, Morin *et al.* 2016, Etkind *et al.* 2017). A recent report projected that by 2060, an estimated 48 million people (47% of all deaths globally) will die with serious health-related suffering, which represents an 87% increase from 26 million people in 2016 (Sleeman *et al.* 2019).

Ireland has been highlighted as one of the countries with the highest need for palliative care globally (The Economist Intelligence Unit 2015), as a result of our ageing population, between 2011 and 2031, and an estimated increase in deaths in Ireland of 27% (Central Statistics Office 2017). A study undertaken by Kane *et al.* (2015) has estimated that the minimal level of palliative care need in Ireland is considerable, with 80% of deaths in Ireland annually from conditions considered to have palliative care needs. Mainstream health and social care systems are struggling in the face of a mounting need to deliver palliative care for all who could benefit from it (World Health Assembly 2014). Efforts to include NSPC as an important public health solution are principally visible within primary palliative care initiatives which are NSPC driven (Milligan 2012, Abel & Kellehear 2016). Following a review of literature, Dempers & Gott (2017) identified three different paradigms of a public health approach to palliative care. These are the WHO approach, which focuses on systems at country level, a health-promotion approach focusing on empowerment at community level, and a population-based approach, which typically views palliative care issues from an epidemiological perspective (Dempers & Gott 2017). Although what these paradigms encompass and the nature and extent of NSPC involvement is very much determined by the complexities of each healthcare system such as culture, beliefs, finance, and access to SPC (Stjernsward *et al.* 2007, Kellehear 2013, Sallnow *et al.* 2016, Zaman *et al.* 2017, Whitelaw & Clark 2019). Based on the population estimates described above, the rapidly rising demand for palliative care globally requires optimal utilisation of all components of service delivery within the health system, including hospitals (Gott & Robinson 2018). How best to address the NSPC needs of the people who are cared for within the hospital environment however, has received much less attention and is discussed in detail in the following section.

2.8 Palliative care in hospitals

Hospitals have occupied a relatively ambiguous position within the provision of palliative and end of life care (Cohen *et al.* 2012, Clark *et al.* 2014), and is not considered a preferential place to die (Higginson *et al.* 2017). Cicely Saunders' vision for palliative care was that it could apply beyond hospice settings, and that the basic principles could be delivered by anyone caring for terminally ill patients (Saunders & Baines 1983). Before her death, and upon reflection on her life's work, Saunders herself regretted that although palliative care is a philosophy not based on physical facilities but on attitudes and skills, the original concentration in a building, at least in the UK at St.

Christopher's Hospice, tended to outweigh the emphasis on healthcare providers role in the provision of palliative care in other settings (Saunders 2001).

Due to the vast differences in the provision of healthcare globally, there is no universally agreed definition of a hospital (English *et al.* 2006). However it is generally accepted that hospital services may include emergency care, urgent care, short term stabilisation, scheduled care, trauma, acute surgery and critical care (Health Service Executive. 2018). Hospitals have an important role in the care of people with palliative care needs (Gott & Robinson 2018). Estimates indicate that the likelihood of dying in hospital varies between countries but is generally high. For example, an international comparison of over 16 million deaths reported in 45 populations found that half reported 54% or more of all deaths occurred in hospitals (Broad *et al.* 2013). In Ireland, approximately 43% of all deaths occur in an acute hospital (13,000 people) (Irish Hospice Foundation 2014b), while 60% of all deaths are attributed to chronic illnesses (Health Service Executive & The Irish Hospice Foundation 2009). Place-of-death statistics however do not provide the full representation of hospitalisations near the end of life, nor do they consider those patients with chronic advanced disease, or serious health related suffering who may benefit from palliative care in hospitals. For example, although the numbers of deaths in hospitals in England has reduced from 58% (Broad *et al.* 2013) to 48% (Bone *et al.* 2018), a trend of increasing emergency hospital admissions in the year before death has also been observed (Marie Curie 2018). Furthermore, Clark *et al.* (2014) reported that nearly 30% of an entire Scottish hospital inpatient cohort died within 12 months of their hospital admission.

Other than ageing populations with increasing palliative care need there could be other factors which contribute to the increasing role of the hospital in palliative care provision. Some researchers have indicated social reasons such as the decline in family size and other community supports (Fahey & Field 2008, Canavan 2012). Other authors have pointed to the 'medicalisation of everyday life' (Szasz 2007, McKeown *et al.* 2010c). This predisposes individuals to think of life's difficulties, including dying, as abnormal or pathological, and leads institutions such as hospitals to offer 'treatments' for these difficulties (Clark 2002). In summary, healthcare providers working in hospitals have significant exposure to patients with palliative care needs, and for most of these patients, these reflect non-specialist rather than SPC needs (Clark *et al.* 2014).

The establishment of formal palliative care services in hospitals is relatively recent, occurring since the 1970's. Heavily influenced by Cicely Saunders, Balfour Mount established a ward for the dying at the Royal Victoria Hospital in Canada in 1973, followed shortly by the introduction of a palliative care team in St. Thomas' hospital London in 1976. Since then the numbers of hospital-based SPC teams has proliferated (Clark 2007). Various models for delivering SPC in hospitals are currently in existence internationally such as multi-disciplinary SPC consultation teams, SPC outpatient services, or dedicated SPC inpatient wards or ward area within an acute hospital (Milligan 2012). However, a national audit in the UK in 2014 found that only 21% of hospitals provide access to SPC seven days per week, despite national recommendations that they do so, and only 2% provided 24-hour access (Royal College of Physicians of London 2014). In Ireland, approximately 38 of the 42 acute general hospitals have access to dedicated SPC teams, with most of the teams providing services five days per week within office hours. All hospitals have access to on-call telephone support for advice from SPC teams, however large variations exist in staffing levels of these SPC teams (Brick *et al.* 2015). Even when there are SPC teams in place in the acute hospital setting, they may not operate well, and quality of care can depend on the hospital that the patient receives care in (Milligan 2012). Inconsistencies in referral pathways and in SPC provision have also been identified as significant barriers to effective palliative care provision (Cohen *et al.* 2012). Some SPC services only take referrals from certain patient groups (Gardiner *et al.* 2012), and often SPC services receive inappropriate referrals, or engage in care that should be delivered by NSPC providers (Gott *et al.* 2011, Kulkar 2011). These inconsistencies in the provision of SPC services in hospitals highlight the importance of developing the capacity of NSPC providers so as to provide comprehensive and responsive hospital-based palliative care. Furthermore, within the context of acute hospital care, there is strong evidence to support the view that many patient groups in hospital have unmet palliative care needs; as far back as 1995, the SUPPORT study of 10,000 seriously unwell patients, in five American hospitals, found that many patients suffered prior to death, predominately due to pain and poor doctor-patient communication (Connors *et al.* 1995).

The reporting of unmet palliative care needs in hospitals continues to be a concern (Murray & Boyd 2011, Gardiner *et al.* 2013a, Hynes *et al.* 2015), and the reasons for this appear to be varied. There is some evidence on hospitalist NSPC providers' perceptions of their role in palliative care delivery. Issues such as role uncertainty (Gärtner *et al.* 2019) and concerns regarding uncertain and complex disease trajectories have been identified (Murray & Boyd 2011, Cohen *et al.* 2012, Kavalieratos *et al.* 2014). Lack of resources and time (Gélinas *et al.* 2012, Fink *et al.* 2013, Firn *et al.* 2016, Glogowska *et al.* 2016), and a lack of preparation for imminent death (Witkamp *et al.* 2015) are also described. In Ireland, a survey of doctors and nurses working in hospitals (n=737) found that these hospital-based healthcare providers, at that time, were actually less likely to favour dying in hospital than the general public (McKeown *et al.* 2010a, 2010b).

A more recent Canadian ethnographic study of NSPC in hospital medical departments suggested that poor NSPC delivery in hospitals may be caused by a clash between the curative versus healing traditions of care (Chan *et al.* 2018). It could be that unlike hospices where a core healing philosophy permeates throughout the organisation, there is a much greater conflict of opposing philosophies in the hospital care environment. The intensive medical model of acute care in the hospital setting supports this as a central value through its physical and organisational structures (Hynes 2011). However the culture of hospitals must become more attuned to the high proportion of inpatients in imminent need of end of life care (Clark *et al.* 2014). Embedding NSPC in everyday hospital practice necessitates a major change in core assumptions about the organisation and delivery of acute care, requiring a multi-level approach to change (Ingram 2014, Hynes *et al.* 2015).

There are also wider issues to consider that arguably impact on palliative care provision in hospitals. Palliative care philosophy is based on the concept of 'a good death', therefore when it comes to hospital based palliative care, perception of the ability of achieving a good death in this care environment is also a factor. A large-scale attempt to implement a care pathway for end of life care in acute hospital settings in the UK, the Liverpool Care Pathway, was hastily withdrawn. This followed widespread criticism from the media who perceived that it placed patients on an accelerated trajectory towards death (Neuberger 2013), and academics who critiqued the lack of research and poor implementation (Seymour & Clark 2018). This provided a clear warning that hospice care principles cannot be easily packaged and implemented within acute care environments without careful attention being given to the complexities of the culture and context of that environment (Seymour & Clark 2018).

Other examples of the negative rhetoric surrounding the hospital as an appropriate care setting for people to experience a good death in, include a recent review of international palliative care policy in five countries (including Ireland), which were considered to have 'advanced' levels of palliative care integration (Robinson *et al.* 2016). Findings indicated that no positive role for hospitals in palliative care provision was envisaged within these policies. Furthermore, where any strategies to improve the quality of palliative care were identified, these centred on SPC service capacity (Robinson *et al.* 2016). Hospitals in this review of policies were viewed as a care setting to be avoided in order to save healthcare costs. However, assumptions about the cost savings were not evidence based, and the costs incurred by family caregivers were not considered in these policies. This also indicates that political and financial motivation is a driver in the perception that it is more favourable to receive palliative care outside of the hospital environment. Lolich & Lynch (2017) argue that in Ireland this move towards the conceptualisation of a 'good death' being a home death occurred within a wider context of declining religious influence in public policy and increased privatisation and decentralisation.

Unlike the mix of public and private insurers operating in healthcare systems associated with Ireland and across Europe, there are further challenges to integrating palliative care in hospitals that operate healthcare payment systems such as the in the USA. (Connor 2007, Buck 2011, Morrison 2013). A review of literature carried out by Aldridge *et al.* (2016) found that the USA healthcare system, which rewards the volume of medical procedures and therapies carried out by fragmented medical multi-subspecialty teams in hospitals, typically neither recognises nor pays for aspects associated with comfort care. Furthermore, reimbursement mechanisms fail to provide support for the interdisciplinary team beyond physician reimbursement, reinforcing the dominant medical worldview, and in order to receive publicly funded hospice benefit a patient must forego active treatments (Morrison 2013, Hughes & Smith 2014). This arguably creates a difficult dichotomy between pursuing potentially life-prolonging treatments and pursuing palliative treatments which is a major policy related barrier to realising NSPC and SPC potential in hospitals under these conditions. It also raises that question of the 'moral economy' whereby decisions taken to stop costly active treatments could potentially be influenced by insurers' and providers' efforts to economise near the end of life (Livne 2014).

2.9 Clinical guidance for palliative care provision in hospitals

Several authors have called for the need to measure and evaluate the effectiveness of NSPC provision (Schneider *et al.* 2010, Shadd *et al.* 2013, Grubbs *et al.* 2014). However no actual framework exists as to how NSPC specifically should be operationalised throughout all organisational levels within the hospital care setting. In order to do this, it is necessary to first describe and provide clear direction for the delivery of NSPC in hospitals. While there is evidence of generic guidance of standards and norms for palliative care delivery and core competencies for palliative care (Radbruch & Payne 2009, Gamondi *et al.* 2013b), efforts to provide clinical guidance for NSPC provision specifically in hospitals are sparse in the published literature. In Ireland, healthcare providers are encouraged to refer to the palliative care competencies required of various healthcare disciplines and to incorporate a generic palliative care needs assessment tool within their clinical practice (National Clinical Programme for Palliative Care 2014a, Ryan *et al.* 2014). Also, there have been some attempts to provide palliative care guidance in relation to the experience of particular groups of patients in hospitals in Ireland, such as those with dementia (DemPath Project St. James Hospital & Health Service Executive 2018). Furthermore, care at end of life (last days and hours) is a core feature of the training activities to support NSPC provision in hospitals in Ireland in the last ten years (Irish Hospice Foundation 2019). While a very important aspect of palliative care relates to care at the end of life, and there is published guidance on essential elements of care for the dying (Ellershaw & Lakhani 2013), healthcare providers in hospitals also need to be provided with support and training to recognise and deliver NSPC earlier for patients.

In principle, it is not possible to evaluate quality of care without clear understanding and guidance on what that care actually entails. Clinical indicators are a means to achieve this, and are used for a variety of purposes to support the quality and safety of health services (The Centre for Clinical Governance Research in Health 2009). For the purposes of this study, an ‘indicator’ of NSPC is considered a statement that describes an aspect of NSPC which is relevant within the hospital care environment. The processes for developing previous indicators relating to palliative care were examined to identify areas for improvement and guide the development of clinical indicators of NSPC in hospitals in the current study. In a review of palliative care quality indicators by De Roo *et al.* (2013a) only one example of SPC hospital based indicators was identified (Twaddle *et al.* 2007). Most of the quality indicators of palliative care identified in this review reflected care processes and outcomes, with very few that reflected structural aspects which support quality palliative care (De Roo *et al.* 2013a). This means that important contextual concerns such as infrastructure and resources which will affect NSPC delivery were not considered (Mainz 2003). Therefore, a broad NSPC guidance framework which provides direction for hospital provision that addresses ways to integrate NSPC within all levels of the organisation is required.

Furthermore, De Roo *et al.* (2013a) described a significant lack of transparency in the included studies reporting the process of indicator development. To have confidence in the output of any clinical indicators development activity, clear and transparent methods should be utilised (Wollersheim *et al.* 2007). Indicators were also predominately required to be measurable to be considered an indicator of quality palliative care (De Roo *et al.* 2013a). However the pitfall of focusing exclusively on indicators that are amenable to measurement (e.g. percentage of deaths in a single room as a representation of quality end of life care in a hospital), may mean that key aspects of care are missed, also known as the ‘quantitative’ or ‘McNamara’ fallacy (Bowen & Kreindler 2008, O'Mahony 2017). However, ‘what’ NSPC care consists of and ‘how’ it may be measured can be two different things. If the philosophy of palliative care is underpinned by the concept of total pain, it would be difficult to describe the consequences or quality of that in merely quantitative terms, which could lead to a loss of essential palliative care values (Floriani & Schramm 2012). Therefore, to provide guidance on core CCPIs for NSPC in hospitals that merely reflects items that are amenable to measurement, would render them incompatible with a palliative care philosophy and limit the scope of their utility to support the development of NSPC integration in hospitals.

Lastly, there was little evidence of patient and/or family involvement in the development of the hospital based palliative care quality indicators described by Twaddle *et al.* (2007). While there is some evidence reporting patients and/or families experiences of receiving palliative care in hospitals (Robinson *et al.* 2013), little attention has been given to the patient and family perspective in developing guidance for the provision of NSPC in hospitals (Frey *et al.* 2011b). This important perspective is sorely lacking when one considers the evidence, as discussed above, pointing to unmet palliative care needs in hospitals and that the general public consistently indicate their preferences for place of death as being the home (Robinson *et al.* 2016). If NSPC is to be considered a 'whole-person' response to total pain, then the patients' perspective should inform any initiative which seeks to develop this care. This is supported by the Council of Europe (2003) who have stated that the perspective of patients should be encouraged in the definition and adoption of indicators of good palliative care from all dimensions of care.

2.10 Summary and conclusion

Palliative care is an approach to the prevention and relief of total pain and suffering, emanating from the Asclepius tradition of medicine, which can be delivered by all healthcare providers in all settings. This philosophy has been supported since its inception and is reinforced internationally by the WHO and in countries with national palliative care policies including Ireland. It was originally conceived as care for those who were terminally ill, predominately from cancer, however there is now an awareness that palliative care can be applicable much earlier in disease trajectories of many different groups of patients. Since palliative care became recognised as a medical sub speciality, internationally and in Ireland, the emphasis on the role, delivery, and impact of palliative care has focused on its place as a specialist service while the role of NSPC provision particularly within the hospital care environment has received less attention. Terminology associated with NSPC is ambiguous and while there is some evidence pointing to developments in NSPC provision outside of the hospital care setting, this has been very context dependant. Furthermore, there is evidence of patients with unmet palliative care needs and NSPC providers' difficulties in identifying transitions to a palliative approach, managing pain and other symptoms, communicating bad news to patients and families, and responding to suffering, particularly in the hospital setting. Due to the rising numbers of patients globally who now are believed to have palliative care needs, and are likely to be hospitalised, palliative care has been recognised as a public health concern internationally. This has once again emphasised the need to increase the capacity of all healthcare providers working with those who have palliative care needs to meet this demand. Hospitals have an important role to play in palliative care delivery, however clinical guidance for the integration of NSPC at all levels within hospitals is lacking.

Chapter 3 Introducing the research study

3.1 Introduction

In this chapter the aim and objectives of the study, the research design, including an overview of the philosophical assumptions underpinning the study, and the general research methodology or guiding framework, adopted to achieve the study's aim are presented. The chapter concludes with a description of research methods utilised to achieve the aim and objectives of the study.

3.2 Aim

The aim of this research study was to develop a core set of Clinical Care Provision Indicators (CCPIs) for NSPC in hospitals.

3.2.1 Objectives

This research was operationalized in three discrete yet complimentary phases, with each phase addressing specific objectives to achieve the study's overall aim.

Phase I: **A concept analysis of NSPC**

1. To examine how NSPC is currently understood in the healthcare literature including determination of the key attributes of this type of care, through formal concept analysis.
2. To provide clarity surrounding NSPC terminology to support the development of the search strategy in phase II.
3. To provide initial CCPIs for NSPC for use in phase III.

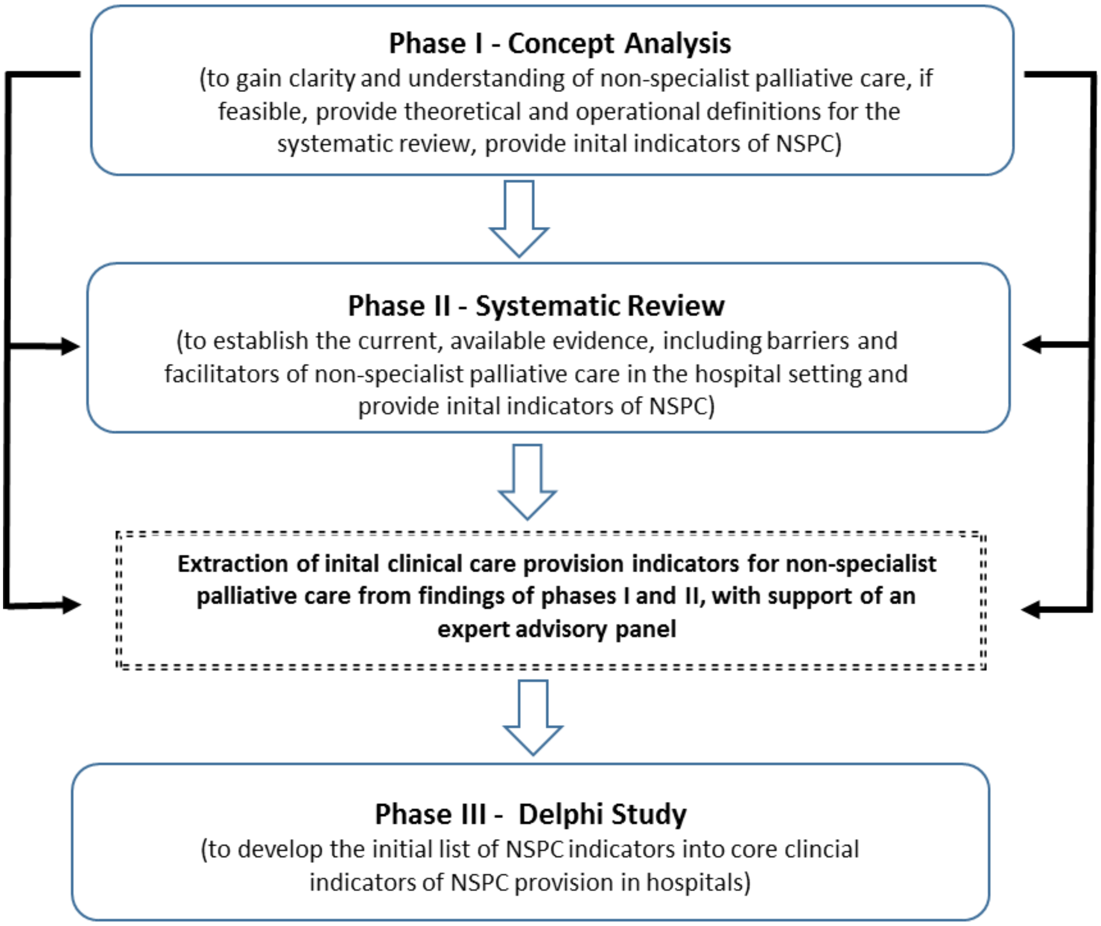
Phase II: A systematic review of healthcare providers' views and experiences of NSPC in hospitals

4. To examine the totality of the evidence of the experiences of healthcare providers in applying NSPC in the hospital setting through systematic review and thematic synthesis.
5. To provide initial CCPIs for NSPC for use in phase III.

Phase III: **A Delphi study to achieve international consensus on the core set of CCPIs for NSPC in hospitals**

6. To conduct a Delphi study, drawing on the findings of objective 3, phase I and objective 5, phase II, to achieve international consensus on a minimum (core) set of CCPIs that will be used to optimise NSPC for the hospital setting.
7. To make recommendations for future policy, practice, research and education.

Figure 3 illustrates the sequential conduct of the study phases in achieving the study's aim and objectives.



Phase I - Concept Analysis
(to gain clarity and understanding of non-specialist palliative care, if feasible, provide theoretical and operational definitions for the systematic review, provide inital indicators of NSPC)

Phase II - Systematic Review
(to establish the current, available evidence, including barriers and facilitators of non-specialist palliative care in the hospital setting and provide inital indicators of NSPC)

Extraction of inital clinical care provision indicators for non-specialist palliative care from findings of phases I and II, with support of an expert advisory panel

Phase III - Delphi Study
(to develop the initial list of NSPC indicators into core clincial indicators of NSPC provision in hospitals)

Figure 3 Research phases to achieve study aim and objectives

3.3 Research design

In this section the overall ontological and epistemological assumptions underpinning this study are discussed. This is followed by a description of the overarching general methodological approach which was chosen to frame and guide the study phases. The detailed methodological aspects specific to each distinct phase of the research are then discussed.

3.3.1 Ontology, epistemology and health research

The research paradigm underpinning any study can be considered a set of fundamental assumptions and beliefs as to how the world is perceived (Jonker & Pennink 2010, Wahyuni 2012). This ultimately serves as a 'thinking framework' that guides the behaviour of the researcher (Morgan 2007). The main philosophical dimensions to distinguish existing research paradigms are ontology (relating to the nature of social reality) and epistemology (how that social reality is constructed) (Wahyuni 2012). Pursuing this research degree has caused me to reflect upon my own fundamental understanding of reality, and how it may be constructed. Epistemologically, while I believe there are aspects of reality that can be measured, and that it is possible to develop valid and reliable measurement tools for capturing this, ontologically, I do not believe that there is one single reality or truth (positivism). Conversely, I consider that, as human beings, we actively create, interpret, and reorganize knowledge in individual ways. Reality, however, is not entirely constructed either, nor is there a single reality or truth (constructivism). As such, the meaning of human experience resides neither exclusively in the objective real world, nor exclusively in the internal mind of the knower, but rather in their interaction or transaction (Morgan 2014).

The superiority of one ontological position over the other (i.e. positivism and constructivism) has been consistently debated in the literature (Guba & Lincoln 2005, Onwuegbuzie & Leech 2005). Arguments between these different approaches are implicitly predicated on the non-pragmatist question: Which form of knowledge-making brings us closest to the 'Truth'? An argument has also emerged that different research paradigms cannot be utilised in the same research, also known as the incompatibility thesis (Onwuegbuzie & Leech 2005); an argument which I don't subscribe to as, fundamentally, I believe that positivist and constructivist ontologies are reconcilable through interaction or transaction. Focusing only on one research paradigm can potentially be limiting and debating the superiority of quantitative (positivist) over qualitative (constructivist) research, or vice versa, I believe, is potentially divisive. My current personal research philosophical position, based on wider reading, previous research experience and sustained, considered reflection, thus resonates with that described by Morgan (2014). He argues that diverse approaches can be complementary and can legitimately influence the formation of knowledge with scientific rigor and theory accommodated alongside the subjective nature of qualitative research (Morgan 2014).

3.3.2 Pragmatism

My views in relation to ontology and epistemology most closely align with the philosophical paradigm of pragmatism, and it is this philosophical perspective that underpins the research study. A paradigm can be considered a set of ontological and epistemological assumptions, often expressed as a 'worldview' (Morgan 2007). A pragmatist approach adds a helpful frame to such critiques, arguing that there is no absolute 'best' method, but each method is good at achieving particular ends (Morgan 2007). Charles Saunders Peirce (Peirce 1905, 1906), William James (James 1907, 1909) and John Dewey (Dewey 1929, 1938) were considered the founders of pragmatism; an American philosophical movement which came to prominence in the late 19th and early 20th century. At the center of pragmatism is a rejection of the 'impossible question' of philosophy, that of the nature of the mind's relationship to reality (Rorty 1980). The central tenant of this movement was that knowledge is only meaningful when coupled with action. As such, pragmatism is a philosophy deeply embedded in everyday life, concerned firstly with the person’s direct experience of the world they inhabit. Pragmatism places methodology at the centre whereby it is not the abstract pursuit of knowledge through “inquiry” that is central to a pragmatic approach, but rather the attempt to gain knowledge in the pursuit of desired ends (Morgan 2007).

Johnson *et al.* (2016) call this a new research paradigm or “culture” comprised of shared ontological, epistemological, axiological (value ethics), aesthetic (ethic principles) and methodological beliefs, values and assumptions. Pragmatism places an emphasis on the research problem and consequences of research, exploiting the strengths of quantitative and qualitative research methodologies to answer the research question (Feilzer 2010, Morgan 2014). The problem of embedding NSPC in hospitals has been the central focus and guiding aspect of my research study. Pragmatism’s focus on usefulness is sometimes interpreted (and criticised) as narrow utilitarianism. These criticisms centre largely on how we define what it means to say a belief "works", or that it is "useful to believe". The vague usage of these terms, first popularized by James (James 1907, 1909) has led to much debate (Rorty 1980, Guba & Lincoln 2005, Gordon 2009), and even the original authors held conflicting views. Saunders Pierce, for example, did not agree with James’ more permissive and expansive notion of truth as ‘whatever works’. He believed that there was one truth, but what that is was open to interpretation, and as a consequence of this changed the name of his theoretical perspective to ‘pragmaticism’ (Peirce 1906).

Dewey moved away from focusing primarily on theoretical issues and towards social application, asserting that pragmatism is an ongoing and historical mode of enquiry whereby knowledge is just the output of competent enquiry (Dewey 1929, 1938). This view that there can be no foundation for any overarching theory of truth has since been developed by Rorty (1980). This anti-foundational stance is central to Rorty’s work, whereby truth is not the goal for inquiry, rather the goal is to achieve agreement about what to do and to bring about consensus on what is to be achieved and the means to be employed towards that achievement (Rorty 1999). Therefore pragmatism is action orientated, and offers an effective approach to knowledge generation through an emphasis on the abductive-intersubjective-transferable aspects of opposing quantitative and qualitative approaches (Morgan 2007). In this sense pragmatism is deeply pluralist, recognising the validity of a variety of interests, perspectives, and forms of knowledge.

To achieve the overall aim of my study, multiple methods of enquiry across three distinct yet complementary phases, were conducted. The pragmatist position is that these methods are not in competition with each other, because each serves a different purpose. That is, the use of a combination of methods and ideas helps best frame, address and provide tentative answers to one's research question (Johnson *et al.* 2016). Pragmatism also includes a sensitivity to research context, a focus on applied research, and the valuing of different forms of knowledge (Cornish & Gillespie 2009). Simply put, as the ultimate outcome of this research study seeks to offer practical outcomes for clinical practice in a given context, that is, to produce meaningful and relevant core CCPIs for NSPC in hospitals, the aim can be effectively achieved using a pragmatic philosophical approach.

3.4 The research project

The overall aim of the study is to develop a core set of Clinical Care Provision Indicators (CCPIs) for NSPC in hospitals. While there appears to be a lack of consensus in the literature regarding a definition for the term 'indicator' (McCance *et al.* 2012) it is well established that clinical care indicators assess particular health structures, processes and outcomes, and provide a basis for quality improvement (Klazinga *et al.* 2001, Mainz 2003, Health Information and Quality Authority 2012, Catumbela *et al.* 2013). Mainz (2003) goes so far as to say that 'monitoring health care quality is impossible without the use of clinical indicators' (Mainz 2003, p523), and there is significant policy support for the use of clinical care indicators (Hospice Friendly Hospitals (HFH) 2010, Health Information and Quality Authority 2012, Health Service Executive 2019b). A 'clinical indicator' is a broad term that can serve a multitude of functions. The purposes of clinical care indicators can include aspects such as measuring the impact of care, maximising outputs/outcomes of care, stabilising resources, embedding values associated with the care indicators in practise, and allowing for benchmarking between organisations (The Centre for Clinical Governance Research in Health 2009).

3.4.1 Purpose of the clinical indicators in this study

The threshold of an indicator is essential when ascertaining the quality of care as it describes a critical level between what is considered good or not (Bowen & Kreindler 2008). Therefore it is essential to provide clarity as to the purpose and scope of indicators for maximum clinical utility. Berg & Schellekens (2002) describe two major types of indicators; internal and external, and these authors make clear distinctions between each type. Government, inspection and health insurers seek to use, or rely on indicators in assessing quality care delivery (external indicators). These indicators tend to be selected for their quantitative measurability, requiring exhaustive validation, and such indicators are of little use for self-management within an organisation (Berg & Schellekens 2002). In contrast, health care organisations (such as hospitals) need indicators to be able to guide their care processes and improve their service (internal indicators). For example, reporting statistics relating to deaths in single rooms (external indicator), while useful to an extent in allowing comparisons across multiple hospitals, does not solely reflect the quality of end of life care in a hospital, or provide direction as to how the care process relating to this can be improved.

The CCPIs for NSPC developed in this study describe a 'core' or 'minimum' set of indicators for NSPC provision in hospitals. These indicators are not intended to be performance measures required for external appraisal of an organisation (Wollersheim *et al.* 2007) nor are they specific to any particular disease, professional group or cultural context, for example. Rather, the core set, represents broad statements which articulate the core aspects for NSPC provision that, at a minimum, should be in place in hospitals. These core NSPC care provision indicators also reflect the need for organisation level support for the adoption, and implementation of NSPC (The Centre for Clinical Governance Research in Health 2009). This does not imply, however that indicators in any particular hospital should be restricted only to those in the core set, recognising that care structures and processes are context dependant. Rather, there is an expectation that these core indicators are utilised as a basis for hospitals to benchmark the degree of integration of NSPC throughout all levels of their organisation (Berg & Schellekens 2002). The CCPIs are thus intended to provide managers and healthcare providers with care structures and care processes essential to NSPC provision, and in doing so, help identify where there are gaps and how these might be addressed, thus providing hospitals with a means to assess and monitor their progress towards meaningful and relevant NSPC integration.

3.4.2 Clinical indicator development methodological framework

The development processes which seek to direct clinical care will depend on their purpose and scope (Bowen & Kreindler 2008). All development activities which inform, and guide practice generally use some type of engagement with the published literature and evidence, and/or consultation with experts and key stakeholders. This engagement should be undertaken using scientific rigour and a transparent process (Mant 2001, Mainz 2003, Wollersheim *et al.* 2007, The Centre for Clinical Governance Research in Health 2009). For example, the Medical Research Council (2019), provide a framework to support the development of complex healthcare interventions, and the COMET (Core Outcome Measures in Effectiveness Trials) initiative (2019) supports the development and application of agreed standardised sets of outcome known as 'Core Outcome Sets' (COS) for measuring in randomised trials and other research on the same health condition or topic.

To provide an overall methodological basis to guide the development of the CCPIs in this study, Wollersheim *et al.* (2007) methodological framework was utilised. Wollersheim *et al.* (2007) propose a seven-step systematic process for both the development and application of clinical indicators (Table 1). Step one involves the selection of a relevant patient group or care process, which, prudently, should focus on a healthcare concern that is of high importance or volume (Wollersheim *et al.* (2007). Mainz (2003) further asserts that where there is evidence that the quality of care is either variable or substandard, the more useful clinical indicators are likely to be those that reflect the important aspects of core clinical care. Chapters one and two of this thesis have addressed step one of this framework, in detailing the prevalence of patients with palliative care needs in hospitals, and the justification for the need to provide clinical guidance to direct NSPC in hospitals.

Steps two (a thorough search of relevant literature to identify current indicators of NSPC) and step three (the application of a structured clinical indicator development process) are described in detail in the following section of this chapter. Steps four to seven are concerned with the testing and application of clinical indicators, which are beyond the scope of the current study, but future post-doctoral work is described in the conclusions and recommendations section of this thesis (Chapter 9).

Table 1 Steps in the development and application of clinical indicators (Wollersheim 2007)

	Framework for Development and Application of Clinical Indicators	**Relevant Thesis Section**
1	Selection of relevant patient group or care process	Chapters 1 & 2 - provide the justification for the importance of having clinical indicators for the provision of NSPC in hospitals
2	Literature search for indicators already developed or data about optimal care available (preferably recent evidence based guidelines)	Chapter 4 & 5 (concept analysis and systematic review) - provide the available evidence from which to extract an initial list of NSPC indicators
3	Composition of a balanced consensus group and application of a structured development procedure; A. Specification (Extraction of concrete recommendations from the literature) B. Prioritising (Selection by an expert panel on the basis of relevance)	Specification – Chapter 6 summarises the major findings from phases I & II, and describes the process for extracting and refining the initial list of NSPC indicators Prioritisation – Chapter 7 describes phase III, the Delphi study, which culminates in consensus on a core set CCPIs for NSPC in hospitals, and these are further discussed in chapter 8
4	Operationalisation	Chapter 9 - Recommendations for future research discussed
5	Practical testing	
6	Reporting	
7	Application to the system of quality improvement	

3.5 Research methods

Wollersheim *et al.* (2007) describe the need for a thorough search of relevant literature to identify current indicators of selected care processes. Following an initial scoping of the literature, a considerable challenge with ambiguity and potential diversity surrounding objective (i.e. policy) versus subjective understandings (i.e. healthcare providers' views) of NSPC was envisaged. Therefore, to fully understand the current state of knowledge of NSPC and to provide the best available evidence of what indicators of NSPC may currently exist, two separate enquires, both of which contributed directly to developing the Delphi survey were undertaken. These were a concept analysis of NSPC (phase I), and a systematic review of healthcare provider's views and experiences of NSPC (phase II). Although the concept analysis and systematic review had distinct research aims, both were necessarily undertaken so as to explore the literature in-depth, albeit at diverse levels, and to potentially identify selected NSPC processes and associated indictors while doing so. The resulting initial indicators were extracted and formed the basis of the round one questionnaire for phase III (Delphi study). These three research methods are now discussed in detail. The conduct and findings from these three phases are presented separately in Chapter 4 (concept analysis), Chapter 5 (systematic review), and Chapter 7 (Delphi study).

3.5.1 Phase I – Concept analysis of NSPC

In light of the ambiguity that surrounds the terminology associated with NSPC in the literature, the lack of clarity surrounding what it entails, and the absence of a clear definition of NSPC, I conducted a formal concept analysis. The concept analysis explored NSPC at a higher, structural, organisational, objective, and theoretical level, so as to gain 'balcony view' clarification and understanding of NSPC. This provides a more rigorous and in-depth analysis of this concept, to ascertain if NSPC meets the criteria of a well-developed and understood concept, and to provide important initial indicators of NSPC.

3.5.1.1 Choosing the concept analysis framework

Concept analysis can be described as an activity where concepts, their characteristics and relations to other concepts are clarified (Nuopponen 2010a, 2010b). Concept analysis offers the opportunity to capture the way a concept is currently articulated in relation to the phenomena associated with it (Morse *et al.* 2002, Cronin *et al.* 2010). Identifying similarities and differences between related concepts such as NSPC and a palliative approach, for example, is beneficial as it can enhance understanding of the concept itself, as well as ensuring that related practice is more explicit. The examination of concepts in nursing may be traced to Catherine Norris (1982) who published a detailed book on concept clarification. In undertaking the present analysis, several concept analysis methods developed in nursing science were firstly reviewed for appropriateness. These reflect key and seminal contributions to theory of concept analysis within healthcare. They included the evolutionary model (Rodgers 1989, Rogers & Knafl 2000), the process model (Walker & Avant 2005), the pragmatic utility method (Morse *et al.* 1996, Morse *et al.* 2002), and more recently, the principle based method of concept analysis (Penrod & Hupcey 2005b). In addition, examples of previously published concept analyses were reviewed in an effort to further understand operational/conduct differences between the methods (Meghani 2004, Larkin *et al.* 2007, Smith *et al.* 2012, Fenstermacher & Hupcey 2013). Table 2 provides a comparison of major aspects of these selected methods of concept analysis.

Table 2 Comparison of major methods of concept analysis

Author(s)	**Rodgers (1989, 2000)**	**Walker & Avant (2005, 2010)**	**Morse *et al* (1995, 1996, 2000)**	**Penrod & Hupcey (2005a, 2005b)**
Method	The evolutionary model	The process model	The pragmatic utility method	The 'principles based' approach
Number of steps	6-step framework	8-step framework	3 phases	Concept examined under 4 broad philosophical principles
Literature	Random selection of literature	Literature for all potential interpretations of the concept searched	Extensive literature search and use of rich data sources	Extensive literature search within bodies of large multidisciplinary literature

Rodger's (1989, 2000) method of concept analysis is an inductive, iterative, descriptive process that occurs simultaneously with literature retrieval, based on the idea that concepts are constantly modifying and changing. The Rogers method assumes a dispositional worldview in contrast to the essentialist view that she claims has predominated in earlier approaches to concept analysis. Rodgers (1989, 2000) however suggests a random selection of literature from diverse domains over many years in conducting the concept analysis. Acknowledging the value of this, I was concerned however, that this potentially could have resulted in missing important literature for the comprehensive examination of NSPC. Walker & Avant (2005) were the first to develop an eight step model for analysing concepts. In contrast to Rodgers, these authors posit logical positivism in their approach to concept analysis. They viewed concepts as categories of information that contain defining attributes. The Walker and Avant method, while offering structured guidance and a linear approach to concept analysis, however, has been criticized as being rooted in positivist philosophy, static with a lack of consideration for multiple meanings from different perspectives (Risjord 2009). Also, Walker & Avant (2005) assume operational definitions as an end-point to the analysis. While an operational definition(s) was desirable, it was not the overall requirement of the analysis of NSPC in this study, not least because of the ambiguous nature of NSPC and use of multiple terminology, one single definition may not have been feasible.

Morse *et al* (1995, 1996, 2000) in formulating a criterion for evaluating concepts put forward an argument to examine the 'maturity' of a concept as a means of clarifying a concept. A concept must have clear characteristics, delineated boundaries, with clearly outlined preconditions and outcomes and with agreement on its use, in order to be considered mature (Morse *et al.* 1996). They proposed the use of rich data sources to achieve this level of in-depth analysis. The work of Morse and colleagues forms much of the foundation of the 'Principles Based' approach which was subsequently described by Penrod & Hupcey (2005b). Using this approach, a concept is examined under four major philosophical principles. These are the epistemological (clarity of definition), pragmatic (usefulness and application), linguistic (consistency in use of language/terms) and logical principles (relationship with other similar concepts) which frame the analysis of a concept's comprehensive meaning. Penrod & Hupcey (2005b) maintain that concept advancement is the purpose of concept analysis, whereby a concept is not static rather it is dynamic, changing over time. This method delineates the state of the science (or probable truth), whereby it focuses on the use of a concept in science and not of interpretations found in fiction, art or other representative forms. Thus, extraction of the dataset is strategic and intentional.

Penrod & Hupcey's Principles-based framework was chosen to investigate NSPC as it allowed me to determine the current state of the science surrounding the concept of NSPC at a given (and contemporaneous; 2017) point in time. This approach allowed for a degree of methodological flexibility and broad exploration in my analysis due to the expanse of the four broad philosophical principles, something which I considered the more rigid six step (Rodgers 1989) or eight step (Walker & Avant 2005) frameworks couldn't offer to the same extent. Furthermore, given the topic under study, the principle-based model offered the means of achieving a deeper clarity and understanding of NSPC, because a thorough search of relevant literature was required as opposed to a random selection (Rodgers 1989). Penrod and Hupcey describe the outcome of their concept analysis method as the *'best estimate of probable truth* [as revealed in the scientific literature] *surrounding the concept at that point in time'* (Penrod & Hupcey 2005b, p. 404). To explore NSPC under the epistemological principle, one examines what is already known about NSPC and identifies whether it is clearly defined and differentiated from other concepts. Investigation of NSPC under the pragmatic principle is concerned with the usefulness or application of it within the healthcare environment. Examining NSPC from the linguistic principle explores the consistency of use and meaning attached to the concept within the literature. Lastly, from the logical perspective, NSPC is assessed to determine if it is well differentiated from other related concepts such as patient-centred care. In this sense it was scrutinised independently in relation to its integration to other related concepts to determine if it has established boundaries, that is, can it 'hold its own' when positioned theoretically with other concepts. Using the principle-based approach it was also possible to identify preconditions (antecedents that influence NSPC) and outcomes (the effects of the occurrence of NSPC) of the concept of NSPC. Morse (1996) described how these are indicative of the maturity of a concept and add to the richness of the analysis.

3.5.2 Phase II –Systematic review of the views and experiences of NSPC from the perspectives of providers of NSPC in the hospital setting

In order to provide a comprehensive evidence base to inform the initial list of CCPIs for NSPC, contextual evidence, that is from the hospital setting and associated stakeholders, a systematic review was undertaken. This systematic review investigated NSPC at a subjective, personal, individual level ('ground view'), through an exploration of personal views and understandings of NSPC from those directly involved in the front-line provision of NSPC in hospitals. In a systematic review, as in research, the choice of method used should reflect the type of question posed (Grant & Booth 2009, Gough *et al.* 2012, Munn *et al.* 2018). As my primary purpose in phase II was to gain a deeper understanding of NSPC in hospitals from healthcare providers' perspectives, a systematic review and thematic synthesis of qualitative studies was conducted. I acknowledge that some within the qualitative research community argue that the integrity of contributing primary studies may be challenged when synthesising data across multiple qualitative studies (Sandelowski *et al.* 1997, Sandelowski 2015, Thorne 2017). However, Tong *et al.* (2012) describe how the synthesis of findings from multiple qualitative studies actually produces a further depth of experience and perspectives of the population(s) involved. Qualitative evidence synthesis can generate new knowledge, identify research gaps and inform the development of primary studies (Tong *et al.* 2012). Simply put, qualitative enquiry can help to identify what a phenomenon 'is', and the need for this type of fundamental enquiry has been articulated in the NSPC literature (Gott *et al.* 2012, Chan *et al.* 2018).

3.5.2.1 Choosing the qualitative evidence synthesis framework

Numerous methods of qualitative evidence synthesis have emerged in the last ten years (Hannes & Macaitis 2012, Tong *et al.* 2012). Table 3 presents three distinct approaches to qualitative evidence synthesis and some differences between each which were of relevance when selecting the method of synthesis for this review.

Table 3 Approaches to qualitative evidence synthesis

Methodology	Framework	Thematic synthesis	Meta-ethnography
Seminal methodological reference	Bryam & Burgess (1993)	Thomas & Harden (2008)	Noblit & Hare (1988)
Approach	Largely Deductive (Barnett-Page & Thomas 2009)	Inductive (Barnett-Page & Thomas 2009)	Inductive (Barnett-Page & Thomas 2009)
Identification of Themes	Extracts data against predefined (*a priori*) framework from the outset (Dixon-Woods 2011)	Themes identified from the synthesis	New insights emerge from the synthesis
Level of Synthesis output	Data are extracted and synthesised into predefined themes, although new topics may emerge in a 'best fit' approach (Carroll *et al.* 2013)	Analytical themes produce knowledge that goes beyond the primary studies	Translation of codes into 3rd order constructs (Tong *et al.* 2012)

Cooke *et al.* (2012) describe how factors that influence the choice of method of synthesis include the extent to which the synthesis is intended to be theory generating or theory validating. Framework synthesis could be considered theory validating because themes are selected before the synthesis. A limit to this approach could be that the researcher is unconsciously motivated to provide evidence within these pre-identified themes, and may overlook evidence that offers a contrasting view (Dixon-Woods 2011). Given the likely nebulous nature of NSPC, I was reluctant to choose a synthesis approach that restrictively provided a priori list of outcomes illustrative of predetermined views, rather I believed it was vitally important to allow the outcomes (themes) emerge inductively from the narratives. Unlike framework synthesis (which focuses on describing and summarising primary data), both thematic synthesis and meta-ethnography methods attempt to transform data into new interpretations of the topic of interest. However, meta-ethnography ascribes a fluid translational iterative process to the generation of new knowledge, where a line of argument is developed. In this sense, Booth *et al.* (2016) argue that meta-ethnography serves as a means to generate theory.

Contrastingly, a key feature of thematic synthesis is the exploration of theory (rather than generation), moving from descriptive categories to analytical themes that move beyond individual studies' findings to offer higher level evidence on the phenomenon of interest (Booth *et al.* 2016). For this reason, I choose thematic synthesis as the most appropriate approach because it allowed me to go beyond the content of the included original studies, while also staying close to the original data. Using this method, I believed, would offer an accurate, and higher-level, reflection of healthcare providers' personal views and experiences of NSPC in the hospital setting. Furthermore, Booth *et al.* (2016) explain that an important aspect in considering the method of qualitative synthesis is the audience and purpose of the review. As it was anticipated that the findings from this systematic review would provide an important evidence base to inform initial CCPIs for NSPC, a thematic synthesis approach appeared more relevant as the analytical themes produced, derived from those providing or involved in NSPC would, ultimately, be meaningful for NSPC practice.

In step three of Wollersheim *et al.* (2007) framework two distinct stages; specification and prioritisation (Table 1), are described. Specification involves the extraction and refinement of indicators from the literature. To do this I employed an iterative process whereby the main findings from the concept analysis and the systematic review (phases I and II) were interrogated, extracted and collated in developing preliminary clinical indicator statements. To validate and quality assure the specification process an expert advisory panel, consisting of a NSPC hospital-based clinician, a NSPC academic/researcher, a person with a chronic illness, a Delphi researcher, the medical director of a clinical audit department in a large acute care hospital setting, and an end-of-life care co-ordinator of a large acute care hospital setting were consulted and their feedback sought (see Chapter 6 for full details). The result was an initial list of CCPIs for NSPC, for use in phase III (prioritisation).

3.5.3 Phase III - development of core CCPIs for NSPC in the hospital setting; a Delphi study

This final phase of the study, which meets Wollersheim's (2007) description of prioritisation (i.e. selection by an expert panel based on relevance) involved conducting a Delphi study. This is a formal consensus process whereby an international expert panel of multiple stakeholders was asked to review and rate the initial list of NSPC CCPIs on the basis of relevancy as 'core' indicators for NSPC specifically within the hospital care setting.

3.5.3.1 Choosing the consensus method

The purpose of consensus methods is to synthesis the judgements of a group of people, and to determine levels of agreement on a particular topic (Fink *et al.* 1984, Thangaratinam & Redman 2005, Vernon 2009). Social psychological research from the mid-1900s regarding the role of social facilitation would suggest there are several advantages of a group decision. These include a wider range of focused knowledge and experience is ascertained, and the interaction of participants through evaluating responses encourages them to challenge received ideas and new ones (Murphy *et al.* 1998). Furthermore, several people are less likely to arrive at a wrong decision than an individual, and the group as a whole carries more weight than any one individual (Skulmoski *et al.* 2007, Nair *et al.* 2011). Consensus methods can be considered formal or informal, depending on the level of structure they involve. Formal consensus methods follow pre-defined, systematic procedures, with a clear, agreed-upon approach to decision-making. This allows group members to have explicit and reasonable expectations and to engage in a respectful and productive process (World Health Organisation 2014).

Formal consensus development methods are considered scientifically credible (Murphy *et al.* 1998, Black *et al.* 1999, Okoli & Pawlowski 2004, Skulmoski *et al.* 2007), and have been advocated as a very useful means of developing high-quality clinical guidelines (Black *et al.* 1999, Nair *et al.* 2011, World Health Organisation 2014). Nair *et al.* (2011) further asserts that in the development of clinical guidelines (or in the case of this research study, indicators of care which should serve as a guide for practice), it is essential to provide participants with the best available published evidence relating to the field as a basis to inform their judgements. In an evaluation of evidence based clinical guidelines, Cruse *et al.* (2002) found that evidence based guidelines scored the highest on quality, whereas strictly consensus-based guidelines scored that lowest (Cruse *et al.* 2002). This further supports the need for phase I and II of this research in providing the evidence to inform the initial list of CCPIs for rating by the experts in the consensus development process (phase III) of this research.

Several approaches to formal consensus development are used in the health field. A summary of the major differences of these methods is presented in Table 4.

Table 4 Characteristics of formal consensus development methods

Characteristic	**Nominal Group Technique**	**Consensus Development Conference**	**Delphi Method**	**Transparent Expert Consultation**
Face to Face contact	Yes	Yes	No	Yes
Emailed questionnaire/survey	No	No	Yes	Yes
Private decisions elicited	Yes	No	Yes	Yes
Interaction structured	Yes	No	Yes	Yes
Aggregation Method	Explicit	Implicit	Explicit	Explicit

The nominal group technique (NGT) aims to structure interaction within a group. Firstly, participants record their ideas about the phenomenon of interest independently and privately, then participants come together, and ideas are collected from each person and listed in front of the group by a facilitator. Individual judgements are aggregated statistically to obtain the overall group judgement (Black *et al.* 1999, Nair *et al.* 2011, Junger *et al.* 2012). Nair *et al.* (2011) asserts that personal contact between participants is an advantage, whereby all participants can voice opinions, and group voting can occur, however, an experienced moderator is required to prevent any individual dominating the process. NGT can also be costly and time consuming, and has been described as producing less stable consensus than other methods (Nair *et al.* 2011). A consensus development conference (CDC) process involves stakeholders coming together (about 10 people) to evaluate the appropriateness of using an existing technology such as a drug, a procedure or a device in health care. This takes place in a chaired, open meeting, sometimes over the course of a few days, where evidence is presented by various special interest groups or experts who do not have a role in the decision-making process. Following this a separate chaired meeting takes place where only the decision-making group meet to consider the evidence and to reach a consensus. This type of format has been criticised for being very costly, but more-so because the interaction between group members is not structured and this can affect the credibility of the resulting consensus (Jones & Hunter 1995, Nair *et al.* 2011). A Transparent Expert Consultation is a more recent development in consensus building (Yardley *et al.* 2007). This method draws on Delphi and NGT, in providing a rapid means to agree on recommendations, and uses online ranking to ascertain consensus (Yardley *et al.* 2007, Gysels *et al.* 2013, Higginson *et al.* 2013, Payne *et al.* 2019).

The Delphi method was developed in the late 1940s at the Rand Corporation and was originally conceived to create a method, using expert opinions, to forecast long range trends related to the military potential of future science and technology and their effects on political issues (Linstone & Turoff 1975). It was named after the Greek oracle at Delphi, who, as legend believes, was able to predict the future (Murphy *et al.* 1998). Consensus is based on the results of multiple rounds of questionnaires that are sent to a panel of experts. The classical Delphi comprises of four key features (Rowe & Wright 1999, Skulmoski *et al.* 2007);

1. *Anonymity of Delphi participants:* participants can freely express their opinions without undue social pressures to conform from others in the group. Decisions are evaluated on their merit, rather than who has proposed the idea.
2. *Iteration*: participants can refine their views in light of the progress of the group's work from round to round. Typically, a Delphi study consists of two to four rounds.
3. *Controlled feedback*: informs the participants of the other participant's aggregated rating and provides the opportunity for Delphi participants to clarify or change their rating.
4. *Statistical aggregation of group response:* allows for a quantitative analysis and interpretation of data.

In the first round, the panel of experts provide their rating regarding the items in the initial questionnaire individually and anonymously on a given issue, usually via a postal or an internet-based platform. These results are then calculated and reported to the entire group anonymously via email or post. The panel of experts then has the ability to reconsider their original response on the basis of group opinion and re-rate each item. Responses are calculated once again and returned to the group for consideration. This may occur over a number of rounds until consensus is achieved (Hsu & Sandford 2007, Skulmoski *et al.* 2007, Vernon 2009, Von der Gracht 2012). There are many advantages to using the Delphi technique. The process is relatively easy to understand, participants can express views anonymously in an iterative process, without being unduly influenced by others, it generally involves low costs, can be conducted over a relatively short period of time depending on the number of rounds, is flexible, and does not require expert moderation (Fink *et al.* 1984, Walker & Selfe 1996, Hasson *et al.* 2000, Hsu & Sandford 2007, Vernon 2009). There are challenges associated with this method however. There is a risk of attrition due to the time commitment required of participants, the participant selection process may be a source of bias, and because the Delphi method does not utilise face to face contact, it does not facilitate potentially positive aspects of group interaction, such as resolving disagreements (Fink *et al.* 1984, Jones & Hunter 1995, Keeney *et al.* 2001, Nair *et al.* 2011).

Notwithstanding this, the Delphi method has been adopted by researchers and opinion leaders in palliative care for the development of clinical guidelines, treatment recommendations and assessment tools; to define diagnostic criteria, disease classification and quality indicators; and to establish frameworks for policy and advocacy. For example in palliative care tool development (Biondo *et al.* 2008, Raijmakers *et al.* 2012), and in the development of consensus norms for particular groups with palliative care needs (Van der Steen *et al.* 2014, Tuffrey-Wijne *et al.* 2016, Van der Steen *et al.* 2016), referral standards for palliative care (Sasahara *et al.* 2009, Hui *et al.* 2018), symptom management (Mahler *et al.* 2010) and aspects relating to communication in advanced disease and end of life (Downar & Hawryluck 2010, Raijmakers *et al.* 2012, Sinuff *et al.* 2015). Therefore, the results of Delphi studies in palliative care constitute an important foundation to guide clinical decision making and future research in palliative care.

The Delphi method was thus chosen as a suitable method of consensus development in this research study for reasons, aligned to the criteria that can be used to determine when the Delphi Technique should be used, as provided by Linstone & Turoff (1975);

1. A problem does not lend itself to precise analytical techniques but can benefit from subjective collective judgments.

2. The individuals needed to contribute to the examination of a broad or complex problem have no history of adequate communication and may represent diverse backgrounds with respect to expertise or experience.

3. The heterogeneity of the participants must be preserved to assure validity of the results.

The objective of this Delphi study is to review and rate the initial list of NSPC CCPIs to reach a consensus on what are core CCPIs for NSPC in the hospital setting. Phases I and II of this research support the conclusion that NSPC is a complex concept, and more guidance is required surrounding how NSPC is applied in clinical hospital practice. Using the Delphi method allowed me to source international experts in a cost effective and efficient manner. In doing so I was able to gain the perspectives of multiple key stakeholders associated with NSPC delivery in hospitals efficiently, and over a relatively short duration of time.

3.6 Evaluation of quality of methods

The literature was searched for guidelines on the conduct and reporting of each of the three methods of enquiry utilised in this study so as to ensure comprehensive and transparent processes. Published quality guidelines for conducting or reporting concept analysis were not identified, therefore measures, such as the development of both a data extraction and quality assessment tool to support this phase, were undertaken (discussed in detail in Chapter 4). The enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong *et al.* 2012) guided the conduct and reporting of phase II (systematic review). Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care was used as the guiding framework in supporting phase III of the study (Junger *et al.* 2017). In all stages of this study input from the expertise of my supervision team provided support and oversight for the quality of the methods employed.

3.7 Conclusion

To conclude, this chapter presented the overall philosophical assumptions and pragmatic approach which supported the research methodology utilised in this multi phased study. The purpose of clinical indicators is discussed and the guiding methodological framework which supported the development of these in this study is then described. This is followed by a section which addressed the individual methods relevant to each of the three phases of the study. Lastly, the guiding tools for ensuring quality of the research methods and reporting processes is described.

Chapter 4 Phase I – A concept analysis of non-specialist palliative care

4.1 Introduction

This chapter represents the first phase in developing the core CCPIs for NSPC in the hospital setting. It presents the conduct and findings of a concept analysis of NSPC[1]. The objective of analysing NSPC conceptually was to gain contemporary high-level (theoretical, organisational, structural) understanding of NSPC and conceptual clarity. Fundamentally, the concept analysis was undertaken so as to potentially derive initial NSPC indicators that could be merged/combined with any further indicators derived from the systematic review (phase II) for use in round 1 of phase III (Delphi). As such, this chapter represents a distinct methodological phase within the overall general methodological approach in developing clinical indicators. Figure 4 provides a diagrammatic representation of my chosen method for the conceptual analysis of NSPC.

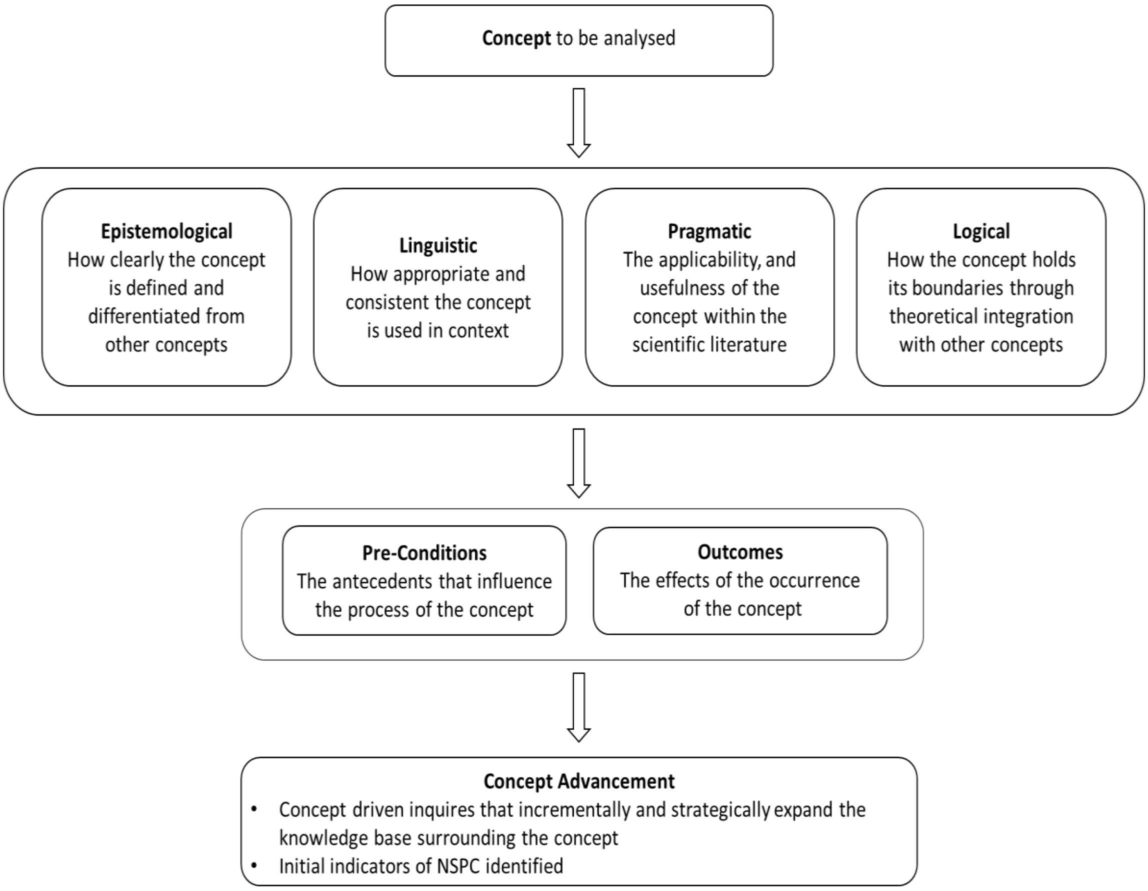


Figure 4 Penrod and Hupcey's framework adapted for this concept analysis

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[1] The following journal publication is based on this chapter: Nevin M., Smith V., Hynes G. (2019). Non-Specialist Palliative Care. A Principle-Based Concept Analysis. *Palliative Medicine*. Vol. 33(6) 634-649 (Impact Factor 4.956)

4.1.1 Literature search strategy

The terms used to describe palliative care provision outside of the SPC domain vary widely highlighting a challenge, from the outset, in conducting a literature search for NSPC specific literature. Therefore, to identify the most suitable search terms which would capture relevant literature relating to NSPC, I conducted an initial scoping review of International palliative care policy where NSPC is described. From this, I identified what terms were used. A list of preliminary search terms was populated and subsequently reviewed by and discussed with my research supervisors. Following this, and with further scoping, trialling of some of the key-terms in the databases and further discussions, the preliminary list of search terms was refined, finalised and included; *non-specialist palliative care*, *palliative approach*, *generalist palliative care*, *basic palliative care, primary palliative care*. Penrod and Hupcey (2005a) state that a principle based concept analysis requires a comprehensive search of the literature. This search needed to include sources of literature beyond the scope of the electronic databases, because how NSPC is defined and ultimately operationalized is heavily influenced by National policy and through guidelines and position statements of stakeholder organisations. Therefore, to capture a wide breadth of literature a thorough search strategy for published and unpublished (grey) literature was developed. Literature from all disciplines (medicine, nursing, psychology, sociology etc.), considered applicable to NSPC was eligible for inclusion to obtain a broad perspective of the concept (Morse 2000, Penrod & Hupcey 2005a).

The complete literature search was undertaken between December 2016 and April 2017. Electronic databases were firstly searched combining the various search terms with the Boolean ‘AND’ and ‘OR’ operands, as appropriate. Electronic databases searched were CINAHL (1980-2017), PUBMED (1966-2017), PsycInfo (1980-2017), The Cochrane Library (2017, Issue 4) and EMBASE (1980-2017). The reference lists of retrieved full text papers were also searched for any additional potentially relevant papers that might not have been captured by the database searches. Full details of the search terms and the search results are provided in Appendix 2. No date restrictions or language restrictions were applied to the searches, although selection of full-text papers was limited to English language publications due to unavailability of funding for translation services. Searching all languages helped me to identify the potential for language bias by identifying the number of non-English papers that might possibly have been relevant.

A search for grey (unpublished) literature was then performed. This included a search for guidelines, and other reports, in LENUS (Ireland’s online repository of health-related reports, research and official publications), in the World Health Organisation (WHO) and in EThOS (e-theses online services of the British Library). The full details of the search terms and the search results used to search the grey literature are provided in Appendix 3. I limited the inclusion of textbooks to the two definitive palliative care core textbooks; the Oxford Textbook of Palliative Medicine and the Oxford Textbook of Palliative Nursing. These are comprehensive core palliative care texts in medical and nursing curricula, and most likely to address this topic from a clinical basis over and above other text book sources. A comprehensive review of websites of palliative care organisations, chronic illness organisations and international palliative care policies was also undertaken. Searches of chronic conditions websites that were likely to contain information of most relevance were limited to cardiovascular, respiratory and cancers. This decision was based on these accounting for the most non-communicable deaths globally in accordance with WHO Global status report on non-communicable diseases (Connor & Sepulveda Bermedo 2014). A systematic procedure was also used to search the websites to ensure important information was not missed. This involved reading the *'about us'* section, the *'mission/position statement'* section where available and then searching the *'publications/research'* section or any similar section that provided guidelines, recommendations or articles. Finally, where additional clarification of terms used in a particular country was needed, relevant authors and key individuals were contacted via email and their responses were included in the analysis. The full list of websites that were searched and the results of these searches is presented in Appendix 4. The complete literature search filtering process and the results are presented in Figure 5.

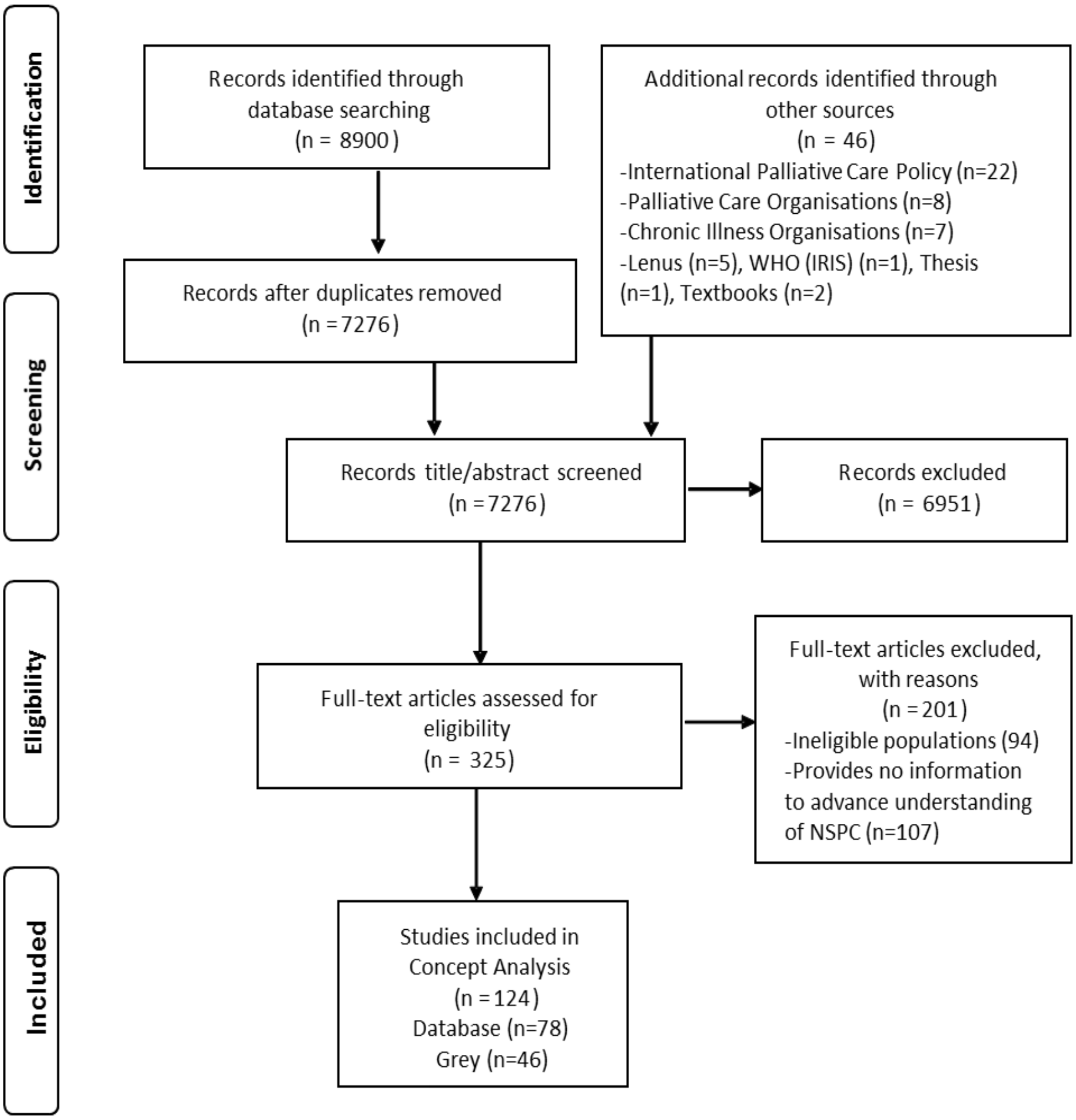


Figure 5 Literature search filtering and search results

In meeting the aim of this analysis and achieving a high-level ‘balcony view’ of understandings and clarity surrounding NSPC, literature whose purpose was to provide definitions, attributes, indicators of, or theoretical discussion about the nature of NSPC, was retrieved. In order to ensure a high degree of specificity, and to provide data that was ‘*theoretically rich’* (Morse 2000, p. 350), literature with NSPC or related search terms in the title, abstract, or main discussion section only were included. Primary research where the aim of the study was to report subjective views of healthcare workers experiences/understandings of non–specialist palliative care was excluded but noted for potential inclusion in phase II (systematic review; Chapter 5). The search and selection strategy yielded 124 articles for informing the analysis.

4.1.2 Data extraction and analysis

A Data Extraction Tool (DET), based on the four philosophical principles was developed to assist extraction of the most appropriate, conceptually driven data. These data included, for example, type of report, country of origin and aim. In addition, the DET posed questions as to how well the data from each included source 'met' the four philosophical principles. Examples of these questions included: Was the concept clearly defined? Is the concept used consistently and appropriately within the context? Does the concept hold its boundaries? What are the key attributes of the concept and is it integrated with other concepts? (Table 5); with data from the sources extracted in answering these questions. Appendix 5 provides an example of data extraction from one study to illustrate the DET and processes. To enhance the validity and reliability of the DET, it was pilot tested on three randomly selected papers, by myself and my supervision team independently, and the results were compared. Agreement on DET items was satisfactory, and minor amendments only were required; for example following discussion, a 'medical speciality' and 'summary section' was added to the tool to support interpretive analysis.

An overall quality rating was also applied to the data source using a four-point alphabetical score as follows:

- A - provides significant information to advance understanding of the concept
- B - provides good information to advance understanding of the concept
- C - provides some useful information to advance understanding of the concept
- D - provides minimal information to advance understanding of the concept

This scoring system was developed purposively for this concept analysis as a means to ascertain an overview of the type of literature that provided the strongest available information (i.e. policy documents or primary studies) as data extraction occurred. Overall, policy and palliative care competency documents provided most of the information regarding NSPC, with few primary studies which examined the concept of NSPC as the central aim. The analysis of the concept of NSPC was both iterative and congruent with the data extraction process, whereby key points and trends extracted from the included papers were collated and tagged against the overarching philosophical principle to which they most closely aligned. Based on interpretive analyses, emerging themes addressing the concept of NSPC within each philosophical principle were identified, explored and analysed to enhance clarity and understanding of NSPC.

Table 5 Examples of questions posed within the Data Extraction Tool

Principle	Some questions posed in Data Extraction Tool
Epistemological	Is the concept clearly defined/definitional elements? Is it well differentiated from other concepts? Are other concepts mentioned (not necessarily defined)?
Pragmatic	Is it useful for clinical practice? Is it useful for research? How has it been operationalised?
Linguistic	Is the language around the concept used consistently? Is the language used appropriately within the context?
Logical	Does the concept hold its boundaries? Has it been theoretically integrated with other concepts? Has the concept been appropriately operationalized? Have the key characteristics of the concept been identified? Are key characteristics consistent?

Included grey literature was read closely, and the findings interwoven with the data extracted from primary studies to provide a complete picture of the current state of the concept of NSPC. Similar to previous published work that used this approach to concept analysis (Smith *et al.* 2012, O'Malley *et al.* 2015), the summative findings and discussion relevant to each principle, are interwoven and presented together. The preconditions (antecedents that influence NSPC in practice) and outcomes (the effects of NSPC in practice) resulting from the concept analysis are then presented and discussed. The major findings from this concept analysis were then extracted and used to inform the initial list of CCPIs for NSPC. This process is discussed in detail in Chapter 6.

4.2 Results

4.3 Epistemological principle

The epistemological maturity of NSPC depended on how well it was differentiated in the literature from other terms such as SPC for example (Penrod & Hupcey 2005b). SPC is clearly defined and understood as a specialist medicine, nursing or related healthcare discipline. The Department of Health and Children (2001) states that *“Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine”* (Dept of Health and Children 2001, p. 21). Attempting to define palliative care outside of the specialist setting (NSPC), however, is challenging (Gardiner *et al.* 2012), and the term appears to be more inferred in relation to ‘not’ SPC rather than being assigned a definition in its own right. In this analysis, no single, consistent definition of NSPC was identified, rather various definitions were identified (Table 6). Three terms that appeared frequently in describing NSPC, however, were identified; these were generalist palliative care, primary palliative care and a palliative approach, which are now discussed.

4.3.1 Common terms used to describe/define NSPC

In a systematic review exploring partnership working between generalist and SPC practitioners (Gardiner *et al.* 2012), the authors describe how a clear definition of generalist palliative care doesn't exist and is required. They define generalist palliative care for the purposes of their review in terms of academic accreditation; '*health professionals with no specialist or accredited training in palliative care'* (Gardiner *et al.* 2012, p. e353). A very similar definition is proposed by McLaren *et al.* (1999), who stated that *'general palliative care refers to the provision of palliative care by health professionals, in the community or in hospitals, who are not specialists in palliative care'* (McLaren *et al.* 1999, p. 1574). Bergenholtz *et al.* (2015a) examined the concept of generalist palliative care specifically within the hospital environment and described it more in relation to a level of exposure to palliative care. They defined it in line with the Danish National Board of Health as *"care performed by health professionals who do not provide palliative care as the main focus of their work. This includes both hospitals and primary care."* (Bergenholtz *et al.* 2015, p. 1). These authors further explain that in hospitals, generalist palliative care is provided by health care practitioners who work in non-palliative departments. Responsibility for delivering generalist palliative care is further teased out by Frey *et al.* (2011b). In their review of literature around generalist palliative care competency, they define NSPC as *'care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team'* (Frey *et al.* 2011b, p. 19).

One obvious commonality shared by these definitions is that the care provided is described as care by individuals who are 'NOT' specialists in palliative care provision. So while these authors provide broad all-encompassing definitions, without being prescriptive (Gaertner *et al.* 2013, Quill & Abernethy 2013, Afshar *et al.* 2015), the *non-specialist* aspect is clearly an important component of how authors are trying to describe, define and understand NSPC, and they all do this independent of each other. Interestingly the most recent palliative care definitions provided by the New Zealand Ministry of Health (2015) states that; *'The term 'Generalist Palliative Care' is used in some countries but is not considered to adequately describe the nature of palliative care provided by health services that are other than specialist palliative care services. In New Zealand we use the term "Primary Palliative Care".* I engaged in email correspondence with the first author of this report to seek further explanation as to why this decision was taken but the author could not provide further clarification, except to say that; "*significant discussion was undertaken, and primary palliative care was considered a more comprehensive term*" (email correspondence 2/11/2016).

Primary palliative care has also been identified as a term used by others to describe NSPC, although different interpretations of its meaning are apparent. Some authors for example, have described it in terms of palliative care skills that all health care providers should provide in any practise setting (The Council of Palliative Care Australia 2005, Merel *et al.* 2014, Ministry of Health 2015, Rocker *et al.* 2015, National Coalition for Hospice and Palliative Care 2018). Linnemann *et al.* (2016) in their study developed a palliative care curriculum for individuals with cystic fibrosis and were of the view that primary palliative care was very much a responsibility of the cystic fibrosis team. They stated that *'Primary palliative care refers to basic skills that healthcare providers can learn and employ at any stage of chronic disease, saving specialist referral for more complex cases'* (Linnemann *et al.* 2016, p. 91). The term 'primary' in primary palliative care can thus be interpreted as reference to the patients' primary carers; that is, those health care practitioners who are directly involved in the care provision as opposed to SPC providers. This leads to ambiguity in definition, as others have described primary palliative care as palliative care that is delivered specifically in the community setting; with primary palliative care discussed in the context of SPC and NSPC integration in the community setting by several authors (Daniels & Linnane 2001, Mitchell 2010, Schneider *et al.* 2010, Mason *et al.* 2015, Murray *et al.* 2015, Pesut *et al.* 2015).

Authors that have used the term palliative approach to define NSPC appear to offer the most in-depth information regarding this concept in the literature, and these definitions are less negatively worded (i.e. 'not' SPC). For example, Dickens (2004) states *"A palliative care approach is the formation of a close relationship between a person/patient, his or her significant others and a multi-skilled team of health professionals, whatever the illness, its stage or context of the care setting. The approach is based on total care, trust, and teamwork enabling the person/patient to be empowered and remain as much in control of his or her own quality of life as possible"* (Dickens 2004, p. 18). Quill & Abernethy (2013) go further in their definition of a palliative approach by including the issue of equity of care stating that *"Access to a palliative approach in primary care need not be monolithic, but it must be universal. We do not all need to do the same things the same way, but a palliative approach to care should be practised by all health care providers who look after patients living with life-threatening illnesses".* (Quill & Abernethy 2013, p. 1149). Many professional organisations and various chronic illness associations have also used the term 'a palliative approach' such as the International Society of Nurses in Cancer Care (2017), American Heart Association (Braun *et al.* 2016), the United States National Comprehensive Cancer Network (2017), the European Society of Cardiology (Jaarsma *et al.* 2009) and the Canadian Nurses Association (2015). Table 6 illustrates the various ways that NSPC is being defined.

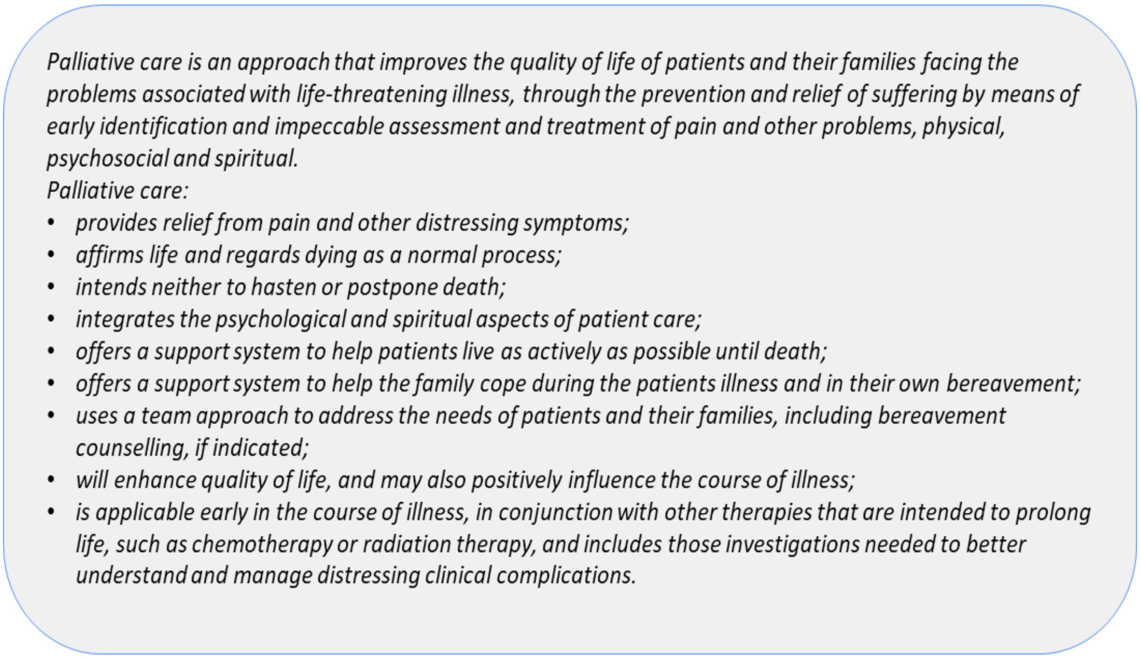
Table 6 Examples of definitions of NSPC

Source	Origin	Term Used	Definition
McLaren et al (1999)	UK	Generalist	General palliative care refers to the provision of palliative care by health professionals, in the community or in hospitals, who are not specialists in palliative care'
Kristjanson et al (2003)	Australia	Palliative Approach	Defined within the WHO 2002 definition of Palliative Care
Ahmedzai et al (2004)	UK	Basic Palliative Care	Basic palliative care is the standard of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their normal duties to patients with life-limiting disease
Dickens (2004)	UK	Palliative Approach	A palliative care approach is the formation of a close relationship between a person/patient, his or her significant others and a multi-skilled team of health professionals, whatever the illness, its stage or context of the care setting. The approach is based on total care, trust, and teamwork enabling the person/patient to be empowered and remain as much in control of his or her own QOL as possible'
Berry (2005)	USA	Basic Palliative Care	Defined within the WHO 2002 definition of Palliative Care
Gofton (2009)	Canada	Palliative Approach	Defined within the WHO 2002 definition of Palliative Care
Frey (2011)	NZ	Generalist	Generalist palliative care is provided by health professionals who do not have specialist training in palliative care and/or work in specialist settings, but who routinely work with patients at the end of life
Disler et al (2012)	Australia	Palliative Approach	Defined within the WHO 2002 definition of Palliative Care
Gardiner (2012)	UK	Generalist	'Generalist' providers are defined as health professionals with no specialist or accredited training in palliative care.
Shadd (2013)	Canada	Palliative Approach	As an approach to care, palliative care appreciates death as a normal life event, emphasizes good communication and clarification of goals of care, and focuses on quality of life including symptom management.
Bergenholtz (2015)	Denmark	Generalist	Generalist palliative care is defined as care provided to those affected by life-threatening diseases as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. So, in hospitals, generalist palliative care refers to the care provided by professionals working in non-palliative departments, while specialist palliative care refers to care provided by palliative units.
Linnemann et al (2016)	USA	Primary palliative care	Primary palliative care refers to basic skills that healthcare providers can learn and employ at any stage of chronic disease, saving specialist referral for more complex cases

4.3.2 Non-specialist palliative care as a component of palliative care provision

Notwithstanding the variations in how NSPC has been defined in the literature, a central overarching theme is the view that applying palliative care principles to the care of patients with chronic life limiting conditions is the responsibility of each and every healthcare provider (Ahmedzai *et al.* 2004, Berry 2005, Health Service Executive & The Irish Hospice Foundation 2009, Radbruch & Payne 2009, Gardiner *et al.* 2012, Johnson & Fallon 2013, Quill & Abernethy 2013, Ryan *et al.* 2014, Gadoud & Johnson 2015). Therefore, important words in analysing the concept of NSPC (or related terms) are the words *palliative care*. Having a clear understanding of what constitutes palliative care provision is required, yet, the very definition and stated philosophy of palliative care has also come under criticism for being unclear (Radall & Downie 2006). Fundamentally, the original foundation and intention of palliative care is understood as a philosophy of care or an approach to care (Ahmedzai *et al.* 2004). Hupcey *et al.* (2009) describe how, as a philosophy of care, any and all health care providers can provide palliative care interventions. In much of the Western World, however, the term palliative care is equated with service provision and its progression over the last twenty years has largely been concerned with its development as a specialty.

The most recent definition from the World Health Organisation (WHO) (2002) (re)leans towards the origin of palliative care by describing it as an 'approach to care' (see Figure 6), and more recently stating that *'a palliative care approach be adopted by all, not just specialist health care professionals,* and that *"general palliative care" be provided by primary care professionals who have a good basic understanding of palliative care principles.'* (Connor & Sepulveda Bermedo 2014, p. 7). Since 2002, numerous authors and national palliative care policy have used this comprehensive definition as a basis to describe and define NSPC (Kristjanson *et al.* 2003, Sampson *et al.* 2005, Gofton *et al.* 2009, Disler *et al.* 2012, Hynes *et al.* 2015, Johnston *et al.* 2015).



Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

Figure 6 World Health Organisation, definition of palliative care (World Health Organisation 2002, p. 84)

This definition however is not without its critics. Firstly, there is a well-established view that palliative care has moved beyond the traditional boundaries of cancer care and is necessary for those with non-malignancies (Kristjanson *et al.* 2003, Mitchell *et al.* 2010, Hines *et al.* 2011, Hynes 2011, Stajduhar 2011, Afshar *et al.* 2015, Gadoud & Johnson 2015), therefore, it is disappointing to see the definition positioned by the WHO within a cancer-specific guideline document entitled *National cancer control programmes: policies and managerial guidelines* (World Health Organisation 2002). Secondly, Hupcey *et al.* (2009) takes issue with the section of this WHO definition that states *'uses a team approach to address the needs of patients and their families..'* arguing that this definition conceptualises palliative care as a particular medical service (team) or system of care delivery, most often requiring a referral or consultation. The term 'team approach' suggests that this requires close multidisciplinary working in order to be able to provide effective care. Another major definition of palliative care provided by the National Coalition for Hospice and Palliative Care, a group representing the leading USA hospice and palliative care organisations, is in the Clinical Practice Guidelines for Quality Palliative Care document (National Coalition for Hospice and Palliative Care 2018). This organisation situates palliative care firmly within medicine as a specific discipline, and the most recent version of their practice guidelines states that palliative care focuses on *'expert assessment'* and they characterise palliative care as *'interdisciplinary'*. However, they do acknowledge in this document, unlike previous versions, that *'palliative care principles and practices can be delivered by any clinician caring for the seriously ill, and in any setting'*. Nonetheless, these definitions of palliative care may present a challenge as to how palliative care may be provided in hospitals by non-specialists, where creating opportunities for interdisciplinary shared working or decision making can be challenging (Hynes *et al.* 2015). Other authors have also described confusion around the term palliative care and whether it is to be interpreted as a philosophy of care or a specialised care team (Shadd *et al.* 2013), with some calling for an update to the WHO (2002) definition of palliative care so as to provide a more explicit and transparent definition that reflects the diverse nature of all palliative care delivery, both specialist and non-specialists (Ahmedzai *et al.* 2004, Pastrana *et al.* 2008). The International Association for Hospice and Palliative Care (IAHPC) have responded to these concerns and identified a consensus based definition of palliative care which does attempt to offer some guidance as to how SPC and 'basic' palliative care integration should be achieved (Radbruch *et al.* 2018).

4.3.3 Non-specialist palliative care as defined within levels of palliative care provision

Findings from the grey literature demonstrate geographical diversity in the visibility of the term NSPC (or related terms) in policy documents, and in how NSPC has developed. In particular, it is evident that NSPC is neither identified nor defined in policy in many low to middle income regions who have poorly developed health systems or no national palliative care policies (Pastrana *et al.* 2012, African Palliative Care Association 2016, Knaul *et al.* 2018). There have been efforts to build capacity for palliative care by, for example, the Institute of Palliative Medicine in India, through community participation initiatives. Contrastingly, in high income countries where there are well developed national palliative care policies, NSPC is specifically defined and described. In many instances, authors define palliative care according to levels of specialism in care provision to change the perception that palliative care is a specialist type of medical care by describing levels of palliative care provision for all health care providers (The Council of Palliative Care Australia 2005, Department of Health 2008, Northern Ireland Department of Health & Social Services and Public Safety 2010). Since 2001 (Dept of Health and Children 2001) Irish health policy has advocated that both non-specialist and SPC should be available to all people in all settings. This report identified three levels of palliative care provision; Level one - a palliative approach, Level 2 - generalist palliative care (both of which are NSPC levels) and Level 3 - specialist palliative care (Chapter 2, Figure 2).

Table 7 provides examples of where palliative care has been described as, and divided into, levels of care provision in national/international policy documents and other reports, and by international palliative care associations and how they define each NSPC level. In these reports, NSPC is generally described within either an educational preparation perspective or involvement in palliative care as part of a practitioner's normal work. Providing palliative care within levels is advocated by the

European School of Oncology (Ahmedzai *et al.* 2004), the Worldwide Palliative Care Alliance (Connor & Sepulveda Bermedo 2014) and the European Association for Palliative Care (EAPC) (Radbruch & Payne 2009). In particular the EAPC attest that while there may be three levels of palliative care in some countries, there should at least be a minimum of two levels of palliative care provision; a palliative approach and SPC. The Worldwide Palliative Care Alliance further adds that the requirement for three levels will differ from country to country and may depend on factors such as models of healthcare, and the nature and extent of integration of palliative care within these models (Connor & Sepulveda Bermedo 2014). In particular, where there are three levels of palliative care identified, this adds a degree of complexity to how we understand NSPC. For example, in Irish policy, use of the terms palliative approach, and generalist palliative care do not reflect the subtle but significant differences between these two levels, and this presents a challenge as to how NSPC is understood and applied in clinical practice. Of note, authors of the 2019 Adult Palliative Care Services Model of Care for Ireland observed that over the course of engaging with stakeholders, the term 'generalist palliative care provider' was not liked or comprehended by many. Therefore, they decided to use the term 'professionals providing a palliative care approach as part of usual care provision' in its place (National Clinical Programme for Palliative Care 2019), further highlighting the nuances in language and terminology associated with NSPC.

Table 7 Palliative care provision and explanation of non-specialist palliative care levels

Source	No. of Levels	Term(s) used and explanation of levels
Australian Policy (2018)	2	1. Primary Palliative Care - all those health services and staff that have a primary or 'first contact' relationship with the patient with a life limiting illness. These staff, while specialist in their own areas, may undertake an ongoing role in the support of patients with life limiting illness by adopting a palliative approach to the care they provide. 2. Specialist palliative care
Ireland Policy (Dept of Health and Children 2001, National Clinical Programme for Palliative Care 2019)	3	1. Palliative Approach - Palliative care principles practiced by all health care practitioners in hospital or community 2. Generalist palliative care - Practitioners who have had some additional training and experience in palliative care perhaps to diploma level' 3. Specialist palliative care
New Zealand Policy (Ministry of Health 2001, 2015)	2	1. Primary Palliative Care- is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team. 2. Specialist palliative care
England and Wales Policy (2008)	3	1. Group A - Specialist palliative care 2. Group B - Staff who frequently deal with palliative and end of life care 3. Group C - Staff Infrequently deal with end of life care
Northern Ireland (2010, 2011)	3	1. Tier 1 - Staff Infrequently deal with end of life care 2. Tier 2 - Staff who frequently deal with palliative and end of life care 3. Tier 3 - Specialist palliative care
Africa Palliative Association, Core Palliative care Competencies (2012)	3	1. Basic level - minimum competencies that are expected of the different cadres following an introductory training in palliative care that is accompanied by support supervision and mentorship from more experienced care providers 2. Intermediate - those that care providers would be able to display after having undertaken further training, having had the opportunity to practise in their respective field and having had mentorship support from expert palliative care provider 3. Specialist level
European Association for palliative care (Radbruch & Payne 2009, Radbruch & Payne 2010, Gamondi *et al.* 2013b)	3	1. Palliative Approach - Used in settings and services only occasionally treating palliative care patients 2. Generalist palliative care - Practitioners who are more frequently involved in palliative care (although it is not the main focus of their work) and may have acquired special education and training in palliative care 3. Specialist palliative care
Worldwide Palliative Care Alliance (Connor & Sepulveda Bermedo 2014)	3	1. Palliative care approach- adopted by all healthcare professionals, provided they are educated and skilled through appropriate training 2. General palliative care - provided by primary care professionals and those treating patients with life-threatening diseases, with a good basic knowledge of palliative care 3. Specialist palliative care
(Ahmedzai *et al.* 2004)	2	1. Basic Palliative care - a standard that should be provided by all healthcare professionals in all settings within their normal duties to patients with life-limiting disease. 2. Specialist palliative care

4.3.4 Contextual nature of how non-specialist palliative care is defined

The term ‘basic palliative care’ is used in some descriptions of NSPC to describe the skills that healthcare providers should possess to deliver this kind of care; for example, basic management of pain (Ahmedzai *et al.* 2004, Quill & Abernethy 2013). An accepted view, apparent in publications from middle to high income countries, in particular, is that NSPC at its most basic level is only delivered by health care professionals (Department of Health 2008, Northern Ireland Department of Health & Social Services and Public Safety 2010, Ryan *et al.* 2014, Palliative Care Australia 2018). Gupta (2004) provides an interesting discussion in the literature around the notion of context in palliative care provision. This author queries what defines ‘basic’ palliative care in low income countries where volunteers and lay community workers deliver much of the NSPC in the community under the supervision of health care practitioners. She questions whether this can truly be called palliative care if it is not delivered by health care practitioners. It should be acknowledged however, that the volunteers’ scope of practice is typically restricted, and there is ample literature that supports the involvement of volunteers/lay community workers in palliative care provision (The Council of Palliative Care Australia 2005, Toye *et al.* 2012, Connor & Sepulveda Bermedo 2014, Pesut *et al.* 2015), albeit under the specific care and direction of formal palliative care services. Also volunteers and other workers require training and supervision (Radbruch & Payne 2010). While this may feasibly favour high income countries with significant access to SPC support, Gupta (2005) advises that patients in India, for example, are extremely vulnerable to negative stereotyping and social isolation particularly around a cancer diagnosis, and volunteers from this community may harbour these prejudices despite training. The difficult political, economic, or social context within some countries that impacts on the type of delivery of NSPC should not, however, be a barrier to the accessibility and availability of palliative care to all. Though it could be argued that the main challenge for low income countries is getting palliative care coverage, and this has given rise to interest in compassionate communities’ initiatives that are also based on NSPC (Kellehear 2013). The African Palliative Care Association (2012) have advanced in addressing the reservations of some by producing very comprehensive competencies for community lay workers (described as community leaders, traditional healers, and family caregivers), highlighting the importance and level of involvement of these people in palliative care provision in African countries. Downing (2005), while also acknowledging that NSPC provision is context dependant, advises, however, that standards should be maintained (or improved), and that NSPC should not be perceived as simplistic, rather providing this type of care is a skill that has to be learnt and developed.

4.3.5 Non-specialist palliative care as defined in life limiting illnesses

NSPC has an important role in the management of non-malignant life limiting illnesses (Mitchell *et al.* 2010, Afshar *et al.* 2015, Gadoud & Johnson 2015, Hynes *et al.* 2015). NSPC is well defined in the literature for many conditions such as various neurodegenerative diseases (Kristjanson *et al.* 2003, Sampson *et al.* 2005, Gofton *et al.* 2009, Hines *et al.* 2011, Van der Steen *et al.* 2014). Van der Steen *et al.* (2016, p. 134), for example, describes palliative care for people with dementia as having two aspects, whereby the baseline care for all patients is a palliative approach and includes '*treatment of behavioural and psychological symptoms of dementia, comorbid diseases, and (inter- or concurrent) health problems'*, and only those patients with complex problems require SPC. Grubbs *et al.* (2014) described the importance of defining NSPC within a specific disease management framework. They define in detail how a palliative approach should be adopted*; 'as a transition from a conventional disease-oriented focus on dialysis as rehabilitative treatment to an approach prioritizing comfort and alignment with patient preferences and goals of care to improve quality of life and reduce symptom burden for maintenance dialysis patients in their final year of life.'* (Grubbs *et al.* 2014, p.2203). Sawatzky *et al.* (2016a, 2016b) further support this view stating that *'A palliative approach is not simply applying knowledge and expertise from palliative care to practice; it requires adaptation to different patient populations and their unique disease profiles'* (Sawatzky *et al*. 2016a, p. 8).

While there is general agreement as to the need for all health care providers to engage in palliative care delivery, a common thread of 'not specialist' in attempts to define NSPC, and a variety of commonly used terms and levels of palliative care, mean that no clear evidence of a single definition of NSPC emerged from the analysis. An official position paper published by the EAPC assert that "*an effective European approach to quality palliative care demands an unambiguous use of terms, which implies, as a prerequisite, the mutual agreement on the definitions of these terms"* (Radbruch & Payne 2009, p. 280). This lack of theoretical and/or operational definition, combined with inconsistency across countries in descriptions of levels of NSPC provision, indicates that the concept of NSPC, from an epistemological perspective, is relatively immature; that is, NSPC is not well defined or clearly positioned in the literature at this point of time.

4.4 The Pragmatic principle

Pragmatism relates to the usefulness of a concept in a discipline. Penrod & Hupcey (2005b) describe how concepts are pragmatically mature if they have a high degree of operationalization. That is, to what extent the concept is operationalised or used in clinical practice. The pragmatic utility of NSPC was explored by identifying the essential attributes or characteristics of NSPC, relevant for use in practice and how they have been described in the literature. Essential attributes of NSPC are those that are present in all instances where the concept appears, yet it is possible that attributes can vary in their clinical utility (Morse *et al.* 1996). This is very much the case for NSPC and its associated attributes that emerged from this concept analysis, which are best presented in a tiered way. These tiers (n=3) relate to the level of abstractness/operationalization of the attributes; that is, their level of clinical utility, illustrated in Figure 7. What is consistent within all tiers is that responding to total pain, that is the multidimensional nature of the palliative patient's pain experience to include the physical, psychological, social, and spiritual domains (Mehta & Chan 2008) remains central to NSPC.

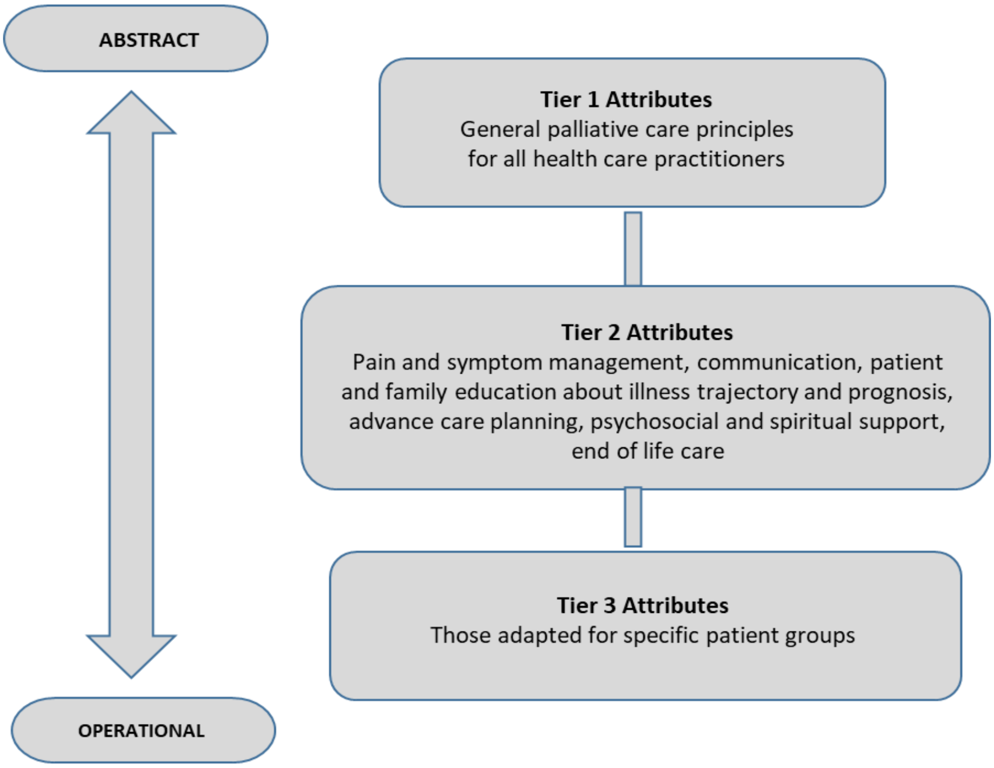


Figure 7 Attributes of Non-specialist palliative care and levels of operationalization

4.4.1 Tier 1. Attributes within the context of Global Healthcare Provision

At the most abstract level, tier 1 attributes of NSPC have been identified within various publications that describe essential principles, practices or guidelines on palliative care, and essentially state that these palliative care principles need to be integrated into care provision by all health care providers. For example a range of palliative care organisations such as the EAPC, the International Association for Hospice and Palliative Care, and the Worldwide Hospice and Palliative Care Alliance have described terms such as autonomy, dignity, quality of life, patient centred care, symptom management, communication, and grief and bereavement care as central to providing quality palliative care by non-specialist health care providers (Radbruch & Payne 2009, De Lima *et al.* 2012, Gamondi *et al.* 2013b, Connor & Sepulveda Bermedo 2014). Tier 1 attributes were also sourced in literature that identified universal attributes of NSPC suitable for all patients with life limiting chronic conditions in varied settings, but this literature did not provide any further clarification or depth as to their meaning or application within NSPC provision. These tier 1 attributes include communication skills (Hallenbeck 2006, Hughes *et al.* 2006, Disler *et al.* 2012, Gaertner *et al.* 2013, Potter *et al.* 2015), psychological and spiritual care (Griffie *et al.* 1999, Ahmedzai *et al.* 2004, Graham & Clark 2005, Gaertner *et al.* 2013, Quill & Abernethy 2013), family/carer support and psychosocial support (Daniels & Linnane 2001, Becker 2009, Toye *et al.* 2012, Stajduhar & Tayler 2014). Within this tier, attributes of NSPC are so broad, how they might be understood or what they mean in clinical NSPC care is vague and implied within the context of overall palliative care provision. They are therefore too abstract to provide any meaningful impact for clinical practise. Furthermore, at this level it is difficult to explicate how these attributes are specific to NSPC, and how their clinical utility in non-specialist and SPC is fundamentally different.

4.4.2 Tier 2. Attributes of non-specialist palliative care described at a National/Regional level

Tier 2 attributes identified are also universal (applicable to any patient group or setting) NSPC attributes and are relatively consistent with those identified in tier 1. However, the data sources informing tier 2 identify and describe attributes of NSPC in sufficient detail for them to be operationalized in practice. Sources include national palliative care competency/standards documentation from various regions such as Ireland, Africa, Scotland, Northern Ireland and Australia, guidance from the EAPC and some primary intervention studies. Central attributes for NSPC at this tier consistently include pain and symptom management, communication skills, patient and family education about illness trajectory and prognosis, advance care planning, psychosocial and spiritual support, and end of life care (Scottish Partnership for Palliative Care 2007, Northern Ireland Practice and Education Council 2011, African Palliative Care Association 2012, Ryan *et al.* 2014, Canadian Hospice Palliative Care Association & Government of Canada 2015). Many of these attributes are also identified as core components of palliative care education by the EAPC (Gamondi *et al.* 2013a, Gamondi *et al.* 2013b), and in educational intervention studies in NSPC for example by Hughes *et al.* (2006) and Pesut *et al.* (2015). Furthermore, they were identified as indicators measured by tools to address palliative care competence amongst generalist palliative care providers (Frey *et al.* 2011a, Frey *et al.* 2011b). Additionally, in a review of palliative care education for nurses by Pesut *et al.* (2014) all attributes were consistently identified as common topics of generic palliative care nursing education. A table presenting these essential attributes of NSPC, including the types of sources that the evidence was drawn from is provided in Table 8.

Table 8 Essential attributes of Non-Specialist Palliative Care and types of sources

Attributes	Types of sources
• Pain and symptom management • Communication • Patient and family education about illness trajectory, prognosis and goals of care • Advance care planning • Psychosocial and spiritual support • End of life care	International palliative care organisations; National palliative care policies; Palliative care competency documents; Chronic illness policies, guidelines and intervention studies; Palliative care education guidelines and intervention studies

Tier 2 attributes provide a more concrete basis to develop clinical practice than those at tier 1. However, while they are expected to or must exist for NSPC to occur in practice, the problem is that they, themselves (the attributes), at this tier level, are not well-described or explained as to how one might apply or implement them in practice. It was also observed that tier 1 and tier 2 attributes of NSPC have predominately been produced by SPC practitioners. Key characteristics of NSPC should be derived from multiple perspectives of healthcare practitioners, including patients. This has the potential to maximise understanding of the concept, and positively affect the pragmatic maturity of the concept.

4.4.3 Tier 3. Attributes at the population group/condition specific/setting level

The generic attributes identified in tier 2 (Table 8) exist in this tier also, although at the highest operational level where authors have recognised the uniqueness of the experiences of particular groups of patients and have adapted NSPC attributes to reflect this. Identified NSPC attributes have been specifically adapted to cancer care (National Institute for Clincial Excellence 2005, National Institute for Health and Care Excellence 2011, Bausewein *et al.* 2015, National Comprehensive Cancer Network 2017), neurological conditions (Sampson *et al.* 2005, Hines *et al.* 2011, Department of Health 2014, Merel *et al.* 2014, Van der Steen *et al.* 2014, Weafer 2014), heart failure and other cardiac diseases (Hupcey *et al.* 2009, Jaarsma *et al.* 2009, Braun *et al.* 2016, Ponikowski *et al.* 2016), chronic lung conditions (Irish Hospice Foundation & Health Service Executive 2008, Hynes 2011, Disler *et al.* 2012, Rocker *et al.* 2015), diabetes (Johnston *et al.* 2015), people with an intellectual disability (Tuffrey-Wijnea & McLaughlin 2015), cystic fibrosis (Linnemann *et al.* 2016) and those requiring dialysis (Grubbs *et al.* 2014). This also has a direct impact on the expertise and knowledge that healthcare providers will establish when working with these specific patient groups.

To give some examples of health condition adapted attributes of NSPC, Johnson & Fallon (2013) describes that generally the evidence base supports use of low dose morphine for breathlessness as a palliative care symptom in pain and symptom management for patients with cancer. However, in randomised controlled trial data for people with heart failure associated breathlessness, response to opioids is conflicting (Johnson & Fallon 2013). For pain and symptom management in patients with chronic obstructive pathways disease (COPD) Rocker *et al.* (2015) describes how specific education around fatigue management and breathing training is required for these patients. Specific guidance related to the NSPC generic attributes of communication and advance care planning have been published for patients with dementia due to the presence of confusion, agitation, aggression, and delirium (Hines *et al.* 2011, Merel *et al.* 2014). It could be argued that practitioners working with specific groups of patients on a daily basis such as respiratory nurse specialists develop knowledge and expertise of the palliative care needs of these groups of patients and are potentially operating at level 2 NSPC provision.

Ultimately, for a concept to be pragmatically mature, members of the discipline should be able to recognise manifestations of the concept (Penrod & Hupcey 2005b). It can be seen therefore that at this tier, NSPC has the most pragmatic utility where practitioners can give targeted and specific NSPC when issues to particular patient groups are identified. Furthermore, attributes in this tier have consistently been developed with input from both NSPC and SPC. Of note, while not a specific attribute of NSPC per se, the importance of good multidisciplinary teamwork was mentioned by most authors who described attributes of NSPC. However, in many cases there was no clear differentiation between multi- and inter-disciplinary cooperation (Gardiner *et al.* 2012). While the gold standard for SPC is an interdisciplinary team approach to care (World Health Organisation 2002), arguably it may be more challenging to adopt a multi-disciplinary team approach to NSPC, particularly within the hospital setting where the organisation and delivery of care tends to be structured around healthcare providers groups working independently of each other (Hynes *et al.* 2015).

4.4.4 Non-specialist palliative care evaluation methods

The lack of a clear and concise definition of NSPC has been uncovered in the epistemological principle. How NSPC is defined, however, has a direct relationship to how it can be evaluated. Literature as far back as the mid to late nineties has called for the need to evaluate NSPC. McLaren *et al.* (1999) espoused the need to nurture and harness the contribution of NSPC practitioners which would entail the need to develop local standards for general palliative care and introduce better monitoring and audit of NSPC. Yet in this same article the author states that generalist palliative care is care delivered by healthcare practitioners who are not specialists. This definition provides no real insight into what NSPC entails and provides a limited basis for any meaningful evaluation. There are a number of examples of published competencies and standards for NSPC in many national palliative care strategies for a variety of professional disciplines (The Council of

Palliative Care Australia 2005, Ministry of Health 2007, Department of Health 2010, Northern Ireland Practice and Education Council 2011, African Palliative Care Association 2012, Health Service Executive 2014), and the NHS in Scotland have produced a guide to using palliative care competency frameworks (Scottish Partnership for Palliative Care 2007). However, no evaluation methods were included and very little guidance is provided for professionals where actions need to be taken to improve competence in specific areas which limits the pragmatic utility of the concept. For example, within the Irish palliative care competency framework, within the competency domain of communication, nurses at level 1 NSPC are expected to *"Recognise and contribute to the management of potential conflict in decision-making in the context of palliative care"* (Ryan *et al.* 2014, p. 40). While those practicing at level 2 should be able to *"Demonstrate an understanding of palliative care related issues and difficulties which may arise and which may impact on interactions with the individual and her/his family"* (Ryan *et al.* 2014, p. 41). From these two statements, it is difficult to make a clear distinction between the expected levels of NSPC competency, nor is it very clear how one might demonstrate the required competency.

There are examples in the literature where NSPC has been operationalized in measurement tools. Frey *et al*. (2011a, 2011b) conducted a systematic review, involving 19 studies (16 quantitative, 3 mixed methods), of questionnaires that measured the perceived competence of generalists in palliative care provision. Overall, key domains of NSPC provision did emerge such as communication and pain and symptom management indicating some degree of conceptual consistency. However other measures are so varied that the concept lacks operationalized maturity. Authors reported a focus upon the physical aspects of symptom management and no single validated questionnaire was identified. Furthermore, measurements of patient outcomes were not included in study designs. It is ironic that many authors describe NSPC as espousing the values of patient-centred care (Becker 2009, Grubbs *et al.* 2014, Schaefer *et al.* 2014, Van der Steen *et al.* 2014), yet the patients' experiences of this care have not been addressed in any measurement tools.

In relation to evaluation of NSPC from a global context, two aspects are considered; measures of coverage and measurements of specific competencies or care outcomes. For many years, the palliative care community has advocated for systematic monitoring of palliative care at national and global levels. Several authors have developed reports on the status of palliative care development worldwide (Lynch *et al.* 2013, Arias-Casais *et al.* 2019), within the EU (Woitha *et al.* 2016), and in Latin America (Pastrana *et al.* 2012). On examination of the evaluation measures utilised within these reports however, the outcomes appear very orientated to SPC such as the number of palliative care specialist medical practitioners per capita or the number of SPC inpatient units. Standards for NSPC need to be incorporated into systematic monitoring of palliative care at national and global levels so as to ensure pragmatic clinical utility. Measuring the international development of palliative care is challenging but is important for policy makers and for planning healthcare spending (Loucka *et al.* 2014). For example, in a global social policy analysis of international palliative care development (PhD dissertation), Clark (2016) concluded that countries which have not developed palliative care are likely to face significant challenges in the delivery of basic healthcare. The challenge however is to ensure that these NSPC attributes can be linked to specific outcome measures to facilitate accurate monitoring, evaluation and to ultimately influence future palliative care service delivery. For example, in a published report regarding the status of palliative care in Latin America (Pastrana *et al.* 2012), the only outcome measure relating to palliative care education was whether countries had official PC accreditation as a medical speciality. This was subsequently acknowledged as a very narrow outcome measure by The Latin American Association of Palliative Care and the International Association for Hospice and Palliative Care (De Lima *et al.* 2013).

In a joint project to develop palliative care indicators for the Latin America region they described the need for health care providers to have basic knowledge of palliative care which should include the ability to identify and treat the most common palliative symptoms, attend to psychological and social aspects of palliative care and to address communication issues that patients and their relatives/caregivers experience. In addition to the SPC medical educational programmes, these authors identified two further palliative care education indicators for non-specialist practitioners which are very amenable to measurement. These included the proportion of medical and nursing schools which include palliative care education in undergraduate curricula (De Lima *et al.* 2013). The Quality of Death Index report has also broadened the evaluation of palliative care globally by including indicators related to the general medical and nursing knowledge of palliative care, which is a positive step in acknowledging the importance of NSPC (The Economist Intelligence Unit 2015). To conclude, essential attributes of NSPC were identified in this analysis, while there is literature that points to NSPC having pragmatic maturity, particularly within tier three attributes, the lack of robust evaluation techniques, at national, regional or global levels indicates that currently the concept is moderately mature.

4.5 The Logical principle

Logic relates to the assimilation of a concept with related concepts. Penrod & Hupcey (2005b) describe how a logically mature concept has clearly defined relationships to other concepts within a theory or construct that do not violate or conflict with its attributes. The boundaries of a concept are generally identified by what is and what is not part of the concept (Morse *et al.* 1996). Mehta & Chan (2008) attest that responding to total pain remains a central concept of palliative care and one of the most important defining characteristics that distinguishes palliative care from other care provided to patients in hospital. Attributes of NSPC identified in this concept analysis (Table 8) reflect the fundamental need to respond to the multidimensional nature of the palliative patient's pain experience (total pain). What has also emerged, predominately in this concept analysis is that NSPC is a relatively high-level abstract concept encompassing a number of underlying concepts such as patient centred care, holism and quality of life. Morse (2004) describes how high-level concepts are extremely expansive in scope and have the potential for a broad application.

In many discussions of NSPC, across reports, quality of life is described as a central component (Ahmedzai *et al.* 2004, Dickens 2004, Downing 2005, Hupcey *et al.* 2009, De Lima *et al.* 2012, Toye *et al.* 2012, Linnemann *et al.* 2016). Quality of life is also specifically referred to within the World Health Organisation (2002) definition of palliative care (Figure 6). Patient-centred care also features heavily within descriptions of NSPC (Gofton *et al.* 2009, Van der Steen *et al.* 2014, Rocker *et al.* 2015). Grubbs *et al.* (2014), in their paper on end stage renal failure describe the significant symptom burden of maintenance dialysis, and where a palliative approach is initiated, dialysis prescription targets are relaxed, thereby reducing aggressive intervention which is essentially a patient centred care transition prioritising comfort and aligning with patient preferences. Schaefer *et al.* (2014) go so far as to argue that the development of NSPC skills for clinicians is essential to the development and implementation of patient centred models of care. The concept of holism is also inextricably linked to the concept of NSPC (Downing 2005, African Palliative Care Association 2012, Disler *et al.* 2012, Toye *et al.* 2012). A holistic assessment has been described as a central component of NSPC by Gadoud & Johnson (2015). Hunt & Cameron (2005) further assert the need for a thorough holistic approach with NSPC. Findings from the analysis indicate that while the concepts of patient-centred care, holism and quality of life are heavily associated with NSPC, generally, these concepts themselves are not specifically defined by authors and their association to NSPC is poorly described.

End of life care has been identified under the pragmatic principle as one essential attribute of NSPC (Hughes *et al.* 2006, De Lima *et al.* 2012, Schaefer *et al.* 2014, Bausewein *et al.* 2015). The European Society of Oncology (Ahmedzai *et al.* 2004) describe how end of life care is the specific application of palliative care interventions in the last hours, days or weeks of life. Similarly, within an Irish context, the Health Services Executive (2014) states that '*end of life care is the term used to describe care that is provided during the period when death is imminent, and life expectancy is limited to a short number of hours or days.'* (Health Service Executive 2014, p. 4). NSPC encompasses so much more than just end of life care and its benefits are well supported in the literature as an early intervention in a wide range of chronic life limiting illnesses (Radbruch & Payne 2009, Dalgaard *et* *al.* 2014). The World Health Organization also asserts that palliative care need not be confined to the last days or hours of life when it advocates that palliative care is 'applicable early in the course of the illness' (World Health Organisation 2002), although findings in this concept analysis indicate that a conflation and blurring of boundaries between these two concepts exists. National strategies were identified that adopted the term 'end-of-life' for their work, such as the End of Life Care Strategy for England and Wales (Department of Health 2008). Other countries such as Canada and Northern Ireland use the terms 'palliative care' and 'end-of-life' care interchangeably (Northern Ireland Department of Health & Social Services and Public Safety 2010, Bede *et al.* 2011). These terms were also used interchangeably by many authors (Kristjanson *et al.* 2003, Sampson *et al.* 2005, Shadd *et al.* 2013, Merel *et al.* 2014, Stajduhar & Tayler 2014, Afshar *et al.* 2015, Bergenholtz *et al.* 2015, Johnston *et al.* 2015, Rocker *et al.* 2015).

In Ireland, useful guidance documents supporting the early integration of generalist palliative care in neurological disease (Weafer 2014), Parkinson's disease (The Irish Palliative Care in Parkinson's Disease Group 2016), dementia (Department of Health 2014), heart failure and chronic obstructive pulmonary disease (Irish Hospice Foundation & Health Service Executive 2008) have been produced, suggesting that implementing NSPC earlier is being progressed. However, the Department of Health and the Irish Hospice Foundation (a powerful palliative care policy driver organisation in Ireland) may have competing viewpoints around the concept of end of life care, and in particular how NSPC is interpreted within clinical practice in hospitals. Inspection of the Irish Hospice Foundation website reveals their logo *'striving for the best care at end of life for all'* (Irish Hospice Foundation 2017). Furthermore, in 2007, the Irish Hospice Foundation, in partnership with the Health Service Executive introduced the Hospice Friendly Hospitals Programme to ensure that 'end-of-life, palliative and bereavement care are central to the everyday business of hospitals in Ireland'. An inspection of the resource materials of this programme particularly around professional education workshops for NSPC staff, reveals a focus on care for patients who are in their final days or hours of life in Irish hospitals (Irish Hospice Foundation 2017). Conflation between end of life care and NSPC in Irish hospitals is also recognised by Hynes *et al.* (2015), who describes an inherent conflict of organisational culture in the delivery of NSPC in hospitals. Ultimately, this analysis of NSPC gives rise to questions as to whether NSPC can hold its own as a single theoretical concept, and it may be considered logically immature since the conceptual basis of NSPC continues to be inadequately articulated. Further development of the concept, to enable it to 'hold its own' as a concept when positioned with other related or similar concepts is required.

4.6 The Linguistic principle

Linguistics is essentially the science of language and human speech. The linguistic maturity of NSPC is indicated by the consistent use and meaning of the concept across a variety of contexts or theoretical constructs (Penrod & Hupcey 2005a). Throughout all of the terms used (generalist palliative care, palliative approach, and primary palliative care), and the various definitions and descriptions identified in this concept analysis, recurrent themes have emerged. These include the foundations of holism, quality of life, and patient-centred care and that NSPC is suitable for and highly applicable to all people with chronic life limiting conditions. While this analysis has established that NSPC is the responsibility of all health care providers (Gardiner *et al.* 2012, Gamondi *et al.* 2013a, Knaul *et al.* 2018, National Clinical Programme for Palliative Care 2019)**,** blurring of boundaries with SPC were identified, in particular due to the frequent use of the WHO (2002) palliative care definition to describe NSPC which impact on the concept's linguistic maturity. Many authors have described issues such as a lack of clarity around roles, frustration, and tension that exists between specialist and NSPC practitioners (Gardiner *et al.* 2012, Quill & Abernethy 2013, Shadd *et al.* 2013, Hynes *et al.* 2015, Bergenholtz *et al.* 2016, Sawatzky *et al.* 2016a, Sawatzky *et al.* 2016b). Gardiner *et al.* (2012), conducted a systematic review about the interface of specialist and NSPC and concluded that clear definitions of roles and responsibilities were required as a priority in order to address the professional territorialism that exists in palliative care provision.

Consistency in use and meaning of NSPC can depend on the context or setting in which it occurs. Risjord (2009) and Penrod & Hupcey (2005a) affirm the importance of context for conceptual meaning. Some authors have investigated elements of NSPC specifically within the acute care hospital setting, where specific challenges for the implementation of NSPC around the disease-orientated culture and organisation of care in hospitals have been identified (Gott *et al.* 2013, Bergenholtz *et al.* 2015, Hynes *et al.* 2015, Bergenholtz *et al.* 2015a, Bergenholtz *et al.* 2016). Others have focused on the community or residential setting (Schneider *et al.* 2010, Toye *et al.* 2012, Shadd *et al.* 2013, Mason *et al.* 2015, Murray *et al.* 2015, Pesut *et al.* 2015). In this concept analysis, consistent NSPC attributes specific to each particular setting were not identified due to the varied nature and purpose of the studies. Neither was a consistent definition of NSPC specific for any individual care setting identified. Shadd *et al.* (2013), from a community perspective warns that to ensure patients are getting access to NSPC in the community, it needs to be defined, described and made explicit in this context in order to support and measure its impact in primary care. Sawatzky *et al.* (2016b) has also described the importance of defining nursing responsibilities at the specialist and non-specialist level within each context of care in order to build capacity of both sets of professionals. It is important that attempts to standardise care practices for care contexts, or groups of patients with palliative care needs do not just focus on symptomology, but must reflect the fundamental notion of total pain, which recognises the uniqueness of the individual patient's experience, a central tenant of the philosophy of palliative care (Saunders *et al.* 1995).

While there appears to be consensus on the suitability and benefits of NSPC for a wide variety of chronic conditions, the clinical application of the concept of NSPC varies considerably within the context of individual conditions, which is to be expected. For example, advance care planning as a central component of NSPC provision is complicated in dementia, due to unpredictable cognitive decline and family involvement in decision making (Hines *et al.* 2011, Department of Health 2014, Merel *et al.* 2014, Van der Steen *et al.* 2014). Some argue that NSPC is more appropriate late in the disease trajectory (the final year) in patients with end stage renal failure on dialysis (Grubbs *et al.* 2014) and diabetes (Johnston *et al.* 2015). Unpredictable disease trajectories in chronic illness is cited as a challenge by multiple authors (Irish Hospice Foundation & Health Service Executive 2008, Hupcey *et al.* 2009, Mitchell *et al.* 2010, Dalgaard *et al.* 2014, Weafer 2014, Gadoud & Johnson 2015), with consensus on terms such as 'end of life' and 'end stage' far from universal for patients who have a prolonged and unpredictable terminal phase such as that in chronic obstructive pathways disease, heart failure and neurological disease. Murray *et al.* (2005) made important advances to support clinicians to plan and deliver primary appropriate care. They, in recognising that a 'one size fits all' approach is not best practice, identified major illnesses trajectories, which provides a broad timeframe and patterns of probable needs and interactions with healthcare. Ultimately recognising the symptoms and experiences of different patient populations is therefore essential to providing effective care. To this end, some authors have called for all medical specialities to define a set of NSPC skills for which they will be primarily responsible and distinguish them from palliative care challenges that require formal consultation with the SPC team (Quill & Abernethy 2013, Linnemann *et al.* 2016). It could be argued that the challenges associated with the application of palliative care principles may, in turn, pose challenges for how NSPC is interpreted in different conditions. While variability in NSPC roles is expected and indeed desirable in chronic illness, consistency in core characteristics is important for the linguistic maturity of NSPC and for addressing the concerns raised about the protection of the philosophy of palliative care when applied across different settings, disciplines and specialisms (Royal College of Physicians of London 2007).

4.7 Preconditions

Morse *et al.* (1996) describe how a concept must be preceded by similar conditions or phenomena (i.e. have similar antecedents). Several preconditions for the concept of NSPC were identified in this analysis. Firstly, there is an increasing awareness of need for palliative care. The 1990s saw an increasing number of publications highlighting the palliative care needs of people with different conditions, and more recently (2000 onwards), this is also reflected in the visibility of NSPC within national palliative care policy. NSPC has become a priority of palliative care policies in high income countries across the world (Ministry of Health 2001, The Council of Palliative Care Australia 2005, Ministry of Health 2007, Department of Health 2008, Ryan *et al.* 2014). Through this, there is a growing assumption that palliative care is part of the remit and workload of every health care provider who is in contact with patients with chronic illnesses, and not just the responsibility of SPC services (McLaren *et al.* 1999, Berry 2005, Hupcey *et al.* 2009, Gibbins *et al.* 2010, Gott *et al.* 2012, Canadian Hospice Palliative Care Association & Government of Canada 2015, Murray *et al.* 2015). Sawatzky *et al.* (2016b) describes how, in order to meet the needs of persons who have life-limiting conditions, it is imperative that the values and tenets of NSPC are embedded in nursing care delivery across all sectors of care. Also, the demand for NSPC is rising due to several reasons, as illustrated in Figure 8 (and previously in Chapter 2). The increasing amount of people facing old age in many countries makes it likely that serious chronic and life limiting illness will present a dominant challenge for healthcare delivery in the future which means that the numbers of patients requiring NSPC services is increasing (McKinlay & Marceau 2008, Stajduhar 2011, Quill & Abernethy 2013, Pesut *et al.* 2014, Clark 2016).

The World Health Organisation also reports a growing demand for palliative care provision globally (Connor & Sepulveda Bermedo 2014). Current models of palliative care delivery, primarily SPC models do not have the capacity to meet future palliative care demands (Ahmedzai *et al.* 2004, Gupta 2004, Mitchell *et al.* 2010, Gardiner *et al.* 2012, Toye *et al.* 2012, Quill & Abernethy 2013, Shadd *et al.* 2013, Gadoud & Johnson 2015, Rocker *et al.* 2015). Furthermore Mitchell *et al.* (2010) describe how, with aging populations, the predominant disease trajectory is a gradual decline due to frailty, multi-organ failure or comorbidity, and these patients are largely cared for by NSPC practitioners. Other authors have also described increasing service needs for NSPC delivery in patients with heart failure, dementia, chronic obstructive pathways disease and other chronic illnesses, to name a few (Hupcey *et al.* 2009, Van der Steen *et al.* 2014, Rocker *et al.* 2015, Van der Steen *et al.* 2016). This relates not only to the increasing numbers of patients with these diseases but also the view that NSPC should be offered early in the disease trajectories of many chronic illnesses (Gaertner *et al.* 2013, Stajduhar & Tayler 2014, Sawatzky *et al.* 2016a).

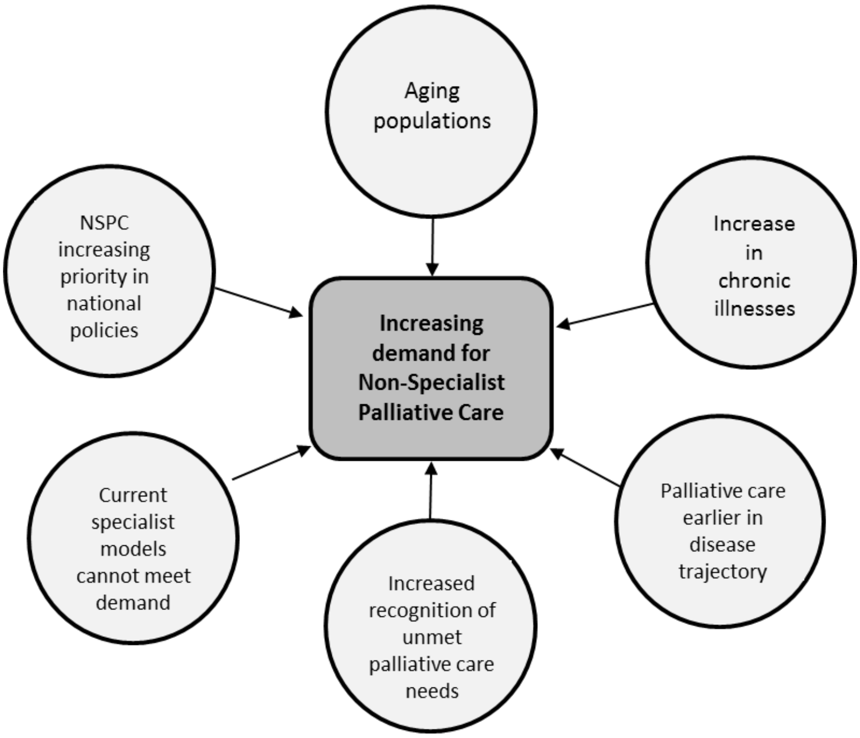


Figure 8 Factors increasing demand for non-specialist palliative care

Another precondition relates to the educational preparation for NSPC delivery. A common theme that emerged in this analysis is the need for health care providers to be educated appropriately in order to deliver effective NSPC (Schiessl *et al.* 2013, Horowitz *et al.* 2014, Linklater *et al.* 2014, Malloy *et al.* 2014, Chiu *et al.* 2015, Schulz *et al.* 2015, Head *et al.* 2016). However, NSPC does not appear to be very visible within undergraduate medical and nursing curricula (Hallenbeck 2006, Ramjan *et al.* 2010, Horowitz *et al.* 2014, Chiu *et al.* 2015). It is also relatively scant in core palliative care textbooks (Cherny *et al.* 2015, Ferrell *et al.* 2015). Guidance for the development of palliative care nursing (De Vlieger *et al.* 2004), medical (EAPC Steering Group 2013), psychology (Jünger *et al.* 2010) and social work (Gamondi *et al.* 2013b) education in Europe has been produced by the European Association of Palliative Care. Similarly, in Ireland, the Irish Hospice Foundation (2007) published a discussion paper on the future of palliative care education in Ireland which identified five expanded levels of palliative care education. In this document the authors determined that *"the current pre-qualification provision for non-specialists is deemed to be fragmented with little integration of core palliative care competencies"* (Irish Hospice Foundation 2007, p. 3).

The World Health Organisation (2014) identified two levels of NSPC education; namely basic palliative care training for all health professionals and intermediate training for those routinely working with patients with life-threatening illnesses, but worryingly these authors also concluded that *"the vast majority of health professionals worldwide have little or no knowledge of the* *principles and practices of palliative care"* (Connor & Sepulveda Bermedo 2014, p. 27). Pesut *et al.* (2014) in a scoping review of 58 studies on nurse education in palliative care and found that although there was a positive effect of palliative education, the diverse educational approaches and lack of rigorous study designs made it difficult to recommend an evidenced based approach to educate nurses in palliative care. Furthermore, these authors found that there was a lack of studies that examined the impact of educational interventions in nursing care.

4.8 Outcomes

Consequences (outcomes) normally follow an occurrence of the concept (Morse 1995). In the literature many researchers argue that NSPC can improve the pain and symptom burden of illness, improve quality of life, and can enable patients and families to feel empowered based on their own goals and values and on a clear understanding of their prognosis and treatment options (Griffie *et al.* 1999, Ahmedzai *et al.* 2004, Dickens 2004, Becker 2009, Gofton *et al.* 2009, De Lima *et al.* 2012, Gadoud & Johnson 2015, Potter *et al.* 2015, Sawatzky *et al.* 2016b). Johnson & Fallon (2013) poses the question, '*is this just good care?'* One could argue that this is indeed the case, however it must be investigated why so many patients have unmet palliative care needs (Murray & Boyd 2011, Gardiner *et al.* 2012). Findings from this concept analysis indicate that the evidence base for NSPC is limited and challenges exist around how this concept is defined, understood and measured in practice.

The implications, for example, can be observed through invalidated NSPC competency tools and educational strategies so varied it is impossible to determine the effect of these interventions on practice. Little is also known about the consequences of NSPC when delineated according to two discrete levels of palliative care provision, or from the perspective of patients and families. The findings of this concept analysis have perhaps provided a basis to determine outcomes of NSPC, based on the existence of identified essential attributes identified (Table 8), such as the existence of advance care planning in a hospital. However, if the philosophy of palliative care is underpinned by the concept of total pain (as described in Chapter 2), arguably the challenge is how to articulate the consequences of that. This would suggest that developing clinical indicators at an individual level which reflect only care process associated with symptomology alone will not be enough to improve NSPC that healthcare providers in hospitals provide. It will require identification of indicators at all levels within the organisation to strive to permeate a palliative care philosophy throughout the entire organisation.

SPC has an important role to support NSPC providers, and Rocker *et al.* (2015) describe how building palliative care capacity within SPC will be fundamental to any model which strives to provide more holistic, responsive and sustainable care. Several authors have voiced the need for a partnership model of SPC and NSPC working together (Disler *et al.* 2012, Toye *et al.* 2012, Quill & Abernethy 2013, Shadd *et al.* 2013, Afshar *et al.* 2015, Bergenholtz *et al.* 2015a, Sawatzky *et al.* 2016a). It is likely therefore that the outcome of NSPC may be dependent on the presence/absence of, and the relationship with SPC services. Much of the literature surrounding integrated palliative care has focused on the role and impact of SPC services when integrated early (Temel *et al.* 2010, Michael *et al.* 2016, Vanbutsele *et al.* 2018), and less is known about the relationship between SPC and NSPC in these studies, or the impact on NSPC provision when SPC is integrated early. Identifying factors which support good partnership working between non-specialist and SPC practitioners which may improve the outcome of NSPC is crucial to respond appropriately to the many health care providers who require support, and ultimately improve patient care (Gardiner *et al.* 2012).

4.9 Conclusion

This chapter has presented the findings of a concept analysis on NSPC. Given the diversity of terms used to describe this care, the process of concept analysis was challenging, but was aided significantly with the use of a modified data extraction tool. Using the principle-based method this concept analysis was achieved under the guidance of four broad principles; epistemological, pragmatic, logical and linguistic. Under the epistemological principle it was concluded that NSPC is described in a variety of different ways, and a clear definition of NSPC remains elusive. It is perhaps within the pragmatic principle, that NSPC is best portrayed. This principle concerned with the utility of a concept offered an in-depth analysis of the attributes and evaluation measures of NSPC. Findings indicated that NSPC was identifiable within three tiers of operationalization/abstractness but was generally poorly measured and understood in practice. The logical principle explored the concept in relation to other concepts and concluded that NSPC, although reflecting the fundamental palliative care multidimensional basis of total pain, is also strongly associated with quality of life, holism and patient-centred care. There is often blurring of the boundary of NSPC with end of life care, and presently, a clear conceptual separation of the two has not been attained, and, perhaps, it may never be. The linguistic principle explored the use and meaning of the concept across a variety of contexts. It was found that while there was consistency in the attributes of NSPC across healthcare disciplines, there was blurring of boundaries particularly with SPC and a lack of clear roles in NSPC provision. This concept was also clinically applied in different ways across illnesses and healthcare conditions, and there was a lack of evidence to facilitate a full exploration of the concept across healthcare settings. In conclusion, concepts guide a discipline by forming the units that comprise and link theory, research, and practice (Weaver & Mitcham 2008). The concept of NSPC has been found to be diverse. Through the process of concept analysis I have provided an increased understanding of the issues associated with NSPC. Penrod & Hupcey (2005b) themselves recognise that as a discrete strategy concept analysis does little to advance the concept however, the power of concept analysis is to *'identify the theoretical strands that define a concept of interest, and provide important preliminary work which produces evidence for the selection of appropriate techniques for progressively developing the concept'* (Penrod & Hupcey 2005b, p. 408). The results of this concept analysis provide important findings which have been used to inform the initial list of CCPIs for NSPC. The process involved in this is described in Chapter 6.

Chapter 5 Phase II - Systematic review of healthcare providers' views and experiences of non-specialist palliative care in the hospital setting

5.1 Introduction

This chapter presents the conduct and findings of a systematic review that explored and synthesised the evidence on healthcare providers (nurses, doctors and allied healthcare staff) experiences and views of NSPC in the hospital setting[2]. This represents the second phase of my overall research study. In this phase, NSPC was explored from a more subjective, personal, individual level ('ground view') through an examination of personal views and understandings of NSPC from those directly involved in the front-line provision of this care in hospitals. As with the concept analysis, the intention in conducting this review, in addition to its value as a singular piece of empirical research, is to further inform the development of the Delphi survey round 1 questionnaire. Previous systematic reviews exploring NSPC have focused on collaboration between generalists and SPC (Gardiner *et al.* 2012, Firn *et al.* 2016), and experiences of NSPC nurses caring for patients undergoing transitions during palliative and end of life care (Thorn & Uhrenfeldt 2017). While there is some evidence about hospitalist NSPC providers' perceptions of their role in palliative care delivery in the literature, this has not been systematically assessed. Conducting a systematic review would thus provide the opportunity to synthesise all available evidence on this topic, with the synthesised findings from multiple studies further strengthening the potential to inform the initial list of CCPIs of NSPC.

5.2 Methodology

5.2.1 Aim

To identify and synthesise the current evidence on healthcare providers' (nurses, doctors and allied healthcare staff) experiences and views of NSPC in the hospital setting.

The objectives of the review are:

1. To determine hospital based NSPC providers' views and experiences of NSPC provision;
2. To discover key aspects of this care from the perspectives of healthcare providers;
3. To explore how the acute-care hospital context influences the delivery of NSPC;
4. To use the findings of this review to inform the initial list of CCPIs of NSPC

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[2] The following journal publication is based on this chapter: Nevin M., Hynes G., Smith V. (2019). Healthcare providers' views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis. *Palliative Medicine*. Vol. 34(5) 605-618 (Impact Factor 4.956)

5.2.2 Review design

Reporting of the review adheres to the Enhancing Transparency in Reporting the synthesis of Qualitative Research (ENTREQ) guidelines (Tong *et al.* 2012) (Appendix 6), as recommended. The review protocol was prospectively registered with PROSPERO (registration number: CRD42018092202).

5.2.3 Inclusion/Exclusion criteria

The inclusion criteria for this review was based on the aim of the review and was described using the PEOS (Participants/Exposure/Outcomes/Study type) acronym (Table 9).

Table 9 PEOS review criteria

Participants	Hospital based NSPC and SPC healthcare providers (e.g. nurses, doctors, social workers, pastoral workers, administrators), in any departments
Exposure	NSPC provision in the adult general hospital setting
Outcomes	Views, experiences, knowledge and perceptions of NSPC
Study type	Qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research

This review considered studies that included the views of both NSPC and SPC healthcare providers about their views and experiences of NSPC provision in hospitals. I acknowledge that there is quantitative literature, predominately survey methods reporting on attitudes and evaluations regarding specific aspects of, or tools related to NSPC provision in hospitals (Al Qadire 2014, Murray-Brown *et al.* 2015, Bergenholtz *et al.* 2015a). However, the aim of this review was to identify the most theoretically rich data of healthcare providers views and experiences of hospital based NSPC. Therefore, based on preliminary scoping which identified a significant body of qualitative literature which supported the aim of the review, and discussion with my supervisors, it was agreed that the qualitative body of evidence was most suitable to provide the richness and depth of enquiry required. Any departments within a hospital were eligible for inclusion. Studies were excluded where it was not stipulated that the care providers worked in hospitals or the study reported views of a variety of settings, and the hospital data could not be isolated and extracted separately. Furthermore, studies were excluded that focused on providers' views of specific integration/integrated models/tools of palliative care where the NSPC aspects of care could not be isolated and extracted.

5.2.4 Literature search and selection strategy

A search strategy was developed, based on the PEOS, in order to locate all potentially relevant studies and include those meeting the review's eligibility criteria. Searches were not limited by date or language restrictions; however, only studies published in English were selected for inclusion due to an inability to translate non-English language texts, and the unavailability of funding for translation services. Where two publications reported on the same study sample, these were only included if the data/findings were reporting on different aspects of NSPC provision, or where they provided different data that could contribute to the thematic synthesis. Although Thomas & Harden (2008) describe how aiming for conceptual saturation rather than locating every available study is acceptable, the thorough search strategy developed for this review would ensure that the risk of missing important data would be reduced.

The literature search was undertaken between January and March 2018. All healthcare disciplines were included to obtain a wide clinical perspective on the delivery of NSPC in hospitals. Electronic databases searched included MEDLINE (Inception – March 2018), PUBMED (Inception - March 2018), CINAHL (Inception - March 2018), PsycINFO (Inception - March 2018), and EMBASE (Inception - March 2018), using search terms that included *non-specialist palliative care*, *palliative approach*, *generalist palliative care*, *basic palliative care*, *primary palliative care*, combining terms with the Boolean 'OR' operands, as appropriate. In consultation with a specialist subject librarian, I conducted initial scoping searches which combined these terms with terminology reflecting the hospital setting (examples included *'hospital'*, *'acute care'*, *'acute care setting'*) using the Boolean 'AND' operands. I also attempted searches using terminology related to *'views'*, *'experiences', 'perceptions'* combined with the NSPC and hospital search terms using the Boolean 'AND' operands. However, this significantly reduced the number of results and I was concerned that these searches may be too specific. Following consultation with the librarian and my supervision team, and to balance specificity and sensitivity of searching I decided to use a conservative approach using only the NSPC search terms to ensure I would not miss any studies of relevance. The search strategy and results is presented in Figure 9, and the CINAHL search strategy, adapted across other databases is presented in Appendix 7, as an illustrative example. The reference lists of retrieved full text papers were also searched for any additionally potential papers that might not have been captured by the database searches.

Systematic review screening software (Covidence: https://covidence.org/) was utilised to support the screening process. This involved me screening the title and abstracts of all retrieved citations against the reviews eligibility criteria and forwarding those that appeared relevant for full text review. I then screened all full-texts for inclusion/exclusion. At this stage my supervisor independently screened a 10% random selection of full-texts also, to ascertain decisional agreement. This follows AMSTAR-2[3] guidance which states *"In the event that one individual carried out selection of studies a second reviewer should have checked agreement on a sample of representative studies and they should have achieved a kappa score of 0.80 or greater."* (Shea *et al.* 2017, p. 3); an agreement score of 0.93 was achieved indicating excellent agreement and a robust screening process.

5.2.5 Quality assessment

Assessing the methodological quality of included studies is a key component of systematic reviews (Barnett-Page & Thomas 2009, Booth *et al.* 2016), and perhaps even more-so in thematic synthesis, as Tong *et al.* (2012) argue, the process of appraisal itself can facilitate a deeper understanding of the included studies. Qualitative research is becoming increasingly important as an evidence base for clinical practice, thus, checklists, as an appraisal method of this type of research are becoming more common. The criteria used to assess studies, however, can vary across these quality appraisal tools. This might be an important consideration in choice of tool, as there are those who assert that the quality appraisal process can have an impact on the final results of a synthesis (Dixon-Woods 2004, Hannes & Macaitis 2012, Tong *et al.* 2012).

The characteristics of three frequently used checklists in qualitative evidence synthesis reviews were compared and reviewed for suitability for this review; two tools produced by the EPPI-Centre (Evidence for Policy and Practice Information and Co-ordinating Centre) (Thomas *et al.* 2003, Brunton *et al.* 2011), and the CASP tool (Critical Appraisal Skills Programme 2018) (Table 10). Important study characteristics appraised to some extent in all of these tools include aspects of methodological reliability/validity, quality of reporting of study characteristics and appropriateness of the study to answer the research question. Hannes *et al.* (2010) in a review of qualitative quality appraisal tools concluded that the CASP-tool did not score particularly well in evaluating the intrinsic methodological quality of an original study in comparison to others. Furthermore Hannes & Macaitis (2012) attest that synthesis benefits from clear instructions on the basic methodological and philosophical underpinnings on the approach as well as the purpose it serves. The framework provided by the EPPI-Centre, (Thomas et al 2003) contains 12 quality appraisal criteria. Five of these criteria are concerned with the quality of reporting of study methods; a further four are used to address whether there had been adequate attempts to establish the reliability and validity of data

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[3] AMSTAR: A MeaSurement Tool to Assess systematic Reviews; first published in 2007 and revised in 2017.
Sources of information on AMSTAR-2 include:

- https://amstar.ca/Amstar-2.php
- https://www.bmj.com/content/bmj/358/bmj.j4008.full.pdf
- https://amstar.ca/docs/AMSTAR%202-Guidance-document.pdf

collection tools or the results of the data analysis. The remaining three criteria address to what extent the studies had used methods to ensure that their findings were rooted in the perspectives of the participants themselves rather than the researcher. Given the scope of these 12 criteria, this tool was deemed highly suitable for this review and was chosen for use. Studies that met 10-12 of the quality criteria, 7-9 criteria, 4-6 criteria and 0-3 criteria, were considered to be of high, moderate, low and very low methodological quality, respectively.

I wish to acknowledge, explicitly, however, that placing a quality judgement on qualitative evidence, is both complex and subjective. As Sandelowski (2015) attests that meaningful evaluation of the quality of a piece of qualitative research cannot be relegated to a *"mindless consumption of any single set of criteria"* alone, but instead constitutes a *"positioned, perspectival human judgement"* situated within a specific community of practice (Sandelowski 2015, p. 91). This quality assessment tool was thus used as a supportive tool to stimulate my reflection on the merits of the included studies as well as my own perspectival human judgement as I read and re read the included studies. The reliability of the quality appraisal process was further enhanced whereby a random sample of 10% (4 studies) of the included studies was appraised by two reviewers independently (one supervisor and I), and following discussion, agreement was reached on all 12 criteria in the assessment tool. Following this I subsequently quality assessed the remaining studies. I decided not to exclude any studies on the basis of quality. The justification for this decision was based on the view that even poorly reported studies may include some very relevant views data, and it was important not to risk excluding these. As Thorne (2017) warns, the decision to eliminate a study arbitrarily by virtue of its fit with particular quality appraisal guidelines "*may obscure a germ of possibility that, if used to interrogate the reports of other studies, could have led to important new angles of consideration"* (Thorne 2017, p. 7).

Table 10 Comparison of qualitative quality assessment tools

Tool Characteristics	**EPPI-Centre** (Thomas *et al.* 2003)	**EPPI-Centre** (Brunton *et al.* 2011)	**CASP checklist** (Critical Appraisal Skills Programme 2018)
Number of Questions	12	10	10
Preliminary Screening	No	No	Yes (2 questions)
Quality of reporting studies characteristics	5/12	6/10 (3 re. participants alone)	6/10
Reliability/Validity of methods	4/12	2/10	1/10
Appropriateness of study	3/12	2/10	1/10

Other questions?	No	No	1 re. Ethics 1 re. Participant/researcher relationship
Prompts provided to assist decision-making	No	No	Yes

5.2.6 Data Extraction

Data extraction was based on the aim of the review, and was conducted using NVivo11 computer software (QSR International Melbourne Australia 2013). Data were gathered for coding by uploading full text PDF files into the NVivo project file. A data extraction table was also developed in order to present the summary characteristics of the included studies (Table 11 in results section). Data extracted included the aim of the study, description of participants and setting, method of data collection and analysis and results/data related to healthcare providers' views/experiences of NSPC provision.

5.2.7 Data Synthesis

In accordance with the method described by Thomas & Harden (2008), thematic synthesis involves three stages; line by line coding of text, development of descriptive themes and finally generating analytical themes from the studies' data. To conduct line by line coding, studies' text was extracted from the findings/results section of the studies including relevant participant quotes using the Nvivo11 software. The abstract and discussion sections were also checked, and relevant data extracted for coding. Use of line-by-line coding enabled the performance of one of the key tasks in the synthesis of qualitative research which is the translation of concepts from one study to another. Similarities and differences between codes were identified and clustered to generate descriptive themes. Analytical themes and sub themes were generated through additional coding, reflection, iteration and discussion with my supervision team. While the 3 stages may initially appear quite linear in description, the complexity of synthesising qualitative research requires constant iteration of emerging evidence (Thorne 2017). In my review, these stages constantly overlapped, and the inductively derived descriptive themes were continuously refined as new findings evolved and the analytical themes developed.

5.2.8 Assessment of confidence

Lewin *et al.* (2018) attest that the wider use of qualitative evidence used by organizations for example the World Health Organization (WHO) and the National Institute for Health and Care Excellence (NICE) highlights the need to develop transparent approaches that assist the users in deciding how much emphasis to give to such qualitative evidence in their decision-making. Data from qualitative research exploring the views and experiences of those directly involved in providing NSPC in hospitals contributes very important information to inform the initial list of CCPIs of NSPC for phase III. Ultimately though the strength and clinical applicability of the final list of core CCPIs for NSPC in hospitals will lie with the strength of evidence used to create them. Therefore, I decided to conduct a sensitivity analysis of the confidence in the themes (i.e. synthesized findings) produced by the thematic synthesis. This involved scrutinizing the analytical themes, identifying the number of sources contributing to each theme, and giving consideration to the quality assessment ratings of each study that was used to inform each theme. The end result of this process provides an overview of the confidence in the evidence produced in this systematic review.

5.3 Results

5.3.1 Search and selection strategy

The search and selection strategy identified 10773 citations from the databases search and an additional 6 records through manual searching of the reference lists of included studies. Of these, 8422 were excluded because they did not relate to NSPC in the hospital setting. The remaining full texts (n=187) were reviewed thoroughly and a further 148 were excluded for the following reasons; four were duplicate studies, five were not available in English, 46 did not elicit views or experiences of providers, 29 were not primary studies, and 64 studies were excluded because the exposure was not NSPC in the hospital setting. Of the five full texts not available in English, two contained abstracts in English which on reading suggested that they met the inclusion criteria. These originated in Norway and France. The three remaining full texts (originating in Germany and Denmark) did not provide English language abstracts and, as such, I could not ascertain whether these studies may have met the inclusion criteria. In total, 39 papers, reporting on 37 studies were included in this review. The two studies that yielded two publications each (Hanratty *et al.* 2002, Hanratty *et al.* 2006, Broom *et al.* 2013, 2014) were included because they reported on different aspects of their findings across these publications. Figure 9 presents a flow diagram of search and selection results.

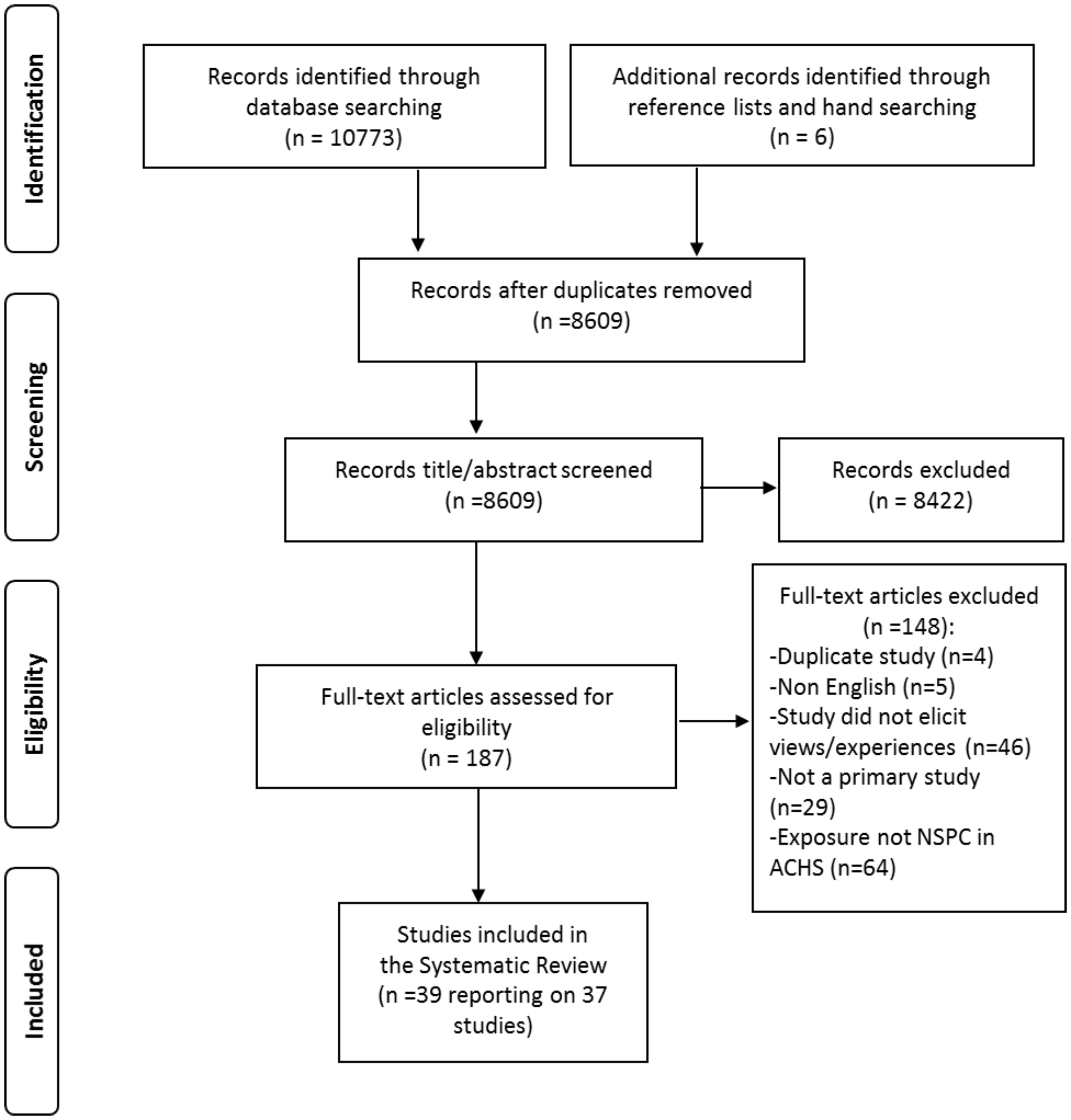

Figure 9 Search and selection strategy and results

5.3.2 Overview of included studies

Table 11 provides details of the characteristics of each included study. The publication dates of the included papers ranged from 1997 to 2017, with 21 of the 39 papers (53%) published in the last five years. The studies originated from wide range of countries; 11 from the UK, six from Canada, four each from Australia and USA, three from Ireland, two in Switzerland and one each in Thailand, Denmark, Sweden, Brazil, India, Iran, Tanzania and Taiwan. One study presented findings from two countries; UK and New Zealand. Nineteen of the 37 studies included samples of nurses only (n=301+ as one study did not state the sample size), five included doctors only (n=123), and two included a mixture of doctors and nurses (n=62). The remaining 11 studies included heterogeneous samples of nurses, doctors, and allied health workers (social workers, chaplain, physiotherapy, pharmacist, and administrators) (n=499). In 32 of 37 included studies, the research took place solely in the hospital (Medical/surgical units n=34, intensive care unit n=2, emergency department n=1). The remaining five studies included multi-site settings of both hospital and community care settings. Twenty-two of the 37 studies collected data using the interview method, five utilised focus groups and a further seven studies reported a combination of both interview and focus groups, while two studies reported a combination of observation, interview and focus groups. One study used co-operative inquiry for data collection. Most studies reported using thematic analysis (n=10), while a further nine stated ‘grounded theory’, and seven stated ‘phenomenology’ as the data analysis method. Some authors were unclear about their analysis method describing it as ‘qualitative’, or not described (n=7), while ethnography was described as the data analysis method in two studies. Finally, one study reported their data analysis method as narrative synthesis and one was reported as case/cross case analysis.

Table 11 Summary characteristics of included studies

Author (year) & Country of Origin	Aim	Participants and Location	Data Collection	Stated Data Analysis Method
Bergenholtz (2015) Denmark	To explore the General Palliative Nursing Care culture in medical departments.	Nurses from three medical departments in a Danish regional hospital (sample size not stated)	Focus groups interviews	12 step ethnographic analysis
Bloomer (2013) Australia	To explore nurses' 'recognition of' and 'responsiveness to' dying patients and to understand the nurses' influence on end-of-life care in the acute care hospital setting	25 nurses in two acute medical wards in one health service	Observation Focus groups individual interviews	Not described
Broom (2013) Australia	Experiences of Medical Specialists dilemmas around when and how to talk about dying and palliation; the art of referral and practices of representation; and, accounts of emotion and subjective influences on referral	20 Senior doctors (16 doctors, 4 surgeons) from a range of specialties within a private hospital which also provides government-funded beds and community-based palliative care for public patients.	Interviews	Thematic analysis
Broom (2014) Australia	To develop an understanding of the logics that underpin their communication strategies when negotiating transition to specialist palliative care	20 Senior doctors (16 doctors, 4 surgeons) from a range of specialties within a private hospital which also provides government-funded beds and community-based palliative care for public patients.	Interviews	Thematic Analysis
Casey (2011) Ireland	To explore key stakeholders and direct care managers' perspectives on the current provision of end-of-life care for older people in acute and long-stay care settings in Ireland and to construct a model of these	33 staff involved in the delivery of end-of-life care to older people working in six sites were selected (one acute care hospital setting)	Interviews	Grounded Theory
Caswell (2015) UK	To understand the factors and processes which affect the quality of care provided to frail older people who are dying in hospital and their family carers	32 members of staff (no further information) Four acute wards in an English University teaching hospital	Interviews	Constant comparative method
Chan (2017) Canada	A focused ethnography was conducted on an acute medical ward in Canada to better understand how this curative/life-prolonging care environment shapes the care of dying patients.	14 Staff members in an inpatient acute medical unit. This unit was within a university affiliated teaching hospital located in Montreal	Interviews	Thematic analysis

deAraujo (2004) **Brazil**	To find out how nurses cope with daily confrontation with the death and suffering of dying patients	14 nurses from the unit of haematology at a general hospital in the city of Sao Paulo, Brazil	Interviews	Qualitative method proposed by Bardin (1977)
Fortin & Bouchard (2009) **Canada**	To describe the experience of caring for individuals at the end of life by five nurses working in curative care units	5 Nurses working in curative care units at a Montreal university hospital	Interviews	Giorgi's phenomenological method (1997)
Gardiner (2011) **UK**	To explore the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals	10 Health Professionals in two large city hospitals	Interviews focus groups	Thematic analysis
Gardiner (2013) **UK**	To explore the perspectives of health professionals regarding the provision of palliative and end-of-life care in UK stroke units.	66 Health Professionals working in stroke units in a large teaching hospital, district general hospitals and community hospitals	Interviews focus groups	Thematic analysis
Gélinas (2012) **Canada**	To describe stressors experienced by nurses in providing end-of-life palliative care (EoL/PC) in intensive care units (ICUs)	42 nurses from 5 ICUs in rural and urban hospitals in the province of Quebec	Focus groups	Thematic analysis
Glogowska (2016) **UK**	To explore the perceptions and experiences of health care professionals (HCPs) working with patients with heart failure around end of life care	24 HCPs across primary, secondary (12 in hospital setting) and community care in three locations in England, UK	Interviews	Grounded Theory, constant comparative method
Gott (2011) **England**	To explore how transitions to a palliative care approach are perceived to be managed in acute hospital settings in England	58 health professionals involved in the provision of palliative care in secondary or primary care (10 in the acute hospital)	Interviews focus groups	Thematic Analysis
Gott (2012) **England & New Zealand**	To explore understandings of, and perceived roles in relation to, palliative care provision amongst generalist and specialist health care providers	Generalist and specialist palliative care providers working in a variety of settings in England n=58 (10 in acute setting) and New Zealand n 80 (5 in acute setting)	Interviews focus groups	Modified grounded theory approach
Hanratty (2006) **UK**	To explore doctors' understanding of palliative care	Consultant doctors (five general practitioners (GPs), five academic GPs, five district general cardiologists, five tertiary centre cardiologists, six geriatricians, six palliative care doctors, four general doctors)	Focus groups	Principles of constant comparison'
Hanratty (2002) **UK**	As above	As above	As above	As above

Holmes (1997) Switzerland	To develop an understanding of the perceptions of general nurses towards palliative care	17 Nurses in a large County hospital	Interviews	Systematic content analysis adapting the procedures for grounded analysis
Hopkinson (2003) UK	To develop an understanding of care for dying people in hospital, from the perspective of newly qualified staff nurses	28 newly qualified nurses in two acute hospitals in England	Interviews	Phenomenological approach
Hynes (2015) Ireland	To understand the challenges of palliative care in everyday clinical practice: an example from a COPD action research project	Nurses working in an acute care hospital. 3 from the respiratory unit (RUNS), two respiratory nurse specialists (RNS) and one palliative care nurse specialist (PNS)	Co-operative group Inquiry	Thematic analysis
Iranmanesh (2009) Iran	To explore the meaning of Iranian oncology nurses' experiences of caring for people at the end of life	15 nurses working in oncology units in two major teaching hospitals in Tehran	Interviews	Phenomenological hermeneutic interpretation
Jack (2002) UK	To explore the impact of the clinical nurse specialist within a palliative care team in a large acute hospital	31 HCPs Drs and Nurses working in a large acute hospital	Interviews	Case and cross case analysis
Johansson (2012) Sweden	To describe the meanings of generalist registered nurses' experiences of caring for palliative care patients on general wards in hospitals	Eight registered nurses in two different hospitals in Sweden	Interviews	Phenomenological hermeneutical approach
Kawaguchi (2017) Canada	To explore internal medicine residents understanding of and experiences with palliative care.	Ten internal medicine residents from 2 teaching hospital sites in Toronto	Interviews	Content analysis
Kongsuwan (2016) Thailand	To describe the meaning of nurses' lived experience of caring for critical and dying patients in the emergency rooms.	12 nurses in three emergency rooms of tertiary hospitals in southern Thailand	Interviews	van Manen's hermeneutic
LeBaron (2017) India	To explore challenges encountered by nurses in India and offer recommendations to improve the delivery of oncology and palliative care	Thirty-seven oncology/palliative care nurses and 22 others (doctors, social workers, pharmacists, patients/family members) at a government cancer hospital in urban South India	Interviews	Systematic qualitative analysis
Ledford (2016) USA	To explore how inpatient medicine teams conceptualize palliative care and how they regard the communicative structures that underlie its delivery	39 members of inpatient medicine care teams at a metropolitan Washington, DC, hospital	Interviews	Grounded Theory

Lewis (2017) **Tanzania**	To explore the views of nursing staff and medical professionals on providing palliative and end-of-life care to hospital inpatients in Tanzania	32 HCPs (11 doctors, 20 nurses) in one hospital in northern Tanzania	focus groups Interview	Thematic approach
Luthy (2009) **Switzerland**	To investigate the difficulties junior residents perceive in end-of-life care	24 junior resident doctors in an internal medicine subacute ward of a public teaching hospital in Geneva	Interviews	Constant comparative method
Mytton (2003) **UK**	To investigate understandings of role expectation and to establish the conditions under which generalists exhibited empowered or de-skilled behaviour	Eight general nurses and two specialist nurses in one UK NHS trust	Interviews	Thematic analysis
Oliver & O'Connor (2015) **UK**	To ascertain general nurses' perceptions and experiences of a good death in an acute hospital setting	13 general nurses working in an acute hospital	Interviews	Nolan's (2008) analytical framework
O'Shea (2014) **USA**	To explore the perceptions of staff nurses regarding palliative care for hospitalized older adults	18 staff nurses employed at three community and two urban hospitals in the North-Eastern United States	Focus groups	Qualitative descriptive guided by Ritchie and Spencer's framework
Pavlish & Ceronsky (2007) **USA**	To explore oncology nurses' perceptions about palliative care	33 oncology nurses who were working in three different hospitals in a large Mid-Western healthcare service organization	Focus groups	Narrative Analysis
Reimer-Kirkham (2016) **Canada**	To examine nurses' and nursing assistants' perspectives of a palliative approach in a variety of nursing care settings that do not specialise in palliative care	Twenty-five nurses and five nursing assistants from across British Columbia	Interviews focus groups	Interpretive description
Roche-Fahy & Dowling (2009) **Ireland**	To explore the lived experience of nurses who provide comfort to palliative care patients in an acute setting in a small urban hospital in the west of Ireland	12 nurses in an acute hospital	Interviews	Gadamerian hermeneutic phenomenology
Smith (2009) **USA**	To explore the attitudes, experiences, and beliefs of emergency providers about palliative care in the Emergency Department	26 HCPs, 14 doctors (10 residents, 4 attending doctors), 6 nurses, 2 social workers, and 4 technicians, working in 2 academic EDs in Boston	Focus groups	Standard grounded theory techniques

Thompson (2006) **Canada**	To generate a conceptual model of the nursing behaviours and social processes inherent in the provision of quality end-of-life care from the perspective of nurses working in an acute care setting	10 nurses working on acute medical units at two tertiary university-affiliated hospitals in central Canada	Interviews participant observation	Grounded Theory
Yang & McIlfatrick (2001) **Taiwan**	To explore the experiences of intensive care nurses caring for patients who are dying	ten nurses who had experience of caring for dying patients in ICUs in two teaching hospitals in Taiwan	Interviews	Colaizzi's (1978) 7 stage approach
Zambrano (2012) **Australia**	To explore the experiences and coping mechanisms of medical specialists, when dealing with death and dying and their emotional connection with dying patients in the context of a life-threatening illness	33 Medical Specialists (Eleven oncologists, nine surgeons, six intensive care specialists and seven palliative medicine specialists)	Interviews	Thematic Analysis

5.3.3 Quality assessment

The results of the quality assessment are presented in Table 12. Overall the quality of the included studies was high. Of the thirty-seven included studies (39 publications), thirty-four achieved nine or more of the 12 quality criteria (quality criteria described below). The lowest assessed study addressed six of the 12 quality assessment criteria (n=1).

Quality of the study reporting:

A= aims and objectives clearly reported
B= adequately described the context of the research
C= adequately described the sample and sampling methods
D= adequately described the data collection methods
E= adequately described the data analysis methods

There was good or some attempt to establish the:

F= reliability of the data collection tools
G= validity of the data collection tools
H= reliability of the data analysis
I= validity of the data analysis

Quality of the methods:

J= used the appropriate data collection methods to allow for expression of views
K= used the appropriate methods for ensuring the analysis was grounded in the views
L= actively involved the participants in the design and conduct of the study

(Source: Thomas et al, 2003)

Table 12 Quality assessment results

Study	Quality criteria met	Number of criteria met	Level of Quality
Bergenholtz (2015)	A, B, C, D, E, F, G, H, I, J, K	11	High
Bloomer (2013)	A, B, C, D, E, F, G, H, J, K	10	High
Broom (2013)	A, B, C, D, E, F, G, H, I, J, K	11	High
Broom (2014)	A, B, C, D, E, F, G, H, I, J, K	11	High
Casey (2011)	A, B, D, E, H, I, J, K	8	Moderate
Caswell (2015)	B, C, D, E, F, G, H, J, K	9	Moderate
Chan (2017)	A, B, C, D, E, F, G, H, I, J, K	11	High
deAraujo (2004)	A, B, C, D, E, J, K	7	Moderate
Fortin & Bouchard (2009)	A, B, C, D, E, F, G, H, I, J, K	11	High
Gardiner (2011)	A, B, C, D, E, F, G, H, I, J, K	11	High
Gardiner (2013)	A, B, C, D, E, F, G, H, I, J, K	11	High
Gélinas (2012)	A, B, C, D, E, F, G, H, I, J, K	11	High
Glogowska (2016)	A, B, C, D, E, H, J, K	8	Moderate
Gott (2011)	A, B, C, D, E, F, G, H, J, K	10	High
Gott (2012)	A, B, C, D, E, F, G, H, J, K	10	High
Hanratty (2006)	A, B, C, D, E, F, H, J, K	9	Moderate
Hanratty (2002)	A, B, C, D, E, F, H, J, K	9	Moderate
Holmes (1997)	A, B, C, D, E, F, G, H, I, J, K	11	High
Hopkinson (2003)	A, B, C, D, E, F, H, J, K	9	Moderate
Hynes (2015)	A, B, C, D, E, F, G, H, I, J, K, L	12	High
Iranmanesh (2009)	A, B, C, D, E, F, G, H, I, J, K	11	High
Jack (2002)	A, B, C, D, E, F, G, H, I, J, K	11	High
Johansson (2012)	A, B, C, D, E, F, H, I, J, K	10	High
Kawaguchi (2017)	A, B, C, D, E, F, G, H, J, K	10	High
Kongsuwan (2016)	A, B, C, D, E, F, G, H, I, J, K	11	High
LeBaron (2017)	A, C, D, E, F, H, I, J, K	9	Moderate
Ledford (2016)	A, B, C, D, E, F, G, H, I, J, K	11	High
Lewis (2017)	A, B, C, D, E, F, H, I, J, K	10	High
Luthy (2009)	A, B, C, D, E, H, I, K	8	Moderate
Mytton (2003)	A, B, C, D, E, F, G, H, I, J, K	11	High
Oliver (2015)	A, B, D, E, J, K	6	Low
O'Shea (2014)	A, B, C, D, E, F, G, H, I, J, K	11	High
Pavlish (2007)	A, B, C, D, E, F, G, H, I, J, K	11	High
Reimer-Kirkham (2016)	A, B, C, D, E, F, H, J, K	9	Moderate
Roche-Fahy (2009)	A, C, D, E, F, G, H, I, J, K	10	High
Smith (2009)	A, B, C, D, E, F, G, H, I, J, K	11	High
Thompson (2006)	A, B, C, D, E, F, G, H, I, J, K	11	High
Yang (2001)	A, B, D, E, F, G, H, I, J, K	10	High
Zambrano (2012)	A, B, C, D, E, F, G, H, I, J, K	11	High

5.4 Thematic synthesis

The thematic synthesis produced 43 initial codes, collated and collapsed into 12 descriptive themes. Of these, the following four major analytical themes were identified from data synthesis: Understanding of palliative care; the complexities of communication; the hospital ecosystem; and Nurses and Doctors – a different lens. An audit trail of the data synthesis process is provided in Appendix 8. The four themes, their sub themes, and the studies that contributed data to these themes are presented in summary Table 13. To facilitate the flow of the findings, the numbers of studies that contributed to each theme and sub theme is provided, but not the individual references – please refer to Table 13 for these

Table 13 Overview of themes and sub themes from included studies

Themes:	**Understanding of palliative care**		**The complexities of communication**	**The hospital ecosystem**		**Nurses and Doctors – a different lens**
Sub Themes:	*Knowledge and Competency*	*Recognition of Palliative Care Needs*		*Physical Structure of the hospital*	*Culture and Organization of Care*	
No. of Studies	**32**	**21**	**27**	**12**	**29**	**30**
Bergenholtz (2015)	**x**	**x**	**x**	**x**	**x**	**x**
Bloomer (2013)	**x**			**x**	**x**	**x**
Broom (2013)	**x**	**x**	**x**		**x**	**x**
Broom (2014)			**x**			**x**
Casey (2011)				**x**		**x**
Caswell (2015)	**x**		**x**		**x**	**x**
Chan (2017)	**x**	**x**			**x**	**x**
deAraujo (2004)	**x**		**x**		**x**	**x**
Fortin (2009)	**x**		**x**		**x**	**x**
Gardiner (2011)	**x**	**x**			**x**	
Gardiner(2013)	**x**	**x**				**x**
Gélinas (2012)	**x**		**x**	**x**	**x**	**x**
Glogowska (2016)	**x**	**x**	**x**			**x**
Gott (2011)	**x**	**x**	**x**			
Gott(2012)		**x**			**x**	
Hanratty(2006)	**x**	**x**	**x**			**x**
Hanratty (2002)	**x**	**x**	**x**		**x**	**x**
Holmes (1997)	**x**	**x**			**x**	**x**
Hopkinson (2003)	**x**		**x**		**x**	**x**
Hynes (2015)	**x**		**x**		**x**	**x**
Iranmanesh (2009)	**x**	**x**	**x**		**x**	**x**
Jack (2002)			**x**			
Johansson (2012)				**x**	**x**	**x**
Kawaguchi (2017)	**x**	**x**	**x**		**x**	
Kongsuwan (2016)			**x**	**x**	**x**	
LeBaron (2017)					**x**	**x**
Ledford (2016)	**x**	**x**	**x**	**x**		**x**
Lewis (2017)	**x**	**x**	**x**	**x**	**x**	**x**

Themes:	**Understanding of palliative care**		**The complexities of communication**	**The hospital ecosystem**		**Nurses and Doctors – a different lens**
Sub Themes:	*Knowledge and Competency*	*Recognition of Palliative Care Needs*		*Physical Structure of the hospital*	*Culture and Organization of Care*	
No. of Studies	**32**	**21**	**27**	**12**	**29**	**30**
Luthy (2009)	x		x		x	x
Mytton (2003)	x		x		x	x
Oliver (2015)	x		x	x	x	x
O'Shea (2014)	x	x			x	x
Pavlish (2007)	x	x	x		x	
Reimer (2016)	x	x	x		x	
Roche-Fahy (2009)	x			x	x	x
Smith (2009)	x	x	x	x	x	x
Thompson (2006)	x	x	x	x	x	x
Yang (2001)	x		x			x
Zambrano (2012)	x	x				

5.4.1 Understanding of palliative care

This theme emerged from 33 of the 39 publications. The two sub themes of knowledge and competency, and recognition of palliative care needs emerged from this dominant theme.

5.4.1.1 Knowledge and competency

Thirty-two studies contributed data to the sub-theme of healthcare providers' views of their knowledge and competency in NSPC provision. There was a consensus that NSPC was associated with caring not only for the physical needs of the patient, but also the psychological and spiritual issues. Healthcare providers commonly described NSPC in terms of alleviating suffering by managing symptoms, and by providing holistic, patient-centred care:

> *"You're looking at all aspects—social lives, spiritual beliefs and backgrounds, their medical and surgical issues. You really have to look at the whole biopsychosocial model." (Specialist Physician)* (Ledford *et al.* 2016, p. 538)

> *"Comfort care, enhancing somebody's quality of life. Knowing that later on there could be a potential end-of-life. It also brings to mind making sure that patients aren't in any pain or discomfort, that everything is done to maximize their quality of life." (Social Worker)* (Ledford *et al.* 2016, p. 540)

However, many respondents described a poor understanding of and a lack of clarity around a clear definition of NSPC (Mytton & Adams 2003, Pavlish & Ceronsky 2007, Smith *et al.* 2009, Gélinas *et al.* 2012, Gott *et al.* 2012, O'Shea 2014, Hynes *et al.* 2015), and this was a source of frustration because their role in NSPC provision was not clearly delineated. Furthermore, respondents felt that how palliative care is understood is very individual and varies between providers of care;

> *"Who's told [the patient] what 'palliative' means? I still hear the view that we can't treat your cancer anymore so we'll have to do some palliative stuff. I mean where does palliative care fit and who's to define palliative?.....A nurse needs to be comfortable operating in a gray zone because palliative care is a gray zone. It's so individual, and that's so gray". (Oncology Nurse)* (Pavlish & Ceronsky 2007, p. 798)

Discussions on whose role it should be to deliver palliative care indicated general agreement on the appropriateness of NSPC in the hospital, with providers articulating that care providers on a basic level should be able to deliver palliative care (Mytton & Adams 2003, Hanratty *et al.* 2006, Gardiner *et al.* 2013b, Caswell *et al.* 2015, Ledford *et al.* 2016, Reimer-Kirkham *et al.* 2016, Lewis *et al.* 2017).

However, in Smith *et al.* (2009) the researchers described how palliative care was neither a goal of emergency medicine trainees nor a focus of their training, and only a minority of doctors (2 attending doctors and 1 resident) described caring for patients with palliative care needs as part of their professional responsibility. Experience was also a factor; the experience of the healthcare provider in delivering NSPC was highlighted in a number of studies with healthcare providers describing how, for inexperienced colleagues attending to patients' palliative care needs was challenging and the more experience a provider had, the easier it was to deal with palliative care issues (Yang & McIlfatrick 2001, Zambrano *et al.* 2012).

> *"I have become maybe a bit more emotionally involved, because as you get older you experience things in your own life, for instance, the death of parents, you have children…maybe in a way you almost become more empathetic (…) you do tend to identify, personalise it a bit more"* (Zambrano *et al.* 2012, p. 12)

Data synthesis revealed that many providers described feeling poorly equipped to deal with many issues encountered in palliative and end of life care, particularly pain and symptom management (Mytton & Adams 2003, Pavlish & Ceronsky 2007, Luthy *et al.* 2009, Smith *et al.* 2009, Gélinas *et al.* 2012, O'Shea 2014, Kongsuwan *et al.* 2016, Reimer-Kirkham *et al.* 2016, Lewis *et al.* 2017). This caused significant distress to some;

> *"At school, we never really did that [palliative care]. When I did my rotations, I never did any in palliative care… I never had to do any, I never thought about doing that. So… when I lived through my first experiences, it was really… overwhelming, because there was a lot of suffering, as the patient had dyspnea… and I truly did not know what to do."(Nurse)* (Fortin & Bouchard 2009, p. 5)

In relation to knowledge acquisition, the need for education in palliative care was advocated by many providers of care, and lack of specific training opportunities in palliative care principles was highlighted as an issue, with some healthcare providers feeling that training on palliative care principles should be mandatory (Fortin & Bouchard 2009, Roche-Fahy & Dowling 2009, Smith *et al.* 2009, Gélinas *et al.* 2012, O'Shea 2014, Oliver & O'Connor 2015, Reimer-Kirkham *et al.* 2016, Kawaguchi *et al.* 2017, LeBaron *et al.* 2017, Lewis *et al.* 2017). Topics identified by healthcare providers' included pain and symptom management, syringe drivers and communication skills training. In contrast however, some providers viewed that learning, and becoming competent in NSPC provision was gained through watching senior colleagues, was related to personal development, and not necessarily something to be learned through professional development activities (Bloomer *et al.* 2013, Broom *et al.* 2013, Bergenholtz *et al.* 2015, Oliver & O'Connor 2015).

The educational and supportive relationship between NSPC and SPC was considered important to improve the knowledge base of NSPC providers, and the importance of the presence of a SPC team to provide support for challenging cases was highlighted by NSPC providers (Hanratty *et al.* 2002, Mytton & Adams 2003, Hanratty *et al.* 2006, Smith *et al.* 2009, Ledford *et al.* 2016, Kawaguchi *et al.* 2017, Lewis *et al.* 2017). Furthermore, doing a rotation with, or observing SPC teams, and receiving taught sessions from SPC providers in practice was viewed as an important educational and supportive tool by NSPC providers (Jack *et al.* 2002, Kawaguchi *et al.* 2017). Healthcare providers in some studies however expressed concerns that the presence of SPC teams has led to fragmentation of care and some staff may 'switch off' and become deskilled in addressing patients palliative care needs if they feel the SPC team are involved (Hanratty *et al.* 2002, Jack *et al.* 2002, Gott *et al.* 2012).

> *"The only thing I worry about sometimes, with the nurses and indeed the doctors, is that they try to leave too much for the palliative care team to sort out, like pain relief. If it is my patient on the ward then I should also be concerned about the pain relief of my patient and not totally dependent on the palliative care team." (Consultant Doctor)* (Jack et al. 2002, p. 338)

5.4.1.2. Recognition of palliative care needs

Twenty-one of the included studies contributed data on recognition of palliative care needs. Responses were mixed as to palliative care needs of different patient groups. In general, there was a prominent view that patients with a cancer diagnosis were synonymous with potentially having palliative care needs. Some respondents recognised that patients with other chronic conditions had palliative care needs (Hanratty *et al.* 2006, Pavlish & Ceronsky 2007, Bergenholtz *et al.* 2015, Kawaguchi *et al.* 2017). Despite this, barriers to providing NSPC to non-cancer patients were identified such as attitude of staff, lack of knowledge, and uncertain illness trajectories (Hanratty *et al.* 2002, Gardiner *et al.* 2013b, Glogowska *et al.* 2016, Lewis *et al.* 2017, Chan *et al.* 2018).

> *"…you've had a gentleman that's on his third admission in six months with heart failure, well shouldn't that be ringing warning bells…that this gentleman is not getting any better with treatment that we've started him and actually we should be having those conversations with him about what does he expect in the future…" (Specialist heart failure nurse)* (Glogowska et al. 2016, p. 5)

Many providers, on reflecting upon the scope of palliative care understood it to be entirely related to care for the dying. Palliative care was something to consider very late in the disease trajectory, when active treatments are diminished (Hanratty *et al.* 2006, Pavlish & Ceronsky 2007, Smith *et al.* 2009, Gott *et al.* 2011, Gott *et al.* 2012, Gardiner *et al.* 2013b, Bergenholtz *et al.* 2015, Ledford *et al.* 2016, Kawaguchi *et al.* 2017, Chan *et al.* 2018).

> *"When I think of palliative care I think ... When there is nothing more to do...You stop treatment ... The patient is allowed to have peace." (Nurse)* (Bergenholtz *et al.* 2015, p. 198)

Opposing views, albeit reported to a lesser extent, were also evident, whereby healthcare providers considered that NSPC was suitable early in the disease trajectory (Holmes *et al.* 1997, Bergenholtz *et al.* 2015, Kawaguchi *et al.* 2017), acknowledging, however that in practice it was most often observed as end of life care. Providers expressed uncertainty around identifying transitions, in particular to end of life care (Hanratty *et al.* 2002, Thompson *et al.* 2006, Gott *et al.* 2011, Broom *et al.* 2013, Gardiner *et al.* 2013b, Glogowska *et al.* 2016, Kawaguchi *et al.* 2017, Lewis *et al.* 2017, Chan *et al.* 2018).

> *"I think they're good at making decisions about whether somebody is going to die imminently, but if say someone is in the last year of their life or it's not as obvious, I don't think they get the continuity really that they need" (Speech and Language Therapist)* (Gardiner *et al.* 2013b)

Some healthcare providers expressed frustration at a lack of clear guidelines/protocols in palliative care delivery (Smith *et al.* 2009, Gélinas *et al.* 2012, Kawaguchi *et al.* 2017, Lewis *et al.* 2017). It caused discomfort and frustration to providers of care because there were often 'grey areas' around illness trajectories and interventions such as fluids, antibiotics, resuscitation and advance care planning.

5.4.2 The complexities of communication

The thematic synthesis revealed communication as a prominent theme with data from 27 publications addressing issues related to the challenges of communication in NSPC. Having conversations with patients and their families around goals of care, prognosis and issues relating to mortality was perceived as very challenging. Issues such as lack of confidence or expertise (deAraujo *et al.* 2004, Fortin & Bouchard 2009, Caswell *et al.* 2015), an uncertain prognosis (Hanratty *et al.* 2002, Hopkinson *et al.* 2003, Gott *et al.* 2011) , a fear of saying the wrong thing (Hanratty *et al.* 2002, Bergenholtz *et al.* 2015), and not having built a relationship with the patient (Mytton & Adams

2003, Luthy *et al.* 2009, Reimer-Kirkham *et al.* 2016) were highlighted as barriers to effective communication.

> *"I think for a variety of reasons. We don't routinely do that. It's not because we don't want to provide information but quite often breaking bad news to a patient can be pretty difficult . . . and we take a very different approach which may not be right but unless the patient asks their prognosis we don't tell them the prognosis."(Consultant Geriatrician)* (Gott et al. 2011, p. 3)

Other factors were also identified by providers as barriers to discussing palliative care issues with patients and families, including a lack of acceptance, or denial on the patient, or family's part to talk about a worsening prognosis (Yang & McIlfatrick 2001, deAraujo *et al.* 2004, Thompson *et al.* 2006, Glogowska *et al.* 2016, Ledford *et al.* 2016, Reimer-Kirkham *et al.* 2016, Kawaguchi *et al.* 2017);

> *"Some families could not accept that the patient's condition had deteriorated rapidly, and that he or she would die soon. They denied or fought this situation. I felt stressed dealing with their emotional reactions."* (Yang & McIlfatrick 2001, p. 439)

Ethnic and cultural differences which can influence the patient and family's perception and practices in relation to palliative care issues and dying, such as concealing illness/prognosis from patients, were also evident (Yang & McIlfatrick 2001, Broom *et al.* 2014, Lewis *et al.* 2017). Broom *et al.* (2014) asserted that communication may be shaped by a complex combination of patient/ family biography and characteristics and must be treated as a relational and subjective dynamic. The impact of cultural influences on communication is exemplified in the following quote:

> *"In Taiwanese medical tradition, we comply with families' requests and always conceal illness from patients… I feel stress when I am caring for a patient who doesn't know his/her illness condition".* (Yang & McIlfatrick 2001, p. 439)

It has been suggested in several studies that healthcare providers use tactics which may deflect their own insecurities around having difficult conversations with patients and their families. These include deflecting back to patient issues which hindered communication such as patient denial; avoidance of patients and families at end of life, and a reliance by NSPC providers on SPC to have the difficult conversations with patients and families around prognosis. This reveals the very challenge of acknowledging their own difficulties around palliative care discussions (Jack *et al.* 2002, Broom *et al.* 2013, 2014, Caswell *et al.* 2015). As one doctor said;

> *"We probably don't prepare them adequately for it, and probably we rely on the palliative care doctors and nurses to deal with those sorts of things."(Doctor)* (Broom et al. 2014, p. 156)

5.4.3 The hospital ecosystem

Thirty one publications contributed data, across two sub-themes, on the hospital as a care environment that impacted on the delivery of NSPC, and in particular healthcare providers reflected on the impact of the care environment on care at the end of life.

5.4.3.1. The physical structure of the hospital

The physical structure of the hospital was considered to be incompatible to the delivery of good end of life care. Providers described the importance of providing an aesthetic and quiet environment for the dying patient however there was often a lack of private rooms;

> *"..we try to shield them in a way, we try to put them in a private room if it is possible."* (Bergenholtz *et al.* 2015, p. 197)

This was because the physical environment primarily served treatment-orientated tasks, where there was a constant struggle to free up beds for patients who were acutely ill;

> *"I think a lot of them [nurses] are just getting really fed up with the constant barrage of 'the bed is more important than the patient" (General Nurse)* (Oliver & O'Connor 2015, p. 26)

A lack of privacy actually cost nurses more time as they tried to manipulate the care environment to create more space for family, and screen off areas around the patient (Thompson *et al.* 2006, Roche-Fahy & Dowling 2009). This was also a source of particular frustration for providers in departments such as the emergency department and ICU (Gélinas *et al.* 2012, Kongsuwan *et al.* 2016, Ledford *et al.* 2016) where issues such as privacy, space for family members, technology and monitors around the patients bed which produce alarms, make these stressful environments for end of life care;

> *"An ICU room is not the ideal place to die. There's a monitor, a team . . . a respirator, pumps . . . We try to remove some [of the equipment] to make it as nice as possible, but the fact remains that it's not a nice unit . . . with a view of the river or a garden".* (Gélinas et al. 2012, p. 27)

This need for privacy for dying patients was also acknowledged as a consideration of the needs of other patients, where they are aware that a dying person is beside them it can cause considerable stress (Thompson *et al.* 2006, Bloomer *et al.* 2013). There was however an acknowledgement by some providers of the negative consequences of patients being cared for in private rooms; some patients may feel scared and alone and may not wish to be in a private room. Also there is a risk of the patient being 'forgotten about' where there is an assumption that with relatives present, they would call the nurse if required (Roche-Fahy & Dowling 2009, Bloomer *et al.* 2013).

5.4.3.2. Culture and organisation of care

Twenty-nine studies contributed data on a fundamental conflict between the perceived goals of the acute care environment and that of palliative care. Prioritising care was necessary to manage the significant clinical workload, and biomedical, acute care priorities took precedence over patients with palliative care needs;

> *"In the ICU we save people. We're not at end of life in the ICU. There isn't this mentality. That's not . . . the population . . . In the ICU there are chances that they will survive, absolutely." (Nurse)* (Gélinas et al. 2012, p. 27)

Furthermore, narratives such as *'treat till death', 'winning the battle'* and '*not giving up'* perpetuated providers' accounts of NSPC (Pavlish & Ceronsky, 2007; Broom et al, 2013).

> *"The doctors told me that it was their model that was saving patients' lives and it was like a failure if they let the patients die ... . The priority is on supporting life ... There is no written policy on this. It is like the norm or culture of an ER."* (Kongsuwan et al. 2016, p. 135)

This was a major source of frustration for some because they were forced to be 'task orientated', managing acute medical issues that were usually related to prolonging life, and as a consequence could not provide optimal NSPC. The view of some providers that patients with palliative care needs were low priority because there was *'nothing to do'*, which contrastingly, demonstrated a lack of knowledge of palliative care interventions (Gott *et al.* 2011, Chan *et al.* 2018);

> *"Unfortunately, they're usually left at the end of my priority list […] Even if I'm trying to be more attentive to them […] It's just, task-wise, there's nothing to do. So I always go towards the other patients – dressing changes, IVs to be put in. […] And then leave these towards the end, and I get really frustrated at the end of the day, when I haven't done more for them within the whole day, for a dying patient." (Nurse)* (Chan *et al.* 2018, p. 7)

How care is organised in the hospital, and its effect of the provision of NSPC also emerged from the synthesis. A significant barrier to NSPC provision in the hospital identified by providers related to insufficient time to deliver NSPC (Bergenholtz *et al.* 2015, Hynes *et al.* 2015, Glogowska *et al.* 2016, Kongsuwan *et al.* 2016, Reimer-Kirkham *et al.* 2016, Kawaguchi *et al.* 2017, LeBaron *et al.* 2017). Spending time with patients and responding to their palliative care needs was considered integral to good NSPC provision. However organisational factors created a barrier to spending time with patients;

> *"The staffing levels there [hospital] are often so poor that it isn't a question of not wanting to do it, it's not being able to do it. They're not even able to satisfy the basic requirements, much less go in and listen to people in the way that they'd like to."(Social Worker)* (Gardiner *et al.* 2011)

Providers reported specific barriers to NSPC in relation to night shifts and weekend shifts (Gélinas *et al.* 2012, Bloomer *et al.* 2013, Kawaguchi *et al.* 2017) where there was limited availability of senior doctors and SPC to make treatment decisions, and other professionals such as mental health, spiritual care providers and social workers.

> *"The doctors don't want to make those decisions on the weekends, they won't do it ... but we need to make sure that, at least, we get some NFR* [not for resuscitation] *orders before the weekend, because the docs on the weekends won't talk to families about dying and won't make them palliative."* (Bloomer et al. 2013, p. 762)

Furthermore, care in the hospital setting was often perceived as fragmented, and lacking continuity due to the involvement of multiple services and providers of care (Smith *et al.* 2009, Gott *et al.* 2012, Bergenholtz *et al.* 2015, Hynes *et al.* 2015). Repeat readmissions under different consultant doctors with delays in retrieving patients notes which as a consequence delayed clinical decisions was a further organisational barrier to NSPC (Hanratty *et al.* 2002). Lack of multidisciplinary team meetings to discuss care, and nurses and families lack of access to senior doctors because of the limited time they spend on wards (Caswell *et al.* 2015) was another source of frustration. Other barriers to providing NSPC identified included the amount of time required to document care, which took nurses away from the direct care of patients (LeBaron *et al.* 2017), and lack of continuity of care between the community and hospital (Hanratty *et al.* 2002, O'Shea 2014). Furthermore perceived quality markers relating to the fast pace at which work needed to be completed in the acute hospital environment, such as outpatient clinics and discharges was also perceived to be a barrier to good NSPC (Hynes *et al.* 2015, Kawaguchi *et al.* 2017).

5.4.4 Nurses and Doctors – a different lens

Although the scope of this qualitative evidence synthesis aimed to include any provider of NSPC in the hospital, the majority of the studies involved nurses or doctors (or both) only. This proved advantageous and interesting during data synthesis whereby clear philosophical differences, supported by data from 30 publications, in these groups' views of clinical care emerged. Both nurses and doctors described emotional challenges in dealing with palliative care issues with patients and families, and both groups referred to aspects of getting the 'emotional balance' right, in their interaction with patients (deAraujo *et al.* 2004, Bloomer *et al.* 2013, Broom *et al.* 2013, Bergenholtz *et al.* 2015, Chan *et al.* 2018). However, nurses and doctors appeared to be talking about 'emotional balance' in very different ways. Doctors described the importance of distancing themselves from emotional involvement with patients (Fortin & Bouchard 2009, Zambrano *et al.* 2012, Broom *et al.* 2013, Caswell *et al.* 2015), and how not getting emotionally involved, was deemed an important skill to develop in order to avoid 'burning out' and was a necessary prerequisite to give good medical care;

> *"I do take the emotion out of it, and it's very factual. I don't know if that's offensive to people, but that's just the way I do it, if you get overly involved emotionally, you're not going to give necessarily the best care" (Doctor-Haematology)* (Broom et al. 2013, p. 12)

> *"You are a doctor; you are there to give them your professional support. That can be a manner of things, but you've got to still maintain a certain sort of emotional detachment, if you are to give them the best of your professional ability." (Doctor)* (Zambrano et al. 2012)

In contrast, nurses reported being comfortable in having a closer relationship with their patients who had palliative care needs. NSPC gave nurses a sense of deep satisfaction and fulfilment, and the opportunity to deliver care in accordance with the fundamental caring values of the nursing profession (Holmes *et al.* 1997, deAraujo *et al.* 2004, Fortin & Bouchard 2009, Smith *et al.* 2009, Johansson & Lindahl 2012, Bloomer *et al.* 2013, Gardiner *et al.* 2013b, Bergenholtz *et al.* 2015). As one nurse described;

> *"I think it's very rewarding work. You give a lot of yourself, but you get a lot out of it too, I find. It's like a privilege, at times, to be caring for individuals at the end of life" (Nurse)* (Fortin & Bouchard 2009, p. 3)

Nurses, in further contrast to doctors, also described availability and closeness as prerequisites for being able to get to know the patients and families with palliative care needs, even going as far as being: *'able to endure pain with the patient'* (Holmes *et al.* (1997). This level of emotional involvement was, for nurses, essential to meet the palliative care needs of patients, families, and themselves;

> *"I thought my patients must feel very good when I showed deep concern and caring towards them. When I did this, I felt very satisfied about my caring behaviour… I felt I had grown a lot…" (Nurse)* (Yang & McIlfatrick 2001, p. 438)

In some ways, when the acute care interventions ceased, it allowed more scope and freedom for nurses to be present and feel like they were truly caring for the patient;

> *"When you can pull back all of the wires and everything and be in that room and comfort that family and make that patient comfortable, and give the perfect environment for what they need—to me is a privilege. To be present when the patient dies is a very sacred experience."* (Smith et al. 2009, p. 88)

It has been argued in several studies that doctors' reported discomfort with palliative care issues has led to them aggressively pursuing acute treatment options, which resulted in identifying palliative care needs late in the disease trajectories of patients' illnesses (Hanratty *et al.* 2006, Zambrano *et al.* 2012, Bloomer *et al.* 2013, Bergenholtz *et al.* 2015, Lewis *et al.* 2017). Doctors were described as portraying themselves as bad prognosticators, admitting that they may accept the poor outlook late in the illness. Patients, carers, and nurses were viewed as more realistic predictors of patient deterioration and palliative care needs. This suggests a lack of willingness to 'let go' rather than not seeing the signs that a patient was deteriorating;

> *"I think some doctors, we find it difficult to let go, some doctors find it uncomfortable to admit that the patient is going to die, they feel that they should carry on, doing all they can for them in terms of investigations and treatment" (Consultant Geriatrician)* (Gardiner et al. 2013, p. 236)

Identifying the need for a palliative approach to some patient’s care, yet being met with resistance from their medical colleagues, frustrated nurses, and created a barrier to providing palliative care (Fortin & Bouchard 2009, Gélinas *et al.* 2012, Chan *et al.* 2018);

> *“Because we have to follow the doctor’s prescriptions, and it may be a little against one’s belief.” (Nurse)* (Bergenholtz *et al.* 2015, p. 197)

Communication practices between nurses and doctors was also highlighted as a potential barrier in the hospital. Nurses described how they felt it was the doctors’ responsibility to inform patients and families about their prognosis (Mytton & Adams 2003, Bloomer *et al.* 2013, Bergenholtz *et al.* 2015, Caswell *et al.* 2015, Oliver & O'Connor 2015), however this was described by nurses as often delayed, and not communicated to them appropriately;

> “*I find that physicians do not take the time to do it (announcing the prognosis). And often we’re not even forewarned. So you enter the room and everybody’s been crying and you’re the last one to know.” (Nurse)* (Fortin & Bouchard 2009, p. 4)

This left nurses in a difficult position with patients and families, and was considered a barrier to good continuity of care;

> *“It ended up that both times the doctor didn’t include me in the meeting with the family to find out what had been going on, what had been said, how they felt about it. So all of a sudden the family arrived with the doctor, at the bedside, and he told me, “Okay, unplug everything.” . . . the family members were there and they were looking at me.” (Nurse)* (Gélinas et al. 2012, p. 31)

Nurses also described how they felt they were not given the emotional support they needed to express their emotions and manage the challenges of NSPC. They identified crying away from work (Hopkinson *et al.* 2003, Gélinas *et al.* 2012, O'Shea 2014), nausea and sleeplessness (Hopkinson *et al.* 2003) as symptoms of distress from the challenges of caring for patients with palliative care needs in the hospital. The importance of nursing peer to peer support following difficult cases was evident;

> *“The nurses were here for me after [the death] and said ‘come and have a talk about it’, which is really nice and I let all my emotions out” (Nurse)* (Oliver & O'Connor 2015, p. 6)

This contrasted directly with some doctors views, where palliative care was seen as straightforward medical practice, was 'not glamorous' and presented a burden with little return;

> *"So, do we sit down over a few drinks and talk about that [end-of-life discussions]? No. What do we talk about? Clinical trials, latest treatments you know, how does it apply to these patients? They're the conversations that we have". (Doctor-Medical Oncology)* (Broom et al. 2013, p. 13)

In this qualitative evidence synthesis, the ability to compare the views of the two largest professional groups delivering NSPC in hospitals (nurses and doctors) has yielded important insights into fundamental issues of value that impact on NSPC. How a healthcare provider spends their working day, and how they organise their tasks is ultimately linked to value; the cultural values of an organisation, the values of their profession and their personal values. Arguably there are societal expectations on doctors to provide positive treatment outcomes, and medical training is intensively focused on 'cure'. The intensive medical model of acute care in the hospital setting supports this as a central value through its physical and organisational structures. This could possibly explain doctors reported difficulties in this systematic review, recognising patients with palliative care needs early in their disease trajectories, their desire to maintain an emotional distance from patients, and their challenges in communicating bad news. Nursing philosophy could be considered closely aligned to a palliative philosophy of 'heal', where relationship, presence and holism are considered central values. Many nurses reported much value in, and satisfaction from NSPC provision, however possibly as a result of the culture of care in hospitals, they described a sense of constantly competing with the organisational emphasis on acute care interventions. Furthermore, this may go some way to explaining the communication difficulties between these professional groups, and nurses' frustration in trying to advocate a palliative philosophy of patient care to their medical colleagues.

5.5 Assessment of confidence

Confidence in the findings of the thematic synthesis are considered in relation to the sensitivity analysis conducted. The results of the sensitivity analysis are presented in Table 14. Most included studies (27-33 studies) contributed to all four themes that emerged from the thematic synthesis process. A quality analysis of individual studies that contributed to these themes shows that the strongest theme was 'Understanding of NSPC'. This was due to the high number of sources (studies) that informed this theme (n=33), of which 73% achieved a high-quality rating. The theme 'The hospital environment' was also informed by a large number of studies (n=31) of which 70% achieved a high-quality studies rating. The themes 'communication' and 'Nurses and Doctors- A different lens' were informed by studies of slightly less high-quality ratings (67% respectively), with a further 29% and 30% of contributing studies, respectively receiving moderate quality ratings. Overall these results indicated a high degree of confidence in the thematic evidence on NSPC in hospitals produced by this systematic review.

Table 14 Sensitivity analysis results

Analytical Themes	**Understanding of palliative care**		**The complexities of communication**		**The hospital ecosystem**		**Nurses and Doctors – a different lens**	
All sources	33		27		31		30	
	N=	**%=**	**N=**	**%=**	**N=**	**%=**	**N=**	**%=**
High Quality	24	73	18	67	22	71	20	67
Moderate Quality	8	24	8	29	8	26	9	30
Low Quality	1	3	1	4	1	3	1	3

5.6 Conclusion

This systematic review and thematic synthesis of 37 studies has identified four dominant themes related to healthcare providers' views regarding the provision of NSPC in the hospital. There was general acceptance of the role of and need for NSPC within the hospital care environment, although defining this type of care was problematic for many. Nevertheless, healthcare providers' views of the central tenants of NSPC were similar and included optimising quality of life, a holistic patient centred approach to relieving physical and psychological suffering through pain and symptom management, which resonate with many of the attributes identified in the concept analysis (phase I). Healthcare providers however felt poorly equipped to give effective NSPC, which was particularly apparent for providers who had less experience in dealing with very unwell patients and their families. The role of SPC in supporting and providing ongoing education in NSPC delivery in the hospital setting was also considered very important by healthcare providers in this review.

The benefits of applying palliative care principles earlier in disease trajectories of life limiting illnesses is well established in the literature (as discussed in Chapter 2). However, in this systematic review, while some healthcare providers acknowledged that NSPC was clinically relevant early in disease trajectories of patients, when healthcare providers were asked to recall experiences of delivering NSPC in the hospital there was a significant emphasis on end of life experiences. Most recall from healthcare providers involved care of dying patients and this was a consistent finding across the analytical themes. This suggests that applying NSPC earlier in the disease trajectory in the hospital is difficult for clinicians to even recognise never mind achieve in the hospital environment. Furthermore, while the concept analysis identified the growing body of literature which supports the applicability of palliative care beyond cancer care, within the management of many chronic conditions, the prevailing view of hospital-based healthcare providers was one where

NSPC in the hospital setting is heavily associated with cancer care. These findings provide useful insights into the challenges of the clinical application of NSPC in the hospital. The initial CCPIs of NSPC therefore need to reflect ways in which to achieve NSPC interventions early and within chronic disease care, in conjunction with the organisation and management of active treatments in the hospital.

Healthcare providers in hospitals described significant difficulties with communicating poor prognosis and dealing with dying patients and families. Issues such as lack of private spaces, lack of time, lack of education and training, patient or family resistance for various reasons, and a reluctance to admit that acute care interventions were futile (doctors) were found to be contributing factors. Organisational factors such as fragmented care, a focus on the goals of acute care, and poor communication between healthcare professionals were also barriers to good NSPC provision. This synthesis also revealed that the perspectives and challenges of NSPC provision are not homogeneous to all healthcare providers in the hospital. Nurses and doctors in the hospital have uniquely different perspectives of this care based on their fundamental professional values, and their roles in NSPC care delivery. The culture and organisation of care in the hospital therefore presents different challenges to these two groups of professionals. The clinical application of core CCPIs for NSPC in the hospital will need to reflect this. A common theme throughout the literature identified in phase I of this research is the need for healthcare providers to be educated appropriately to deliver effective NSPC (Schiessl *et al.* 2013, Chiu *et al.* 2015, Schulz *et al.* 2015, Head *et al.* 2016). The findings from this systematic review suggest that structural, organisational and professional challenges exist that mean hospital healthcare providers feel ill equipped to deliver this care, and education and training alone will not ensure that NSPC is embedded in practice in this care setting. The process of merging the evidence derived from the concept analysis and this systematic review that was used for populating the initial list of CCPIs for NSPC is now presented in Chapter 6.

Chapter 6 Initial indicators of NSPC – preparatory work

6.1 Introduction

The purpose of this chapter is to present the structured process involved in developing the initial list of NSPC indicators from the findings of phases I and II of the study, for use in phase III. The purpose of these clinical indicators (as described in Chapter 2) is revisited here as this forms the basis for how the indicators were extracted and constructed. Then the process for identifying, extracting and refining the initial indicators is discussed, including the role of the expert advisory group, and results presented. The chapter concludes with the identification of an initial list of 34 CCPIs for NSPC to be used in round 1 phase III.

6.2 Purpose of the clinical Indicators in this study

The final core set of CCPIs for NSPC in hospitals are intended to serve as a basis for quality improvement initiatives in hospitals, by enabling them to examine their current structural, organisational and clinical practices in accordance with core aspects required in hospitals to deliver NSPC (Berg & Schellekens 2002). In doing so they are intended to provide policy makers, hospital managers and healthcare providers' insights into care structures and care processes essential to NSPC provision in hospitals: identifying where there are problems and how they might be addressed. Based on this, the core set of CCPIs can support multi-level integration of NSPC within acute care delivery in hospitals.

6.3 Process of developing the initial list of NSPC clinical indicators

Developing the initial indicators of NSPC relates to step 3 of the study's general methodology (Chapter 3, Table 1). Wollersheim (2007) suggest that clinical indicators should be derived from the best available evidence; that is, selected from research data with consideration for optimal patient care (preferably evidence-based guidelines), and supplemented by expert opinion. Clinical indicators should also be constructed in a careful and transparent manner, and they should be relevant to the important aspects of care (Mant 2001, Wollersheim *et al.* 2007, The Centre for Clinical Governance Research in Health 2009). An 'ideal' clinical indicator should be valid and reliable, relevant to clinical practice if meant for clinical providers, and can permit useful comparisons of current care practices versus what is required (Mainz 2003). These key clinical indicator requirements underpinned the development process; that is, the extraction of NSPC indicators from the evidence base, and the process used in refining these for use in phase III. A diagrammatic representation of this process is provided in Figure 10.

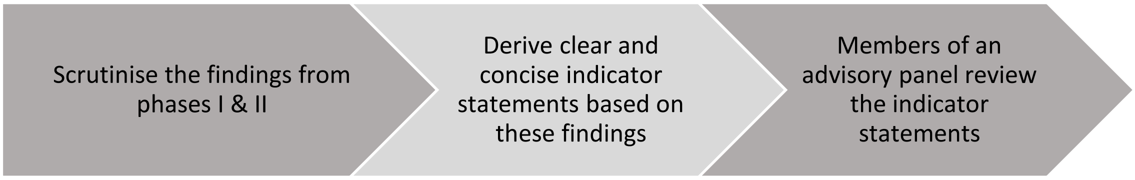

Figure 10 Clinical indicators extraction and refinement process

Developing the initial indicator set began with me reading, re-reading and carefully scrutinizing the findings from phases I and II, separately, rewording the findings into short summary statements which relate to clinical indicators of NSPC in the hospital setting, and deriving clear, concise, NSPC clinical indicator statements. Appendices 9 and 10 present the results of this process for phases I and II, respectively. These NSPC clinical indicator statements were then further scrutinised for similarity and overlap, were edited, and were combined to form one complete list of preliminary indicators of NSPC for hospitals. The indicators were then divided into three sections. Those indicators that related to the infrastructural or strategic governance systems within a hospital were combined into one category. Indicators related to clinical policies, guidelines or care processes were combined into a second category. Finally, any indicators that related to activities of individual hospital staff were categorised together. At this point I asked an expert advisory group to carefully examine these preliminary indicators and provide feedback and suggestions based on their expertise.

6.3.1 Advisory panel

An advisory panel was established to provide input and advice on the initial CCPI set, as a measure of increasing rigor in developing the set. Prospective members were purposively selected and approached/invited on the basis of their expertise. The panel consisted of a NSPC hospital-based clinician, a NSPC academic/researcher, a person with a chronic illness, a Delphi researcher, the medical director of a clinical audit department in a large acute care hospital setting, and an end-of-life care co-ordinator of a large acute care hospital setting. The role of the panel was to review the list of preliminary indicators and to provide feedback in accordance with their individual expertise in relation to;

1. The structure and clarity of wording of the indicators
2. The appropriateness or otherwise of the indicators to the hospital setting
3. The use of plain language and readability of the indicators
4. The structure and clarity of the round one Delphi survey instrument

The preliminary indicators were distributed to all members by email. I then met each person individually (face-to-face) to ascertain and discuss their feedback based on their area of expertise. This proved very useful on a number of levels; for example, the panel member with a chronic illness gave excellent feedback around my use of medical jargon and terminology in places. For example it was unclear to this person what ‘infrastructural’ and ‘strategic governance’ meant therefore I included explanations to improve readability. The clinical audit director of a major hospital confirmed that my terminology relating to the various levels within a hospital was accurate and generic to an international audience. A summary table containing major aspects of feedback from members of the advisory group, and changes I made to refine and produce the initial indicators following consultation is provided in Appendix 11. The development (extraction, scrutiny, categorisation, advisory and refinement) process culminated in a preliminary list of 34 indicators related to NSPC in the hospital setting. This list was subdivided into five structural, 18 organisational and 11 staff indicators (Table 15).

6.4 Conclusion

The next step in the development process as described by Wollersheim *et al.* (2007) involves the prioritisation of this list, to identify only those that could be considered core aspects of NSPC in hospitals. The next chapter will describe phase III of this study; the prioritisation of this list into the final list of core indicators of NSPC provision in hospitals using a 3-round international Delphi study.

Table 15 Initial list of 34 clinical indicators of NSPC and major sources of evidence

	Clinical Indicators	Sources	
	HOSPITAL STRUCTURE	**Concept Analysis chapter sections**	**Systematic review themes**
1	Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	Epistemological Logical Preconditions	The Hospital Ecosystem Understanding of NSPC
2	Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	Pragmatic Outcomes	
3	Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	Pragmatic Outcomes	
4	The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	Preconditions	The Hospital Ecosystem Understanding of NSPC
5	A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	Preconditions	The Hospital Ecosystem
	ORGANISATION OF CARE		
1	Organisational and care practices are structured in a way that supports non-specialist palliative care provision in combination with acute care delivery	Epistemological	The Hospital Ecosystem Understanding of NSPC
2	Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	Epistemological Logical	The Hospital Ecosystem Understanding of NSPC
3	Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	Epistemological Linguistic	Complexities of Communication Understanding of NSPC
4	Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	Epistemological	The Hospital Ecosystem Complexities of Communication Understanding of NSPC
5	Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	Epistemological	

6	Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	Epistemological Logical	Understanding of NSPC
7	Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	Pragmatic	Understanding of NSPC
8	Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	Pragmatic	
9	Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	Pragmatic	
10	Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff	Pragmatic	
11	Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	Pragmatic	
12	Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	Pragmatic	
13	Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	Pragmatic	
14	Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care doctors and nurses caring for patients with life limiting illness		Nurses & Doctors-Different Lens
15	Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family		Nurses & Doctors-Different Lens
16	The hospital has a multidisciplinary specialist palliative care service in place	Linguistic	Understanding of NSPC
17	A structured and standardised care pathway exists between non-specialist palliative care and specialist palliative care, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	Linguistic	Nurses & Doctors-Different Lens
18	Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	Linguistic	Understanding of NSPC
	HOSPITAL STAFF		

1	Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	Pragmatic Preconditions	Understanding of NSPC
2	Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training		Understanding of NSPC
3	Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	Pragmatic Preconditions	Understanding of NSPC
4	Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	Pragmatic Preconditions	Understanding of NSPC
5	Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	Pragmatic Preconditions	Complexities of Communication Understanding of NSPC
6	Non-specialist palliative care staff receive training on advance care planning	Pragmatic Preconditions	Complexities of Communication Understanding of NSPC
7	Non-specialist palliative care staff receive training on compassionate end of life care	Pragmatic Preconditions	Complexities of Communication Understanding of NSPC
8	The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with greater experience of or exposure to patients with life limiting illness	Epistemological	
9	Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between non-specialist palliative care doctors and nurses, caring for patients with life limiting illness		Nurses & Doctors-Different Lens
10	Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness		Nurses & Doctors-Different Lens Understanding of NSPC
11	Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness		Nurses & Doctors-Different Lens Understanding of NSPC

Chapter 7 Phase III – Development of a core set of CCPIs for non-specialist palliative care in the hospital setting; a Delphi study.

7.1 Introduction

This chapter presents an overview of the methods and findings of phase III of the research; the Delphi study. A diagrammatic representation of the Delphi study is provided in Figure 11. The next section of the chapter presents the key methodological aspects addressed in conducting this Delphi. In an effort to enhance transparency in the conduct and reporting of this study, a reporting standard for Conducting and Reporting of Delphi Studies specifically in palliative care (CREDES), produced by Junger *et al.* (2017), following a systematic review of 30 palliative care Delphi studies, involving 16 recommendations (Appendix 12) was utilised to support this study.

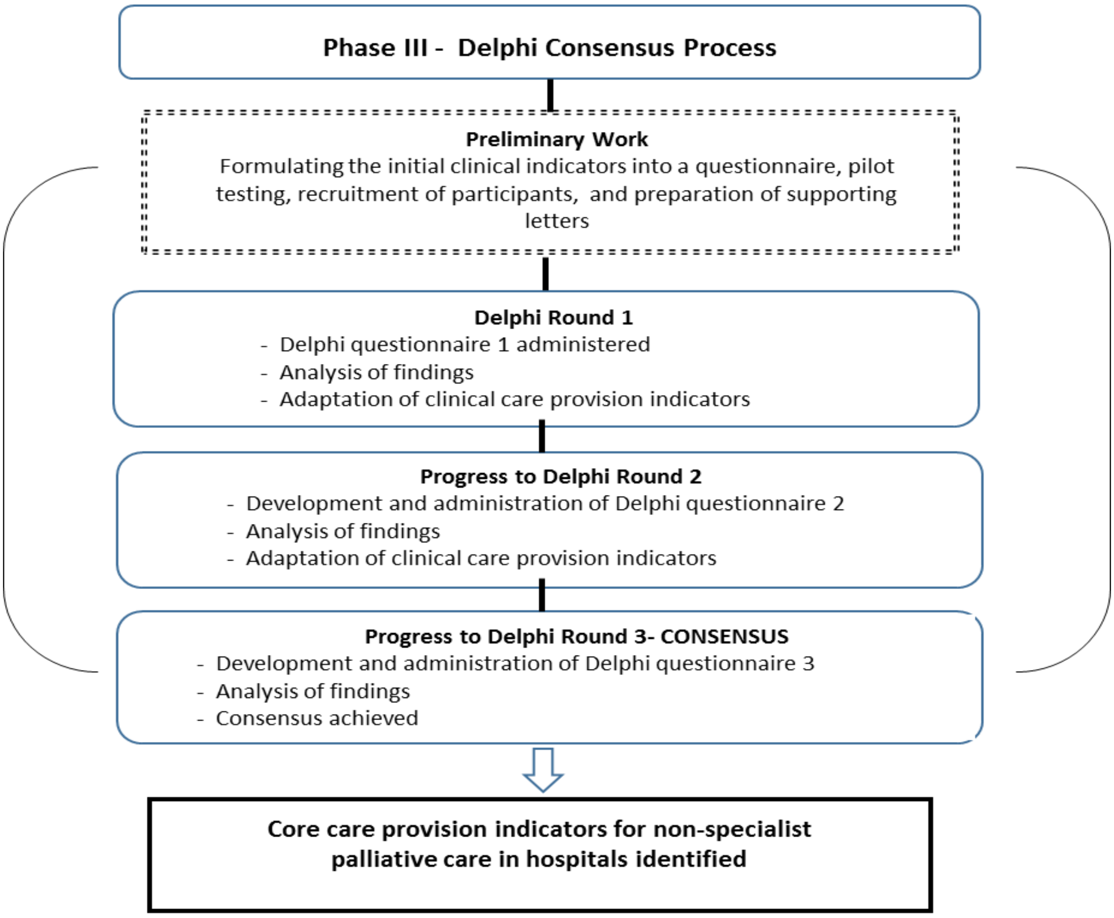

Figure 11 Overview of Delphi study

7.2 Panel of expertise Selection

Creating a panel of expertise is a central component in a Delphi study, and there are several factors to consider such as the criteria for expertise, the size of the panel and how they are recruited and retained for the duration of the survey rounds.

7.2.1 Members of the panel

Boulkedid *et al.* (2011) recommended that in order to enhance the credibility and acceptance of indicators, the expert panel should reflect the full range of stakeholders who have a vested interest in the outcome of the study. Sinha *et al.* (2011) further attest that informed clinical decisions can only be based on the results of studies that have examined the importance of related findings with both clinicians and patients. In this Delphi study, significant consideration was given to identification of panel members, with three aspects identified as critically important, as follows: i) consensus should be based on a cohort of participants with expertise in hospital based NSPC provision from diverse backgrounds, ii) in order to increase the potential applicability of the resulting core CCPIs to a wider geographical context, these participants should be sourced internationally, and iii) while it is possible that one single panel which includes heterogeneous stakeholders could be created, it was decided to create several broad stakeholder groups. The purpose of this was to ensure that one particular group did not dominate the consensus process. Consensus as defined in this study was the attainment of at least 70% agreement in at least two stakeholder groups (discussed in more detail in 7.4.2). Therefore, for the purposes of analysis, three stakeholder groups of expertise were identified as important for the Delphi as follows:

1. Service users of hospital based NSPC - to garner unique experience of those in receipt of NSPC such as adults with a chronic or serious illness, carers, or members of chronic illness advocacy organisations.
2. Hospital based healthcare providers - those in direct provision of clinical care (both non-specialist and SPC) such as doctors, nurses and other allied healthcare providers but also management levels across the hospital who have a unique insight into the structural and organisational practices that impact on the delivery of NSPC.
3. Researchers/Policy makers in palliative care – as these have the knowledge and opinion of existing evidence in the field.

7.2.2 Criteria for expertise

The concept of expertise is central to the Delphi. The credibility of the Delphi technique lies in its ability to draw on expertise, which is promoted by purposeful selection of panel 'experts' rather than relying on a random sample (Keeney *et al.* 2001). What constitutes an 'expert' however is ambiguous, and the expert in a Delphi study can be defined in various ways. This could include knowledge as defined by professional registration or qualification, or by a predefined number of years of relevant experience in the topic of interest. Therefore, expert groups often consist of informed individuals. Expertise in NSPC delivery could not be identified through avenues such as a professional qualification or membership of a particular speciality. Furthermore, the hospital environment is a complex and diverse ecosystem, and healthcare providers have exposure to multiple types of patient groups, within multiple departments, where some providers frequently meet patients with chronic or serious illnesses whereas others may not. Therefore, length of years qualified in a discipline, or years spent working within the hospital environment does not guarantee expertise in NSPC.

Baker *et al.* (2006) asserts that individuals can be in possession of knowledge without significant clinical experience. Therefore, it was deemed important for this study not to set inclusion criteria related to type of clinical specialty, number of years qualified, hospital department, or length of time working in a hospital setting. This was also reflected in the decision not to ask adults or carers of adults a question relating to years of experience with their condition(s), as Baker *et al.* (2006) explains, this is difficult to justify, and may have little to do with their expertise in NSPC provision in hospital. Instead, hospital based NSPC providers on recruitment were encouraged to reflect on their own exposure to and expertise in NSPC in the hospital setting, and participants are considered to have expertise based on their willingness to consent to participate in the study.

7.2.3 Size of the panel

The size of the panel of expertise is an area of much deliberation in the published literature (Keeney *et al.* 2001, 2006, Hsu & Sandford 2007, Vernon 2009, Von der Gracht 2012). Hsu & Sandford (2007) have described how the number of experts chosen have been recommended by various researchers as the minimum number possible that can still be regarded as representative of expertise in the topic area. While Skulmoski *et al.* (2007) noted that in homogenous groups, fewer than 10-15 participants can provide sufficient results, in this study it was anticipated that at least 20 participants per stakeholder group would be secured in round one. This was sought taking into consideration attrition rates between the three rounds, and the fact that only those who responded in a previous round would be eligible to participate in subsequent rounds. Most importantly, however researchers have argued that the Delphi does not call for expert panels to be representative samples for statistical analysis purposes (Murphy *et al.* 1998, Powell 2002).

7.3 Sampling

A purposive sample is a non-representative subset of some larger population which is constructed to serve a very specific need. To maximise the potential to reach international participants it was decided to send the invitation to potential participants electronically. The survey was made available online using SurveyMonkey© and a link to the survey instrument was provided in the invitation email. Participants could then easily access the survey either on a desktop computer or a hand-held device such as a mobile phone or tablet. The initial recruitment phase took place over a three-week period from 24 January to 14 February 2019. Invitation emails were sent to the ‘contact us’ details provided by various palliative care advocacy organisations, and chronic illness organisations internationally with a request to disseminate the invitation email to their members. Furthermore, the contact details of the first authors of all publications sourced for phases I and II, and any policy documents relating to NSPC were identified, and an invitation email was distributed to these individuals. Snowball sampling was achieved by asking participants to suggest or forward the link to others who might have the necessary expertise to participate in the study. A separate link to the survey was created and snowballed through an online Twitter platform. This was widely disseminated and retweeted by oncology associations, oncology advocacy groups, palliative care advocacy organisations, healthcare professional bodies and schools of nursing. Two distinct links to the survey created for Twitter and email enabled me to track the source of the initial survey responses and assisted in channelling my recruitment efforts over the recruitment period in response to the recruitment activity of the two distinct survey links. Participation in this study was based on respondents reading the invitations and participating based on their self-selected expertise on the topic.

7.4 Data collection

Although Delphi studies may contain from 1 to 5 rounds (Hasson & Keeney 2011, Junger *et al.* 2017), on reviewing previously published studies I decided to conduct three rounds in this Delphi study, which is consistent with what can be considered optimal (Boulkedid *et al.* 2011), and with the majority of previous published palliative care Delphi studies (Bridgman & Carr 1998, Junger *et al.* 2017). As the study was online, each participant could choose when and where to complete the surveys once they had access to the link via computer, mobile phone or other hand-held device. Online Delphi is also very cost effective allowing for greater representation from experts.

7.4.1 Retention of participants

One of the key features of Delphi is iteration, as participants are questioned several times about the same topic. As with any multi-phase study, some participant attrition is to be expected. The literature describes many strategies to maximise response rates and minimise attrition in Delphi studies (Walker & Selfe 1996, Black *et al.* 1999, Keeney *et al.* 2006). In order to maximise the response rate between Delphi rounds in this study several strategies were employed. These included providing clear information for participants so they would know exactly what time commitment was involved; for example, information about the amount of rounds to complete, the expected length of time to complete, and clear completion dates for each round. To maintain the interest of participants it was important to maintain momentum during the iterative Delphi rounds in this study (Junger *et al.* 2017). Therefore a 2 week turnaround to conduct analysis and provide participant feedback in the subsequent Delphi round was strictly adhered to.

Several researchers have described the importance of participants feeling that they are partners in a Delphi study and efforts to retain their interest and commitment by the researcher are paramount (Black *et al.* 1999, Hasson *et al.* 2000, Baker *et al.* 2006, Keeney *et al.* 2006). In this study, opportunities to remind participants about their ownership and active participation in the research process i.e. that each round was constructed based on their responses to previous round, were utilised in the invitation and reminder emails, and within the survey itself. Furthermore, personalisation is considered important to improve questionnaire return rates (De Bruijne & Wijnant 2014, Hall *et al.* 2018). Recognising that this could be a challenge in this study given the fact that recruitment and administration of the Delphi was online and there would be no face-to-face contact with participants, personalisation of all emails was given priority so as to increase retention in this study (see personalisation strategy, Table 16). Every person eligible to participate in rounds 2 and 3 received a personalised invitation email. Furthermore, those participants that provided new indicators in round one were specifically thanked for doing so in their invitation email for the round 2 survey. If participants had not responded or had not fully completed a survey one week following the distribution of each Delphi round, a personalised reminder email was sent, and participants were asked to email me if they experienced any technical difficulties accessing the link, or queries regarding the indicators. A further personalised reminder email was sent to non-responders three days before the close of each Delphi round. Any queries I received directly from participants via email during the administration of all Delphi rounds were promptly answered with the necessary information required.

The three surveys were designed to be easily navigated and to minimise the time commitment required of participants. Furthermore, in order to maintain momentum in the process, and guard against participant apathy, all results were analysed and participants received Delphi rounds 2 and 3 exactly one week after the official close of the previous round. The trends in responses to round 2 were closely observed, (which yielded an acceptable retention rate, section 7.7.1.2) and based on this success I replicated this procedure in round 3.

Table 16 Personalisation strategy to retain participants

1.	All invitation emails sent in R2 and R3 were personalised.. i.e. "*Dear John*…"
2.	Where participants contributed new indicators in round 1, this was specifically referred to in their round 2 invitation email and they were thanked for this contribution
3.	Responses were tracked and where participants did not complete a survey fully, in their reminder email this was stated, in case they did not realise this, and they were encouraged to report issues or technical difficulties to me
4.	Any individual communication I received through email by participants throughout the duration of the Delphi study was promptly answered within one hour
5.	Final reminders referred to the participant's country of origin i.e. *"we would appreciate a continued Italian perspective in this study"*
6.	Emails sent to all participants before 12md local time, which required some emails to be sent late at night

7.4.2 Agreement, consensus and stability

'Agreement' can be considered the extent to which participants agree with the topic under investigation, whereas 'consensus' relates to the level of agreement between participants on the topic of question (Jones & Hunter 1995, Murphy *et al.* 1998). There are several standards on how to measure consensus in Delphi studies (von der Gracht, 2012). These include the use of rating scales (numerical or categorical) with average scale scores calculated and measured against a predetermined cut-off average rating that indicates consensus, or voting by participants to determine percentage agreement, or where a majority of participants rate a topic at a certain categorical level of agreement for inclusion such as *Strongly Agree*. In this study, a 5 point categorical rating scale ranging from *Strongly Agree* to *Strongly Disagree* was utilised to ascertain participants' level of agreement as to whether each indicator statement presented to them was essential for NSPC to occur in hospital. The steps on this scale were clearly defined for participants and stated at the beginning of each indicator category (Boulkedid *et al.* 2011). The rating scale is provided in Table 17.

Table 17 Likert scale used in rounds 1 and 2 of the Delphi study

Category	**Explanation**
Strongly Agree	If you think the indicator is **essential** for non-specialist palliative care to occur in hospital
Agree	If you think the indicator is a **high priority** but is not essential for non-specialist palliative care to occur in hospital
Unsure	If you think the indicator is a **medium level priority** for non-specialist palliative care to occur in hospital
Disagree	If you think the indicator is **low priority** for non-specialist palliative care to occur in hospital
Strongly Disagree	If you think the indicator is **not a priority at all** for non-specialist palliative care to occur in hospital

Agreement, in this study for rounds 1 and 2 was defined as those who answered either *strongly agree* or *agree* to each indicator statement. In round three, participants were simply asked to indicate *YES* or *NO* when asked if the indicator was essential for NSPC to occur in hospitals. Agreement in the final round was based on *YES* answers.

Consensus however does not necessarily indicate full agreement between participants on a given topic (Nair *et al.* 2011). As such it is important in a heterogeneous panel of expertise that one group does not dominate the consensus (Boulkedid *et al.* 2011). Therefore, indicators were required to achieve a percentage of 70% agreement or greater in at least two of the three participant groups to ensure strong resulting consensus. This definition of consensus is consistent with previously conducted Delphi studies in palliative care (Downar & Hawryluck 2010, Mahler *et al.* 2010). Stability has been described as the consistency of responses between successive rounds of a study (Dajani *et al.* 1979). This has been identified as an alternative to consensus, and depending on the level of data, various inferential statistical measures to ascertain stability can be utilised (Von der Gracht 2012). Stability of responses can be assessed between rounds in order to decide at what point consensus has been achieved to conclude the consensus process. Following considerable review of relevant literature, and consultation with a statistician, I decided that statistical stability tests were not appropriate in this Delphi study because conducting three Delphi rounds was decided a priori. Notwithstanding this, two different categorical scales were used to attain agreement in this study which meant that statistical tests assessing stability could not be similarly applied between rounds 2 and 3.

7.4.3 Round 1 of the modified Delphi survey

It has long been established that accurate and appropriate wording of the problem statement in the recruitment invitation is of paramount importance to the Delphi process (Delbecq *et al.* 1975) in order to maximise the quality and the quantity of responses. In the round one invitation email (Appendix 13) and Twitter Tweet (Appendix 14) participants were given broad information about the nature of the study and invited to click on the link to the round one questionnaire. The wording of the goal of the research, the purpose of the study and the expertise required to participate so that people who clicked on the link had the necessary expertise to participate was carefully considered. In particular, importance was given to explaining what 'NSPC' was in the invitation given the diversity of terminology used to describe this care as identified (phase I). Furthermore, the decision to use the terms 'chronic or serious illness' rather than 'life limiting illness' when seeking to recruit participants particularly in the service user group was a deliberate attempt to use a term which reflects groups of people that would receive NSPC, while 'life limiting' was considered a potentially more intimidating and negative term which many patients with chronic or serious illness may not identify with and would potentially inhibit their willingness to participate.

The Twitter invitation content was particularly challenging due to the character restrictions (140) per tweet, so a poster containing information about the study was embedded in the tweet for people to click on and view in an attempt to compensate for this. The Surveymonkey link provided in both the invitation email and tweet brought potential participants directly to the participant information and informed consent section in Surveymonkey (Appendix 15). Once consent was indicated, participants were directed to a short demographic section which asked details such as name, email address, country of origin, and area of expertise in hospital based NSPC (Appendix 16). These questions were necessary to identify which stakeholder groups participants belonged to, and the identifying information was required in order to distribute the subsequent rounds of the questionnaire. Depending on the group that a participant self-identified with, they may have been asked additional questions to provide more specific information related to their expertise for example whether they identified as a NSPC or SPC provider. Figure 12 outlines the decision tree of questions following this participant group question. In order to reduce participant burden and time commitment, page logic was applied to the Surveymonkey pages and participants only saw questions that were relevant to their self-identified participant group. Participants were then directed to the round one initial CCPIs for NSPC for rating (see Appendix 17 for round 1 survey).

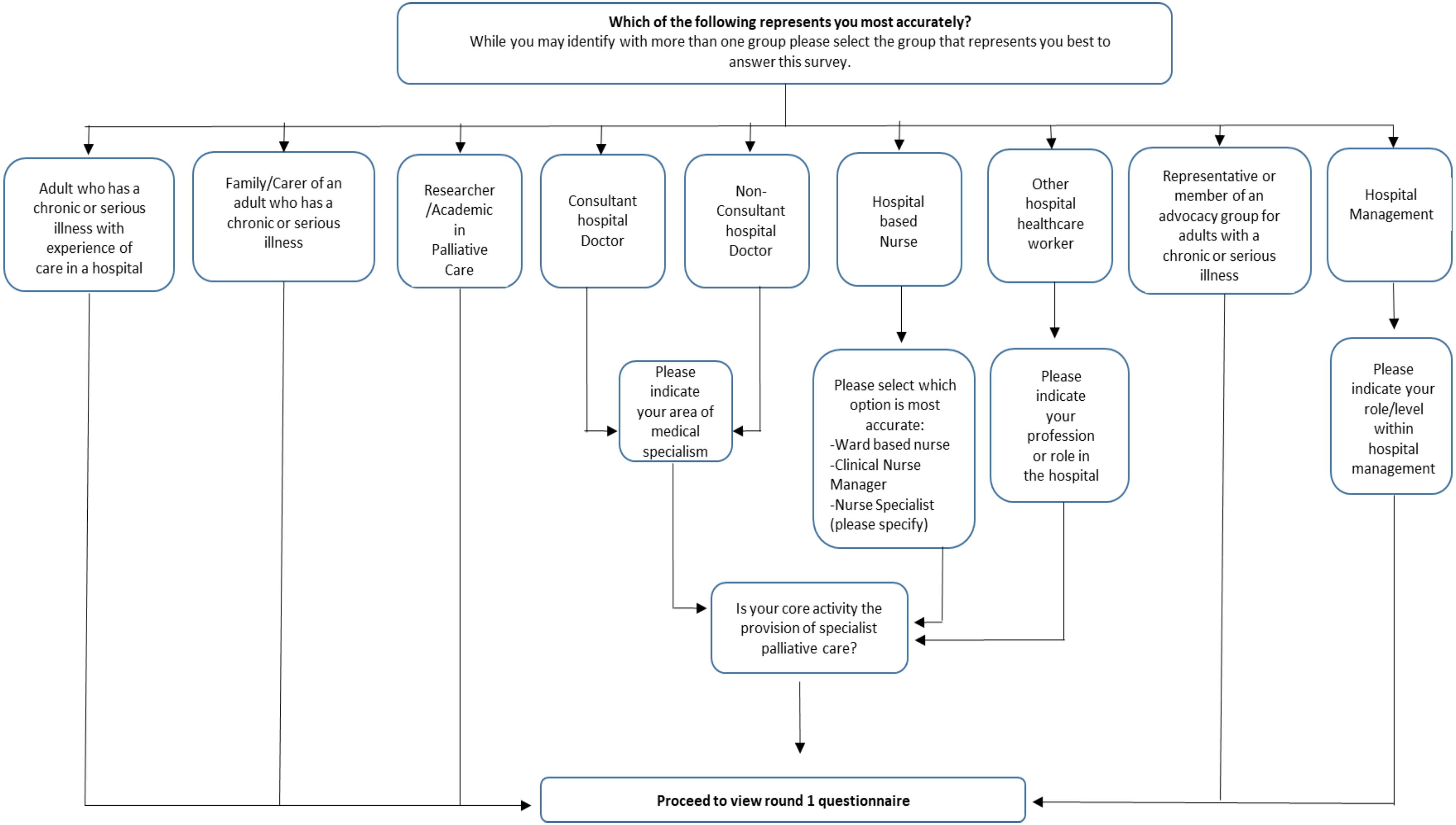

Figure 12 Decision tree following participant group question

In round 1, participants were presented with the initial indicators and invited to rate the degree to which each indicator was essential to providing NSPC in the hospital setting. Participants were also offered the opportunity, in this round to propose additional indicators not already in the list that they considered relevant or important to include. The 34 initial indicators of NSPC were categorised into 'Structural', 'Organisational' and 'Staff' indicators with an explanation of what each category referred to. To emphasise the fact that participants were being asked to rate indicators on the basis of 'what' was essential, and not on the basis of how feasibly they could be measured, a further statement was inserted in red colour to flag this at the beginning of each indicator category;

> *"When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and not how they might be measured or implemented in practice as this is not the focus of the study"*

7.4.4 Round 2 questionnaire

The second round questionnaire was only administered to those who had participated in round 1 and who had provided a valid email address. In some cases, indicators were re-worded on the basis of feedback received following round one (discussed in results section). In this round participants saw all indicators from the previous round plus any additional indicators from round one. To reduce the time commitment in completing further rounds, the only demographic questions participants were asked in rounds 2 and 3 related to their name and email address. Responses could then be linked to round 1 demographic characteristics without having to ask participants for this information again. In round 2 participants were invited to re-rate the indicators provided to them in round 1, using the same round 1 rating scale (Table 17) and also to rate the new indicators. The opportunity to revise previous scores in light of previous ratings is an important element in consensus in a Delphi study (Powell 2002). Therefore, in round 2 participants were presented with a table alongside each indicator with each group's round 1 percentage level of agreement (see Appendix 18 for full Round 2 survey). To facilitate ease of navigation through the round 2 survey, instead of providing a separate section to rate the new indicators, these were embedded within the indicator categories (Structural, Organisational, and Staff) and all indicators, where relevant to do so, were clearly marked as '*new indicator*' or '*reworded indicator*'.

7.4.5 Round 3 questionnaire

The goal of the final Delphi round was to enable participants to consider their opinions in light of the group responses in round 2, and to ascertain final consensus on what participants believed were essential/core indicators of NSPC for the hospital setting. Therefore, in order to emphasise the 'essential' aspect of indicators, the following statement was embedded at the start of each indicator category; *'What structural indicators are ABSOLUTELY ESSENTIAL for non-specialist palliative care* *to occur in hospital?'* To further channel participants into deciding whether an indicator was essential or not, the 5-point Likert scale was replaced by YES/NO response options to the question…. *'Is this indicator ABSOLUTELY ESSENTIAL?'* (See Appendix 19 for full round 3 survey). Further signposting in red text; *'*While you may feel that some indicators are very important, please only tick YES if you think an indicator is absolutely/critically essential*'* was included to optimise the focus on 'essential'. The decision to eliminate frequently high or low scoring items in a Delphi study has been discussed by several researchers (Hasson *et al.* 2000, Hsu & Sandford 2007, Hasson & Keeney 2011, Junger *et al.* 2017). Vázquez-Ramos *et al.* (2016) noted that if a question garners continuing divergence, it can be excluded from the next round, therefore indicators that did not reach at least 70% agreement in at least two participant groups in round 2, were excluded from round 3.

7.4.6 Piloting of the Delphi questionnaire

The online questionnaires were tested by three people; an experienced Delphi researcher, a hospital based NSPC clinician and a carer of a person with a chronic illness, before the study proper commenced, and for each round, to ensure rigour (Okoli & Pawlowski 2004, Hasson & Keeney 2011). For round 1 these people were specifically asked to evaluate whether the Surveymonkey process was easy to access and navigate, on computer and handheld device, whether instructions were clear, and to report the length of time spent completing each questionnaire. This led to some minor re-wording in the demographic section, and some re-ordering of items in round 1. Pilot participants were presented with two different versions of how the new indicators and results table could be presented in round 2 and were unanimous in their opinion as to which format was the easiest to understand and navigate. In round 3, pilot participants were asked to determine whether the survey adequately reflected the purpose of the final round which was for participants to decide which indicators were absolutely essential or not. Questionnaires completed as part of the piloting process were deleted, and not used in the data analysis.

7.5 Data management and analysis

This section discusses how responses, non-responses and missing data were managed in this Delphi study. A description of the data analysis is then presented.

7.5.1 Management of responses, non-responses and missing data

All survey data were transferred into SPSS® version 25 and screened before analysis. SurveyMonkey provides the option to allow or restrict multiple attempts to access a survey from the same location. Since clinicians were being recruited for this Delphi study, the option for multiple attempts from one location was enabled to facilitate staff using shared clinical computers in hospitals. All responses were initially screened and where there was more than one attempt from the same email and Internet Protocol (IP) address to complete the survey, the most completed attempt was retained. If there were two fully completed attempts from the same email and IP address, only the most recent attempt was retained. There does not appear to be a consistent approach to the management of Delphi non-responders in the published palliative care literature (Junger *et al.* 2017), or the wider Delphi literature. Participants in this Delphi study were asked to contribute in all three rounds, and therefore, must have contributed to the previous round in order to be invited to participate in subsequent rounds. Although adopting this approach risked study attrition, I believed that it was the best option in order to produce the most meaningful consensus and would strengthen the validity of the findings of this study.

Finally, although Surveymonkey does provide the facility to force respondents to provide an answer to questions, I decided that it was important to allow participants themselves, to decide which indicators they wished to provide a judgement rating on. Due to the heterogeneity of the panel of expertise it could not be guaranteed that all participants felt that they had the necessary expertise to answer every question. Therefore, while this increased a risk of having missing data, I believed it provided participants greater choice in determining their own expertise in responding to the item, thereby increasing the validity of the results. Subsequently all missing data (returned questionnaires with missing values) were entered into SPSS as missing data.

7.5.2 Data analysis

According to Hsu & Sandford (2007), the type of data analysis researchers use for Delphi studies is at the discretion of the researchers themselves. The new indicators identified by participants in round 1 of this Delphi study generated essentially qualitative material therefore information provided in the 'new indicators' section of the round 1 questionnaire was analysed using content analysis. This involved reading and re-reading of all content to identify overlap and duplicate content, and grouping words and terms that conveyed similar meaning (Chesnay *et al.* 2014). The quantitative data from the Delphi study were analysed using SPSS® version 25. Quantitative analysis of the data included the following descriptive data analysis; response rates, percentages for each level of agreement (i.e. *strongly disagree* to *strongly agree*), and median. Hsu & Sandford (2007) describe how reporting the median is highly acceptable in Delphi studies.

7.6 Ethical conduct of the study

Ethical considerations were required in conducting this online Delphi study. Respecting the rights and dignity of the participants of the study was paramount and was achieved by adhering to models of good practice related to mutual respect, consent, privacy and confidentiality. Ethical approval to conduct the Delphi study was granted by the Research Ethics Committee of the School of Nursing and Midwifery, Trinity College Dublin (Appendix 20), and it’s conduct was bound by the Nursing and Midwifery Board of Ireland, Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (2014), and guided by The Declaration of Helsinki (World Medical Association 2013), the General Data Protection Regulations (2016) and the Data Protection Act (2018).

7.6.1 Respect for persons/autonomy

A researcher must respect an individual’s capacity to make decisions, and their right to full disclosure (Nursing and Midwifery Board of Ireland 2014). Also, researchers are required to ensure that the principle of autonomy is adhered to for those participating in healthcare research (Nursing and Midwifery Board of Ireland 2015). Potential participants of the Delphi study freely choose whether or not to participate in the study. In keeping with the principle of veracity, or truthfulness (Parahoo 2014, Nursing and Midwifery Board of Ireland 2015), all participants received comprehensive information about the study in the participant information leaflet (PIL), at the outset of the study, and at the beginning of each survey round (see Delphi surveys, Appendices 17-19). Participants were free to withdraw from the study at any time with no consequences which they were informed of at the outset of the study, and again at the beginning of each survey round. To ensure the participants understood the consequences of participation, clear explanations related to participation were provided in each survey round. Additionally, participants were encouraged to contact me (email and telephone contact details provided in the PIL at each round), if they required further clarification or additional information about the study and all correspondence from participants was responded to promptly.

7.6.2 Informed consent

All participants autonomously volunteered to take part in the Delphi study. Grove *et al.* (2013) attest that informed consent requires participants to provide competent and voluntary consent to participate, following full disclosure and comprehension of information by the participant. The purpose of informed consent is to protect research participants by facilitating them to make informed choices (Nursing and Midwifery Board of Ireland 2015, Polit & Beck 2018). At the end of the PIL provided in each Delphi round, participants were required to confirm that they had read and understood the study information and were voluntarily agreeing to take part in the study by clicking ‘YES’. Only on confirmation of this could participants proceed to view each round’s survey instrument.

7.6.3 Beneficence and non-maleficence

It is imperative that researchers balance potential benefits against potential risks, and to minimise potential risk to the greatest extent possible, thus safeguarding and protecting participants (Nursing and Midwifery Board of Ireland 2015). Participants in the Delphi study were adults (≥ 18 years of age) and sampled based on their self-identified expertise. This research was considered low risk where there was no foreseeable risk of harm or discomfort, and any foreseeable risk was considered no more than inconvenience. Other than providing an opportunity to express their opinions, there were no direct benefits to participants of the study, and they were informed of this in the PIL. Demographic questions requiring participants' personal information were not sensitive in nature such as medical history, nor was there a requirement to answer each question in order to continue. The only direct personal information required of participants was their email address, which was stored securely and confidentially. In accordance with the principle of justice, participants in this study were treated with fairness and equity at all times so as to ensure the equitable distribution of research burden and benefit and protect those at risk of exploitation (Nursing and Midwifery Board of Ireland 2015, Polit & Beck 2018). Two reminder emails were sent to non-responders during rounds 2 and 3 one week apart. If participants had not responded following the second reminder no further correspondence was initiated.

7.6.4 Privacy, confidentiality and data protection

True anonymity can only be assured when a response cannot be linked in any way to an individual participant. Due to the nature of the Delphi design, true anonymity cannot be achieved (Hasson & Keeney 2011). Although individual responses were not identifiable to other participants in the study, I needed to have access to personal identifiable information (i.e. email addresses) to distribute the subsequent survey rounds, the results of the previous round(s) and to send follow-up emails to non-responders. Job titles to determine which group the participant was aligned to were also sought. This information was necessary to analyse survey data by stakeholder expertise. Keeney *et al.* (2001) refer to this as quasi-anonymity. Only the minimum amount of personal data required were sought and personal data were not used for any purpose other than that specified at the time of data collection (European Union 2016, Department of Justice and Equality 2018). Participant names (if voluntarily provided) and email addresses were disassociated from their responses in the SPSS coding process for each Delphi round. Any comments from participants on the survey, and/or direct participant quotes presented in this thesis are done so anonymously. All information that links participants to their data were stored electronically and password protected throughout the course of the study. This personal information of participants was kept safely from any third party, securely stored on a password protected computer for the duration of the study. Only I, as the primary researcher could access the information, and all data will be destroyed after five years.

7.7 Findings

The following section presents the findings of the Delphi study. It begins with a discussion of the stakeholder group characteristics and the retention flow pattern throughout the 3 Delphi rounds. Then, the results of each survey round are presented. The changes that occurred between rounds are discussed but the main focus of the findings section is on the round 3 results as these represent final consensus on the core indicator set.

7.7.1 Stakeholder group characteristics

7.7.1.1. Round 1

One hundred and twenty-nine individuals completed the consent form to indicate their willingness to participate in the study. Of these, 13 were recruited from the link supplied through Twitter while the remaining 116 (90%) accessed the survey via email. Of the 129, 24 did not supply an email address, and could not, therefore, progress to view the survey, giving a round 1 participation rate of 105. Interestingly, of the 24 that did not progress to round 1 six were recruited through Twitter, giving a 46% attrition rate from this platform. This indicated that although the numbers of reads of my study invitation tweet were high (over 2000 reads), use of this platform did not result in any meaningful engagement with the survey. A targeted recruitment strategy via email, in contrast, proved to be more successful in securing participation in this study. The character restrictions per Tweet restricted the amount of initial study information provided as opposed to the invitation email, and it could be that people having initially consented to participate, withdrew once identifying data was sought as they did not believe they were suitable. The 105 responses were screened and eight were found to be duplicates (i.e. same email and IP addresses), and were deleted, which resulted in a final round one participant number of 97.

Members of the three stakeholder groups were drawn from a variety of backgrounds. The largest group were hospital-based healthcare providers which accounted for over half of all respondents in round 1 (n=52; 53.6%). This provided expertise from diverse perspectives within the hospital environment. Of this, a variety of clinician groups accounted for the largest subgroup (n=45), of which 15 indicated that their core clinical activity was the provision of SPC with the remaining NSPC practitioners. Two did not answer this question. As well as views from those involved in direct clinical care, clinical management and senior hospital administration were also represented (n=7). The second largest stakeholder group was the service user group (n=25; 25.8%). Within this stakeholder group, patients themselves accounted for the largest subgroup (n=10), while carers (n=8) and advocacy group representatives (n=7) made up the remainder of this stakeholder group. Lastly, the palliative care researchers/policy makers group accounted for just over one in five of those who took part in round 1 (n=20; 20.6%). The characteristics of the participants who completed the round 1 survey are presented in Table 18.

Table 18 Characteristics of round 1 Delphi participant groups

Stakeholder Group	**Participants**		**Frequency N=**	**%**
1. Those who have experience receiving hospital based NSPC **N = 25**	Adult who has a chronic or serious illness with experience of care in a hospital		10	10.3
	Family/Carer of an adult who has a chronic or serious illness		8	8.2
	Representative or member of an advocacy group for adults with a chronic or serious illness		7	7.2
2. Hospital based healthcare providers **N= 52** *(of the 45 clinicians;* *15 = SPC (33%)* *28 = NSPC (62%)* *(2 didn't answer)*	Consultant hospital Doctor	Palliative Medicine 6 Respiratory Medicine 3 Geriatric 2 Anaesthesia and Pain 1 Internal Medicine 1	13	13.4
	Hospital based Nurse	Ward level Nurse 5 Clinical Nurse Manager 1 Nurse Specialist 15 *(not specified 4, respiratory 2, emergency 2, palliative care 5, 'consultant' 2)*	21	21.6
	Other hospital healthcare worker	Not Indicated 2 Medical social worker 1 Physiotherapist (2 Cystic Fibrosis) 7 Physiologist 1	11	11.3
	Hospital Management	Director Nursing 1 Assistant Director of Nursing 2 End Of Life Co-ordinator 2 Coordinator Integrated care unit 1 Manager Palliative Care 1	7	7.2
3. Researchers or Policy makers in palliative care **N= 20**	Researcher/Academic in palliative care		20	20.6
Total Responses			**97**	**100**

7.7.1.2 Retention in R2 and R3

Round 2 yielded 88 responses, 7 were duplicates and were deleted, and 3 participants provided an email address but didn't provide answers, which resulted in a round 2 retention rate of 78 (82% of round 1). Of these 78 participants, 73 (92%) responded also to round three. This resulted, overall, in an aggregated response rate of 74% for this Delphi study. These retention figures are presented in Table 19.

Table 19 Delphi retention figures

Overall retention	**Round 1**	**Round 2**	**Round 3**
Number of surveys administered per round	n/a	95	78
Total Valid Responses per round	97	78	72
Percentage response rate from previous round	n/a	82%	92%
Dropout from the previous round	n/a	18%	10%
Overall response rate Rounds 1-3	**74%**		

Table 20 provides a summary of the group participation rates in all 3 Delphi rounds. The hospital-based healthcare provider group was consistently the largest group (approximately 50% of the total number of participants) in all rounds of the study, and it also presented the largest attrition rate, although this did not have a large effect on this group's overall percentage participation (from 53.6% to 45.8%). The numbers in the other two groups remained relatively stable.

Table 20 Summary of Delphi group participation

Delphi Rounds	**Total number of participants per round**	**Stakeholder Groups**					
		Those who have experience receiving hospital based NSPC		Hospital based healthcare providers		Researchers or Policy makers in palliative care	
	N	**N**	**%**	**N**	**%**	**N**	**%**
Round 1	97	25	25.8	52	53.6	20	20.6
Round 2	78	21	26.9	39	50.0	18	23.1
Round 3	72	21	29.2	33	45.8	18	25.0

7.7.1.3 Response flow pattern

The effect of targeted and personalised reminders are presented in Figures 13 and 14. There was a distinct rise in responses on the days that the invitation email and both reminders were sent (red columns, Figures 13 & 14). By monitoring the flow of responses it was deemed appropriate to send the first reminder approximately one week after the invitation email and the final reminder one week after this because the responses had remained consistently low in the day or two beforehand. It is also apparent that responses were consistently low over the weekend and rose on Mondays, so this was not an appropriate day to close the survey. In obtaining a response rate of 82% (n=78) in this round it was deemed appropriate to mimic this strategy in the final round, which produced very similar patterns and a successful retention rate of 92% (n=72) in the final round.

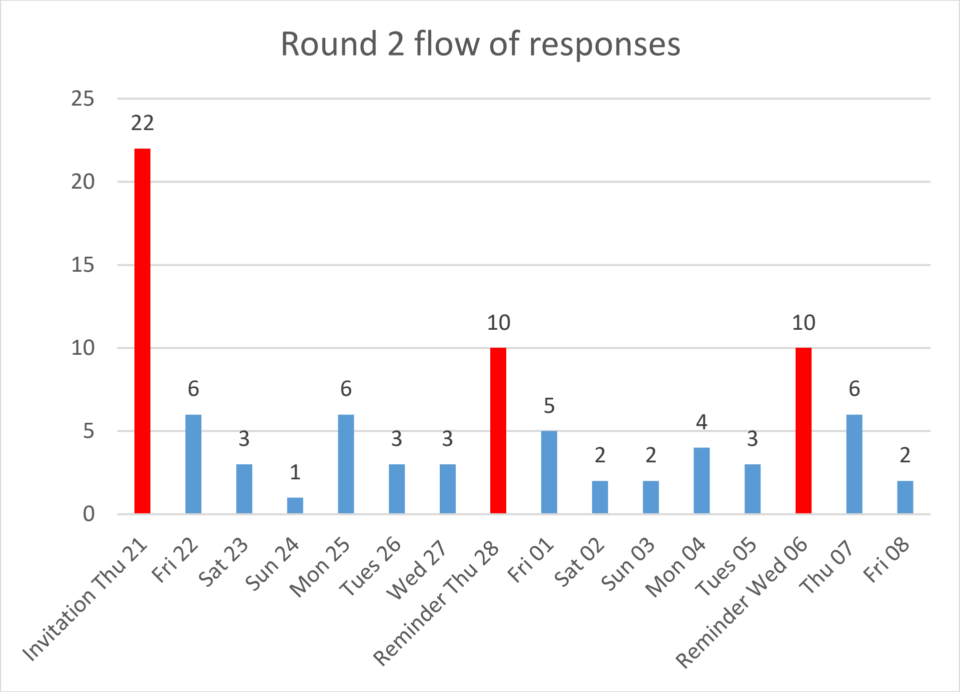

Figure 13 Round 2 flow of responses

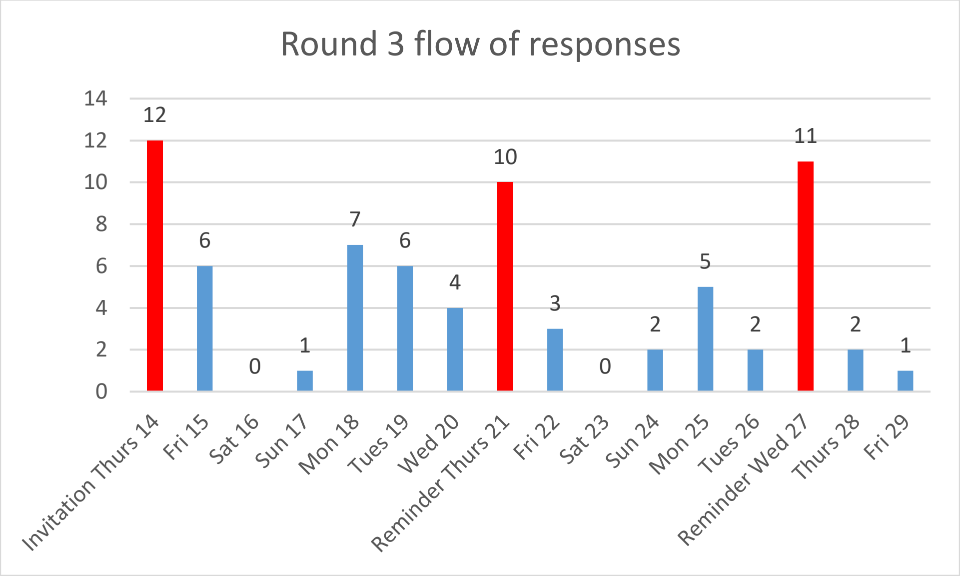

Figure 14 Round 3 flow of responses

7.7.1.4 Country of origin

There was a broad range of international perspectives in this Delphi study with twelve countries represented. In round 1, Ireland was the largest country of origin represented (n=59, 60.8%). New Zealand accounted for a further 11 respondents, with Sweden (n=9), United Kingdom (n=7), Canada (n=3) and Portugal (n=2) providing representation. Finally, Denmark, Finland, Norway, Italy, Spain and the USA each accounted for one participant in round one respectively. Table 21 presents participation by country in all three rounds with all 12 Countries initially represented in round 1 maintained by round 3.

Table 21 Country of origin per Delphi round

Results	**Round 1**		**Round 2**		**Round 3**	
Country of Origin	**Frequency**	**Percent**	**Frequency**	**Percent**	**Frequency**	**Percent**
Canada	3	3.1	2	2.6	2	2.8
Denmark	1	1.0	1	1.3	1	1.4
Finland	1	1.0	1	1.3	1	1.4
Ireland	59	60.8	47	60.3	43	59.7
Italy	1	1.0	1	1.3	1	1.4
New Zealand	11	11.3	9	11.5	8	11.1
Norway	1	1.0	1	1.3	1	1.4
Portugal	2	2.1	1	1.3	1	1.4
Spain	1	1.0	1	1.3	1	1.4
Sweden	9	9.3	6	7.7	5	6.9
United Kingdom	7	7.2	7	9.0	7	9.7
United States of America	1	1.0	1	1.3	1	1.4
Total	**97**	**100.0**	**78**	**100.0**	**72**	**100.0**
No. of Countries per round	**12**		**12**		**12**	

7.7.2 Round 1

7.7.2.1 Initial Indicator results

Overall, consensus agreement (at least 70% agreement in at least two participant groups) was achieved in twenty of the round 1 indicators. Specifically, agreement was reached on one of the five structural indicators, 13 of the 18 organisational indicators and 6 of the 11 staff indicators. A table presenting the round 1 participant group percentage level of agreement results for each indicator is provided in Table 22, with figures presented in red indicating consensus achieved. The complete round 1 results including the scores (expressed as a percentage) for all 5 Likert categories for each group is provided in Appendix 21.

Table 22 Round 1 – Level of agreement

(Figures in red represent consensus achieved)

Participant Group	**Patient/Carer /Advocate**	**Hospitalist**	**Researcher**
Indicator	**Percentage Level of Agreement**		
STRUCTURAL			
1. Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	76	63	55
2. Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	80	59	61
3. Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	76	59	72
4. The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	68	55	67
5. A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	75	66	56
ORGANISATIONAL			
1. Organisational and care practices are structured in a way that supports non-specialist palliative care provision in combination with acute care delivery	66	81	78
2. Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	74	81	67
3. Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	65	68	83
4. Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	74	53	61
5. Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	64	65	44
6. Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	82	78	56
7. Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	73	87	78

8. Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	77	84	72
9. Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	73	75	61
10. Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care	73	70	78
11. Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	68	65	67
12. Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	60	79	56
13. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	82	92	89
14. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care doctors and nurses caring for patients with life limiting illness	78	77	61
15. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	82	73	61
16. The hospital has a multidisciplinary specialist palliative care service in place	82	81	83
17. A structured and standardised care pathway exists between non-specialist palliative care and specialist palliative care, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	76	73	50
18. Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	73	73	83
STAFF			
1. Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	84	67	77
2. Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	83	59	71
3. Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	88	70	82

4. Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	83	72	88
5. Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	89	72	81
6. Non-specialist palliative care staff receive training on advance care planning	82	61	65
7. Non-specialist palliative care staff receive training on compassionate end of life care	89	74	82
8. The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with greater experience of or exposure to patients with life limiting illness	71	50	59
9. Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between non-specialist palliative care doctors and nurses, caring for patients with life limiting illness	77	61	53
10. Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	83	56	53
11. Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	59	69	65

7.7.2.2 New Indicators Identified

Where possible, the exact wording that participants provided was used, but this was not always possible if language or content was unclear. Also, in some cases, participants did not provide new indicators but instead used this section of the survey to ask for clarification about certain indicators. In total 23 textual items were provided by participants in this section of the round 1 survey and these were closely scrutinised during analysis. Based on this, six additions were merged due to similarity, five of the initial round 1 indicators were slightly reworded for clarity, and 12 new indicators were identified and aligned to the most appropriate indicator category. This produced 1 structural, 9 organisational and 2 new staff indicators. For the purposes of flow and readability of this chapter only the list of the 12 new indicators identified from round 1 is provided in Table 23 below. A full audit trail, containing all 23 textual items, and the decisions taken for each item is presented in Appendix 22.

Table 23 New indicators identified in round 1

Structural	
1	Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management
Organisational	
1	The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available.
2	Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation
3	The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists
4	Non-specialist staff are aware of palliative community services when discharging a patient
5	Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place
6	Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying
7	When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner
8	People with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge
9	Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs
Staff	
1	Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality
2	Case presentations at hospital 'grand rounds' include difficult palliative care cases

7.7.3 Round 2

The initial indicators presented in round 1 combined with the new indicators provided a total of 46 indicators for rating in round 2 (6 structural, 27 organisational and 13 staff indicators). Overall, a significant majority of indicators (41 of the 46) achieved at least 70% agreement in at least 2 participant groups, on their importance as indicators of NSPC in hospitals, and were thus retained for re-rating in round 3. The five indicators that did not achieve consensus were excluded from round 3. A table presenting the round 2 participant group percentage level of agreement results for each indicator is presented in Appendix 23. This summary table also lists those indicators that were retained or excluded for inclusion in round 3. In similar presentation style to round 1, complete round 2 results which included the scores (expressed as a percentage) in all 5 Likert categories for each group is provided in Appendix 24

7.7.4 Round 3

The principle focus of this section is to present the final list of core CCPIs for NSPC for hospitals as determined by the panel of experts in this Delphi study. Indicators that did not achieve consensus are also presented.

7.7.4.1 Indicators that achieved consensus

Forty-one indicators progressed from round 2 for rating in round 3, and 32 achieved consensus in this final round (5 structural, 21 organisational and 6 staff indicators). These indicators therefore represent the final list of core CCPIs for NSPC in the hospital setting. The complete results (expressed as the number and percentage *'YES'* and *'NO'*) of each indicator, for each of the 3 participant groups in round 3 are presented in Appendix 25. Tables 24, 25 and 26 detail the final core structural, organisational and staff indicators and the pathway that each indicator in each Delphi round (where applicable) took to achieve consensus. Where N/A (not applicable) is specified in round 1 (R1), this relates to those new indicators that participants provided in round 1, and thus were not rated in this round.

The indicators in the structural category were those mostly retained in the consensus process (5 of 6), indicating that participants in this study highly believed that it was essential to embed NSPC within the core infrastructural and strategic governance systems within a hospital. Four of these achieved consensus in both rounds 2 and 3, with one indicator; *Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation* achieving consensus in all 3 rounds of this Delphi study. This suggests a high level of stability between Delphi rounds 2 and 3.

Table 24 Core structural indicators of NSPC for hospitals and consensus pathway

Structural Indicators	R 1	R 2	R 3
Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	NO	YES	YES
Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	NO	YES	YES
Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	YES	YES	YES
Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management	N/A	YES	YES
A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	NO	YES	YES

Of the 21 organisational indicators relating to aspects of clinical policy, guidelines and clinical care processes of NSPC, over 50% (n=11) achieved consensus in all 3 rounds of this Delphi study. Of the remaining organisational indicators 6 were ‘new’ indicators, achieving consensus in both rounds 2 and 3, and only one indicator; *Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses* changed from non-consensus in round one to consensus in rounds 2 and 3. These findings indicate a high level of stability and inherent strength in these findings.

Table 25 Core organisational indicators of NSPC for hospitals and consensus pathway

Organisational Indicators	R1	R2	R3
Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery	YES	YES	YES
Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place	N/A	YES	YES
Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	YES	YES	YES
When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner	N/A	YES	YES
Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	NO	YES	YES
Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	YES	YES	YES
Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	YES	YES	YES
Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	YES	YES	YES
Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients	YES	YES	YES

physical and mental wellness and ability to function), from non-specialist palliative care staff			
Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs	N/A	YES	YES
Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	YES	YES	YES
Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation	N/A	YES	YES
Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying	N/A	YES	YES
Non-specialist staff are aware of palliative community services when discharging a patient	N/A	YES	YES
The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available	N/A	YES	YES
Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness	YES	YES	YES
Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	YES	YES	YES
The hospital has a multidisciplinary specialist palliative care service in place	YES	YES	YES
A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	YES	YES	YES
The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists	N/A	YES	YES
Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	YES	YES	YES

Indicators in the staff category experienced the highest rate of attrition in this Delphi study, with 6 core indicators remaining from thirteen (Table 26). The panel of expertise in this Delphi were emphatic in their belief that training in many of the key elements of NSPC provision such as pain and symptom management, communication and end of life care is a core requirement for delivering NSPC in hospitals.

Table 26 Core staff indicators of NSPC for hospitals and consensus pathway

Staff Indicators	R1	R2	R3
Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	YES	YES	YES
Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	YES	YES	YES
Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	YES	YES	YES
Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	YES	YES	YES
Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	YES	YES	YES
Non-specialist palliative care staff receive training on compassionate end of life care	YES	YES	YES

7.7.4.2 Indicators that did not achieve consensus

Of the total 46 indicators that were presented for rating throughout this Delphi study, 14 did not meet the threshold required for consensus, with five being eliminated in round 2, and a further nine excluded after round 3. In relation to the structural indicators, the only indicator in this category that participants did not agree was essential, related to visibility of NSPC in the service plan of a hospital. Six organisational indicators were eliminated in this Delphi study; two in round 2 and a further four in round 3. Aspects of the organisation of hospital based NSPC that participants in this Delphi study did not consider essential, related to spiritual/existential support, care planning, prioritised readmission for patients with life limiting illnesses, care delivery regarding NSPC knowledge levels, and adaptation of care in accordance to illness. In relation to the staff indicators that participants rated in this study, over half did not achieve consensus, with two eliminated in round 2 and a further 5 eliminated in the final Delphi round. The themes of care planning and knowledge levels within NSPC provision were also consistently rejected by participants. The complete list of those indicators that did not achieve consensus in this Delphi study are included in Table 27.

Table 27 Indicators of NSPC that did not achieve consensus

Structural Indicators	**R 1**	**R 2**	**R 3**
The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	NO	NO	N/A
Organisational Indicators	**R1**	**R2**	**R3**
Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	NO	YES	NO
Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	NO	NO	N/A
Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	YES	YES	NO
Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	NO	YES	NO
Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	NO	YES	NO
People with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge	N/A	NO	N/A
Staff Indicators	**R1**	**R2**	**R3**
Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality	N/A	YES	NO
Non-specialist palliative care staff receive training on advance care planning	NO	YES	NO
The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with lesser and greater experience of or exposure to patients with life limiting illness	NO	NO	N/A
Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness	NO	YES	NO
Case presentations at hospital 'grand rounds' include difficult palliative care cases	N/A	YES	NO
Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	NO	YES	NO
Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	NO	NO	N/A

7.8 Conclusion

This chapter began with an overview of consensus development methods, followed by a detailed examination of the Delphi method, and how it was applied in this study. The results of the Delphi study were then presented. The expert opinion of this Delphi panel produced a final set of 32 core CCPIs for NSPC in the hospital setting (5 structural, 21 organisational and 6 staff indicators). The next chapter will discuss these findings, in the context of previous literature.

Chapter 8 – Discussion

8.1 Introduction

This chapter presents a discussion of the key findings of this study. These findings are derived from the concept analysis of NSPC (phase I), the systematic review of NSPC in the hospital setting (phase II), and the international Delphi study (phase III), with reference to empirical and theoretical literature. The findings represent an interpretive exploratory and meaningful discussion of core NSPC provision in hospitals and considers how this is currently reflected in Ireland. Lastly, the contribution of the study to the advancement of the concept of NSPC, and the strengths and limitations of the study are discussed.

8.2 Core indicators for NSPC provision within multiple levels in hospitals

The findings from phase III, and the identification of 32 core CCPIs for NSPC in hospitals meets the overall aim of this study. These core CCPIs represent what stakeholders agreed are the essential (core) aspects of hospital based NSPC provision and represent an original contribution to the knowledge base surrounding the organisation and delivery of NSPC across multiple levels within hospitals. The core CCPIs reflect consensus on what NSPC at a core structural (CCPI-1-5), core organisational (CCPI-6-18), and core staff (CCPI-19-32) level should entail (Table 28). This set of 32 core CCPIs illustrate that for meaningful change in individual clinical practice relating to palliative care in hospitals to occur, multi-level engagement within this organisation is essential (Mosenthal *et al.* 2008, Dalgaard *et al.* 2014, Hynes *et al.* 2015, Curry *et al.* 2018, Kamal *et al.* 2019). Results of previous studies also highlight the need for hospitals to invest in strategies to foster an organisational culture that supports improved clinical performance (Taylor *et al.* 2015, Curry *et al.* 2018). This core set of CCPIs can be utilised as a basis for a hospital to benchmark its level of integration of NSPC throughout all levels of an organisation (Berg & Schellekens 2002). Thus, providing hospitals with a means to assess and monitor their progress towards meaningful and relevant NSPC provision.

Table 28 Core clinical care provision indicators for NSPC in the hospital setting

Core CCPIs	
Core CCPI No.	**STRUCTURAL CORE INDICATORS**
CCPI-1	Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital
CCPI -2	A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital
CCPI -3	Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care
CCPI -4	Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation
CCPI -5	Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management
	ORGANISATIONAL CORE INDICATORS
CCPI -6	Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery
CCPI-7	Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place
CCPI -8	Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff
CCPI -9	Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses
CCPI -10	Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness
CCPI -11	Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying
CCPI -12	Non-specialist staff are aware of palliative community services when discharging a patient
CCPI -13	Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness
CCPI -14	Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff
CCPI -15	Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff
CCPI -16	Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs
CCPI -17	Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff
CCPI -18	Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation
CCPI -19	The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available

CCPI -20	Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness
CCPI -21	Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family
CCPI -22	The hospital has a multidisciplinary specialist palliative care service in place
CCPI -23	When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner
CCPI -24	A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care
CCPI -25	The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists
CCPI -26	Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff
	STAFF CORE INDICATORS
CCPI -27	Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management
CCPI -28	Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training
CCPI -29	Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients
CCPI -30	Non-specialist palliative care staff receive training on a palliative approach to patients’ pain and symptom control
CCPI -31	Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness
CCPI -32	Non-specialist palliative care staff receive training on compassionate end of life care

The 32 core CCPIs reflect multi-level organisational support to incorporate a palliative care philosophy which prioritizes patient-specific rather than specialty specific approaches. Where communication, discussing goals of care, weighing benefits and burdens of treatment options, and managing pain and suffering are considered essential elements of patient care along with disease-specific therapies. They can provide a means to support the integration of a palliative care philosophy in the hospital setting. NSPC is underpinned by a philosophy of palliative care which recognises all dimensions of an individual's suffering (Chapter 2). The biomedical model that prevails in hospitals is exemplified in patient–healthcare provider interaction that generally centres on pathology and tailored efforts to contain disease progression (Adorno 2015). However, for patients, their care needs are likely to be much broader. Also, in hospitals, the person receiving care assumes the role of a patient, inhabiting an unfamiliar environment, with order imposed by the institution and its policies and procedures (McKechnie *et al.* 2010). Hospitalisation causes upheaval in patients' lives. Particularly for those with acute exacerbations of chronic or serious illness, this uncertainty may create existential questions about ultimate concern whereby encompassing meaning may present with more urgency than in the routine of their everyday life (Mishel 1988, Long *et al.* 2008).

8.2.1 Clinical applicability of the CCPIs – whom and where?

Before discussing the core CCPIs in more detail, it is important to provide clarity about which patients these core CCPIs are intended to be directed at. Many distinct groups of patients are identified as having palliative care needs (Chapter 4). For the purposes of phase III, the term 'life limiting illness' was used to categorise those in need of NSPC in indicator statements (e.g. CCPIs 5, 10, 13, 21). This term was chosen following engagement with the literature, expert input and considered reflection because it articulated the serious nature of a person's illness, was consistent with the current WHO definition of palliative care (World Health Organisation 2002), and was considered by the expert advisory panel (Chapter 6) acceptable as commonly used terminology for stakeholders to understand. Therefore, core indicators were identified by the panel of experts in phase III based on this categorisation of the patient with palliative care needs. However, the Lancet Commission on palliative care for example (Knaul *et al.* 2018) described how palliative care can benefit anyone with 'serious health related suffering'. This represents a much broader conceptualisation of those in need of palliative care. Arguably, solely linking palliative care need to 'suffering', while congruent with a palliative care philosophy (Chapter 2), has practical implications because suffering is so individualised (Cassell 1991, 2011). Therefore, any person has the potential to experience 'serious' health related suffering regardless of the seriousness of their illness. Simply put, as terminology associated with the patient with palliative care needs is variable and evolving, arguably, the core CCPIs could have applications to a much wider population of patients that receive care in hospitals.

The core CCPIs were developed and are intended for use within hospitals. However, as discussed in Chapter 2, there is no universally agreed definition of a hospital and variations in the size, location, and services that hospitals provide exists internationally. This is also evidenced in Ireland with the identification of four distinct acute hospital categories (Health Services Executive 2010). Therefore, while these core CCPIs are intended to have a broad application in hospitals, they do not presuppose that all core CCPIs are equally relevant in every hospital care environment. Contextual factors such as national palliative care policy, funding, and culture (Zaman *et al.* 2017) for example must be considered in relation to the clinical applicability and operationalisation of these core CCPIs in practice.

8.3 Integrating NSPC in hospitals

Integrated palliative care involves bringing together aspects such as organisational, clinical and service elements to provide continuity of care between all those involved in the care network of patients receiving palliative care (Hasselaar & Payne 2016). The integration of NSPC, and the 32 core CCPIs within acute care delivery in hospitals faces different challenges to that of SPC service integration. In integration models that focus on SPC integration (Siouta *et al.* 2016) the palliative care input is provided by those with a shared philosophy of palliative care working within the boundaries of SPC services, where the main palliative care role of healthcare providers working outside of SPC is considered referral to SPC. However, increasing the capacity of healthcare providers outside of SPC services to provide palliative care, as reflected in these core CCPIs, NSPC providers within the acute biomedical ‘cure’ focused service delivery in hospitals must assume a duality of roles by also integrating the fundamentally different view of ‘heal’ into their practice. As Hutchinson *et al.* (2009) advises, curing and healing are not just different they are diametrically opposed (Chapter 2).

The importance however of incorporating both ‘cure’ and ‘heal’ perspectives within the organisation of acute care delivery in hospitals operationalised through these core CCPIs, to meet future patient needs is important. The rapid advancements in medical technology and treatment options are arguably most visible within the hospital care environment, and there are societal expectations of medicine to achieve positive healthcare outcomes for patients (Lateef 2011, Laiteerapong & Huang 2015). In practice however, the reality is that increasing numbers of patients with chronic illnesses are presenting to hospital (Clark *et al.* 2014), where a cure is unlikely or impossible. Therefore, doctor and patient care expectations may not align. Furthermore, with rising consumerism in healthcare, patients are seeking more treatment choices and are increasingly placed at the centre of decision-making (Mould 2010, Zeckhauser & Sommers 2013, Latimer *et al.* 2017). Consumerism views respect for patient autonomy as sacrosanct (Mould 2010). Increasing patient choice out of a respect for patients as autonomous beings had led to their empowerment in decision-making and addressed some of the imbalance regarding paternalistic medical practice (Latimer *et al.* 2017). However this has arguably created a conflict regarding doctors' and patients' views of patients' 'best interests' (Downie 2017, p. 263).

This aligns closely with previously published literature recognising the need to incorporate a palliative approach, with the patient central in the care and management of various chronic conditions (Phase I). In particular, the need to ensure that care for people with various chronic illnesses or life stages reflects the goal of minimising the impact of burdensome treatment and maximising quality of life (Lorenz *et al.* 2007, Thomas *et al.* 2014). However, it has been observed that the growing body of research on the concept of burdensome treatment as an indicator of quality care in chronic disease is predominately quantitatively measured and conceptualised (Sav *et al.* 2017). Arguably qualitative data could provide a richness and depth of understanding of the patient and families experiences of treatment burden on their lives and identities. Furthermore, it is also apparent in published population-based quality indicators of appropriate end-of-life care in people with cancer, Alzheimer's disease and chronic obstructive pulmonary disease, that measures of quality were limited to physical symptoms, medical treatments and medication (De Schreye *et al.* 2017, Henson *et al.* 2019). CCPIs 6, 7, 8, 9, 10, 14, 19, 20, 21 articulate the core need for clear communication and a partnership approach between healthcare providers, patients and families in the planning and delivery of care in hospitals. This reflects the multidimensional nature of palliative care, not just the physical symptoms/treatment needs and expectations of those patients with various chronic/life limiting conditions. While this highlights the potential value of, and clinical specificity of the 32 core CCPIs for the hospital setting, future work however in piloting/testing this core set of CCPIs must be cognisant of the challenges of incorporating a palliative approach in hospitals identified by healthcare providers in Phase II.

The concern about whether it is feasible to incorporate NSPC within hospitals has been raised by several authors (Gélinas *et al.* 2012, Hynes *et al.* 2015, Glogowska *et al.* 2016). Adopting a whole system approach through the identification of structural, organisational and staff core CCPIs may provide a means to support this integration in clinical practice and may also inform policy and research (detailed in Chapter 9) in this area. However, while the 32 core CCPIs are presented as a list of statements, they should not be interpreted solely as a set of technical skills or tasks. Underpinning the concept of NSPC is the notion of 'total pain' and suffering leading to total care

(Phase I, Chapter 4). This notion of total or whole person care requires attending to the individualised psychological, psychosocial and existential needs, and not just the physical needs of the patient and family. Therefore, ultimately, even though individual hospital departments may serve separate functions in acute patient care, recognising that all hospital departments have a role to play in the delivery of NSPC is important. This set of 32 core CCPIs could have applications in any department within the hospital setting, and previous studies exploring NSPC in individual hospital departments such as the emergency department (Smith *et al.* 2010, Cooper *et al.* 2018) and intensive care (Mosenthal *et al.* 2008, Gélinas *et al.* 2012) support this, and highlight that while specific clinical priorities may occur between hospital departments, there is consistency in the fundamental palliative care philosophical approach to the patient.

Palliative care however, arguably does not closely align with acute care focused measures of quality utilised in the hospital setting (Radall & Downie 2006). This was a very important consideration in the current study when developing the initial indicators of NSPC for hospitals. These final 32 core CCPIs are essentially an attempt to disregard the prerequisite for measurement or performance indicators, in order to uncover what is fundamentally important in NSPC provision for the hospital care environment (i.e. the 'what'). Authors have warned that efforts to articulate the clinical and cost effectiveness of palliative care has led to an emphasis on the identification of measurable aspects of service delivery and *"palliative care could default into a series of competencies directed only at technical control of symptoms"* (Royal College of Physicians of London 2007, p. 1). This has led to discarding other central components of palliative care that do not align easily with measurement as evidenced in a previous systematic review of palliative care quality indicators (De Roo *et al.* 2013a). Spiritual/existential support, for example, did not achieve consensus as a core CCPI in phase III of the current study. The literature supports the view that spirituality is among the resources that many patients turn to as they deal with chronic or advanced illness (Creel & Tillman 2008, Piderman *et al.* 2015, Timmins *et al.* 2018). The word existential can be understood as an ability to find and realize adequate life meaning (Halama & Strizenec 2004), and patients should be supported to find meaning in their suffering. It could be that stakeholders in phase III believed that spiritual/existential support should be the remit of chaplaincy services, a view that is also present in the literature (Sheikh *et al.* 2004, Pesut *et al.* 2012, Timmins *et al.* 2018). Spiritual/existential care was scarcely represented in performance measures for palliative care in the literature (Twaddle *et al.* 2007, De Roo *et al.* 2013a).

Recently, the Lancet Commission (Knaul *et al.* 2018) developed an '*essential palliative care package*', but the authors excluded spiritual and social hardship because of *'the empirical and conceptual challenges of measuring these'* (Knaul *et al.* 2018, p. 11). Arguably unlike spiritual/existential support other aspects of palliative care, such as attending to patients' physical needs are perceived to have higher importance because they are more congruent to how care is planned, organised and measured in the hospital care environment. In this sense, the findings from phase III, and the omission of spiritual/existential care as a core aspect of NSPC provision in hospitals by all three Delphi participant groups strongly aligns with previously published palliative care quality indicators (De Roo *et al.* 2013b, De Schreye *et al.* 2017, Henson *et al.* 2019). Spirituality however remains a central concept within palliative care (findings from Phase I) and why spirituality was excluded from the final list of core CCPIs should be considered in relation how participants were asked this question in the Delphi study. Participants in the Delphi study did recognise and agree that spirituality/existential support was important, because in Delphi round II, using a 5-point Likert scale there was agreement to include spirituality/existential needs within the core list (see Appendix 23). It was only when the level of measurement was changed to a YES/NO binary approach in Delphi round III spirituality was excluded by all participant groups as it was not considered absolutely essential (see Appendix 25). Furthermore, although spirituality was not specifically listed in the final core set, participants recognised that psychosocial support (CCPI 15), and training in relation to palliative care principles, which would incorporate spirituality as a central concept was included in the final core set (CCPIs 27, 28).

Examples of the palliative care tendency towards reductionism in hospitals is also evident in Ireland; death in a private room, and rapid end of life discharges have become established quality measures for good end of life care in hospitals in Ireland (Hospice Friendly Hospitals (HFH) 2010, National Clinical Programme for Palliative Care 2016). However, the numbers of patients/relatives whose preference for a single room is not currently ascertained, and there is evidence to suggest that some patients would choose a shared room because they preferred company and feared being left on their own (Williams & Gardiner 2015). Furthermore, evidence suggests it is highly likely that people in the last year of their life will have multiple readmissions to hospital (Clark *et al.* 2014). Core CCPIs to integrate NSPC reflect the need for hospitals to examine not just rapid discharge at end of life procedures, but their current discharge pathways. This can identify opportunities to reduce readmissions and determine how to best support and maximise the quality of life of those patients earlier in their disease trajectories. Simply put these core CCPIs reflect the fundamental palliative perspective of total pain and whole person care. This requires attention to the whole person, and future research utilising these core CCPIs should not focus solely on what core CCPIs may be considered more amenable to the culture of cost effectiveness and acute based care measurement.

8.4 NSPC- a multidisciplinary approach

An important finding in phase III is that NSPC provision in hospital requires a multidisciplinary approach with the adoption of clear care co-ordination, communication structures and shared decision making between NSPC providers (core CCPIs 7, 20, 21). Palliative care was originally conceived from a multidisciplinary perspective (Saunders 2001). The fundamental importance of attending to the needs of the whole person by incorporating a multidisciplinary approach still holds true in current literature where palliative care requires a *'team approach'* (World Health Organisation 2002), and care is characterised as *'interdisciplinary'* (National Coalition for Hospice and Palliative Care 2018). Baldwin & Woodhouse (2011) state that to function effectively meeting patients' palliative care needs, and to enable collective decision making, it is essential that every team member shares the goals and philosophy of palliative care. This aligns closely with how multidisciplinary SPC services work; however, this is not necessarily how NSPC providers' work (Radbruch & Payne 2009), or how care is organised in hospital-based environments. Care in hospitals is organised within separate healthcare provider disciplines and medical specialties, with communication structures between hospital departments often fragmented and little emphasis on face-to-face contact between professional groups (Hynes *et al.* 2015). Communication relating to patients' care is often condensed into short statements, retrospectively documented in medical notes by members of the medical and allied health professionals, or separately in nursing notes.

Core CCPIs 7, 19, 20, and 21, in particular reflect the need to explore opportunities to increase the capacity for all healthcare providers, along with the patient and family to support clinical decision making. This should be considered in relation to who makes the clinical decisions currently in hospitals. How a healthcare provider organises their tasks is ultimately linked to value; the cultural values of an organisation and the values of their profession (Casey *et al.* 2011, Hynes *et al.* 2012, Mannion & Davies 2018). In hospitals, the focus is on acute care interventions and this permeates the entire organisation (Hynes *et al.* 2015). The burden of addressing patients healthcare expectations, and responsibility to change treatment plans which reflect transitions to a palliative care approach (heal), discuss prognosis, and refer to SPC in hospitals principally rests with doctors (findings from Chapter 5). Hutchinson (2011) however argues that whole person care, which underpins NSPC (Chapter 2) does not require each practitioner to know all about the patient in all dimensions (biological, psychological, social, spiritual etc) and taking responsibility for taking care of all of them, because this would be impossible. Furthermore, not all dimensions need to be addressed at the same time (Hutchinson 2011). For example, the needs of a patient presenting in the emergency department with an acute exacerbation of heart failure, in the initial unstable period are likely to closely align to that of cure i.e. to survive that acute episode. But they must also be supported to heal, which supports them to make sense of their illness and restore their integrity

(Mount & Kearney 2003). Healing is therefore relational and individualised and for patients with palliative care needs, requires recognition and engagement by the medical team with the expertise of the patient, family and other healthcare providers to support clinical decision making.

There are many possibilities to support shared decision making and better communication within an organisation. Core CCPIs 7, 20, 21 and 31 should stimulate reflection and the identification of opportunities within hospitals to improve in this regard. For example, it is well established that healthcare providers require education and training to support end of life related communication (Phases I, II and CCPI-31), and there are examples of interventions to support the implementation of this in the published literature (Selman *et al.* 2017, Mathew *et al.* 2019). Also, previous studies that have explored interventions to improve nursing input on medical ward rounds in hospital have demonstrated favourable results (Binnie & Titchen 2011). In Ireland, building on the work of Kirby *et al.* (2014), there could be scope to explore the role of nurses working at level 2 (generalist) NSPC to take a more active and formalised role within the imminent publication of advance healthcare directives codes. For example, to reflect early integration and shared NSPC, within the multidisciplinary team, the heart failure nurse specialist could take the clinical lead on discussing, formalising and documenting patients care preferences in the anticipation of expected and predictable deteriorating health. An initiative like this relates directly with core CCPIs 7, 18, 20, & 21. Schwartz Rounds also provide a multi-disciplinary forum for staff to meet on a monthly basis to discuss and reflect on the personal and emotional impact of working in healthcare (Chadwick *et al.* 2016). Schwartz rounds were piloted in several hospitals in Ireland, and a recent evaluation by Brady *et al.* (2019) determined that they are a very effective method of bringing two vital components characteristic of teamwork to an organisation, namely, a shared purpose and effective communication (Brady *et al.* 2019). For patients in hospital with increasing multi-morbidity who are under the care of several medical specialties, the decision making, and communication challenges faced by NSPC providers, patients and families in hospital based NSPC are likely to present a much greater challenge (Turner *et al.* 2018). Specifically, the lack of interaction among consulting specialists who are taking care of interconnected problems the same patient is having can result in conflicting messages, drug interactions, and aggravation of one problem while trying to resolve another (Bruera & Hui 2010).

In summary, this section has provided examples of specific hospital based NSPC interventions (albeit primarily at a feasibility/pilot level) from the published literature which reflect aspects related to individual core CCPIs of NSPC identified in Phase III. However, arguably one specific intervention on its own will struggle to effect organisational wide change. The value of the full set of 32 core CCPIs is that it provides a multi-level framework for hospitals to plan initiatives to improve the integration of NSPC within all levels of the entire organisation. For example, to support the integration of communication regarding deteriorating patients throughout the entire organisation, education and training initiatives regarding communication skills for individual NSPC providers (Selman *et al.* 2017, Mathew *et al.* 2019) may only be considered one element (CCPI 31). Organisational communication processes (CCPIs 7, 14, 18, 19, 20, 21) which support healthcare providers to identify, plan, and communicate care for those who are at risk of deteriorating should also be considered, examples of which include the Gold Standards Framework (2016), and the AMBER care bundle (2019). Furthermore, the structural care environment (CCPI 2) should also be optimised to support healthcare providers to communicate with patients and families, such as the availability of family rooms and private spaces (Irish Hospice Foundation 2014a).

In relation to a hierarchy of NSPC skills or expertise, consensus in phase III found that structuring NSPC care delivery or training to reflect knowledge levels of those with greater or lesser experience is not a core aspect of NSPC hospital care. These findings suggest that the panel of expertise considered core NSPC undifferentiated at levels of provision. This is potentially important in those jurisdictions that articulate discrete NSPC levels within national policy such as Ireland (Level 1; a palliative approach, level 2 generalist) (Chapter 2, Figure 2). Irish policy recognised three levels of palliative care provision originally in 2001 (Dept of Health and Children 2001), and further ascribed competencies for clinicians based on these discrete NSPC levels nearly six years ago. Other jurisdictions have also articulated discrete levels of NSPC provision (Chapter 4, Table 7). How this is impacting on the quality of education and clinical NSPC in hospitals has never been evaluated either internationally or within the Irish care context in hospitals.

8.5 Importance of and interface with specialist palliative care

Core CCPIs 22 to 26 have broadened understandings of what, at its core, access to and interaction between NSPC and SPC should entail in order to provide NSPC in hospitals. These findings indicate that hospitals at a minimum should have a SPC team in place (core CCPI-22), which facilitates timely referrals and provides support and training for NSPC staff. This reaffirms the perceived importance of SPC services for the effective provision of NSPC in hospitals as highlighted by NSPC providers in phase II and in the wider literature (Health Service Executive 2015, Firn *et al.* 2016, Robinson *et al.* 2016). Core CCPIs 25 and 26 also articulate a fluidity required within the core interaction between NSPC and SPC in hospitals through consultation and the need for SPC to provide continued clinical support and education to NSPC providers. This finding aligns with the need to build strong networks between SPC and NSPC espoused by the current National Clinical Programme for Palliative Care in Ireland (2019). It could take the form of advice on a difficult case, or following consultation, only part of the SPC team become directly involved with the patient or family (Billings 1998); or as some authors have articulated, palliative care consultations can help to forge partnerships, develop supportive relationships, act as silent partners, promote the palliative approach, in particular, outside the sphere of oncology, and facilitate good outcomes for the patient and the teams concerned (Glare *et al.* 2003, Gaertner *et al.* 2011). Core CCPIs 24 and 25 therefore support the need to broaden the scope of the current rigid and formal referral-based criteria required for access to and discharge from SPC described in palliative care policy internationally and in Ireland (Ministry of Health 2001, Health Service Executive 2016a, 2016b).

Little is currently known about the extent of the requirement of each of the various levels of palliative care provision in hospitals in the literature. Some criterion points to phase of illness (stable, unstable, deteriorating or dying), with other predictors of need identified as problem severity, level of available carer support, functional status and age (National Clinical Programme for Palliative Care 2015). Notwithstanding this, phases II and III of the current study provide strong justification for the need for the presence of SPC services in all hospital settings to support NSPC. However, recognising the contextual nature globally in the provision of palliative care, there are many national and local issues that can give rise to disparities in the provision of SPC services in hospitals such as national policy, recognition of palliative care as a specialty and care funding structures (Clark *et al.* 2017, Zaman *et al.* 2017, Knaul *et al.* 2018). Therefore, although core CCPIs 22 to 26 were identified from international expert perspectives, they are only applicable within the context of countries with well-developed palliative care provision, which recognises the medical speciality of palliative care (Arias-Casais *et al.* 2019). Furthermore, in the U.S context, the highly fragmented specialised medical disciplines working within hospitals and cost reimbursement system, may mean that the potential for greater fluidity regarding consultation, support and shared learning between NSPC and SPC providers may not be tenable. Notwithstanding that, one study which reviewed patients charts in academic hospitals across the U.S found that hospitals where some form of palliative care service is available had a greater likelihood of receiving components of palliative than patients in hospitals where no formal palliative care is available at all, regardless of whether they were seen in consultation (Twaddle *et al.* 2007). The core need for SPC support to provide NSPC in hospitals identified in phase III contradict current palliative care policy in Ireland. Currently in Ireland only two types of hospitals (models 3 and 4, which have an acute medical unit and emergency department) require on-site SPC services, whereas hospital models 1 and 2 (which don't have acute medical unit and emergency department) do not (National Clinical Programme for Palliative Care 2015).

8.6 Educating and supporting healthcare providers to deliver NSPC

The importance of training on palliative care principles, assessment and care management for all NSPC providers, and in particular newly recruited staff, and early career staff emerged in phase III (core CCPIs 27 to 32). This finding is consistent with findings from phases I and II of this study. However, these core CCPIs offer explicit topic guidance as a basis to prioritise core training initiatives specifically for NSPC in hospitals that are currently lacking. Palliative care training initiatives in Irish hospitals for the past several years have focused predominately on end of life care, through the national Hospice Friendly Hospital *Final Journeys* workshops (Irish Hospice Foundation 2019). This course trains healthcare providers to support patients and families in the last days and weeks of life. Core CCPIs 27 through to 31 describe aspects of palliative care training that reflect recognition and care throughout the disease trajectories for patients with serious illness. This would suggest that the current focus on end of life care training initiatives for hospital-based healthcare providers in Ireland do not accurately reflect the totality of core NSPC provision. Furthermore, the identification of six core CCPIs related to training in NSPC could possibly suggest that deficiencies exist in the palliative care undergraduate education healthcare providers receive. This is consistent with the findings of Pesult (2014) who concluded following a scoping review of 58 studies of nursing education in palliative care, that it was difficult to recommend an evidenced based approach to educate nurses in palliative care. Also, these core CCPIs for training in NSPC were derived solely for the hospital care setting. The inherent challenge of the competing demands of acute care interventions with a palliative approach may have been a factor in the core need for training in NSPC for healthcare providers in this setting. This need for core NSPC training may not be replicated in other settings, for example the community.

Although core CCPIs 27-32 acknowledge that staff training is essential to deliver NSPC in hospitals, the panel of experts did not consider that it was necessary for formal multidisciplinary learning between NSPC providers to occur. This contradicts evidence which suggests that facilitating palliative care shared learning experiences between professional groups could provide a means to understand different viewpoints, and learn from the experience of other disciplines (Breiddal 2012). Multidisciplinary shared learning also supports a central tenant of palliative care; that it is fundamentally interdisciplinary (World Health Organisation 2002). This finding could relate to the challenges within all disciplines to find the time to engage in training activities in hospitals; however it is not impossible, as evidenced in the successful feedback following the introduction of Schwartz Rounds in hospitals internationally, and in Ireland.

It was unexpected to observe in phase III that the panel of experts did not consider aspects related to peer support, either formal or informal as core requirements for staff to engage in NSPC in hospitals. NSPC which is true to the principles of whole person care, and attending to suffering, requires the provider to look beyond a disease orientated model of care and engage with the illness experience, and suffering of their patients. Particularly for those with chronic disease, it is likely that close relationships may be built up between healthcare providers and patients over years of engagement with hospital care services. The potential grief and toll that NSPC can have on a healthcare provider should thus be acknowledged and supported. Caring for very sick and dying patients involves high levels of emotional engagement and personal commitment which can lead to burnout (Meier & Beresford 2006), and higher burnout scores have been associated with a lack of psychological support in the workplace (Wenzel *et al.* 2011). This is also evidenced in phase II of this study. Clinically, in nursing, burnout has been described as compassion fatigue, which Aycock & Boyle (2009) asserts, involves an excess of empathy and undue identification with patients' suffering, resulting in an inability to maintain a healthy balance between objectivity and empathy. External factors such as time to care are influential. Therefore empathising, while feeling constrained in one's ability to address another's suffering plays a large role. This, closely aligns with Webster & Baylis (2000) who described the concept of moral distress; when a person's beliefs and values are incoherent with one's actions, and possibly also outcome. Or as it was originally conceived, moral distress was believed to arise *"when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action"* (Jameton 1984, p. 6). It could be argued therefore that institutional constraints such as lack of time and emphasis on acute care interventions also mean that the moral distress of staff is not recognised as a core issue. Moral distress in healthcare however has been identified as a growing concern, and is a wide spread problem for health care providers including nurses, pharmacists, social workers, physicians, and health care managers (Pauly *et al.* 2012). Doctors in phase II also reported stressors around identifying palliative care needs and communicating poor prognosis. With increasing societal demands being placed on the medical profession to provide curative treatments for many conditions (Laiteerapong & Huang 2015) it is likely that doctors also experience moral distress in caring for patients with palliative care needs in hospitals. However less is known in the literature regarding moral distress in medicine (Kearney *et al.* 2009).

8.7 Contribution of the study's findings to the advancement of the concept of NSPC

Arguably, NSPC will always remain a 'fuzzy concept' (Haack 1996, p. 32) whereby it does have a definitive meaning, however this is not fixed or precise and can vary according to context or conditions (Haack 1996, Dietz & Moruzzi 2009). Findings from this study have advanced our understanding of the concept of NSPC as presented in phase I (Chapter 4). From an epistemological perspective, which involves determining if the concept of NSPC has been clearly defined and well differentiated from other concepts, this study contributes to our understanding of NSPC provision in hospitals. Phase II advanced our understanding of the contextual issues that healthcare providers experience in providing NSPC in hospitals. Phase III provided further epistemological insight with the identification of clinical indicators that provide clarity regarding the role of NSPC providers in palliative care provision in hospitals. For example, within these core CCPIs, end of life care is clearly delineated as only one component of NSPC, providing further conceptual clarity that NSPC is not solely care at the end of life.

The pragmatic principle is concerned with the application of a concept within practice, or what can be considered the usefulness of a concept in a discipline. Phase II advanced knowledge of how NSPC is practically understood and applied in the hospital setting from the perspectives of healthcare providers delivering this care. However, the results of phase III provide the greatest contribution to the pragmatic advancement of the concept of NSPC. The identification of 32 core CCPIs provides rich contextual data from multiple stakeholders as to what, at its core, NSPC in hospitals should entail, which are intended to support the operationalisation of NSPC in the hospital setting.

Whether a concept can hold its own boundaries when theoretically integrated with other related concepts is the focus of the logical principle. Healthcare providers in phase II reported that attending to the psychological and psychosocial needs of a person, and not just their physical concerns as conceptual components of NSPC. Furthermore, core attributes of NSPC identified in phase III also reflected this ‘total pain’ multidimensional view of the patient (core CCPI-13 & 15), which reinforces its conceptual boundaries within palliative care. However clear boundaries between this and conceptual components of person-centred, or holistic care, were found to be interwoven (phase I) and therefore have not progressed the logical maturity of the concept. Except in the case of end of life care, where results from phase III contradicted findings from phase II whereby core CCPIs reflected NSPC in much broader terms, indicating the need to assess and care for patients with NSPC needs early, where end of life care represented only one conceptual component of NSPC. From this perspective, the logical maturity of NSPC has been progressed in this study.

The linguistic principle relates to whether there is consistency of use and meaning of NSPC. Phase II did not provide further linguistic conceptual clarity whereby inconsistencies in understanding and engagement with NSPC provision experienced by healthcare providers in the hospital setting emerged. Phase III of this study expands the linguistic principle by providing clarity through formal consensus about how NSPC in the hospital setting at its core should be constructed. These core CCPIs may be adopted by others (internationally) thereby providing a means to address issues with inconsistent use and meaning of multiple terminology to describe NSPC as previously identified (Chapter 4).

8.8 Strengths and limitations of the study

8.8.1 Strengths

This study provides an in-depth exploration of NSPC in the hospital setting. More specifically it has uncovered the contextual nature of NSPC delivery in hospitals, while also achieving consensus on 32 core CCPIs underpinning NSPC provision at all levels within the hospital setting. The strength of the core CCPIs lies in the research design and multiple phases that were conducted to achieve this. A comprehensive examination of NSPC was conducted both objectively, through analysis of the concept (phase I), and subjectively, by systematically reviewing and synthesising the evidence of healthcare providers experiences of NSPC in hospitals (phase II), to provide a strong evidence base which informed the development of initial indicators of NSPC. The strength of the initial indicators is enhanced by several factors. In phase I a data extraction tool was developed to support a structured approach to extracting the relevant data for informing the concept analysis. In phase II a large volume of data; 37 studies reporting on the views and experiences of 985 hospital healthcare providers, from 14 countries contributed to the four emergent themes and subsequent initial NSPC indicators. Also, while acknowledging the subjective and complex nature of qualitative quality assessment, the findings of phase II were derived from studies which were overall, of high methodological quality. Furthermore, the sensitivity analysis conducted in phase II to assess confidence in the review's findings, goes beyond the quality appraisal described in the ENTREQ guidelines (Tong *et al.* 2012), which refers to the quality of the individual primary studies only. This analysis provided reassurance as to the quality of the synthesised evidence in finding a high degree of confidence and trustworthiness in the evidence base regarding NSPC in hospitals.

Strengths of the Delphi study to identify the core CCPIs lies in the panel of experts and retention rate achieved. A wide variety of experts represented all viewpoints in NSPC provision in hospitals in this study. This included the views of patients and carers, which is a perspective that has not been represented in several previous palliative care Delphi studies (Downar & Hawryluck 2010, Raijmakers *et al.* 2012, Van der Steen *et al.* 2016). Also, establishing three separate groups of experts ensured that no group dominated the study, with acceptable numbers in each group, the international representation of the experts (12 countries), and participant retention of 74% over three rounds supporting the integrity of the research findings. Furthermore palliative care derived published guidelines (Junger *et al.* 2017) were applied to guide the conduct and reporting of this Delphi study, with all 16 items comprehensively addressed, and thus enhancing the credibility of the resulting list of core CCPIs.

8.8.2 Limitations

Several limitations in this study are identified. Although exhaustive searches were undertaken in phases I and II, trying to achieve a balance of sensitivity and specificity when searching for relevant NSPC literature was challenging due to varied terminology that surrounds the concept of NSPC. For this reason, I acknowledge the possibility that some literature where NSPC was not the main focus, but where some conceptual clarity, or views and experiences of healthcare providers may have been provided, may not have been identified. The exclusion of data from quantitative studies in phase II may also have had an impact on the resulting themes generated in this systematic review. Furthermore, subjectivity in the analysis of the qualitative data in phase II also presents a challenge for thematic findings; however, systematic data extraction, transparency of reporting and the iterative nature of the synthesis, helped, I believe, largely counteract this. Lastly, the views and experiences of healthcare providers, other than nurses and doctors were collectively presented in the studies in phase II. This limited the scope for nuances between other healthcare providers to emerge.

Conducting Delphi studies is challenging due to ongoing debate surrounding continual modifications to the technique (Hasson & Keeney 2011). Conducting this Delphi study exclusively online limited the scope for inclusion to only computer literate participants, which may have impacted on representation within the expert groups. Furthermore, the survey was only available in English however participants included individuals from several countries where English was not their first language and may have impacted on their translation and understanding of the concepts described and ultimately the completion of the online survey. Also, although twelve countries were represented in the Delphi study, hospital based palliative care provision development globally is heavily influenced by many factors such as national policy, funding, and culture to name a few. Expertise of NSPC was based on self-selection in this Delphi study and while this is supported as acceptable in the literature (Keeney *et al.* 2001, Baker *et al.* 2006) it potentially limits understanding on how representative the participants were of the wider population in which it was derived from. Also, the purpose of the Delphi study was to identify core indicators of NSPC in hospitals. Therefore, in the final Delphi round it was decided that in order to ascertain whether participants thought an indicator was absolutely essential or not, the 5-point Likert scale was replaced by a YES/NO response option. It must be acknowledged however that collapsing the scale into a binary YES/NO and the resulting loss of measurement properties potentially limited understanding and interpretation of the indicators in this final round. Finally, the threshold for agreement in this Delphi study (70%) was chosen based on previously published Delphi studies in palliative care (Downar & Hawryluck 2010, Mahler *et al.* 2010), however it must also be acknowledged that there is no consistently agreed level in the literature and 8.4. These various factors, and the cross-sectional design of Delphi studies has the potential to limit the generalisability of the findings. National and local context must be taken into consideration in future projects using these core CCPIs. The organisation of NSPC and the challenges and opportunities for its integration are also likely to be highly care setting specific, therefore this set of 32 core CCPIs for NSPC provision in hospitals may have limited transferability to other care settings outside of those they are intended for.

8.9 Conclusion

This chapter has provided a discussion of the major findings of this study derived from the three phases. The contribution of the study to the advancement of the concept of NSPC, and the overall strengths and limitations of the study have been also been discussed.

Chapter 9 – Recommendations and conclusion to the thesis

9.1 Introduction

In this final chapter, recommendations for future clinical practice, palliative care policy, education and future research, which have emerged from the findings of this research, are provided. A dissemination plan at national and international levels is outlined. A conclusion to this thesis and personal reflection is then presented.

9.2 Recommendations from thesis

9.2.1 Palliative care policy

The population of Ireland is ageing. By 2046, approximately 21% of the Irish population will be aged 65 years or older, and approximately 7% will be aged 80 years or older (Turner *et al.* 2018). A growing older population who are likely to experience multiple chronic illnesses will require innovative policy approaches to enable healthier, happier and economically viable extended life spans. In 2017, an Irish cross-party parliamentary committee published *Sláintecare* which sets out a high-level policy roadmap to deliver whole system reform and universal healthcare phased over a ten-year period (Houses of the Oireachtas Committee on the future of healthcare 2017). It is welcome that palliative care is specifically listed in the range of services included in a universal entitlement to healthcare in this document, which places it firmly on the agenda for future financial investment. On reviewing this document it would appear that this integrated care strategy is predominately concerned with reorienting the system towards primary and community care, an observation also made by Burke *et al.* (2018). However, the important and evolving role of the hospital in the delivery of palliative care for our ageing population must not be overlooked in future policy initiatives. In hospitals, acute care interventions are continually advancing, and patients have high expectations of the medical profession to provide curative and life-prolonging treatments. The reality in an ageing population, however, is that more patients are presenting to hospitals with chronic conditions, multi-morbidity and unpredictable disease trajectories, with potentially one third of hospital inpatients in their last year of life (Clark *et al.* 2014). For these patients, cure is very unlikely or impossible, but they will require excellent person-centred care to support them throughout the experience of their illness. NSPC therefore, must become integrated within acute care provision in hospitals; the core CCPIs developed in this research provide a basis to support this.

The palliative care role delineation framework document (National Clinical Programme for Palliative Care 2015) was published to provide a needs based approach to guide the organisation of palliative care services in Ireland. In relation to hospital based palliative care provision, it predominately focuses on SPC services. The '*balanced provision of palliative care services'* in Ireland, that this guideline aims to achieve, based on the findings of the current study requires review. The National Clinical Programme for Palliative Care published the Adult Palliative Care Services Model of Care for Ireland (National Clinical Programme for Palliative Care 2019). This model describes what should be in place so that people can access a level of palliative care appropriate to their needs regardless of care setting. It articulates that an enabling environment must be created where hospital healthcare providers are supported to provide a palliative care approach as part of their normal service provision, however little clinical direction is offered. Furthermore, phase III of this study found that at a core level, NSPC provision in hospitals is not delineated according to level of expertise or palliative care knowledge of the healthcare provider. While Irish palliative care policy has advocated three levels of palliative care provision since 2001, strategies for the implementation of levels 1 and 2 (NSPC) in the context of acute care delivery in hospitals has never been articulated. In this sense policy remains more aspirational rather than reflecting the reality of care provision.

Future healthcare policy should also emphasise and provide direction for the evaluation of NSPC provision. This may act as an impetus to support the integration of NSPC in hospitals. In Ireland, the Health Services Executive (HSE) is responsible for health strategy and service delivery, while the Health Information and Quality Authority (HIQA) oversees standards of services and monitors care delivery. The engagement and support of both the HSE and HIQA in the operationalisation of these core CCPIs may support the identification of gaps and opportunities where health policy related to the Integrated Care Programme for prevention and management of chronic disease (Health Service Executive 2019a), Person-centeredness (Health Service Executive 2019b), Palliative Care (National Clinical Programme for Palliative Care 2019) and performance and service delivery relating to NSPC do not align.

It is recommended that:

- Future palliative care strategies in Ireland demonstrate a commitment to integrating NSPC hospital based palliative care. It may be beneficial that those involved in the organisation of hospital-based care are actively involved in policy development
- Clearly defined actions across the organisation and delivery of NSPC in hospitals needs to be considered in future palliative care strategies
- Strategies for the integration of level 1 and 2 palliative care need to be clearly defined in the context of hospital based palliative care provision
- A commitment to evaluate the outcomes and impact of hospital based NSPC care provision at levels 1 and 2 should be articulated in future policy initiatives
- Considering the core importance of SPC service provision in hospitals to support NSPC provision identified in this study, Irish policy direction (National Clinical Programme for

Palliative Care 2015) which requires SPC provision only to be in place in model 3 and 4 hospitals should be reviewed. Due to the current absence of SPC services in models 1 and 2 hospitals, patients in these care environments may not be getting the effective NSPC that they require. Furthermore, NSPC providers working in models 1 and 2 hospitals may not be receiving adequate training and support to deliver NSPC

- Patients with palliative care needs and their carers should be at the centre of future palliative care strategy working groups, with a view to contributing on the aspects of hospital based palliative care provision that are important and relevant to them

9.2.2 Incorporating CCPIs into hospital service provision

This study has established 'what' the core aspects of NSPC provision in hospitals are through the identification of 32 core CCPIs. As per Wollersheim *et al.* (2007) the next step of the process is to establish how they can be operationalised for use in clinical practice. This will require multi-level engagement calling upon each hospital service and department to rigorously examine how these core CCPIs could be brought to bear within the organisation of clinical care directives and work practices. This is likely a complex and challenging process, but one that may ultimately create hospital-wide integration of NSPC with initiatives that can be adapted and applied across similar hospital settings.

Variations and diversity in palliative care provision in hospitals not only between countries, but also within-countries variations in hospitals (Zaman *et al.* 2017) must be taken into account. The clinical application of the core CCPIs should be assessed within the context in which care is delivered and not reviewed in isolation. Therefore, it is important that a range of indicators are used that reflect different aspects of a hospital's performance. Notwithstanding this, all services are expected to embed quality improvement activities into their daily practice, and to identify areas for improvement through thorough rigorous risk assessment processes, quality audits, and standards reviews, and to implement actions relevant to improving performance in identified areas. Improvement actions and outcomes that arise from the use of these core CCPIs should be evaluated to determine whether interventions or changes have been effective.

Currently in Ireland, practices and care directives for the delivery of NSPC in hospitals are largely focused on care in the last weeks and hours of life (Irish Hospice Foundation 2014b, National Clinical Programme for Palliative Care 2016, Ombudsman 2018). Using these core CCPIs to provide evidence on the core aspects of NSPC will highlight areas for practice change and potentially contribute to the reform and modernisation of the organisation and delivery of NSPC in hospitals. In the long term, it may be desirable to link these core CCPIs to a form of practice accreditation and a recognition and reward system, an example of which includes the Gold Standards Framework initiative in the UK, which promotes care quality and patient outcomes in end of life care (Gold Standards Framework 2016). Integration of these core CCPIs into a hospitals quality improvement system that should be followed in order to maintain and continuously improve the standard of palliative care delivery in a hospital. Finally, hospitals should be obliged to plan for future service delivery needs, beyond the next budgetary year to reflect the population and disease trends which will influence how best to serve the needs of the patients they will encounter.

It is recommended that:

- Hospitals should adopt a more vigorous approach to identifying patients who are entering the last years of their lives. These data could support the organisation of NSPC within acute care, and signpost clinicians to reflect on proposed treatment plans and think about the overall goals that should inform a patient's care
- In order to realise the potential to maximise the integration of NSPC in hospitals through these core CCPIs, multi-level commitment and engagement within the hospital is required
- Key stakeholders within all levels and departments of the organisation should be identified to support the collection of relevant information relating to these core CCPIs. This could be operationalised as a working group comprising of representation from key stakeholders to work through the core CCPIs and collect information on the current organisation and delivery of NSPC. This will establish a baseline of current integration of NSPC based on these core CCPIs within the organisation, and can provide a basis for targeting initiatives to support NSPC integration
- A broader conceptualisation of NSPC that acknowledges the needs of patients earlier in their disease trajectories as reflected in these core CCPIs and not solely in end of life care, should be adopted within hospitals
- Core CCPIs could be integrated into the quality improvement system of the hospital, to reflect broader commitment of palliative care provision beyond SPC services
- In order to reduce the amount of inappropriate admissions for patients with chronic illness, hospitals need to develop a more fluid and connected relationship with the primary care setting in which it inhabits. This could take the form of home visits (Gabutti *et al.* 2017) conducted by level 1 or 2 NSPC healthcare providers from the hospital to engage with patients in their own homes to anticipate and plan their admission or follow up on their discharge
- Patients and carers should be included in all activities which aim to evaluate and develop activities to support the integration of these core CCPIs within hospitals

9.2.3 Education regarding NSPC

The findings from all three phases of this study indicate that there is a need for further training and collaborative initiatives targeted at clinicians in order to overcome barriers and facilitate implementation of NSPC integration in daily clinical practice in hospitals. Healthcare providers need to be competent in recognising those patients that would benefit from a palliative approach and attending to their palliative care needs in a timely manner. Findings would also suggest that palliative care education in undergraduate curricula to prepare healthcare providers adequately to provide NSPC is lacking. Palliative care principles and an understanding of total pain and suffering need to be incorporated in a way that highlights the illness experiences of patients and not just disease focused education. Generic education and training on communication skills will not be sufficient rather specific sessions relating to delivering bad news, poor prognosis and discussing death need to be undertaken continuously if healthcare providers are expected to address these tender and necessary conversations with patients and families.

It is recommended that:

- Healthcare providers' education programmes should include education on NSPC. This should include the principles of palliative care, recognition of suffering and those in need of palliative care, and management of pain and other symptoms. It should be integrated within the curriculum and not solely as a stand-alone module
- Healthcare providers' education programmes should include continuous and specific education regarding communicating poor prognosis and death. Practice sessions which may include aspects such as videos, simulation and role play could be incorporated. Interdisciplinary sessions should be facilitated so that students can begin to learn and understand the role of other healthcare providers in NSPC provision
- To highlight its importance with students as an essential component of healthcare provider education, aspects of communicating poor prognosis should be formatively assessed to demonstrate effective skills, such as Organised Structured Clinical Exams (OSCE) throughout the duration of the education programme
- Ongoing education and training in NSPC should be offered to all healthcare providers working in hospitals. Aspects of this should be offered to interdisciplinary groups and should include continuous professional development regarding communication skills

9.2.4 Future research

The current study has provided important contextual information relating to core aspects of NSPC provision in hospitals from the perspectives of multiple international stakeholders. The findings of this study and the discussion have identified several areas that require further research.

It is recommended that:

- Given the contextual nature of palliative care provision between and within countries future research is necessary to explore the utility and applicability of these core CCPIs in specific contexts for example low income countries
- Given the diversity of the range of hospital types future research is also necessary to explore the utility and applicability of these core CCPIs in specific hospital types such as a community hospital versus a large acute hospital. For example, in Ireland it is likely that there are differences in the core provision of NSPC between the four models of hospitals
- The evidence base to inform the need for two distinct levels of NSPC provision is sparse. Future research needs to explore the role of level 2 NSPC provision in hospitals. Also, research is needed to determine differences in the clinical application and impact between level 1 & 2 NSPC provision in hospitals from multiple perspectives including clinicians and patients
- The term ‘palliative care’ incorporates all levels of palliative care provision and is not solely SPC therefore terminology should reflect this. For the purposes of conceptual clarity, future palliative care studies should clearly articulate in the title which level of palliative care provision is the focus of the study
- Evaluation of NSPC education incorporated within healthcare provider education programmes, using rigorous and relevant research studies should take place to assess their effectiveness. Similarly, ongoing professional education and training courses incorporating NSPC should be evaluated
- Research that includes patients’ and relatives’ perspectives of their needs in palliative care trajectories in order to capture the actual experience of receiving hospital based NSPC is needed
- While the current study is concerned with the integration of NSPC within the hospital setting, future research should explore the interface between hospital and community services as this is an important aspect that determines hospital use

9.3 Dissemination plan

I have commenced the dissemination of the findings from this study and will continue to do so (Page V). Further dissemination includes:

- Paper titled: Development of Core Indicators of Non-Specialist Palliative Care in Hospitals – An International Delphi Study. Planned submission December 2019 to *Palliative Medicine* Journal
- Paper titled: Essential palliative care education and training needs of hospital healthcare providers. Planned submission February 2020 to *Nurse Education Today*
- Paper titled: Guidance for conducting and reporting concept analyses. Planned submission April 2020 to *Journal of Advanced Nursing*
- Paper titled: Recruitment and retention in Delphi studies; Lessons learned from an International Delphi study. Planned submission June 2020 to *International Journal of Nursing Studies*
- Continued presentation at national and international conferences. Currently I have submitted abstracts to two further international conferences (Trinity Health and Education International Research Conference March 2020, EAPC World Research Congress May 2020), and I await an outcome
- Distribution of the findings to key stakeholders through professional associations. This includes blogs and newsletters from the All Ireland Institute of Hospice and Palliative Care, Irish Association of Palliative Care, Irish Cancer Society and European Association of Nurses in Oncology of which I am a member
- Dissemination of findings to the expert advisory panel who supported phase III, and to those who participated in the Delphi study, via email (for those who consented to this)
- Dissemination and integration of the findings of the study within my education role for undergraduate nurses, and presentation of findings to nursing students within other third level colleges in Ireland and internationally through my association with the European Academy of Nursing Science
- Presentation of findings to end-of-life care hospital committees (of which I am a member of one), hospital end-of-life care co-ordinators, and at the quarterly meeting of the Hospice Friendly Hospitals Networks meetings, who are key influencers in the provision of NSPC in hospitals in Ireland
- Distributing the findings to chronic illness associations and patient representative organisations in Ireland and internationally via oral presentation and email
- Dissemination of the findings through my social media accounts

9.4 Conclusion

Irish palliative care policy (National Clinical Programme for Palliative Care 2019) is consistent with international recommendations that palliative care can be delivered by all healthcare providers (NSPC), early in disease trajectories, for large groups of patient populations, in all care settings (Radbruch & Payne 2009, World Health Assembly 2014, Murray *et al.* 2015, Sawatzky *et al.* 2016b). However from an Irish context, statements regarding NSPC in current palliative care policy are somewhat aspirational with no clear direction as to how level 1 and 2 NSPC should be implemented or evaluated in hospitals either organisationally, or individually from a patient or clinician perspective (National Clinical Programme for Palliative Care 2019).

Findings from this study have uncovered how NSPC is currently understood in the healthcare literature. Responding to total pain remains a central concept of NSPC and one of the most important defining characteristics that distinguishes NSPC from other care provided to patients in hospital. However, healthcare providers in hospitals face many challenges in integrating NSPC within acute care delivery relating to organisational, cultural, and societal expectations of care. The development of 32 core CCPIs in this study represents multi-level guidance for clinical practice, policy and research related to NSPC provision in hospitals, based on evidence and international consensus from major stakeholder groups. These indicators provide a means to assess, review, and communicate the core elements of NSPC in hospitals, thereby setting a benchmark for changes in policy and practice.

Based on the findings of the current study, this chapter has provided recommendations for future palliative care policy, clinical practice, education and future research, which also includes a dissemination plan at national and international levels. These recommendations I believe may help to illuminate NSPC as a key element in the future planning, delivery and evaluation of palliative care policy and services in hospitals.

9.5 Personal reflection

The process of beginning and shaping this PhD thesis emanated from my professional experiences both as a clinician and educator, and my concerns that patients are not receiving adequate palliative care in hospitals. The PhD research itself has been enlightening in many ways and has had a profound effect on me as a researcher, clinician and educator.

On reflection throughout the research process, the use of multiple methods of enquiry while providing me with rich learning and a broad expertise in research methodologies was much more challenging than I had anticipated. In theory, based on literature regarding clinical indicator development, utilising the best available evidence on NSPC and gaining consensus from stakeholders on what is most important for the hospital care setting seemed relatively straightforward. However, in practice little direction was offered in the literature about how the 'best available evidence' should be extracted and converted to statements for consensus by a sample of stakeholders, and authors of published Delphi studies offered little information in this regard. This process (Chapter 6) took much longer than I had initially expected to ensure transparency and robustness of the initial indicators. This was a steep learning curve for my time management skills.

While I expected to develop my skills as a researcher during this PhD, it has also impacted on me as a clinician. I continued working shifts caring for people in their homes at end-of-life throughout this PhD. My knowledge of NSPC, and care in hospitals has provided a new depth of understanding of the illness experiences of the people I care for, and I would like to believe I am a more thoughtful and critically reflective practitioner as a result. Also, being in the privileged position of caring for, and hearing the anecdotal recollections of these patients and families experiences of care in hospital provided me with a continuous stream of renewed energy and incentive to finish this piece of work, particularly through difficult phases of this study, and life over the past few years. My experiences as a clinician, and more recent personal experiences of NSPC I believe have enabled me to be a well-rounded and empathetic researcher. However, I must also acknowledge that this passion and commitment could also be considered a source of bias. This is something that I have continuously and critically reflected on and discussed frequently with my supervisors throughout this PhD in order to reduce this risk.

Finally, the knowledge gained from this PhD has prompted me to question how I might disseminate these findings in my role as a clinical nurse tutor. I recognise that I have the opportunity to influence the design and content of palliative care lectures and clinical skills for undergraduate and postgraduate nurses. I will endeavour to channel my passion and commitment into advocating for the need to integrate palliative care principles throughout the curriculum at curriculum group meetings, and through my teaching.

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Appendices

Appendix 1 Reflective piece; my role as a night nurse

Publication: Irish Times Health Plus
Date: Tuesday, February 3, 2015
Page: 12
Extract: 1 of 2
Circulation: 84.201
Author: Arlene Harris
Headline: 'Talking to people who are dying, you can learn so much about living'

'Talking to people who are dying, you can learn so much about living'

A week in my…

night nursing role

In this series, Mary Nevin is a night nurse with the Irish Cancer Society. She is 35 and trained at Beaumont Hospital in Dublin and holds a master's degree in nursing education. As well as being a night nurse, she is a clinical nurse tutor at Trinity College Dublin

In conversation with **Arlene Harris**
Portrait by **Dara Mac Dónaill**

Respite for families

My role as a night nurse involves caring for terminally ill patients, providing comfort, managing their symptoms and offering some respite for families, generally at night, who take the brave decision to care for their loved ones in their own homes when death is near.

On a Tuesday I am called to see Áine, a patient who has had lung cancer for the past two years, caused by smoking, and her condition has deteriorated significantly in recent weeks.

She would prefer that her family remember only their best times together at home and so has made the decision to die in a hospice, and her hospice bed will be available on Thursday morning.

She is very weak so I reposition her gently in the bed and give her some medication for pain and nausea.

Her husband and children are exhausted and retreat into other bedrooms to get some much-needed rest. Caring for a loved one at home can be a big undertaking and many family members will take the opportunity to sleep when a night nurse is present.

Áine says she never sleeps much at night, so we talk and she reminisces a lot about her life. She is very accepting and prepared for her imminent death, and has made all her own funeral arrangements. She's very grateful that she got to see her children into their 20s, and takes a lot of comfort in knowing that she is leaving them with strong values about what is important in life.

It's obvious that her bravery is a huge source of strength to her family at this very difficult time.

I return to Áine the following night and am greeted at the door by her husband like an old friend. It's such a privilege to be allowed into a family's private space at such a difficult time.

The family gather in her bedroom for their final night together at home and they talk, laugh and cry long into the night. I tend to her wound dressings, bathe her and give her some medications so she will be comfortable transferring in the ambulance to the hospice.

In the morning, we embrace, I say my final goodbyes to her family and head home. In conversations with people who are dying, I think you can learn so much about living, and I know Áine will be someone I will think of often.

Flexibility

On Thursday I get a call to look after Alan, who has advanced liver cancer. The night-nursing service is generally provided between 11pm and 7am, but this can be flexible depending on the needs of the patient.

I phone Alan's wife at 9.30pm to introduce myself and get directions to the house; she is distressed and feels Alan's breathing is deteriorating, so I arrive before 10pm.

Alan's son greets me at the door and brings me up to Alan's bedroom. On examination, Alan has all the clinical signs that are present when death is very near. I encourage his wife to call the immediate family to the room. They all gather around the bed and I slip into the background.

Twenty minutes later, Alan takes his last breath surrounded by his wife and children, who embrace and cry together. I have seen many different reactions in people, in the immediate aftermath of a loved one's death.

We are all amateurs when it comes to grief, and all reactions are perfectly normal.

After a short time they leave me with Alan to carry out some final aspects of his care that need to be done before the body cools. I remove the tubes connected to him, and close his eyes and mouth. I reposition him on to his back, remove all clinical equipment from the room, dim the lights and light some candles.

Respecting families' religious and cultural wishes is integral in this care and I put some rosary beads and a prayer book in his hands at his wife's request.

The family return and I leave the room to telephone Alan's GP, the hospice and the palliative nursing team to inform them of his death.

I often tell my nursing students that you can't underestimate the therapeutic value of small things, and I bring a pot of tea up to the family.

I write up my notes, discuss the death certificate and undertaker arrangements with Alan's wife, offer my final condolences to the family and head home at 2am.

Football coaching

On Friday night I am not called out to work, and it gives me a chance to get a few more hours' rest. I played with the Dublin Senior Ladies Gaelic football team for 14 years and always found the exercise a great source of relief and distraction from the stresses of work.

I retired a couple of years back and now spend three times a week coaching the minor girls' football team in my local club, Na Fianna.

There's nothing like the infectious energy of 30 teenagers to take your mind off a difficult night's work.

I spend Saturday and Sunday nights with Ellen, who has very advanced cervical cancer. Ellen's adult son and daughter have taken time off work and are caring for her at home. They go to bed when I arrive.

Ellen is unconscious at this stage and appears agitated, so after examining her I put a tube in her bladder. This relieves some pressure and she settles again. I spend the two nights sitting at her bedside, observing closely for signs of deterioration, giving medications when necessary, and keeping her comfortable.

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Ellen's daughter is concerned about what to say to her children about their granny at this time.

Communicating with children about the anticipated death of a loved one can be very challenging, and children's understanding of illness and death also varies at different ages.

I encourage her to talk to her children about what is happening, and give simple, truthful, age-appropriate information. I direct her towards information and resources available from the Irish Cancer Society to help her explain this to her children.

When Ellen's children get up , I let them know how her night was before I go home.

A recent report published by the Irish Hospice Foundation entitled *Irish Attitudes to Death, Dying and Bereavement* found that nearly three-quarters of Irish people would wish to be cared for at home when they are dying but that only about a quarter get to actually do so.

I am often asked what I enjoy about my role as a night nurse, and really I believe that, although the end stage of a terminal illness is a very difficult time for patients and loved ones, with the right support this can be a very comfortable and peaceful journey in their own home. I feel very honoured to be part of this journey.

The Irish Cancer Society's night nursing service is available free of charge. To find out more about it, call the society's helpline on freefone 1800 200 700, or see cancer.ie

> **I have seen many different reactions in people, in the immediate aftermath of a loved one's death. We are all amateurs when it comes to grief, and all reactions are perfectly normal**

Appendix 2 Phase I Electronic DATABASES Results

CINAHL			
No.	Searches	Search type	Citations
1	Generalist palliative care	Keyword	44
2	General palliative care	Keyword	182
3	Non specialist palliative care	Keyword	15
4	Non-specialist palliative care	Keyword	5
5	Basic palliative care	Keyword	68
6	Palliative care approach	Keyword	510
7	Palliative approach	Keyword	610
8	Primary palliative care	Keyword	196
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-	1112
10	Pall*	ti, ab	20450
11	Palliative	ti, ab	18284
12	Palliative care	ti, ab	15273
13	Palliative treatment	ti, ab	1019
14	Palliation	ti, ab	1190
15	Palliating	ti, ab	68
16	Palliate	ti, ab	158
17	palliatively	ti, ab	21
18	palliat	ti, ab	216
19	hospice care	ti, ab	4211
20	end of life	ti, ab	12088
21	end of life care	ti, ab	6934
22	terminal care	ti, ab	839
23	terminally ill	ti, ab	2506
24	Compassionate care	ti, ab	700
25	Comfort care	ti, ab	897
26	Supportive care	ti, ab	3114
27	Hospice and Palliative nursing	MH	3710
28	Palliative care	MH	21138
29	Terminal care+	MH EXP	40838

30	Terminally ill patients+	MH EXP	8326
31	Attitude to death+	MH EXP	8043
32	10-31 combined with OR	-	63846
33	9 AND 32	-	1112(ENG 1085)

PUBMED

No.	Searches	Search type	Citations
1	Generalist palliative care	Keyword	708
2	General palliative care	Keyword	5962
3	Non specialist palliative care	Keyword	713
4	Non-specialist palliative care	Keyword	28
5	Basic palliative care	ti,ab	30
6	Palliative care approach	ti,ab	154
7	Palliative approach	ti,ab	354
8	Primary palliative care	ti,ab	81
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-	7039
10	Pall*	ti, ab	99198
11	Palliative	ti, ab	49223
12	Palliative care	ti, ab	20333
13	Palliative treatment	ti, ab	5791
14	Palliation	ti, ab	12198
15	Palliating	ti, ab	382
16	Palliate	ti, ab	1047
17	palliatively	ti, ab	489
18	palliat	ti, ab	7
19	hospice care	ti, ab	2468
21	end of life care	ti, ab	7222
22	terminal care	ti, ab	1751
24	Compassionate care	ti, ab	614
25	Comfort care	ti, ab	459
26	Supportive care	ti, ab	11601
27	Hospice and Palliative care nursing	MeSH maj topic	260
28	Palliative care	MeSH maj topic	25028

30	Terminally ill	MeSH maj topic	3319
31	Attitude to death	MeSH maj topic	8271
32	10-31 combined with OR	-	130611
33	9 AND 32	-	5792 (5098 ENG)

PsycINFO

No.	Searches	Search type	Citations
1	Generalist palliative care	Keyword	28
2	General palliative care	Keyword	319
3	Non specialist palliative care	Keyword	8
4	Non-specialist palliative care	Keyword	3
5	Basic palliative care	Keyword	54
6	Palliative care approach	Keyword	397
7	Palliative approach	Keyword	457
8	Primary palliative care	Keyword	149
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-	993
10	Pall*	ti, ab	13875
11	Palliative	ti, ab	8980
12	Palliative care	ti, ab	7528
13	Palliative treatment	ti, ab	599
14	Palliation	ti, ab	308
15	Palliating	ti, ab	18
16	Palliate	ti, ab	91
17	palliatively	ti, ab	10
18	palliat	ti, ab	4
19	hospice care	ti, ab	2224
20	end of life	ti, ab	9968
21	end of life care	ti, ab	4222
22	terminal care	ti, ab	568
23	terminally ill	ti, ab	2295
24	Compassionate care	ti, ab	452
25	Comfort care	ti, ab	525
26	Supportive care	ti, ab	1684

27	Hospice and Palliative nursing	Ma MeSH	29
28	Palliative care	Ma MeSH	5243
29	Terminal care	Ma MeSH	3689
30	Terminally ill patients	MH EXP	N/A
31	Attitude to death	MH EXP	3936
32	10-31 combined with OR	-	29479
33	9 AND 32	-	901(ENG 872)

Exerpta Medica Database (EMBASE)

No.	Searches	Search type	Citations
1	‘Generalist palliative care’	All fields	45
2	‘General palliative care’	All fields	42
3	‘Non specialist palliative care’	All fields	7
4	‘Non-specialist palliative care’	All fields	7
5	‘Basic palliative care’	All fields	46
6	‘Palliative care approach’	All fields	218
7	‘Palliative approach’	All fields	523
8	‘Primary palliative care’	All fields	242
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-	1084
10	Pall*	ti, ab	139181
11	Palliative	ti, ab	70778
12	Palliative care	ti, ab	34394
13	Palliative treatment	ti, ab	34101
14	Palliation	ti, ab	16546
15	Palliating	ti, ab	545
16	Palliate	ti, ab	1450
17	palliatively	ti, ab	678
18	palliat	ti, ab	20
19	‘hospice care’	ti, ab	9744
20	‘end of life’	ti, ab	69377
21	‘end of life care’	ti, ab	23444
22	‘terminal care’	ti, ab	9001
23	‘terminally ill’	ti, ab	5636

24	‘Compassionate care’	ti, ab	1825
25	‘Comfort care’	ti, ab	8924
26	‘Supportive care’	ti, ab	30276
27	‘Attitude to death’	ti, ab	1758
28	10-27 combined with OR	-	176737
29	9 AND 28	-	1042

Cochrane Database of Systematic Reviews (CDSR)

No.	Searches	Search type	Citations
1	‘Generalist palliative care’	All fields	0
2	‘General palliative care’	All fields	32
3	‘Non specialist palliative care’	All fields	1
4	‘Non-specialist palliative care’	All fields	0
5	‘Basic palliative care’	All fields	0
6	‘Palliative care approach’	All fields	1
7	‘Palliative approach’	All fields	2
8	‘Primary palliative care’	All fields	25
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-	57
11	Palliative	ti, ab	2383
12	Palliative care	ti, ab	1094
13	Palliative treatment	ti, ab	1312
14	Palliation	ti, ab	716
15	Palliating	ti, ab	118
16	Palliate	ti, ab	118
17	palliatively	ti, ab	19
18	palliat	ti, ab	1
19	hospice care	ti, ab	225
20	end of life	ti, ab	7704
21	end of life care	ti, ab	1568
22	terminal care	ti, ab	288
23	terminally ill	ti, ab	166

24	Compassionate care	ti, ab	41
25	Comfort care	ti, ab	673
26	Supportive care	ti, ab	1369
27	Palliative care	MeSH exp	1608
28	Hospice and Palliative care nursing	MeSH exp	5
29	Terminal Care	MeSH exp	433
30	Attitude to death	MeSH exp	137
28	10-27 combined with OR	-	13404
29	9 AND 28	-	**53**

Appendix 3 Phase I Grey DATABASES Results

World Health Organization International Repository for Information Sharing (IRIS) - general online access				
No.	Searches 29/3/17	Search type	Citations	Kept Full txt
1	General palliative care	Subject	0	
2	Non specialist palliative care	Subject	0	
3	Palliative care	Title contains PC, no limits applied	30 (7 non English)	**1 : WHO 2002 DOC** (others were duplicates/meeting /secretariat reports/opioids related)

Irish Health Repository (LENUS) www.lenus.ie **(TCD library access)**			
No.	Searches 6/3/17	Search type *(all of Lenus)*	Citations
1	"Generalist palliative care"	No Filters	34
2	"Non-specialist palliative care"	No Filters	27
3	"palliative approach"	No Filters	45
4	"basic palliative care"	No Filters	4
5	"primary palliative care"	No Filters	39
Total			149
Duplicates			43
FINAL			**106**
	Title/Abstract Exclusion		88
	Full Text Exclusion		13
	Included		5

Shaare Zedek Cancer Pain and Palliative Care Reference Database (http://www.chernydatabase.org/) (general online access, not through library)			
No.	Searches	Search type	Citations
1	Internal server error could not search		0
2	Tried again 24th March 2017, same error code		0

British Library EThOS				
No.	Searches	Citations	Viewed Full text	Included
1	Non specialist palliative care	13	1	0
2	Generalist palliative Care	6	1	0
3	Palliative care approach	86	4	1

Appendix 4 Phase I Websites Search Results

Chronic conditions Organisations - Clinical guidelines Search

Organisation	Website Address	Country/ Region	Date Accessed	Info retrieved re NSPC	Comment
British Thoracic Society	https://www.brit-thoracic.org.uk/	UK	21/01/17	No (But I have NICE doc)	COPD – don't think there's anything in BTS but they base their content on NICE and PC is mentioned in NICE doc Lung Ca – briefly mentioned i.e. pts should get SPC &NSPC PRN. Focus is on PC treatments O2 therapy—need to check if anything in it
European Respiratory Society	https://www.ersnet.org/	EU	5/4/17	NO – Access denied	Links to 10 journals they publish but need to be a member to access. Checked guidelines section, need to be member to view content
European Society of Cardiology	https://www.escardio.org/	EU	5/4/17	YES – 2docs	Got ESC '16 clinical guidelines for HF includes PC content PLUS Position statement on PC from ESC from 2009 (from refs in '16 doc)
American Heart Association	http://www.heart.org	USA	5/4/17	YES	2016 Policy statement re PC and HF/Stroke
National Comprehensive Cancer Network	https://www.nccn.org/	USA but guidelines are International	5/4/17	YES	2017 Doc specifically related to cancer and PC
European Cancer Organisation	http://www.ecco-org.eu/	EU	5/4/17	NO	Nothing found in position statements or publications
NICE	https://www.nice.org.uk/	UK	8/4/17	YES 2-docs	Improving Supportive and PC for Patients with Cancer. The Manual 2005 Lung Cancer doc 2011
International Society of Nurses in Cancer Care	http://www.isncc.org/	International	25/5/17	YES	Position Statement- Models of Palliative Care (Membership needed- got access to doc from colleague)

International Palliative Care Policy Searches

Country	Source	Website Address(s)	Date Accessed	Policy/Strategy Info retrieved	Info re NSPC
Ireland	Dept. of Health	http://www.hse.ie/palliativecareprogramme	3/12/16	PC toolkit 2014 Glossary 2014 Role Delineation 2105	NSPC well integrated into PC documents sourced
UK	Dept. of Health National Institute of Clinical Excellence (NICE)	https://www.gov.uk/government/organisations/department-of-health www.endoflifecareambitions.org.u	28/10/16 3/12/16	EOLC Strategy 2008 Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020	NSPC well integrated into PC documents sourced Email sent to policy@ncpc.org.uk for further clarification of terms but no response
England	DOH and NICE (see search above)	https://www.gov.uk/government/organisations/department-of-health	4/12/16	NHS England Specialist Palliative Care doc 2016	NSPC well integrated into PC documents sourced
Scotland	Scottish Partnership for Palliative Care/NHS Education for Scotland	www.palliativecarescotland.org.uk	4/12/16	Guide to Palliative Care Competency Frameworks 2007	NSPC well integrated into PC documents sourced
Northern Ireland	Dept. of Health	https://www.health-ni.gov.uk/	3/12/16	Palliative Care and EOLC Strategy 2010 PC and EOLC Competency Toolkit 2011	NSPC well integrated into PC documents sourced

Australia	Dept. of Health	http://palliativecare.org.au	28/10/16	2005 Palliative care standards 2010 National Palliative Care Strategy	NSPC well integrated into PC documents sourced
New Zealand	Ministry of Health	http://www.health.govt.nz/	2/11/16	Glossary of Terms 2015 Palliative Care Strategy 2001	(*I emailed author of the terms doc to find out why General PC term replaced by Primary PC. I got a reply from Emma Hindson, Principal Advisor Cancer Services in the Ministry of Health who said that she did not know how they arrived at this decision*)
USA	National Palliative Care Research Centre USA Congress	http://www.npcrc.org/ (Peter May's suggestion) https://www.congress.gov/	28/10/16 1/11/16	None None	Congress BILL H.R.3119 — 114th Congress (2015-2016)…. TEXT alert set up for updates https://www.congress.gov/ nevinm, usual password Introduced in House (07/21/2015)
Canada	Dept. of Health Canadian Hospice and PC Association – Funded by the Government of Canada	https://www.canada.ca/en/health-canada.html http://www.hpcintegration.ca/resources/the-national-framework.aspx	1/11/16 1/11/16	Canadian Strategy on Palliative and EOLC 2007 The Way Forward National Framework- A Roadmap for and integrated Palliative Approach to Care 2015	NSPC well integrated into PC documents sourced
Africa	African Palliative Care Organisation	info@africanpalliativecare.org	2/11/16	Status of palliative care in ten Southern African countries: A	A paper that summarises PC policy in ten South African Countries

				briefing paper (Powell and Namisango 2016)	*(I also communicated with Eve Namisango through email for further clarification of NSPC terms and she replied that she had no further information re NSPC terms)*
India	Pallium India	http://palliumindia.org/resources/policies/#National_Policies_on_Palliative_Care	7/11/16	No National Policy exists	There is a national programme for palliative care created in 2012; but it didn't define any NSPC terms *(Also verified through email with Pallium India Chairman Dr. M.R.Rajagopal who replied and confirmed this)*
Latin America	The Latin American Association of Palliative Care	http://www.cuidadospaliativos.org/	2/11/16	Found PC policy summary doc 2012 Also found PC Indicators doc from 2013	Pastrana et al (2012). Atlas of Palliative Care in Latin America *(I emailed first author for further information but no reply)*

Palliative Care Organisations Search

Organisation	Website Address	Country/ Region	Date Accessed	Info retrieved re NSPC	Comment
Marie Curie Palliative Care Institute **and** Marie Curie Organisation	http://www.mcpcil.org.uk/ https://www.mariecurie.org.uk/	UK	20/3/17	No- but got article relevant to background chapter re need for PC service improvement	Got docs around PC population needs but nothing specific re NSPC Had condition specific short guides for EOLC
National Council for Palliative Care	http://www.ncpc.org.uk/	UK	2/11/16	None	Followed the link to Ambitions for Palliative and End of life Care: A National Framework for Local Action 2015 – 2020, Language v. EOLC orientated and non-specific to NSPC
Canadian Hospice PC Association (CHPCA)	http://www.chpca.net/	Canada	20/3/17	None	Info relates to Hospice setting, nothing re NSPC delivery addressed. Need to register

					and become a member to access many resources
American Academy of Hospice and Palliative Medicine (AAHPM)	http://aahpm.org/	USA	20/3/17	None	Checked position statement and strategic plan. No publications on website
Center to Advance Palliative Care (CAPC)	https://www.capc.org/	USA	20/3/17	None	Very much SPC orientated, defines PC as care from a specialist PC discipline
Hospice and Palliative Care Nurses Association (HPNA)	http://hpna.advancingexpertcare.org/	USA	20/3/17	None	Need to be registered to view information
National Hospice and Palliative Care Organisation (NHPCO)	http://www.nhpco.org/	USA	20/3/17	None	Many publication resources for members only
National Coalition for Hospice and Palliative Care (A Coalition group of 9 largest PC organisations in the USA)	http://www.nationalcoalitionhpc.org	USA	3/5/17	Yes- Clinical Practice Guidelines for Quality Palliative Care 2013	The document sourced is the output from a National Consensus Project for Quality Palliative Care in the USA
International Association for Hospice and Palliative Care (IAHPC)	https://hospicecare.com	International	26/4/17	Yes..eDelphi generated list of essential practices in palliative care for health workers working in primary care SEE Art. 23 CA	The list includes those practices aimed at meeting the most prevalent physical, social, psychological and spiritual needs of palliative care patients and their families. *(Already included from primary database search De Lima et al '12)*
All Ireland Institute for Hospice and Palliative Care (AIIHPC)	http://aiihpc.org/	Ireland	22/3/17	No - but got PC research priorities doc '15	Checked specific initiatives and ongoing programmes of work-
Irish Hospice Foundation (IHF)	http://hospicefoundation.ie/	Ireland	24/3/17	Yes – A Strategic importance doc, and PC for all doc. Got some other generic PC docs useful for other chapters	Many publications very EOLC orientated, website logo reflects this… *'striving for the best care at end of life for all'*
European Association for Palliative Care (EAPC)	http://www.eapcnet.eu/	Europe	22/3/17	Yes- Consensus norms for ID and White paper on measurement in PC. Got some re challenges	Checked research, policy, publication, recommendation sections. Over 200 titles read. Many cancer/pain/depression related articles. Some articles re PC in

				of PC lit searching and PC quality indicators	chronic conditions apparent but NO titles refer to NSPC or related terms
Palliative Care Nurses Australia	http://www.pcna.org.au	Australia	22/3/17	None	A resource for SPC Nurses, defines competency standards for SPCN, nothing re NSPC
The Australian & New Zealand Society of Palliative Medicine	http://www.anzspm.org.au	Aus/NZ	22/3/17	None	A resource for SPC Medics, Has publications re defining SPC roles, nothing re NSPC
Indian Association of Palliative Care	http://palliativecare.in	India	22/3/17	None	Focus is very much EOLC. Resources links are not available
Canadian Virtual Hospice	http://www.virtualhospice.ca	Canada	10/3/17	Yes – Joint position statement	Position statement of Canadian Nurses Association (CNA), Canadian Hospice Palliative Care Association (CHPCA), and Canadian Hospice Palliative Care Nurses Group (CHPC-NG)
Worldwide Palliative Care Alliance	http://www.thewhpca.org/	International	10/4/17	Yes – Global Atlas of Palliative Care at the end of life 2014	*'With 238 organisational members in over 86 countries, we provide a global voice on hospice and palliative care'*
African Palliative Care Association	https://www.africanpalliativecare.org/	Africa	22/3/17	A Framework of Core Competencies for PC Providers in Africa 2012	Checked specific initiatives and ongoing programmes of work-

Appendix 5 Example of data extracted into Data Extraction Tool

Retrieval details						**NSPC Keyword provided in Title, Abstract or as Keywords**					
Reference	***Primary/ Ancestry Retrieval***	***Type (i.e. Primary Study, Discussion, Editorial)***	***Discipline***	***Speciality/ Setting***	***Country of Origin Study/First Author***	***Non specialist***	***Generalist/ General***	***Primary***	***Palliative Approach***	***Basic***	***Other term***
Johnston *et al* (2015) *Identifying Persons with Diabetes Who Could Benefit from a Palliative Approach to Care.*	Primary	Primary	Not stated	Diabetes Mellitus	Canada	No	No	No	Title & Abstract	No	No

	Epistemological Principle			**Pragmatic Principle**		**Linguistic Principle**		
Reference	***Is the concept clearly defined?***	***Is it well differentiated from other concepts?***	***Other concepts mentioned (not necessarily defined)***	***Is it useful for clinical practice?***	***Is it useful for research?***	***Is the language around the concept used consistently and appropriately within the context?***	***Quantitative measures***	***Qualitative measures***
Johnston *et al* (2015)	Yes, as per WHO 2002 definition of palliative care	Authors link it to QOL	QOL	Partly	Yes	Term ‘palliative approach’ consistently used	Large DM dataset	No

	Logical Principle								
Reference	***Concept hold its boundaries?***	***Theoretically integrated with other concepts?***	***Appropriately operationalized?***	***Key characteristics identified?***	***Key characteristics consistent?***	***What are the antecedents to the concept?***	***What are the outcomes?***	***Theoretically rich? Rating***	***Summary***
Johnston *et al* (2015)	Partly	Yes QOL, argues that PA is applicable within one year of death	No	No	N/A	Those with DM-, and with 1 year of life remaining	Pts & families more prepared for changes in diabetes management that will be beneficial	B	Diabetes associated with increased morbidity and premature mortality and many Pts ID from dataset used in this study could benefit from PA. Only vaguely talks about aspects of PA suitable for this pt cohort. V-imp that All HCP use PA for this pt group - reluctant to refer to SPC

Appendix 6 Phase II Enhancing Transparency in Reporting the synthesis of Qualitative Research (ENTREQ) guidelines

No	Item	Guide and description	Page No.
1	Aim	State the research question the synthesis addresses.	73
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology	35, 36, 37
3	Approach to searching	Indicate whether the search was pre-planned or iterative	74, 75
4	Inclusion criteria	Specify the inclusion/exclusion criteria	74
5	Data sources	Describe the information sources used and when the searches conducted; provide the rationale for using the data sources.	74, 75
6	Electronic Search strategy	Describe the literature search	74, 75
7	Study screening methods	Describe the process of study screening and sifting	74, 75, 76
8	Study characteristics	Present the characteristics of the included studies	80, 81 & Table 11 p82
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion	79 & Figure 9 p80
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings	76,77, 78
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings	77, 78
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	77
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	87, 88, Table 12 & Sensitivity analysis Table 14 p104
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies?	77, 78
15	Software	State the computer software used, if any.	77
16	Number of reviewers	Identify who was involved in coding and analysis.	78
17	Coding	Describe the process for coding of data	78
18	Study comparison	Describe how were comparisons made within and across studies	78
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	78 & Audit trail Appendix 8
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author’s interpretation.	92-103
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies	92-105 & Appendix 10

Appendix 7 CINAHL search strategy, adapted across other databases

CINAHL March 2018		
No.	**Searches**	**Search type**
1	Generalist palliative care	Keyword
2	General palliative care	Keyword
3	Non specialist palliative care	Keyword
4	Non-specialist palliative care	Keyword
5	Basic palliative care	Keyword
6	Palliative care approach	Keyword
7	Palliative approach	Keyword
8	Primary palliative care	Keyword
9	1 OR 2 OR 3 0R 4 OR 5 OR 6 OR 7 OR 8	-
10	Pall*	ti, ab
11	Palliative	ti, ab
12	Palliative care	ti, ab
13	Palliative treatment	ti, ab
14	Palliation	ti, ab
15	Palliating	ti, ab
16	Palliate	ti, ab
17	palliatively	ti, ab
18	palliat	ti, ab
19	hospice care	ti, ab
20	end of life	ti, ab
21	end of life care	ti, ab
22	terminal care	ti, ab
23	terminally ill	ti, ab
24	Compassionate care	ti, ab
25	Comfort care	ti, ab
26	Supportive care	ti, ab
27	Hospice and Palliative nursing	MH
28	Palliative care	MH
29	Terminal care+	MH EXP
30	Terminally ill patients+	MH EXP
31	Attitude to death+	MH EXP
32	10-31 combined with OR	-
33	9 AND 32	-

Appendix 8 Phase II Audit trail - Relationship between themes

Analytical Themes	Descriptive Themes	Codes
Understanding of palliative care	-Knowledge of palliative care -Who needs palliative care and when is it given -Importance of support -Training needs	-Experience of advance care planning -Definitions of palliative care -Handling existential or spiritual issues -Who's job is palliative care -Pain and symptom management -Experience of healthcare provider a factor -Acute care versus palliative care -Cancer versus non-cancer patients -Palliative care is end of life care -Non-specialist palliative care view of specialist palliative care role -Relationship with specialist palliative care -Healthcare providers deskilled due to specialist palliative care -Specialist palliative care view of non-specialist palliative care role -Symptom management and communication training -Educational role of specialist palliative care -Limitations of specialist palliative care service
Nurses and Doctors – a different lens	-Finding the caring balance -Non-specialist providers views of each other -Impact of non-specialist palliative care on practitioners	Maintaining a professional distance from patient Building relationships/getting emotionally involved with patients Death is failure Nurse view of Doctor role Doctor view of Nurse role Transition to palliative care, who decides? Recognition of palliative approach Outcomes of good palliative care Positive views about non-specialist palliative care Negative views about non-specialist palliative care Self-care Peer to peer support
The complexities of communication	-Patient/family communication -Communication between healthcare providers	Fears of communicating bad news Patients or carers don't want to know the truth Pressure from patient to continue treatments Timing of difficult conversations Patient and family issues hinders communication Patient cultural influences on end of life practices Team involvement in decision-making
The hospital ecosystem	-Infrastructural issues -Hospital culture -Systems of care	Lack of private spaces to communicate Lack of private bedrooms Language of Hospital setting Guidelines and protocols for palliative care Organisation of acute care and its impact Continuity of care Insufficient time to give non-specialist palliative care Insufficient staff to give non-specialist palliative care

Appendix 9 Preliminary indicators extracted from phase I (Concept Analysis)

Domain	Concept Analysis Major Findings	Relevance to inform initial indicators of NSPC in hospitals
Epistemological	-NSPC is broadly defined using a variety of terminology such as generalist or primary palliative care. -Some definitions of NSPC make the distinction between levels of NSPC provision	-There needs to be institutional clarity of definition in accordance with national policy documents and best practice guidelines (where applicable) to be adequately implemented in practice. -Where applicable (i.e. reference to national policy) specific levels of NSPC provision, what is expected within these levels, and at what level care providers practice should be clearly articulated
	-NSPC is clearly defined as care delivered by those who are NOT specialists in palliative care	-Everyone caring for patients with chronic serious illness has a role in NSPC provision. This should be clearly articulated institutionally so that all levels of care provision are aware
Pragmatic	-Core attributes of NSPC were identified and include; -Pain and symptom management -Communication -patient and family information about illness trajectory and prognosis -Advance care planning -Psychosocial and spiritual support -End of life care	-Hospital policies and guidelines on NSPC should reflect each of these 6 core attributes
	-These essential components of NSPC are of most clinical utility when adapted for specific patient groups or illnesses	-These core attributes should be adapted and incorporated into disease management frameworks to reflect the various disease trajectories and palliative care needs of different patient groups
	- NSPC is a challenging concept to evaluate. Measurement tools to date have used a variety of outcome measures with an emphasis on physical aspects of symptom management	-Standards of care, and methods to evaluate care in hospital should include NSPC and its core attributes
	-The patients' perspective is not apparent in NSPC evaluation tools	-Patients' feedback should be included as an important component of NSPC evaluation in hospital

Logical	-The concepts of holism, quality of life and patient-centred care are inextricably linked to NSPC but poorly defined -NSPC is operationalised as end of life care in hospitals	-There should be organisational clarity regarding the operationalisation of holism, quality of life and patient-centred care within NSPC in hospitals -All levels of the hospital need to articulate that NSPC is appropriate early in disease trajectories and is not relevant solely in the last few weeks or days. Policies, guidelines and staff training need to emphasis aspects of early integration of NSPC
Linguistic	-There is blurring of boundaries between NSPC and specialist palliative care with issues such as lack of role clarity and frustration between health care providers -While NSPC is suitable and beneficial for a wide variety of chronic conditions, challenges exist in the application of NSPC across chronic illnesses	-Clarity of roles and responsibilities of healthcare providers are needed in palliative care provision -NSPC should be clearly embedded in chronic illness clinical guidelines
Preconditions	Patients with palliative care needs are increasing due to; -Ageing populations, increases in chronic illness, NSPC relevant earlier in many diseases, SPC services do not have capacity to meet future demand, NSPC is increasingly becoming more prominent in policy	-Hospitals need to be adequately funded and resourced to respond to the growing palliative care needs of their service users -All healthcare providers caring for patients with chronic serious illnesses should have the necessary education, training and support within these core components to identify, assess, and manage their patients palliative care needs
Outcomes	-Outcomes associated with NSPC interventions have been identified as improved pain and symptom control and improved quality of life. -Definitions and levels vary widely in NSPC and there is no consistency in how it is measured, which limits our ability to understand outcomes in clinical practice.	-Clear Institutional definition, and clinical guidelines should emphasise a commitment to providing NSPC across all levels of the organisation -Healthcare providers need to be aware of the requirement to embed NSPC in their practice and should the necessary training and support to do this -Methods to evaluate the impact of NSPC need to be in place, and must reflect the patient and family's perspective

Appendix 10 Preliminary indicators extracted from phase II (Systematic review)

Theme	Systematic Review Major Findings	Relevance to inform initial indicators of NSPC in hospitals
Understanding of NSPC	***Knowledge and Competency*** - Healthcare providers are unsure how NSPC is defined but do recognise central aspects such as symptom control, psychological care and spiritual care - Healthcare providers recognise that they do have a role in palliative care provision -They feel poorly equipped to deliver NSPC in hospitals and want training and support, particularly inexperienced practitioners -They view specialist palliative care as central to supporting NSPC ***Recognition of Palliative Care Needs*** -Some recognition that patients other than cancer have palliative care needs too -NSPC providers very much associate their role with end of life care, in the last days and hours	-There needs to be institutional clarity of definition in accordance with national policy documents and best practice guidelines (where applicable) to be adequately implemented in practice. -NSPC providers need to be adequately trained and supported at all hospital levels to provide care -Specialist palliative care services are central to supporting and providing ongoing training to NSPC providers -Everyone caring for patients with chronic serious illness has a role in NSPC provision. This should be clearly articulated institutionally so that all levels of care provision are aware -Care practices and clinical guidelines must emphasise the need for early NSPC in conjunction with acute care interventions
The Complexities of Communication	Having conversations around prognosis and goals of care was considered challenging, issues such as; -Lack of confidence and expertise in dealing with difficult conversations -Uncertain prognosis -Patient, family, ethical and cultural issues can be barriers to effective communication	- All healthcare providers caring for patients/families with chronic serious illnesses should have the necessary communication skills training and support to effectively communicate care - Guidelines relating to NSPC should be clear and adapted for various chronic conditions to support uncertain disease trajectories and future care planning
The Hospital Ecosystem	***The Physical Structure of the Hospital*** -Lack of private bedrooms, private spaces considered a barrier to effective NSPC	-Hospitals should be financed and resourced to support the necessary infrastructure to deliver NSPC

	Culture and Organisation of Care -Acute care interventions prioritised -Not enough time to deliver NSPC -Lack of multidisciplinary team meetings -Care is fragmented in the ACHS -Lack continuity within the hospital and between the hospital and community -Delays in clinical decisions	-Organisational and care practices are structured in a way that recognises and supports the NSPC delivery in combination with acute care interventions -Mechanisms are in place to facilitate shared decision making and to ensure goals of care are effectively communicated between healthcare providers
Nurses and Doctors- A Different Lens	-Nurses described great satisfaction in giving NSPC -For nurses, challenges included lack of time to spend with patients, poor communication structures with doctors which led to delayed decisions and palliative care interventions happening late, which had a significant negative impact on them -Doctors described the importance of maintaining emotional distance from patients -Doctors reported challenges in identifying palliative care needs of deteriorating patients early -Doctors did not report negatively dwelling on aspects of NSPC	- Mechanisms are in place in clinical departments to facilitate multidisciplinary working practices and shared learning between healthcare providers -Mechanisms to provide emotional support to NSPC providers are in place which may include formal or informal peer support

Appendix 11 Advisory group feedback and actions

Advisory Group Member	Summary of Major Feedback	Actions
Person with a chronic illness	*"I don't understand some of the terms you're using"* *"I think these are relatively straightforward and easy to understand"*	All text reviewed for plain English and further information provided to explain some medical terminology highlighted by this advisory group member i.e. 'infrastructural', (see structural indicator no.5 Table 6.1) 'trajectory' & 'prognosis' (see organisation indicator no. 9 Table 6.1)
NSPC hospitalist clinician	*"I think the indicators reflect the categories they've been placed in"* *"I'm a little unsure of what you mean regarding peer support and psychosocial support as this could have multiple interpretations"*	Relevant indicators were reworded for clarity of meaning. Examples of formal and informal peer support added (see staff indicators 10 & 11, Table 6.1), and an explanation of psychosocial support was added (see organisational indicator 10, Table 6.1)
NSPC academic/researcher	*"I think you could separate the peer support indicator into two parts because they are describing different aspects"* *"I like the use of the term healthcare 'providers' and not 'practitioners', I think this is more inclusive"* *"the term 'existential' is more accurate than 'spiritual'*	This indicator were separated into two separate statements for clarity. Initially one indicator collectively related to both formal and informal peer support. This was changed to two separate indicators (see staff indicators 10 & 11, Table 6.1) The term existential was inserted alongside spiritual with an explanation of what it means (see organisational indicator 11 in Table 6.1)
Hospital End of Life Co-ordinator	*"I think all of these indicators are relevant in hospitals"* *"I understand that you want to prioritise this list, perhaps the word 'essential' is better than 'core' for patients to understand"* *"I like how the indicators have been separated into sections, these make sense in hospitals"*	The term 'essential' was used in the survey instrument for the Delphi consensus process

Advisory Group Member	Summary of Major Feedback	Actions
Hospital audit medical director	*“The three sections you put the indicators in adequately represent the levels within a hospital and the wording is generic across countries I believe”* *“People who work in quality departments in hospitals may rate these indicators only on what they think is measurable, make sure to signpost in your survey that you want them rated only according to importance”*	I inserted a signpost (in red text) into the Delphi survey to remind participants to rate according only to how important they felt each indicator was (see round 1 survey appendix 16)

Appendix 12 Conducting and REporting of DElphi Studies (CREDES)

	Rationale for the choice of the Delphi technique	
1	Justification	Chapter 3 p30, 31, 37-41
	Planning and design	
2	Planning and process	Methods utilised & rationale described section 7.1-7.7
3	Definition of consensus	P113 definition and rationale
	Study conduct	
4	Informational input	Preparation -Chapter 6, Piloting p122 Academic supervision throughout the study
5	Prevention of bias	Re. preparation -Chapter 6, re. conduct - Ethics section 7.6 p123-125
6	Interpretation and processing of results	Findings R1,2,3 described Section 7.7
7	External validation	Chapter 9, Recommendations
	Reporting	
8	Purpose and rationale	Chapter 3 & Sections 7.1-7.7
9	Expert panel	Selection and rationale p112, 113, 114
10	Description of the methods	Sections 7.1-7.4 & Figure 11 p112
11	Procedure	Sections 7.2-7.4 p112-123 & Appendices 17-19
12	Definition and attainment of consensus	Definition and rationale Section 7.4.2 p117-118
13	Results	Section 7.7 p126-139 & Table 28 p141, & Appendices 21, 23, 24, 25
14	Discussion of limitations	Chapter 3 p & Chapter 8 P154-155
15	Adequacy of conclusions	Discussion Chapter 8, and Chapter 9 Conclusions and recommendations
16	Publication and dissemination	Results previously disseminated page v, future dissemination plan page 162

Appendix 13 Phase III email invitation

Invitation to take part in an online Delphi Survey

Development of a core set of clinical care provision indicators for non-specialist palliative care in hospitals

My name is Mary Nevin and I am a researcher (PhD candidate) in the School of Nursing and Midwifery, Trinity College Dublin, Ireland. I am conducting an online Delphi survey which seeks to identify essential indicators in managing the palliative care needs of patients with chronic or serious illnesses, by those who do not work within specialist palliative care teams, in the hospital setting. This type of care is referred to as non-specialist palliative care. To identify what these essential indicators are I am seeking the views of the following groups of people:

- Both specialist palliative care and non-specialist palliative care healthcare workers who care for patients with chronic or serious illnesses in hospitals
- Adults (>18) or carers/family members of adults with a chronic or serious illness who have received or are currently receiving care in hospital
- Representatives or members of advocacy groups for adults with a chronic or serious illness
- Hospital management/administration
- Researchers with experience of publishing and/or policy development in palliative care

If you are a member of one of these groups, and think you would like to take part in this study please click on the link below; this will take you to further information about the study, and the round 1 instrument.

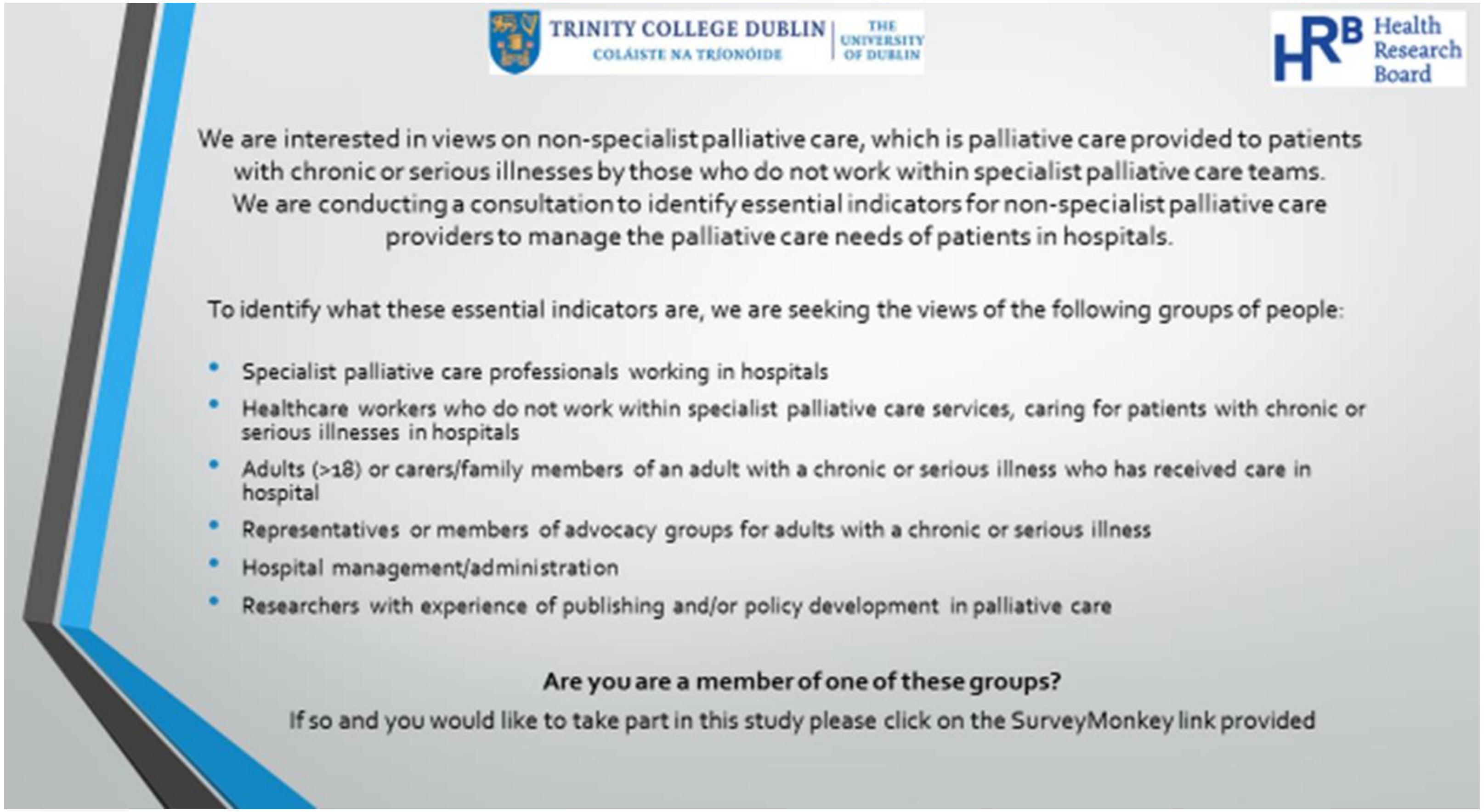
https://www.surveymonkey.com/r/MXZ6W92

If you know of others who also may have the necessary expertise to take part in this study, please feel free to forward this message to them. The survey will be available to complete until Thursday 14th February 2019.
Yours sincerely,

Mary Nevin
HRB Research Fellow/Ph.D. Candidate
School of Nursing & Midwifery
Trinity College Dublin, the University of Dublin
24 D'Olier Street,
Dublin 2, Ireland.

+353 1 896 4732
Email nevinm@tcd.ie
www.nursing-midwifery.tcd.ie/

Appendix 14 Picture embedded into Tweet for Delphi round 1 recruitment



We are interested in views on non-specialist palliative care, which is palliative care provided to patients with chronic or serious illnesses by those who do not work within specialist palliative care teams. We are conducting a consultation to identify essential indicators for non-specialist palliative care providers to manage the palliative care needs of patients in hospitals.

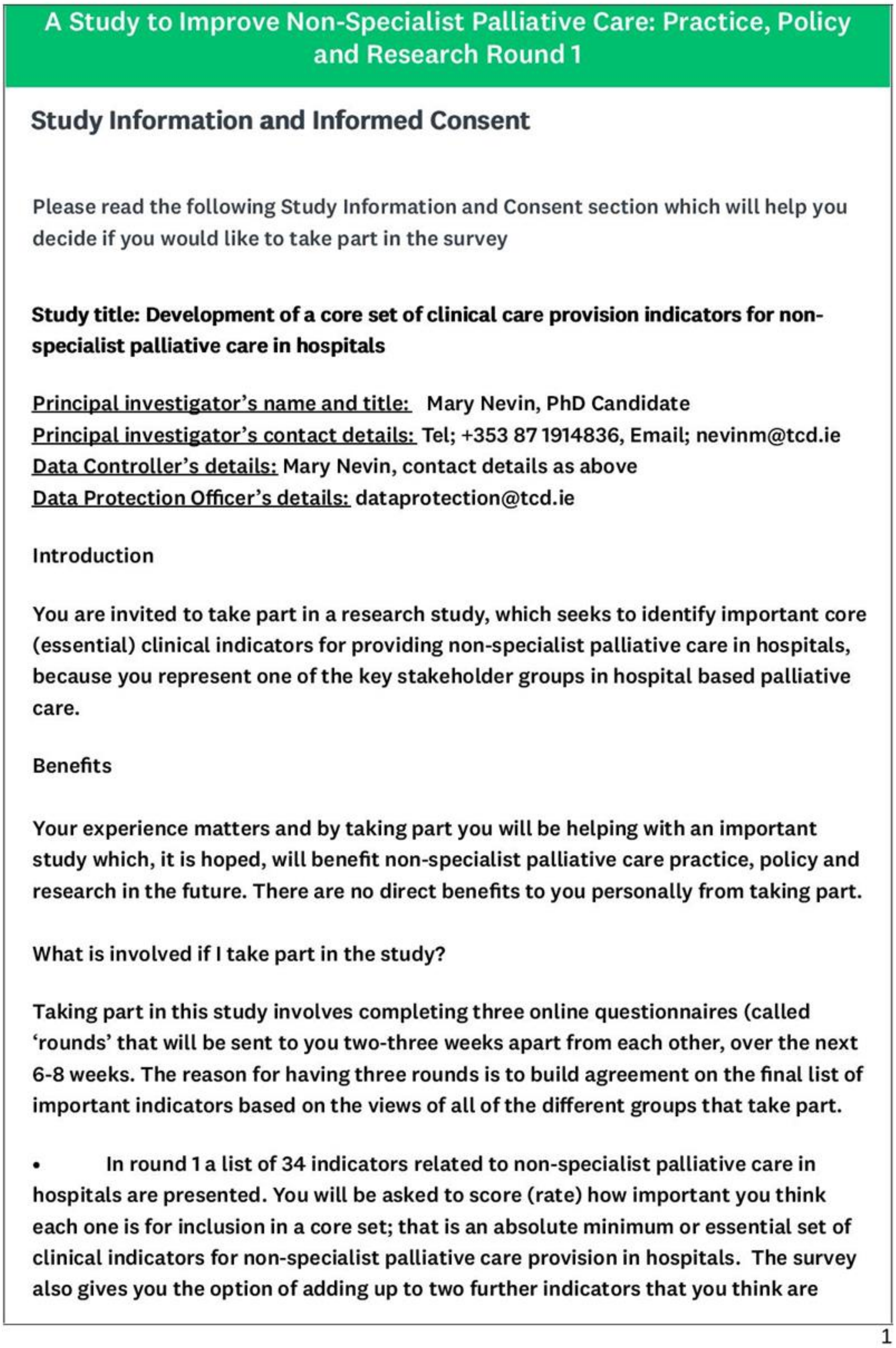
To identify what these essential indicators are, we are seeking the views of the following groups of people:

- Specialist palliative care professionals working in hospitals
- Healthcare workers who do not work within specialist palliative care services, caring for patients with chronic or serious illnesses in hospitals
- Adults (>18) or carers/family members of an adult with a chronic or serious illness who has received care in hospital
- Representatives or members of advocacy groups for adults with a chronic or serious illness
- Hospital management/administration
- Researchers with experience of publishing and/or policy development in palliative care

Are you are a member of one of these groups?

If so and you would like to take part in this study please click on the SurveyMonkey link provided

Appendix 15 Delphi round 1 participant information and informed consent section



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Study Information and Informed Consent

Please read the following Study Information and Consent section which will help you decide if you would like to take part in the survey

Study title: Development of a core set of clinical care provision indicators for non-specialist palliative care in hospitals

Principal investigator's name and title: Mary Nevin, PhD Candidate
Principal investigator's contact details: Tel; +353 87 1914836, Email; nevinm@tcd.ie
Data Controller's details: Mary Nevin, contact details as above
Data Protection Officer's details: dataprotection@tcd.ie

Introduction

You are invited to take part in a research study, which seeks to identify important core (essential) clinical indicators for providing non-specialist palliative care in hospitals, because you represent one of the key stakeholder groups in hospital based palliative care.

Benefits

Your experience matters and by taking part you will be helping with an important study which, it is hoped, will benefit non-specialist palliative care practice, policy and research in the future. There are no direct benefits to you personally from taking part.

What is involved if I take part in the study?

Taking part in this study involves completing three online questionnaires (called 'rounds' that will be sent to you two-three weeks apart from each other, over the next 6-8 weeks. The reason for having three rounds is to build agreement on the final list of important indicators based on the views of all of the different groups that take part.

- In round 1 a list of 34 indicators related to non-specialist palliative care in hospitals are presented. You will be asked to score (rate) how important you think each one is for inclusion in a core set; that is an absolute minimum or essential set of clinical indicators for non-specialist palliative care provision in hospitals. The survey also gives you the option of adding up to two further indicators that you think are

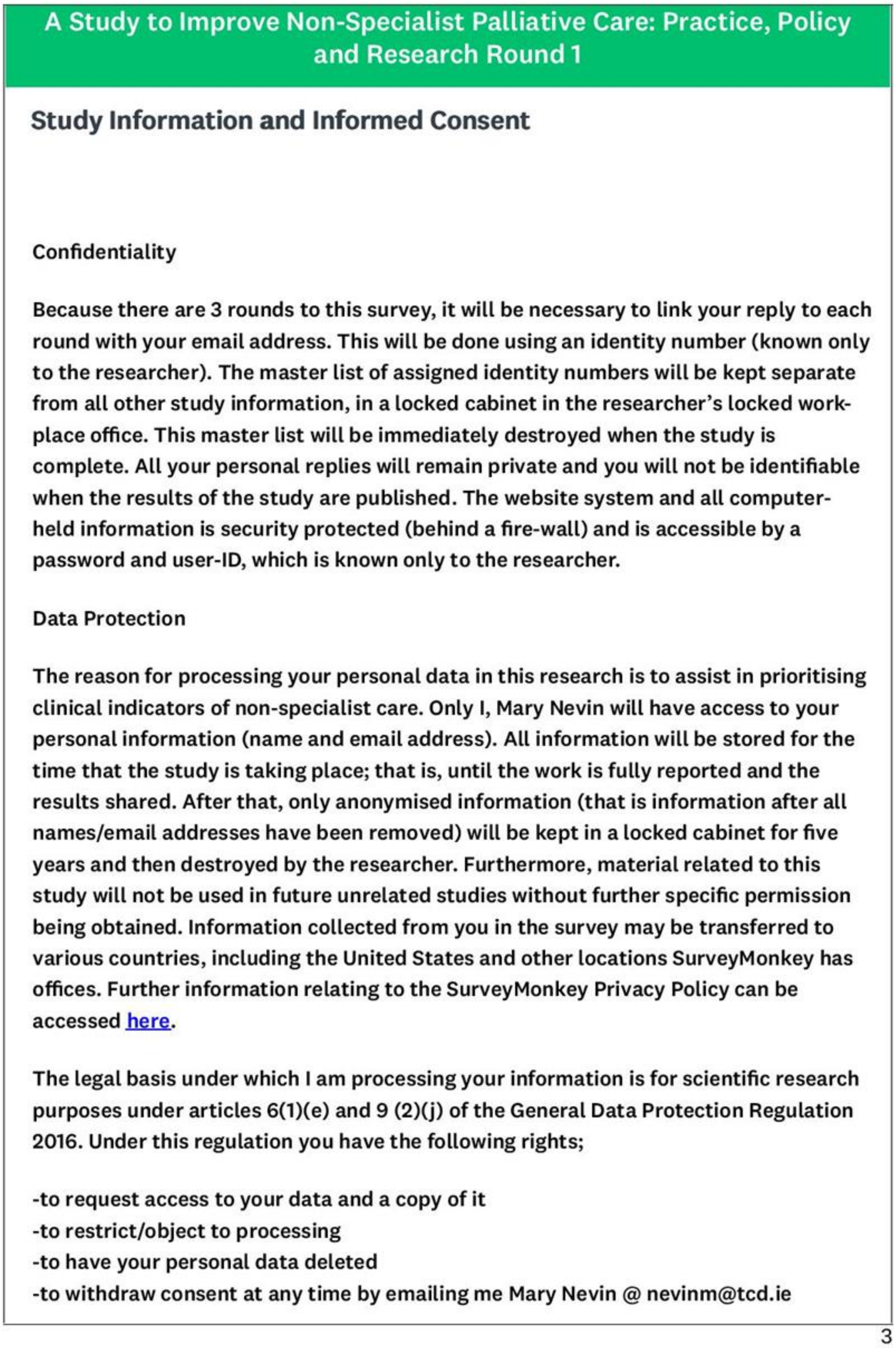
1

important, but are not already in the list, if you so wish. You will also be asked to provide your name and email address so that we can send you the questionnaire for round 2.

- In round 2, the survey will include the core indicators that were scored as being important by more than 70% of individuals from any group in round 1, plus indicators that were added by those taking part in round 1. You will be invited to re-score how important you think each of these indicators are. To help you in round 2, we will provide you with the overall results for your group from round 1. No individual or their personal replies will be identifiable in this, or any other round.

- In round 3, you will again be presented with all the indicators that remain from round 2 based on more than 70% of people from any group scoring them as being important in round 2. In this round, rather than re-rating the indicators you be asked the question of whether you think the indicator should be included in the final set (Yes, No, Unsure).

Taking part will take a maximum of 10-15 minutes per questionnaire (45 minutes in total over the 3 rounds).



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Study Information and Informed Consent

Confidentiality

Because there are 3 rounds to this survey, it will be necessary to link your reply to each round with your email address. This will be done using an identity number (known only to the researcher). The master list of assigned identity numbers will be kept separate from all other study information, in a locked cabinet in the researcher's locked work-place office. This master list will be immediately destroyed when the study is complete. All your personal replies will remain private and you will not be identifiable when the results of the study are published. The website system and all computer-held information is security protected (behind a fire-wall) and is accessible by a password and user-ID, which is known only to the researcher.

Data Protection

The reason for processing your personal data in this research is to assist in prioritising clinical indicators of non-specialist care. Only I, Mary Nevin will have access to your personal information (name and email address). All information will be stored for the time that the study is taking place; that is, until the work is fully reported and the results shared. After that, only anonymised information (that is information after all names/email addresses have been removed) will be kept in a locked cabinet for five years and then destroyed by the researcher. Furthermore, material related to this study will not be used in future unrelated studies without further specific permission being obtained. Information collected from you in the survey may be transferred to various countries, including the United States and other locations SurveyMonkey has offices. Further information relating to the SurveyMonkey Privacy Policy can be accessed here.

The legal basis under which I am processing your information is for scientific research purposes under articles 6(1)(e) and 9 (2)(j) of the General Data Protection Regulation 2016. Under this regulation you have the following rights;

-to request access to your data and a copy of it
-to restrict/object to processing
-to have your personal data deleted
-to withdraw consent at any time by emailing me Mary Nevin @ nevinm@tcd.ie

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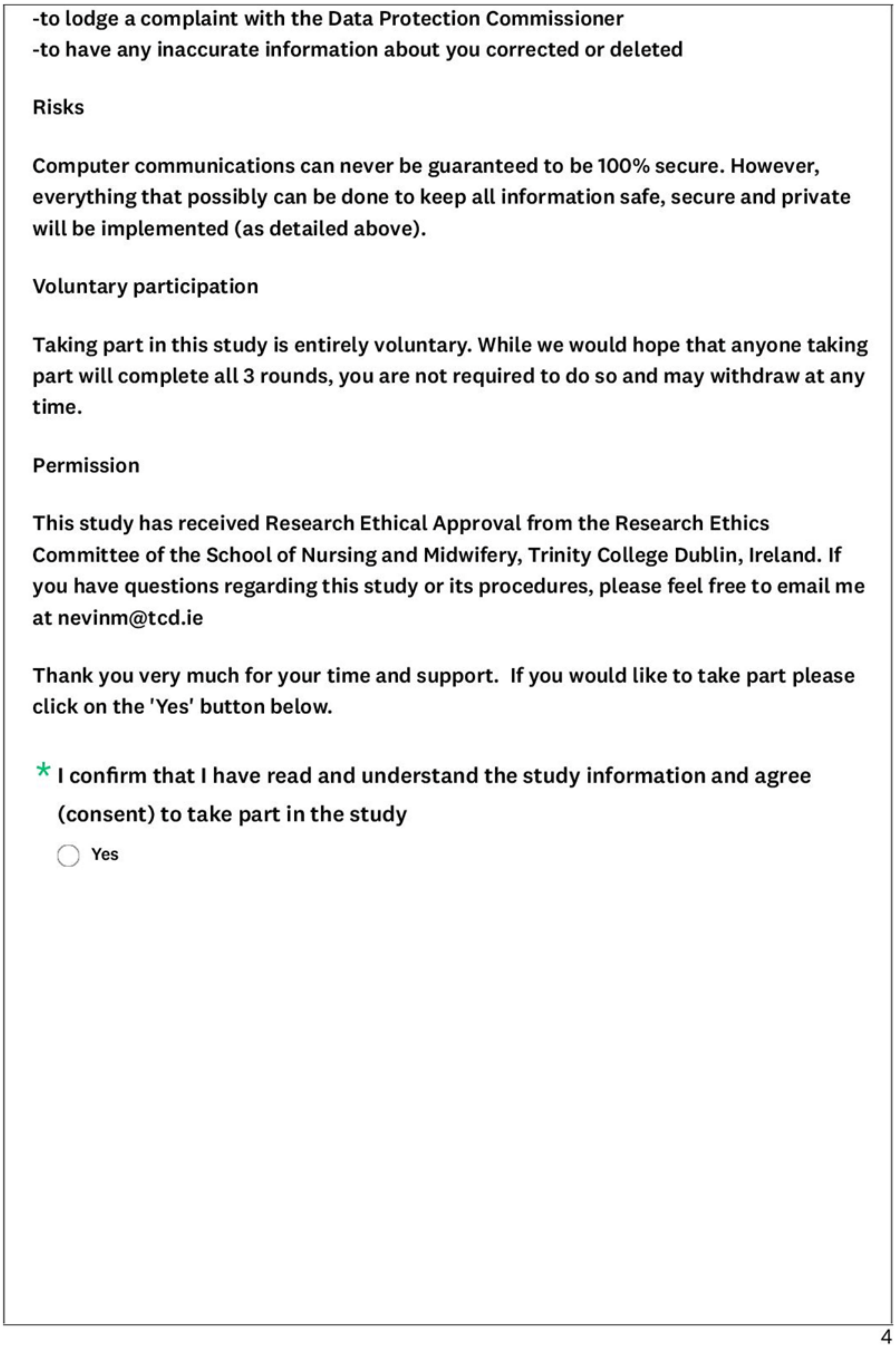


-to lodge a complaint with the Data Protection Commissioner
-to have any inaccurate information about you corrected or deleted

Risks

Computer communications can never be guaranteed to be 100% secure. However, everything that possibly can be done to keep all information safe, secure and private will be implemented (as detailed above).

Voluntary participation

Taking part in this study is entirely voluntary. While we would hope that anyone taking part will complete all 3 rounds, you are not required to do so and may withdraw at any time.

Permission

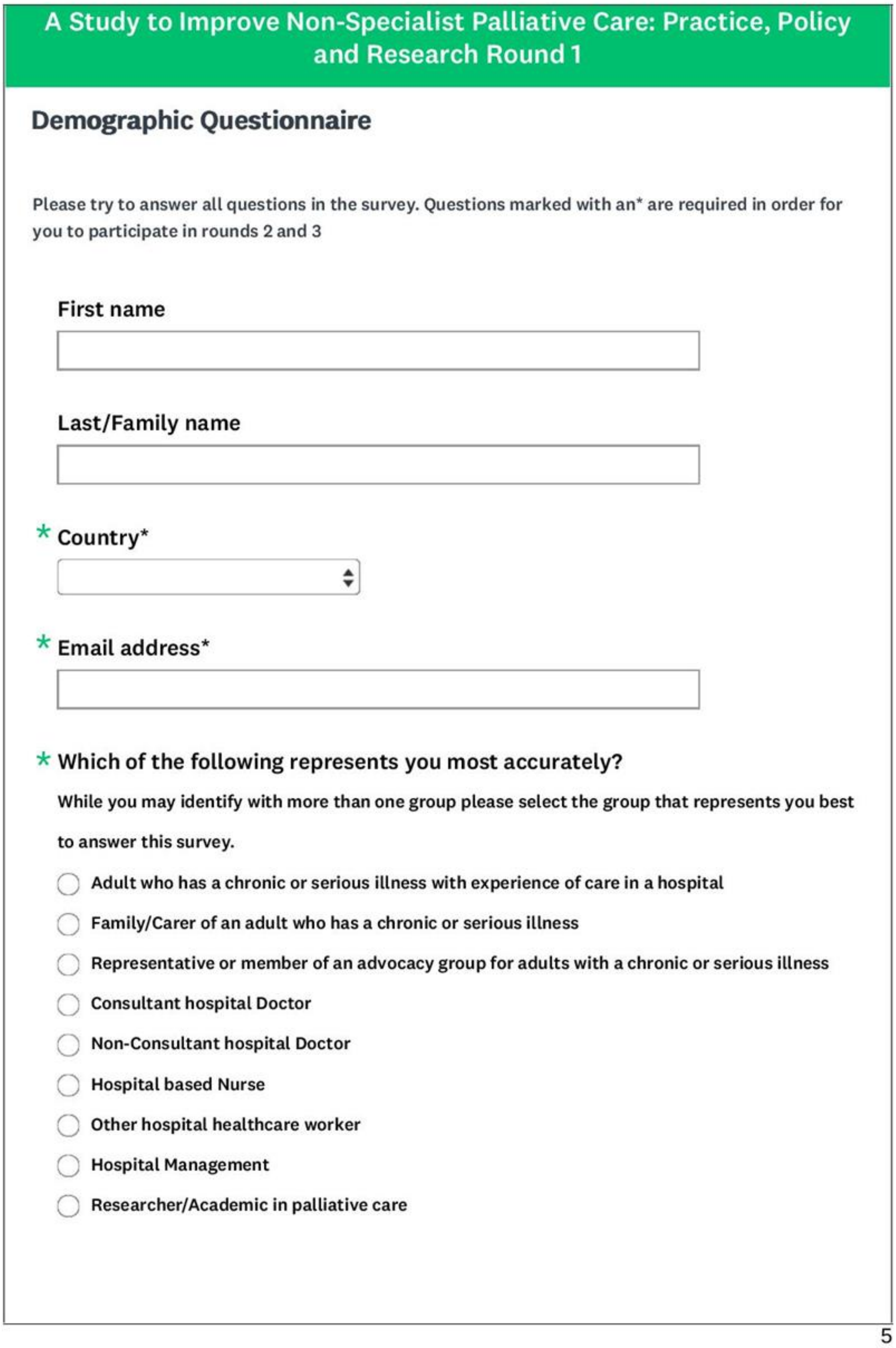
This study has received Research Ethical Approval from the Research Ethics Committee of the School of Nursing and Midwifery, Trinity College Dublin, Ireland. If you have questions regarding this study or its procedures, please feel free to email me at nevinm@tcd.ie

Thank you very much for your time and support. If you would like to take part please click on the 'Yes' button below.

* I confirm that I have read and understand the study information and agree (consent) to take part in the study

○ Yes

Appendix 16 Participant group question of the demographic section



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Demographic Questionnaire

Please try to answer all questions in the survey. Questions marked with an* are required in order for you to participate in rounds 2 and 3

First name

Last/Family name

* Country*

* Email address*

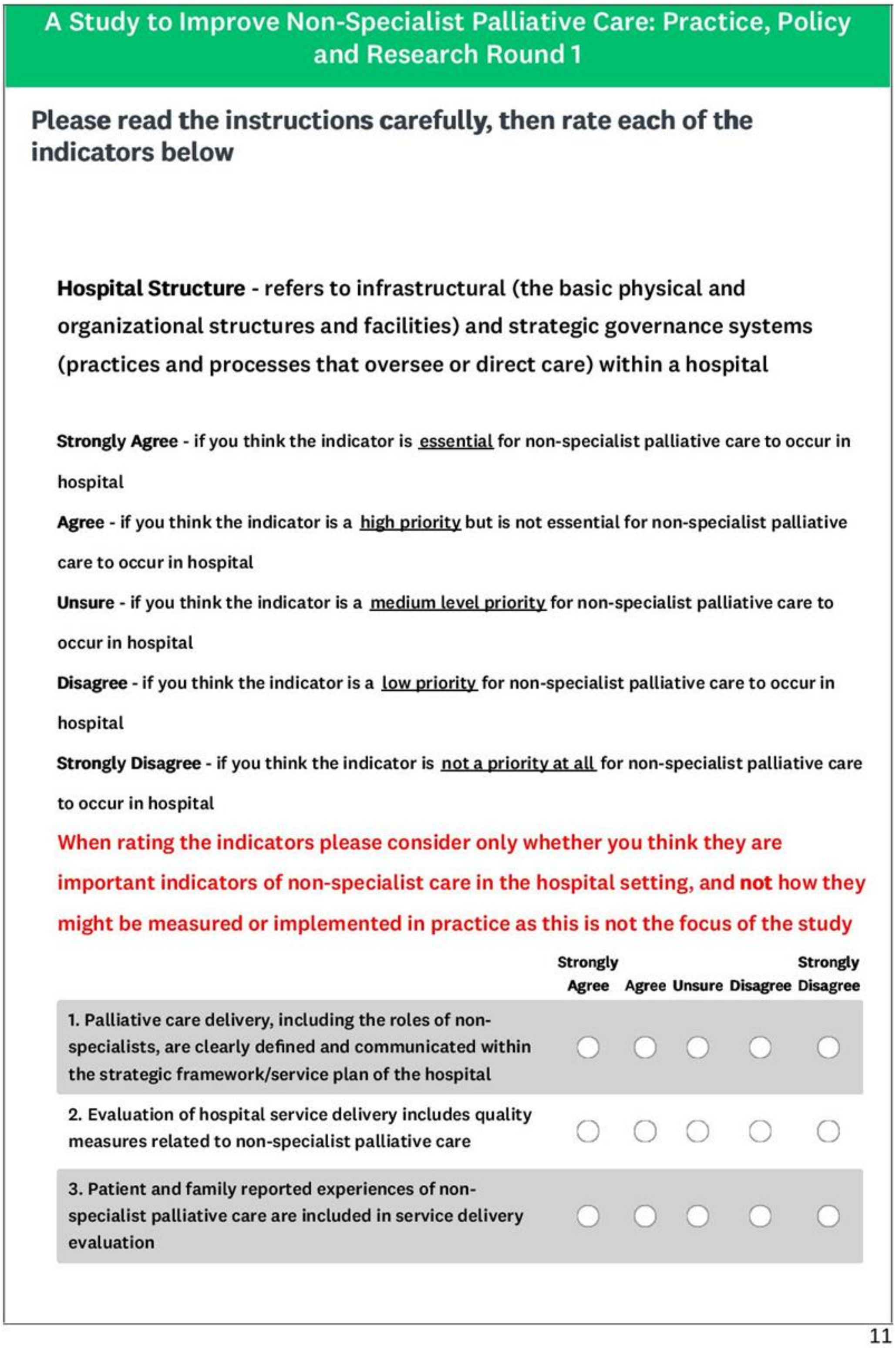
* Which of the following represents you most accurately?

While you may identify with more than one group please select the group that represents you best to answer this survey.

○ Adult who has a chronic or serious illness with experience of care in a hospital
○ Family/Carer of an adult who has a chronic or serious illness
○ Representative or member of an advocacy group for adults with a chronic or serious illness
○ Consultant hospital Doctor
○ Non-Consultant hospital Doctor
○ Hospital based Nurse
○ Other hospital healthcare worker
○ Hospital Management
○ Researcher/Academic in palliative care

5

Appendix 17 Round 1 Delphi survey



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Please read the instructions carefully, then rate each of the indicators below

Hospital Structure - refers to infrastructural (the basic physical and organizational structures and facilities) and strategic governance systems (practices and processes that oversee or direct care) within a hospital

Strongly Agree - if you think the indicator is essential for non-specialist palliative care to occur in hospital

Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital

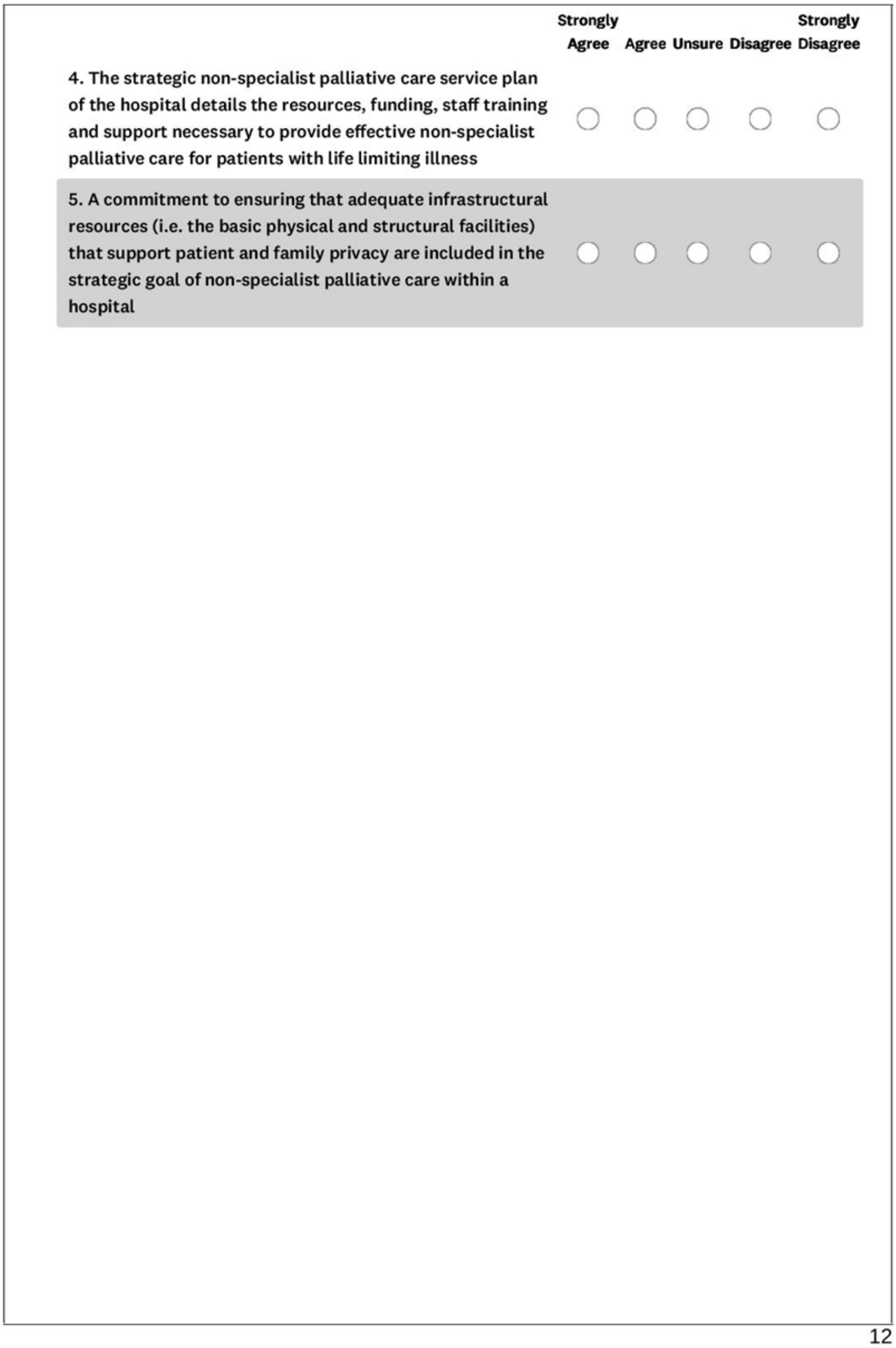
Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital

Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital

Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and **not** how they might be measured or implemented in practice as this is not the focus of the study

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
1. Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	○	○	○	○	○
2. Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	○	○	○	○	○
3. Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	○	○	○	○	○



	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
4. The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	○	○	○	○	○
5. A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	○	○	○	○	○

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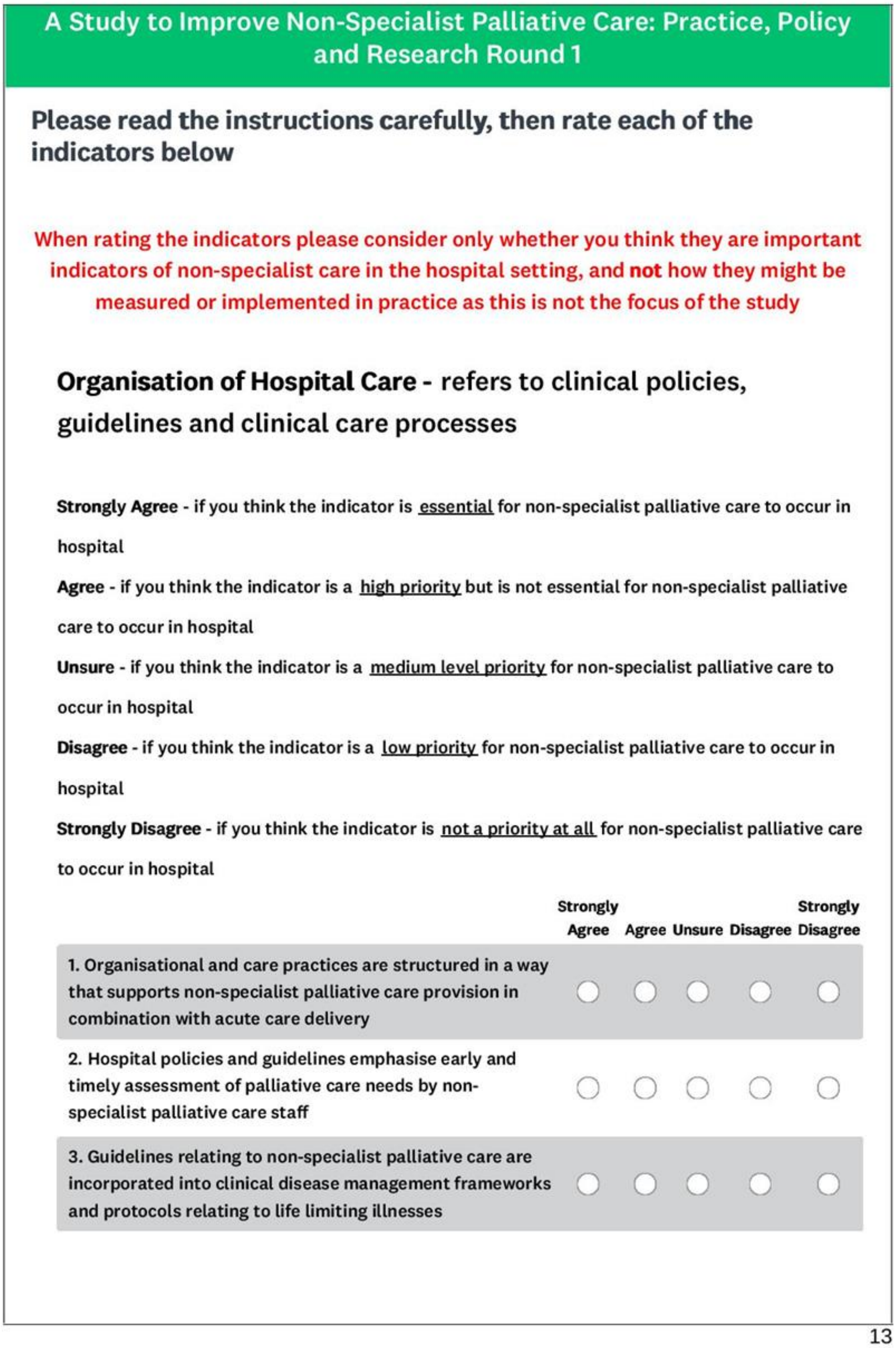

A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Please read the instructions carefully, then rate each of the indicators below

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and **not** how they might be measured or implemented in practice as this is not the focus of the study

Organisation of Hospital Care - refers to clinical policies, guidelines and clinical care processes

Strongly Agree - if you think the indicator is essential for non-specialist palliative care to occur in hospital

Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital

Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital

Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital

Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
1. Organisational and care practices are structured in a way that supports non-specialist palliative care provision in combination with acute care delivery	○	○	○	○	○
2. Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	○	○	○	○	○
3. Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	○	○	○	○	○

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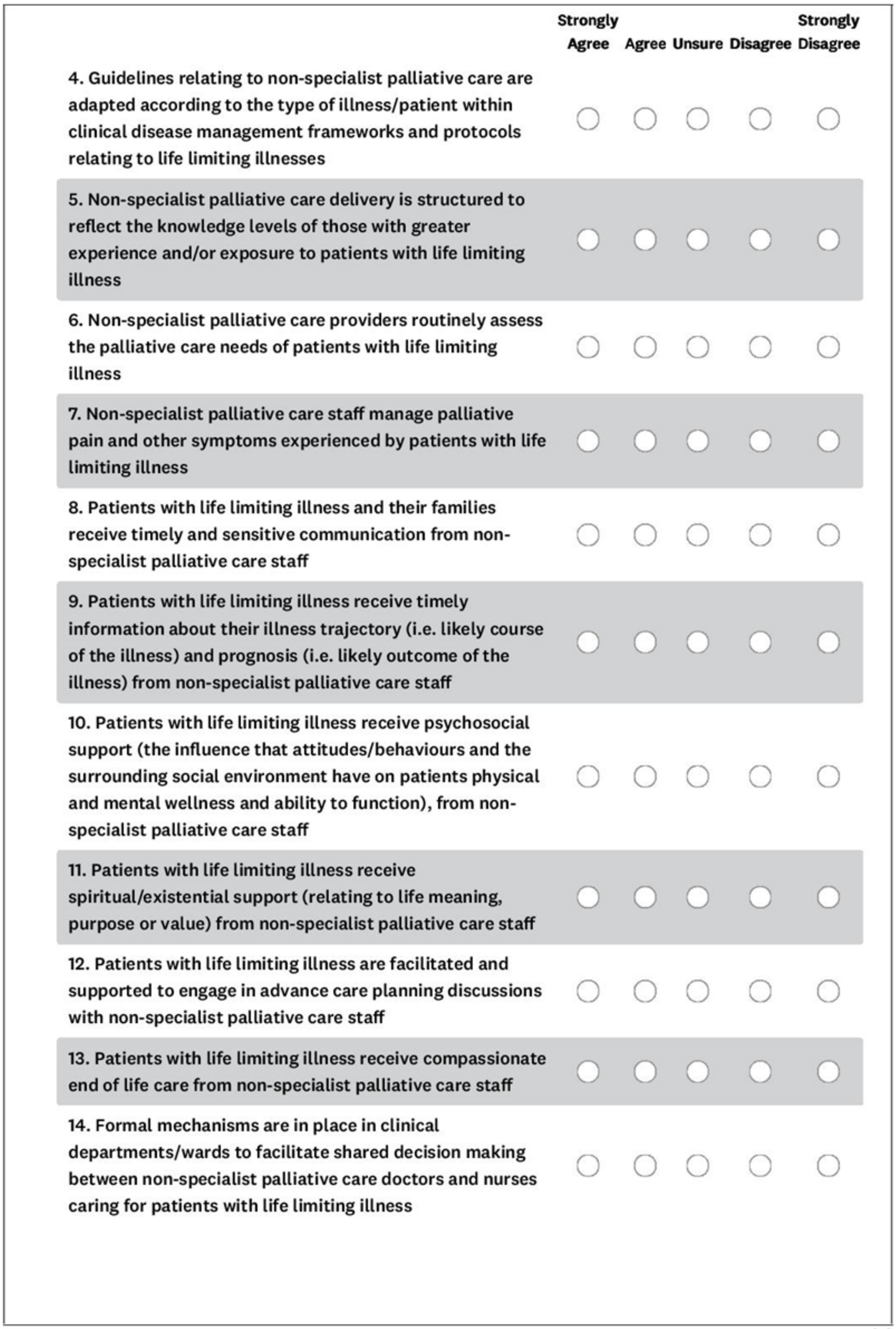
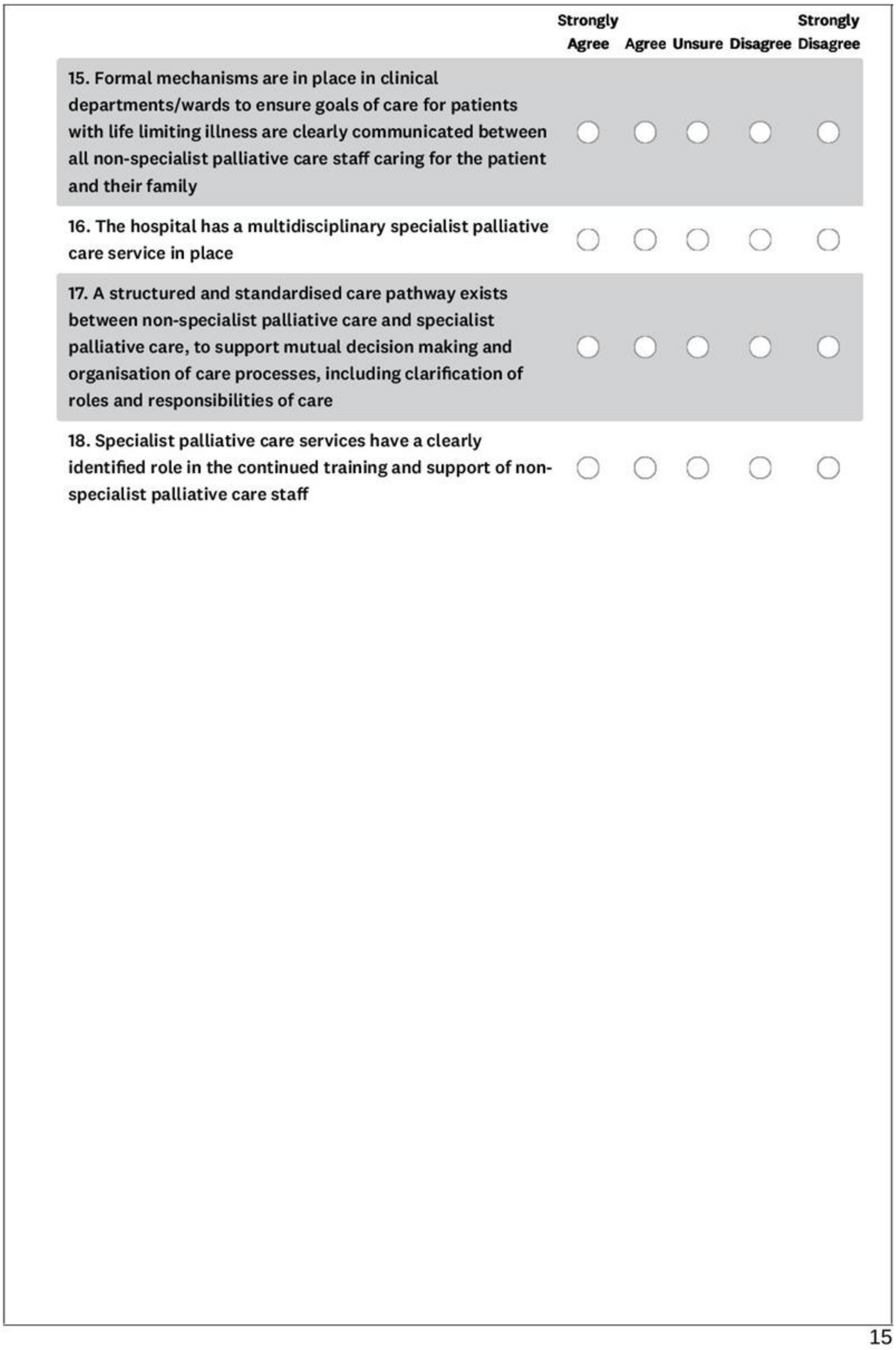


	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
4. Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	○	○	○	○	○
5. Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	○	○	○	○	○
6. Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	○	○	○	○	○
7. Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	○	○	○	○	○
8. Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	○	○	○	○	○
9. Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	○	○	○	○	○
10. Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff	○	○	○	○	○
11. Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	○	○	○	○	○
12. Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	○	○	○	○	○
13. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	○	○	○	○	○
14. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care doctors and nurses caring for patients with life limiting illness	○	○	○	○	○



	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
15. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	○	○	○	○	○
16. The hospital has a multidisciplinary specialist palliative care service in place	○	○	○	○	○
17. A structured and standardised care pathway exists between non-specialist palliative care and specialist palliative care, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	○	○	○	○	○
18. Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	○	○	○	○	○

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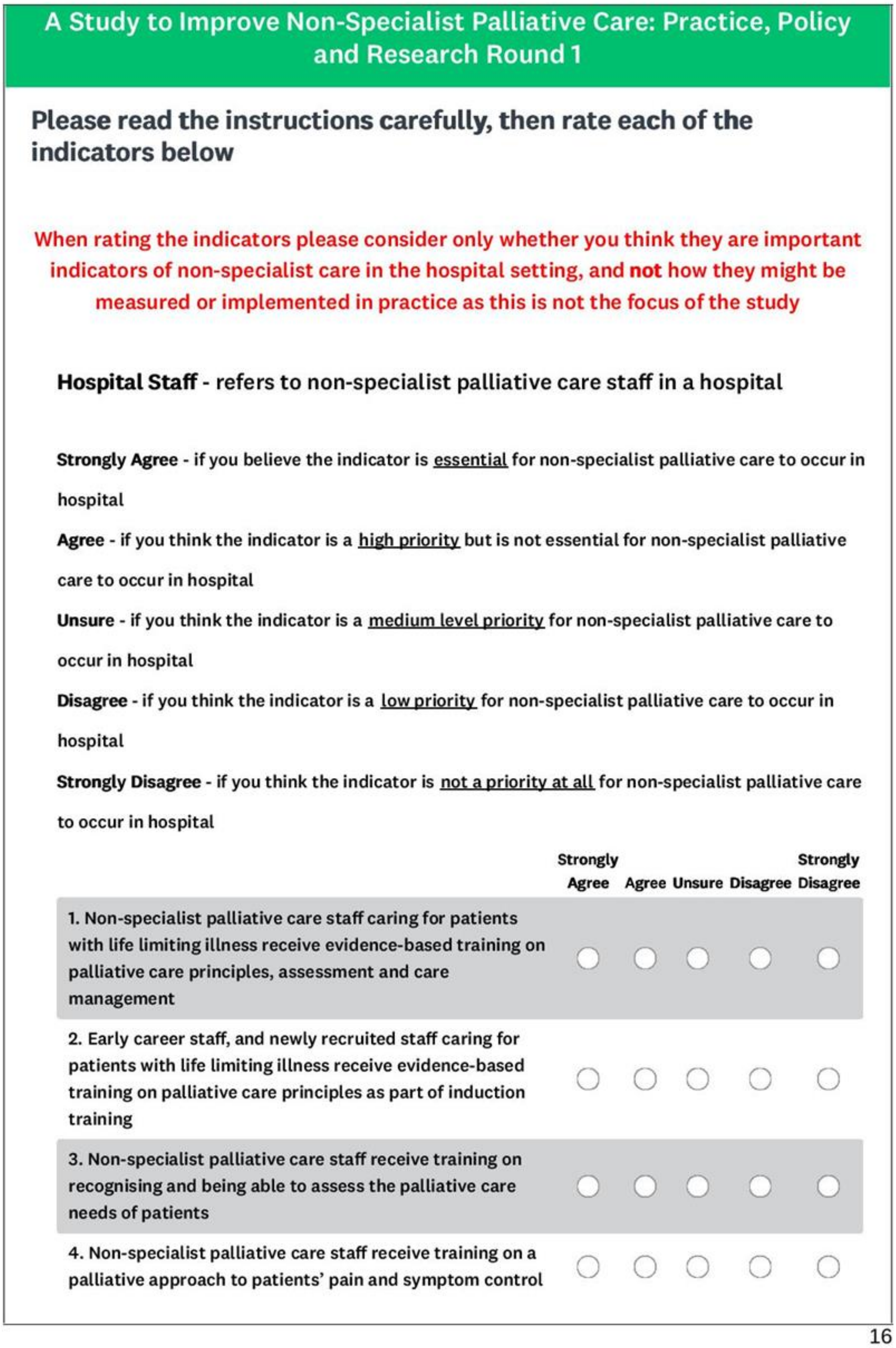

A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

Please read the instructions carefully, then rate each of the indicators below

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and not how they might be measured or implemented in practice as this is not the focus of the study

Hospital Staff - refers to non-specialist palliative care staff in a hospital

Strongly Agree - if you believe the indicator is essential for non-specialist palliative care to occur in hospital

Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital

Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital

Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital

Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
1. Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	○	○	○	○	○
2. Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	○	○	○	○	○
3. Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	○	○	○	○	○
4. Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	○	○	○	○	○

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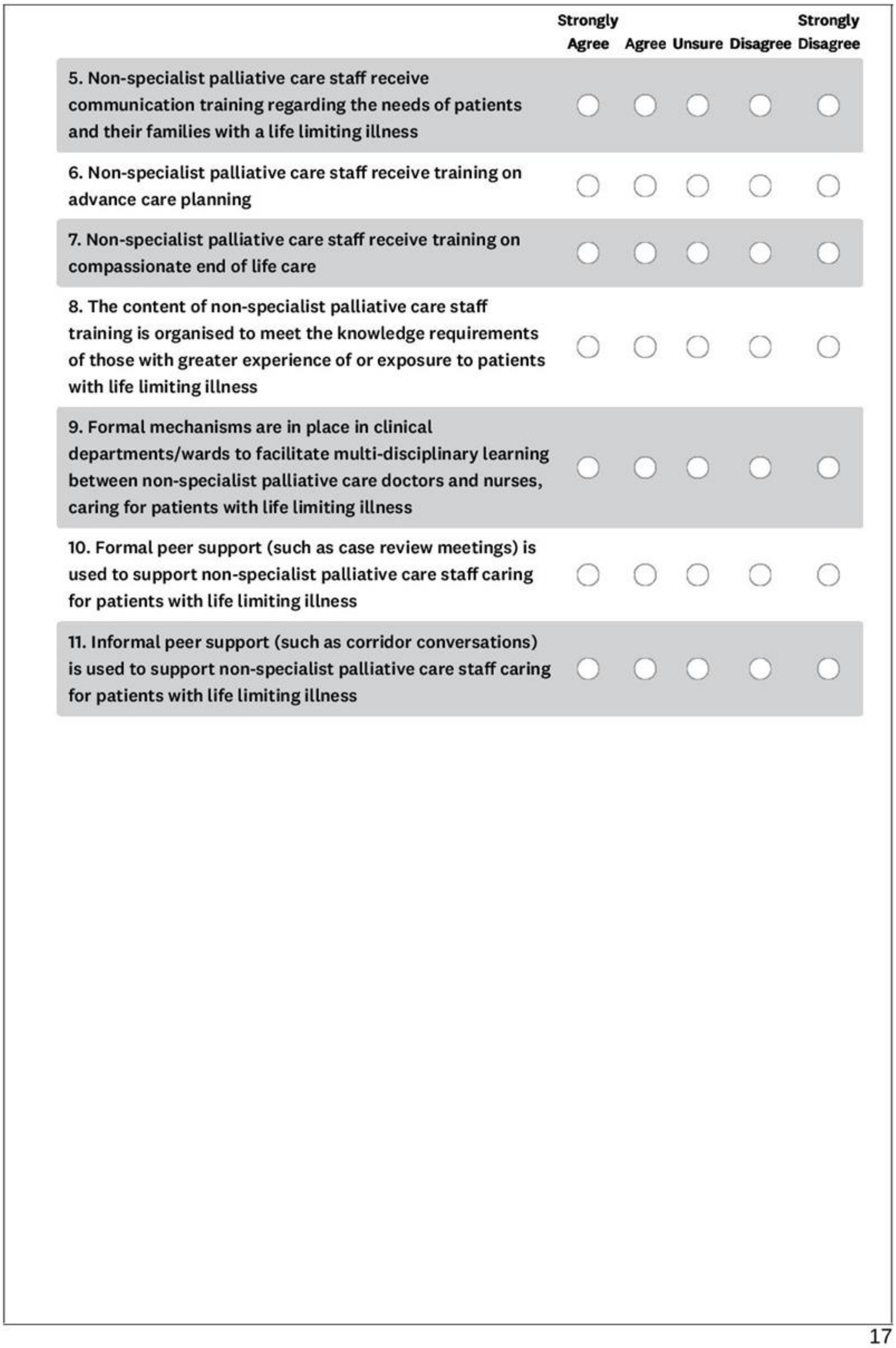
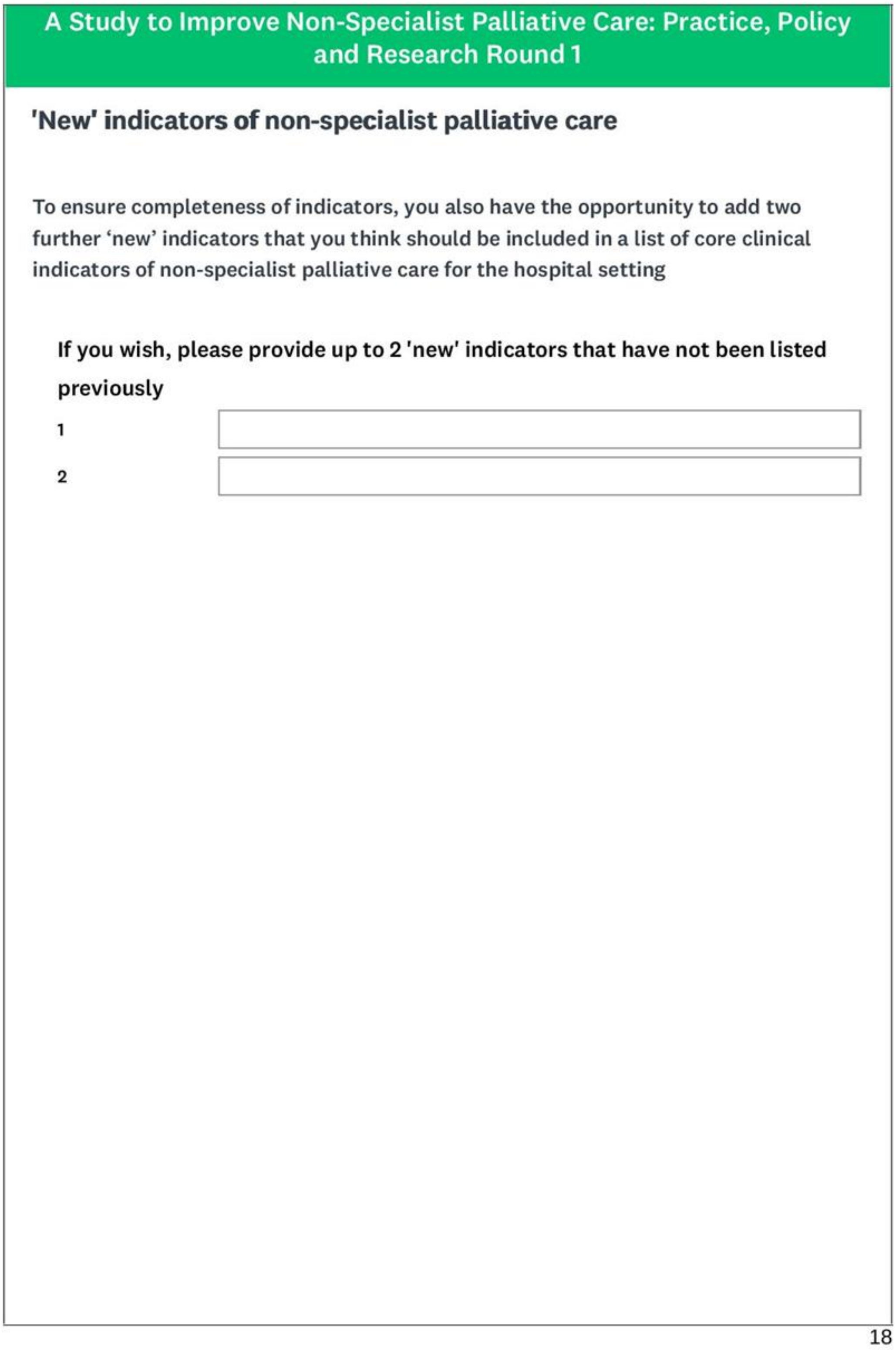


	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
5. Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	○	○	○	○	○
6. Non-specialist palliative care staff receive training on advance care planning	○	○	○	○	○
7. Non-specialist palliative care staff receive training on compassionate end of life care	○	○	○	○	○
8. The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with greater experience of or exposure to patients with life limiting illness	○	○	○	○	○
9. Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between non-specialist palliative care doctors and nurses, caring for patients with life limiting illness	○	○	○	○	○
10. Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	○	○	○	○	○
11. Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	○	○	○	○	○

17



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

'New' indicators of non-specialist palliative care

To ensure completeness of indicators, you also have the opportunity to add two further 'new' indicators that you think should be included in a list of core clinical indicators of non-specialist palliative care for the hospital setting

If you wish, please provide up to 2 'new' indicators that have not been listed previously

1

2

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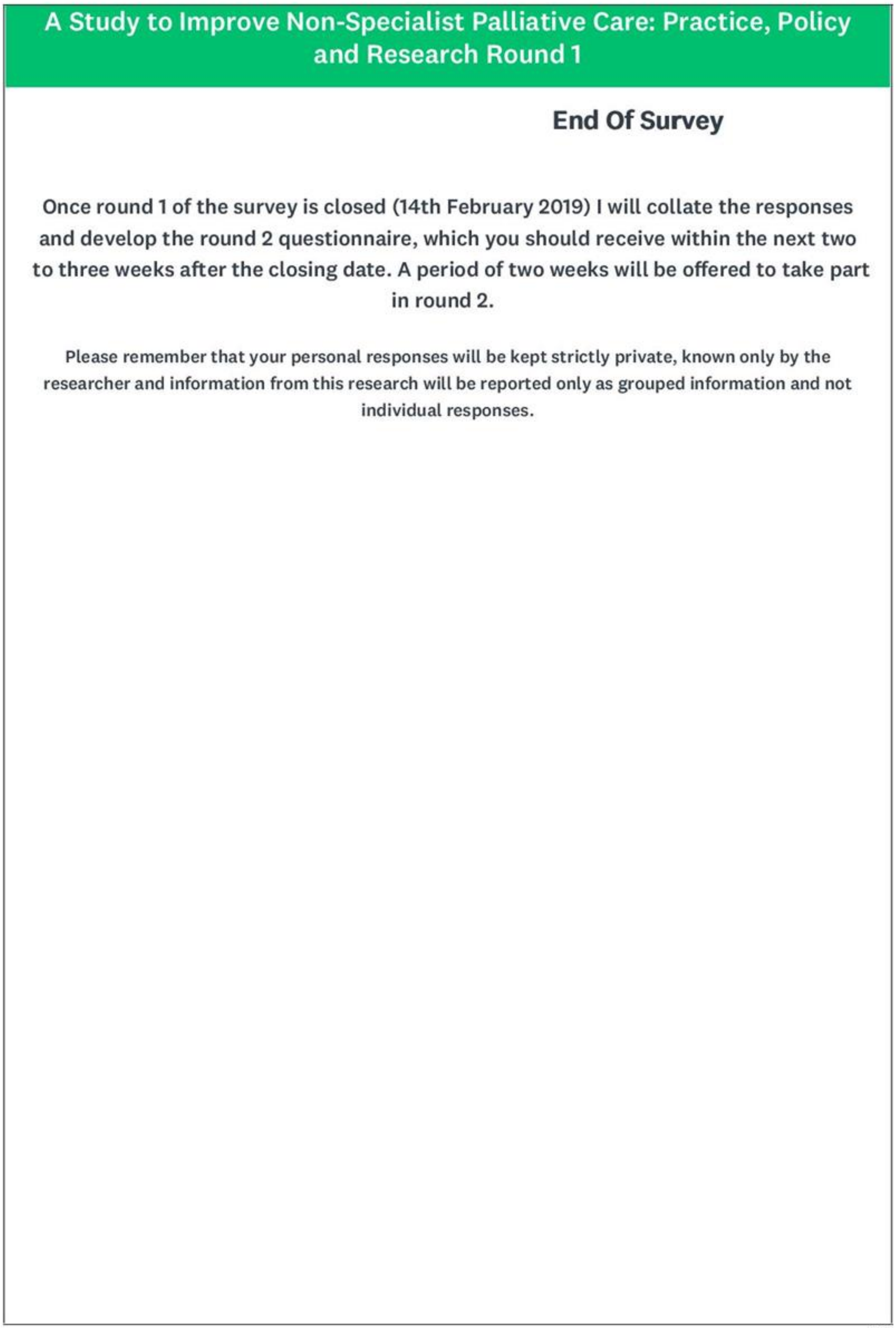


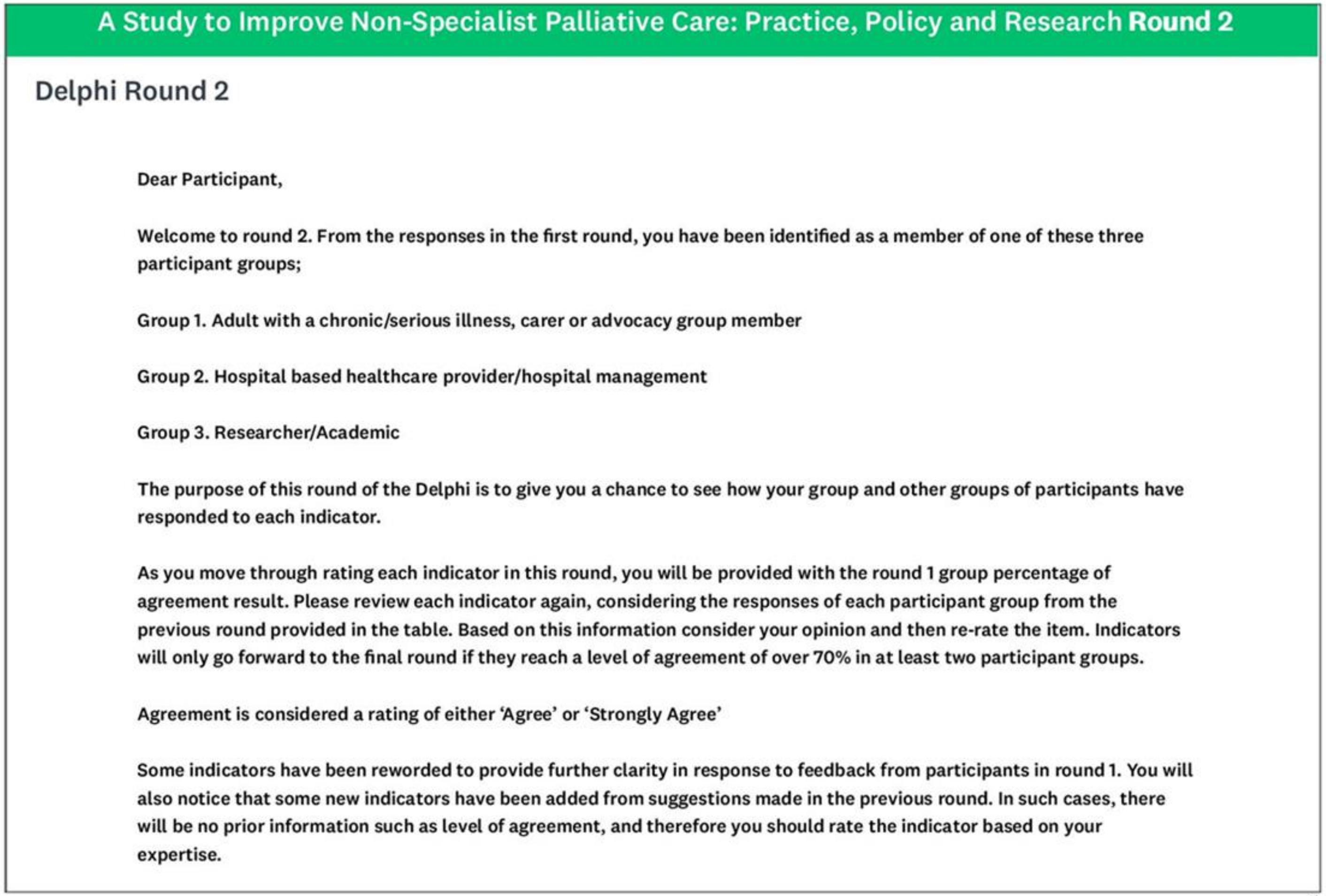
A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 1

End Of Survey

Once round 1 of the survey is closed (14th February 2019) I will collate the responses and develop the round 2 questionnaire, which you should receive within the next two to three weeks after the closing date. A period of two weeks will be offered to take part in round 2.

Please remember that your personal responses will be kept strictly private, known only by the researcher and information from this research will be reported only as grouped information and not individual responses.

Appendix 18 Round 2 Delphi survey



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

Delphi Round 2

Dear Participant,

Welcome to round 2. From the responses in the first round, you have been identified as a member of one of these three participant groups;

Group 1. Adult with a chronic/serious illness, carer or advocacy group member

Group 2. Hospital based healthcare provider/hospital management

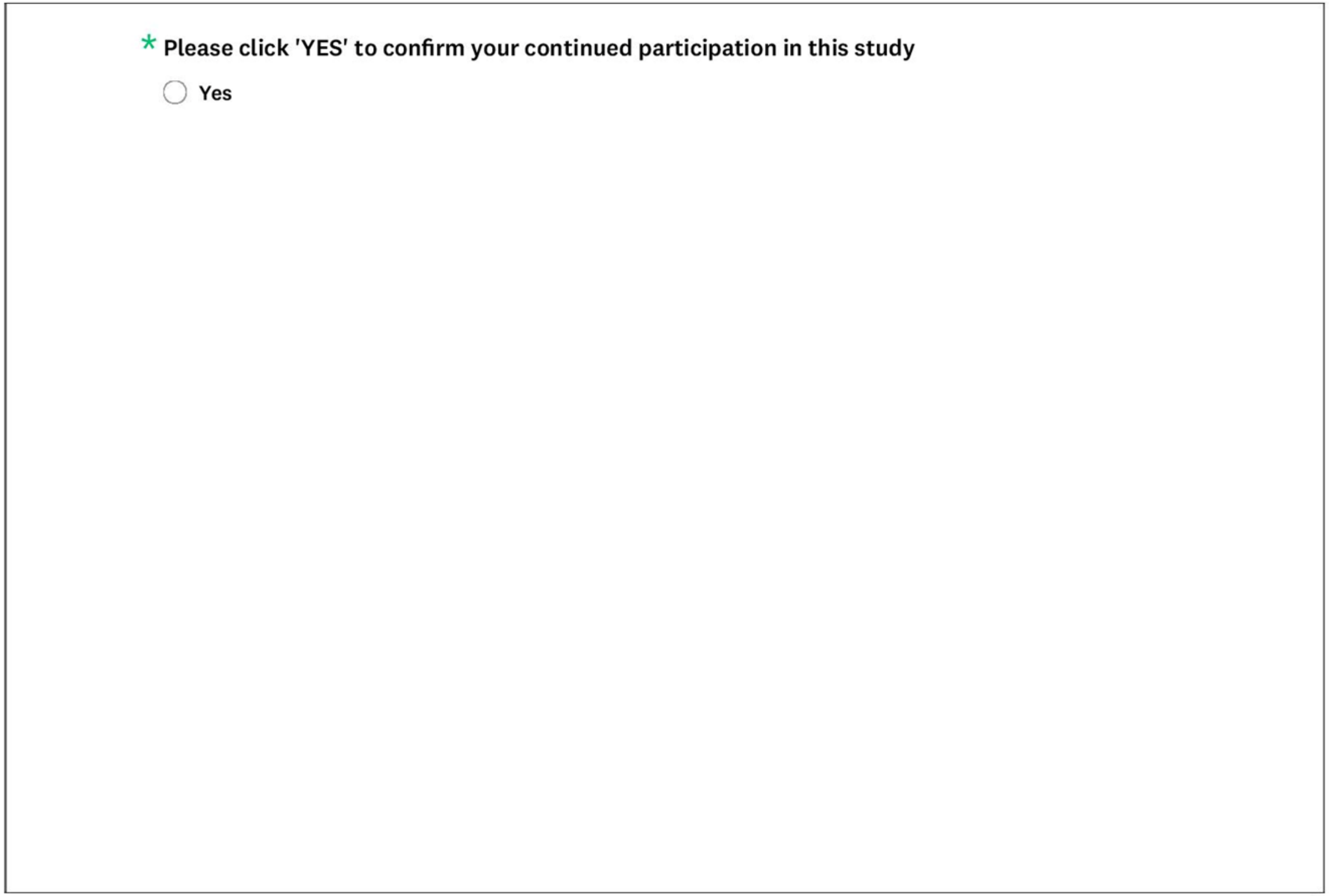
Group 3. Researcher/Academic

The purpose of this round of the Delphi is to give you a chance to see how your group and other groups of participants have responded to each indicator.

As you move through rating each indicator in this round, you will be provided with the round 1 group percentage of agreement result. Please review each indicator again, considering the responses of each participant group from the previous round provided in the table. Based on this information consider your opinion and then re-rate the item. Indicators will only go forward to the final round if they reach a level of agreement of over 70% in at least two participant groups.

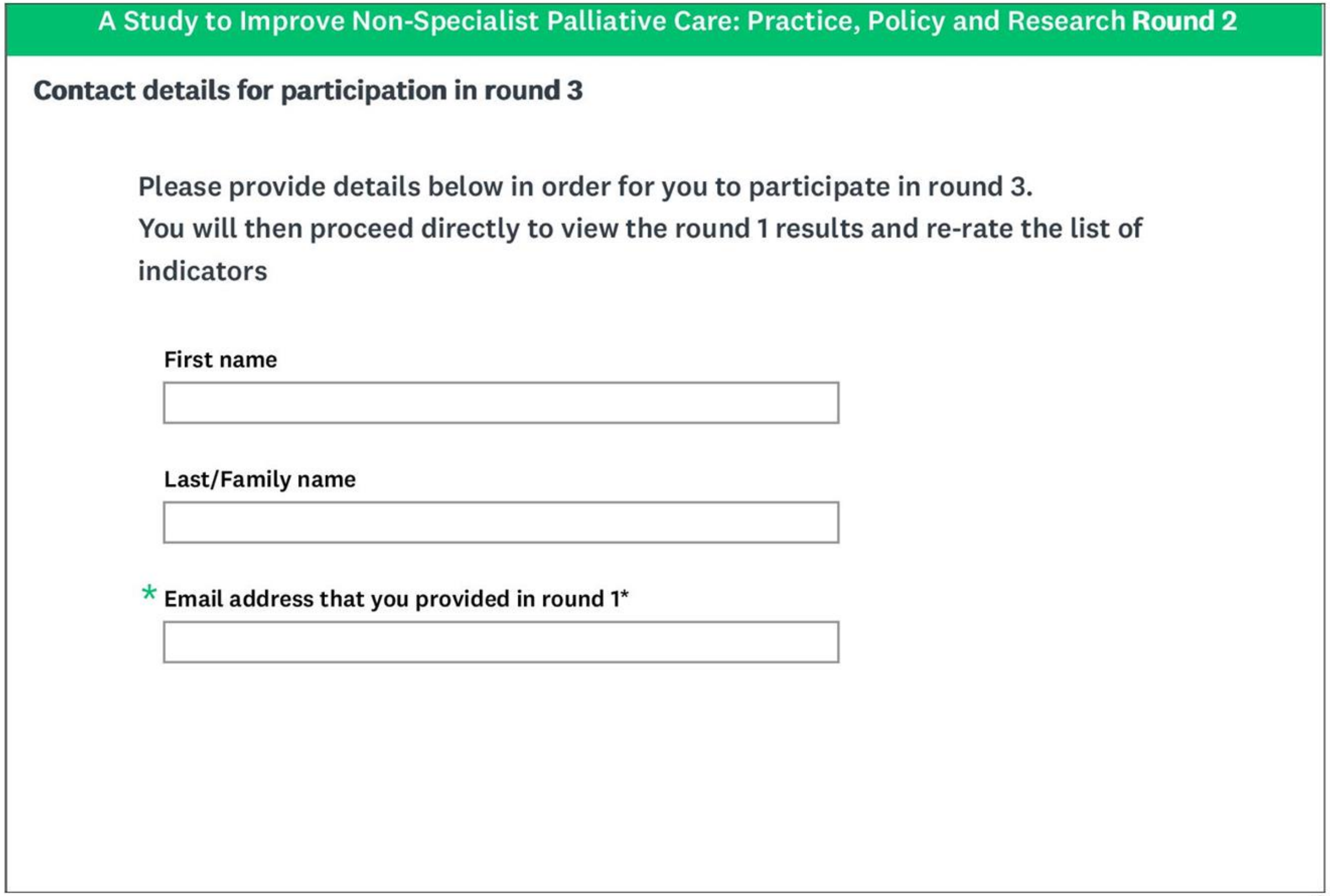
Agreement is considered a rating of either 'Agree' or 'Strongly Agree'

Some indicators have been reworded to provide further clarity in response to feedback from participants in round 1. You will also notice that some new indicators have been added from suggestions made in the previous round. In such cases, there will be no prior information such as level of agreement, and therefore you should rate the indicator based on your expertise.



* Please click 'YES' to confirm your continued participation in this study

○ Yes



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

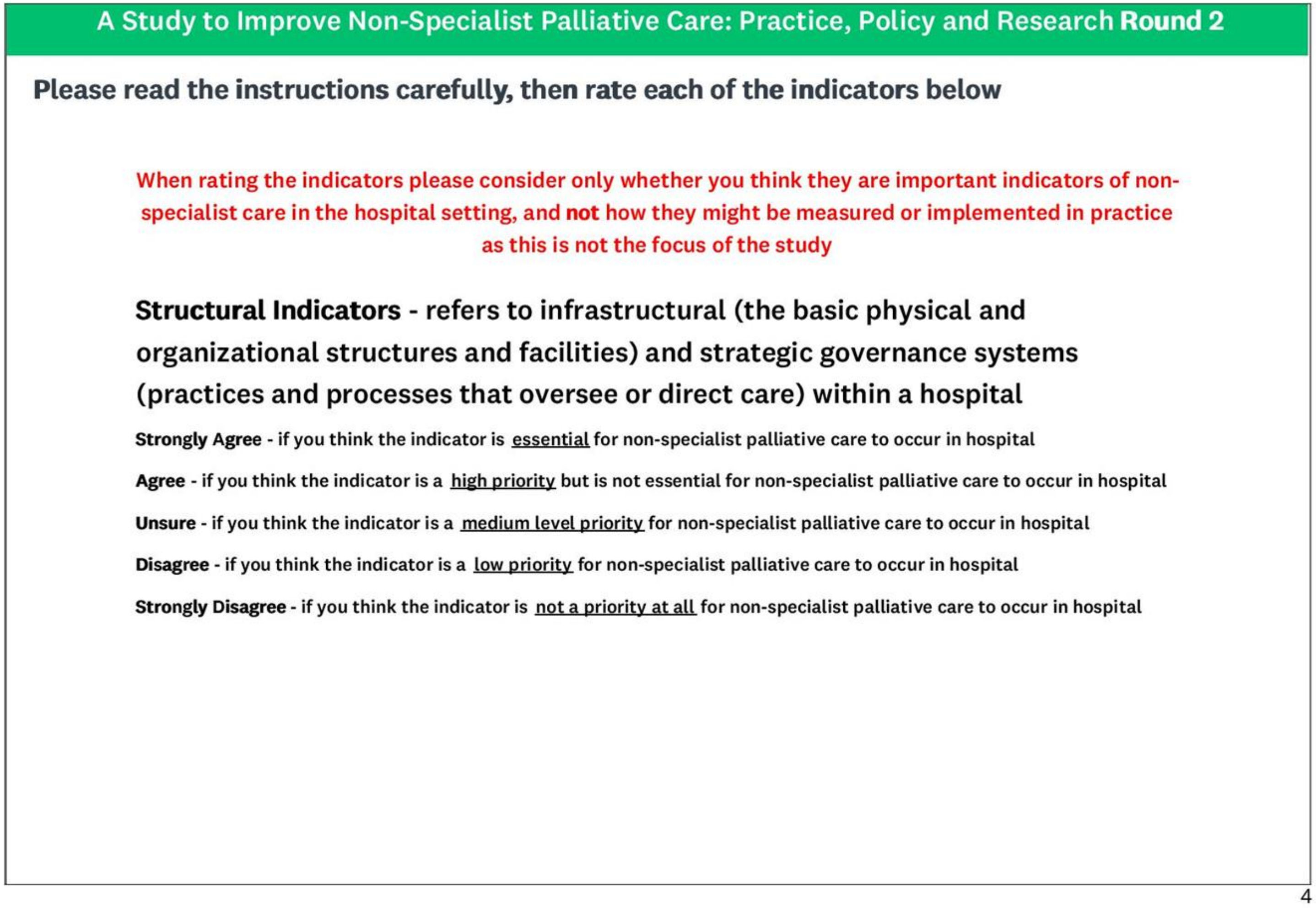
Contact details for participation in round 3

Please provide details below in order for you to participate in round 3.
You will then proceed directly to view the round 1 results and re-rate the list of indicators

First name

Last/Family name

* Email address that you provided in round 1*



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

Please read the instructions carefully, then rate each of the indicators below

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and **not** how they might be measured or implemented in practice as this is not the focus of the study

Structural Indicators - refers to infrastructural (the basic physical and organizational structures and facilities) and strategic governance systems (practices and processes that oversee or direct care) within a hospital

Strongly Agree - if you think the indicator is essential for non-specialist palliative care to occur in hospital

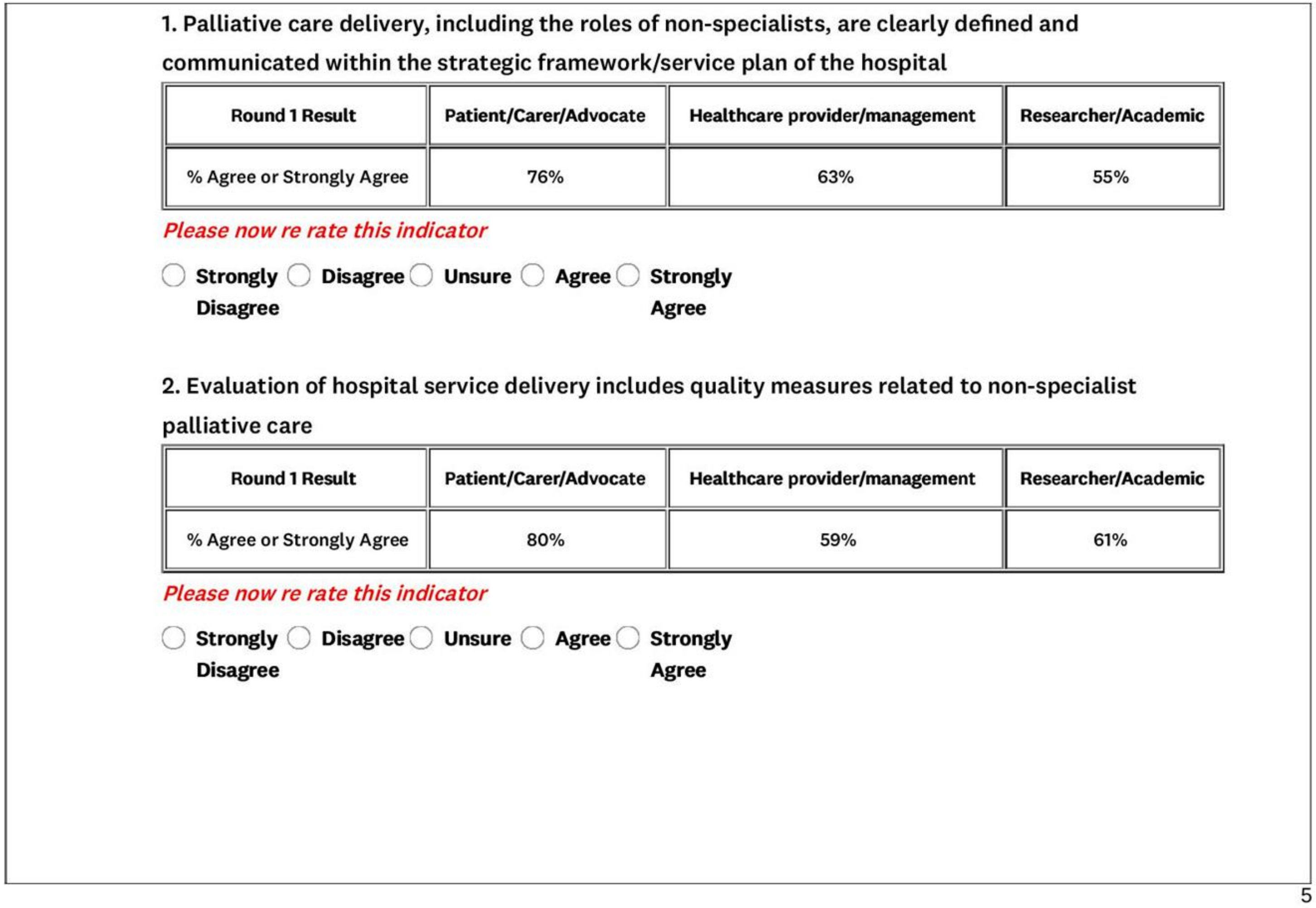
Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital

Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital

Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital

Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital

4



1. Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	76%	63%	55%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

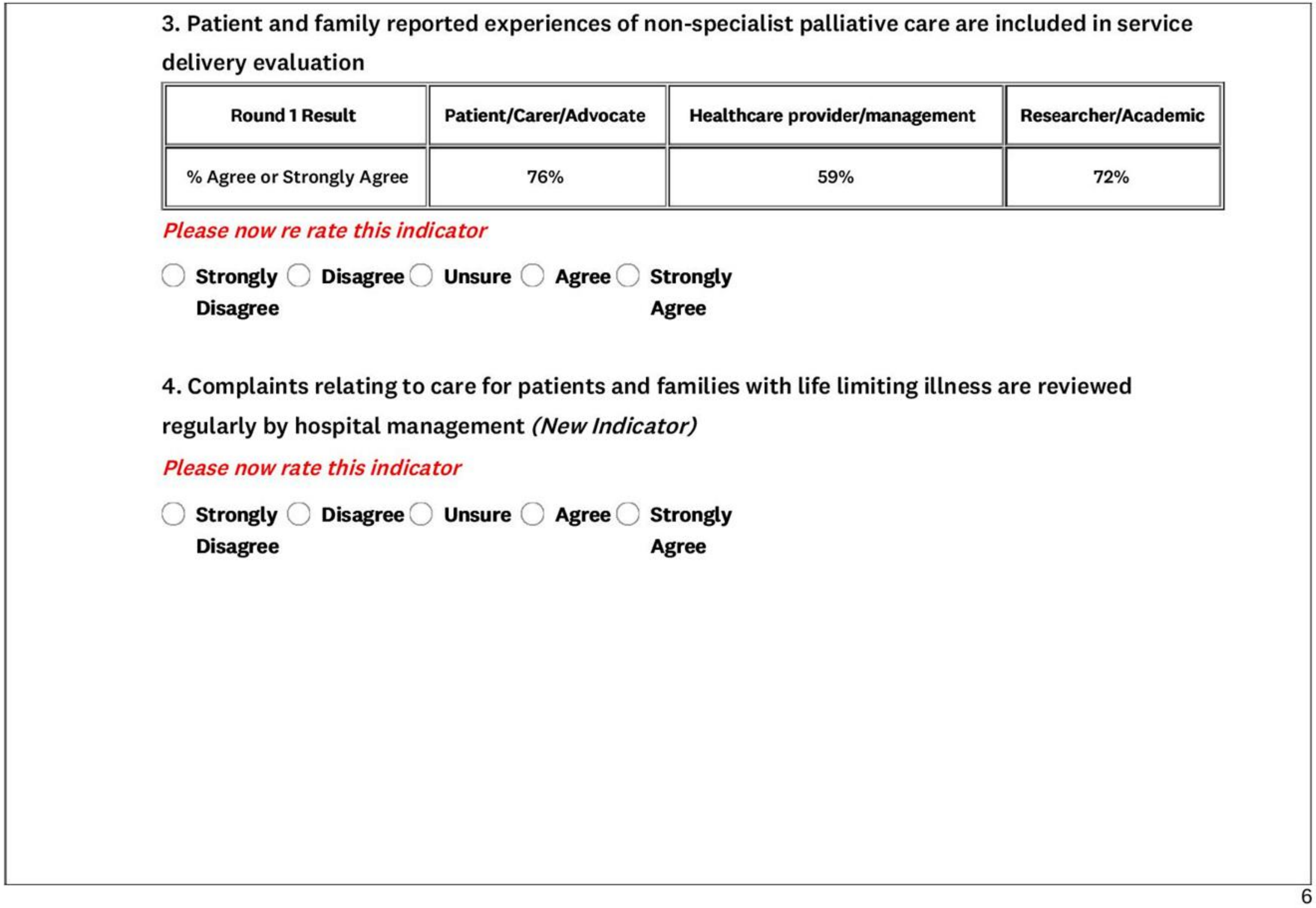
2. Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	59%	61%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

5



3. Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	76%	59%	72%

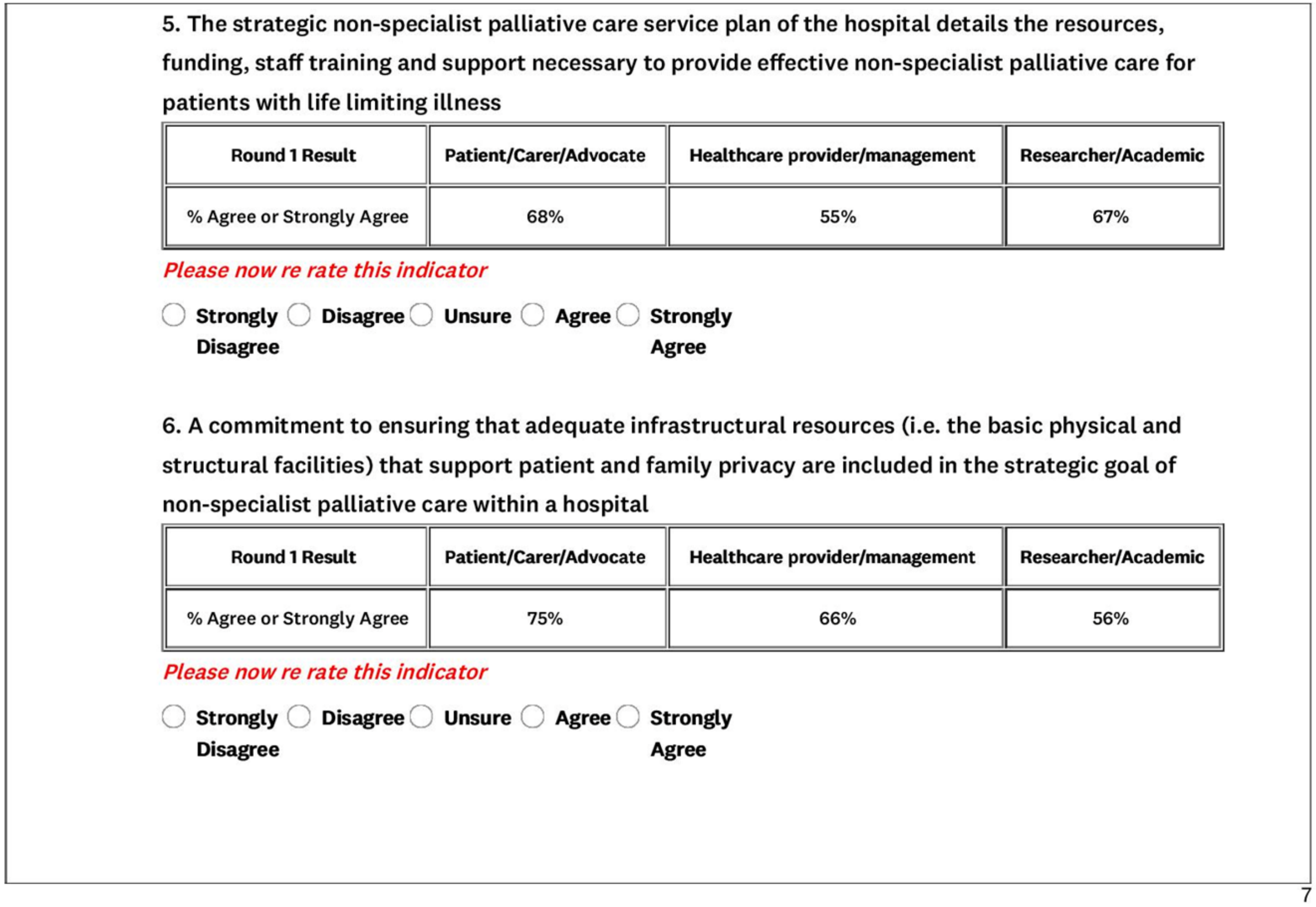
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

4. Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management *(New Indicator)*

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



5. The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	68%	55%	67%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

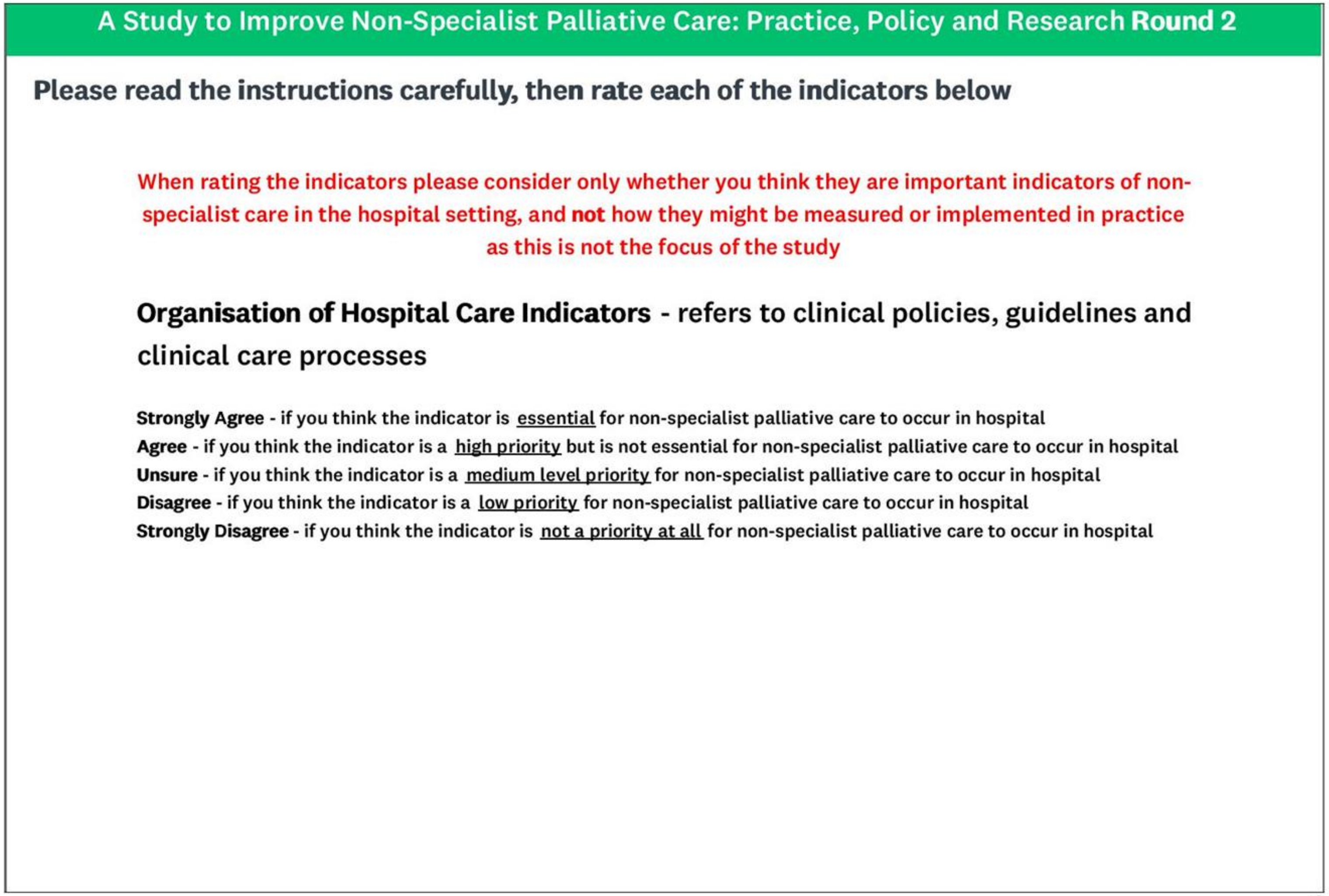
6. A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	66%	56%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

7



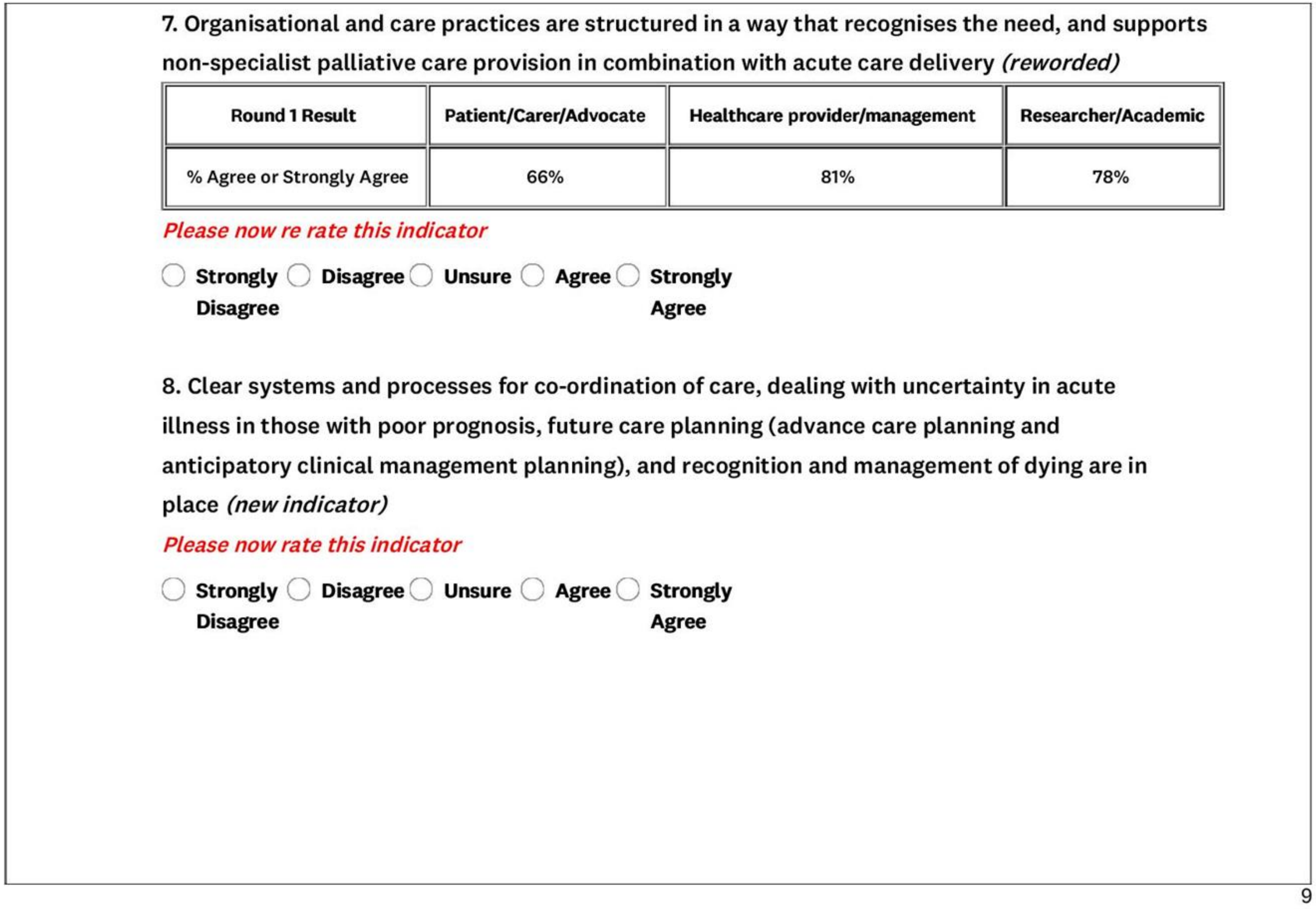
A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

Please read the instructions carefully, then rate each of the indicators below

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and not how they might be measured or implemented in practice as this is not the focus of the study

Organisation of Hospital Care Indicators - refers to clinical policies, guidelines and clinical care processes

Strongly Agree - if you think the indicator is essential for non-specialist palliative care to occur in hospital
Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital
Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital
Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital
Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital



7. Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery *(reworded)*

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	66%	81%	78%

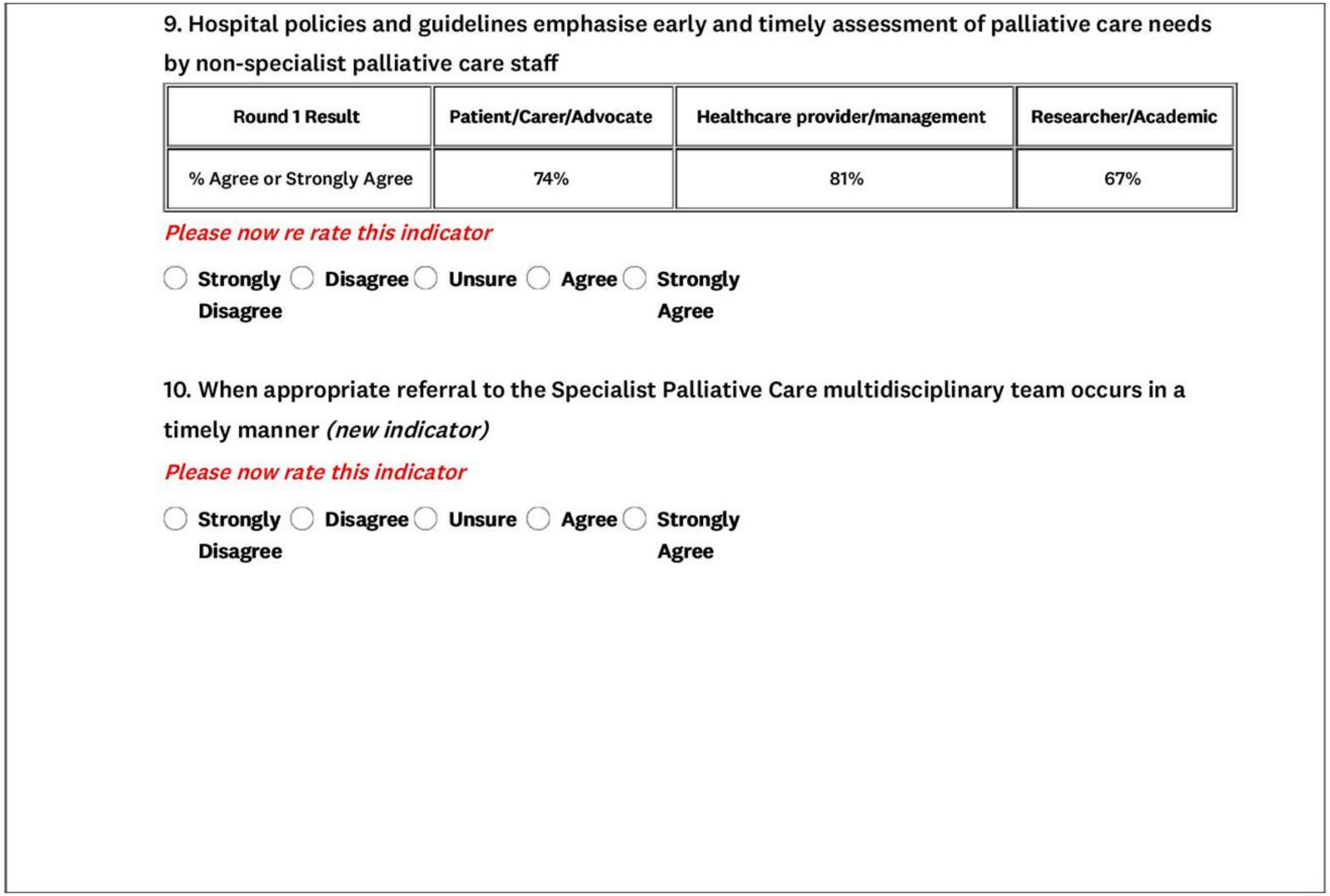
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

8. Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place *(new indicator)*

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



9. Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff

Round 1 Result	**Patient/Carer/Advocate**	**Healthcare provider/management**	**Researcher/Academic**
% Agree or Strongly Agree	74%	81%	67%

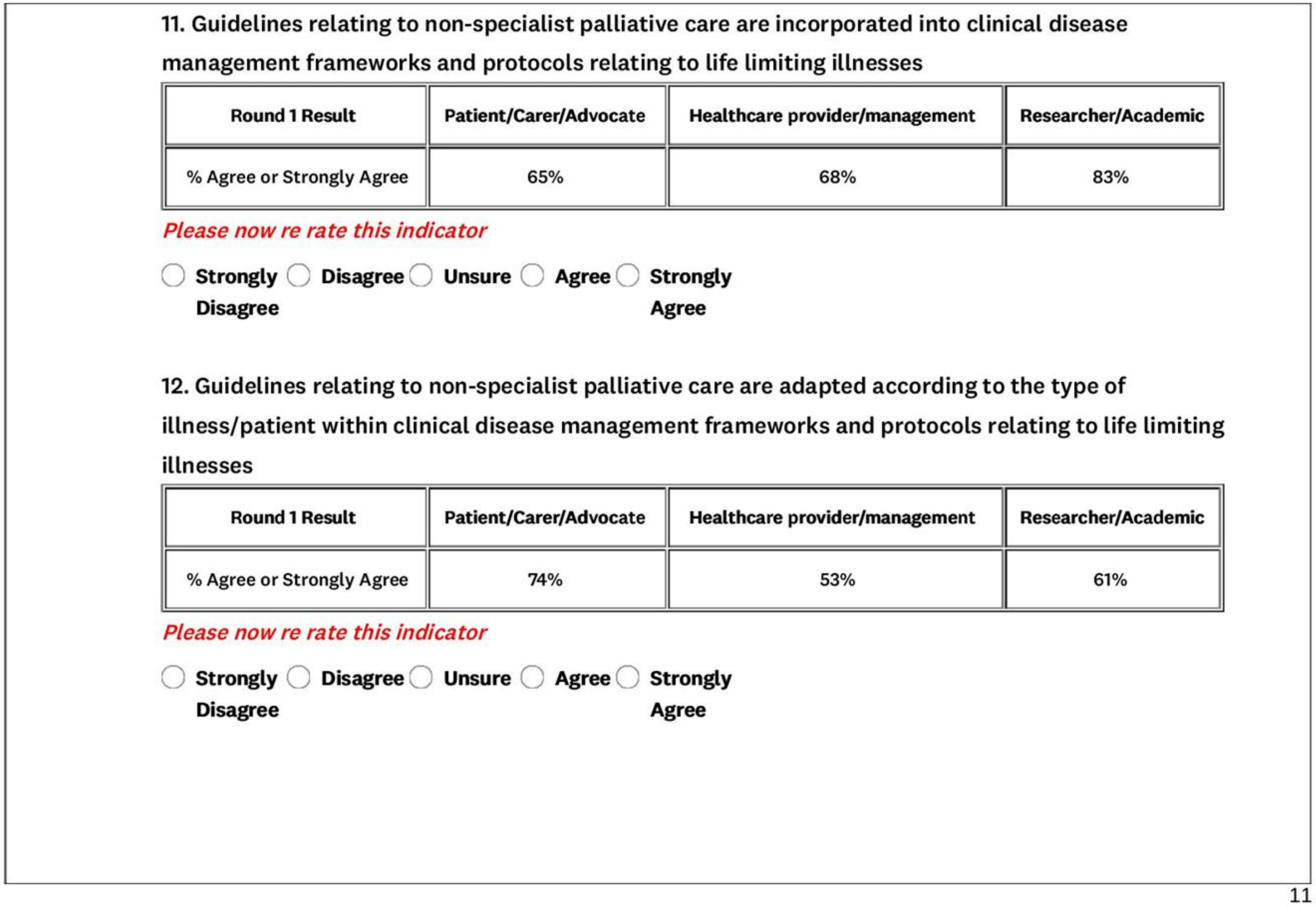
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

10. When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner ***(new indicator)***

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



11. Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	65%	68%	83%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

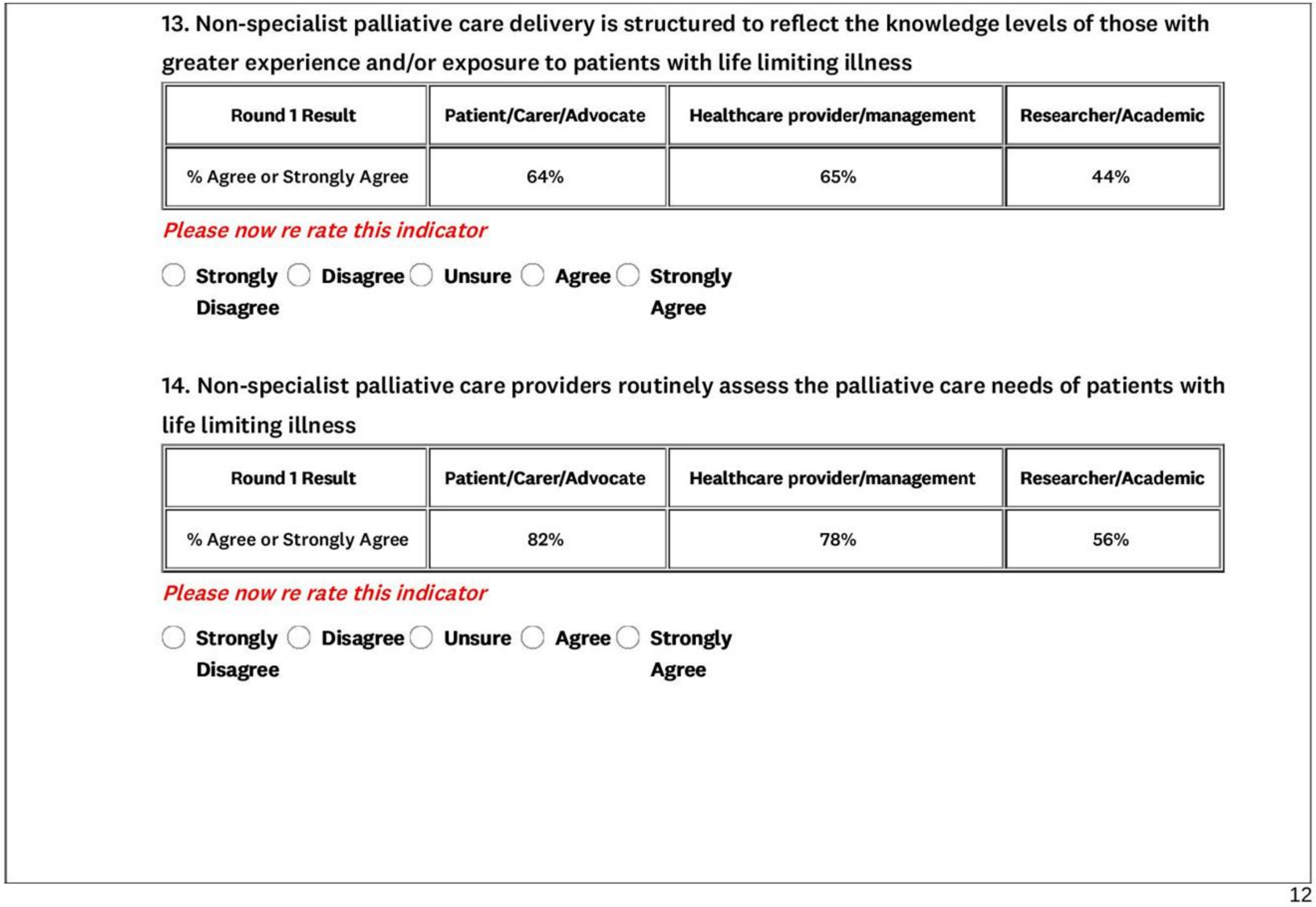
12. Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	74%	53%	61%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

11



13. Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	64%	65%	44%

Please now re rate this indicator

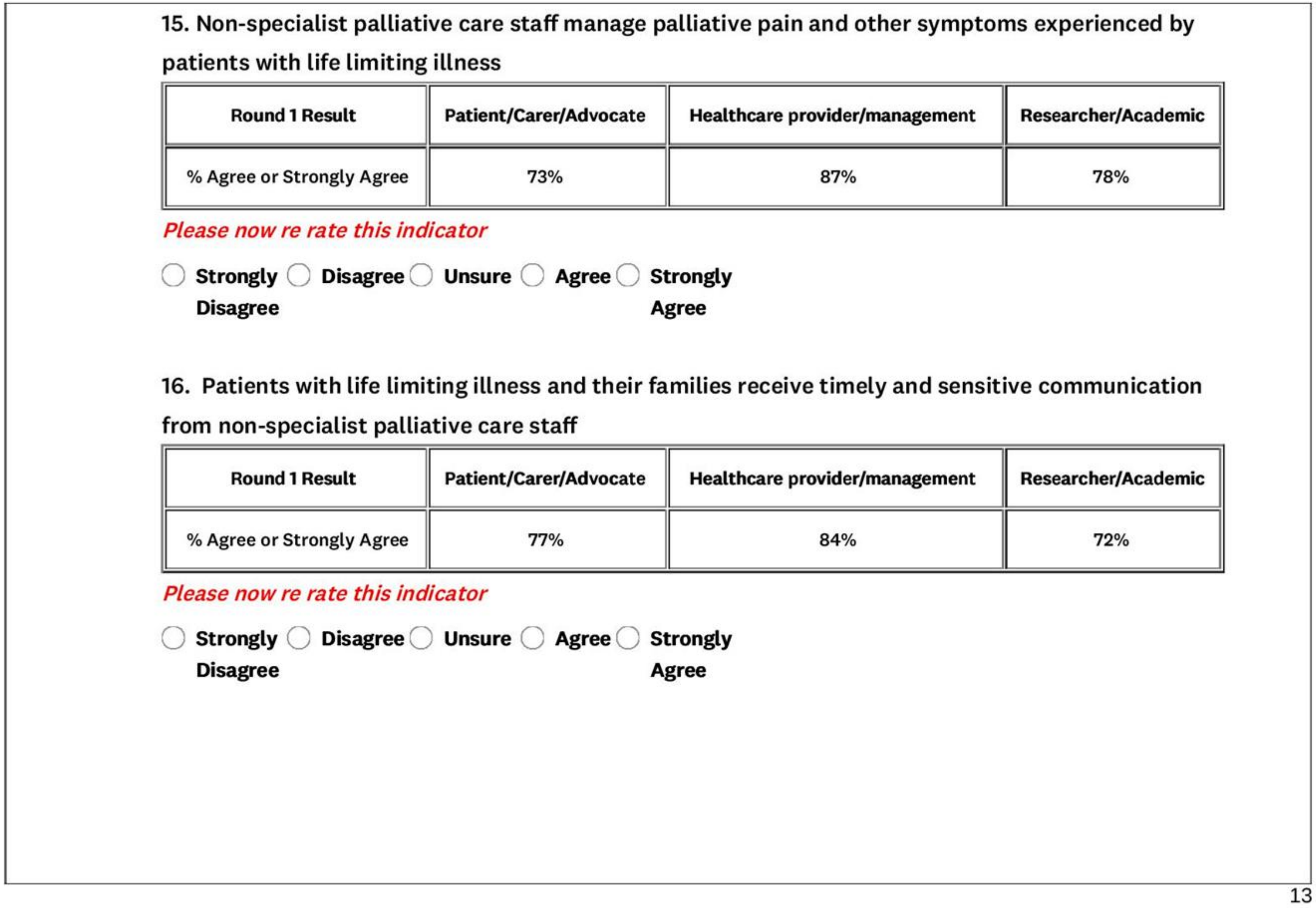
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

14. Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	82%	78%	56%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



15. Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	73%	87%	78%

Please now re rate this indicator

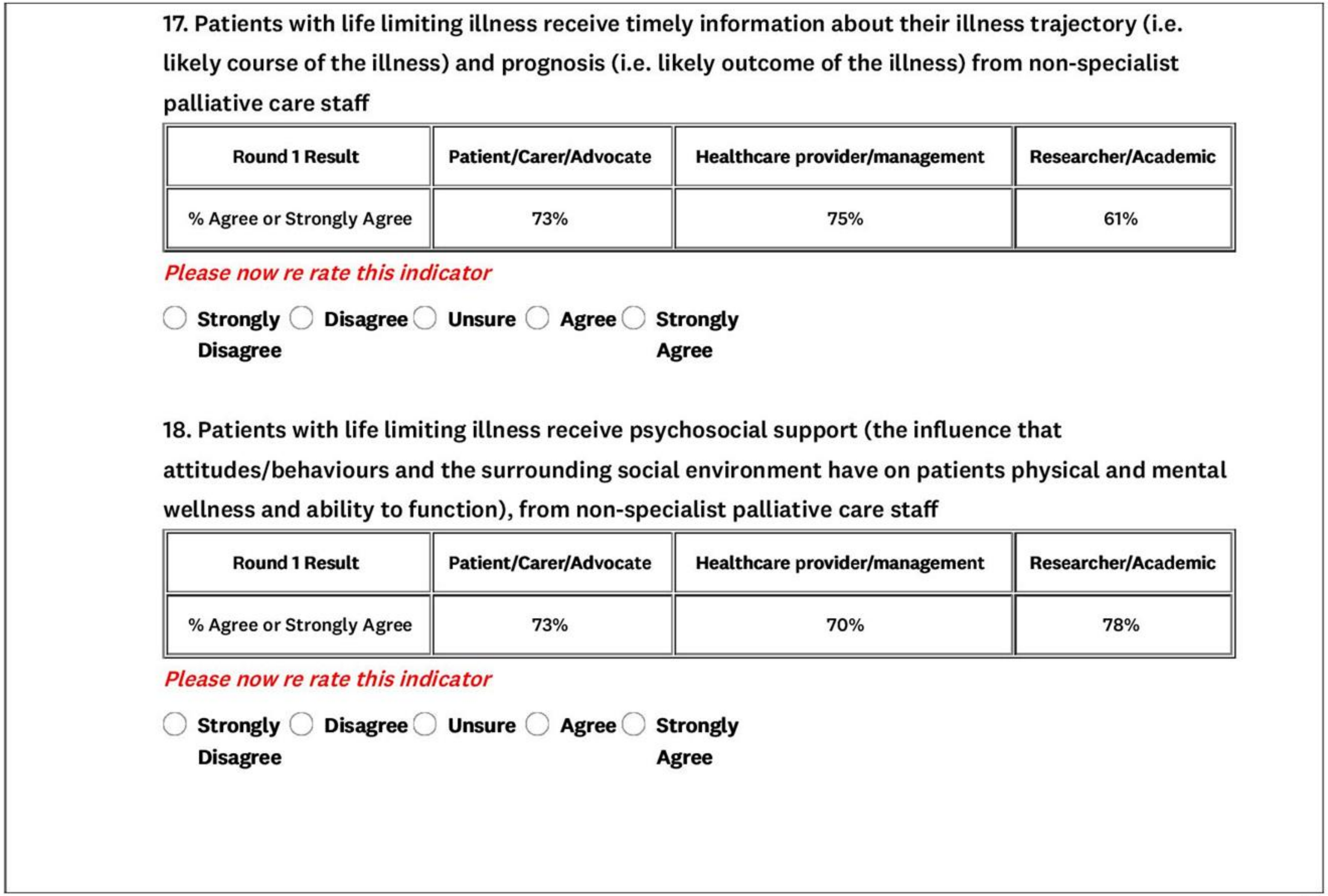
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

16. Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	77%	84%	72%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



17. Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	73%	75%	61%

Please now re rate this indicator

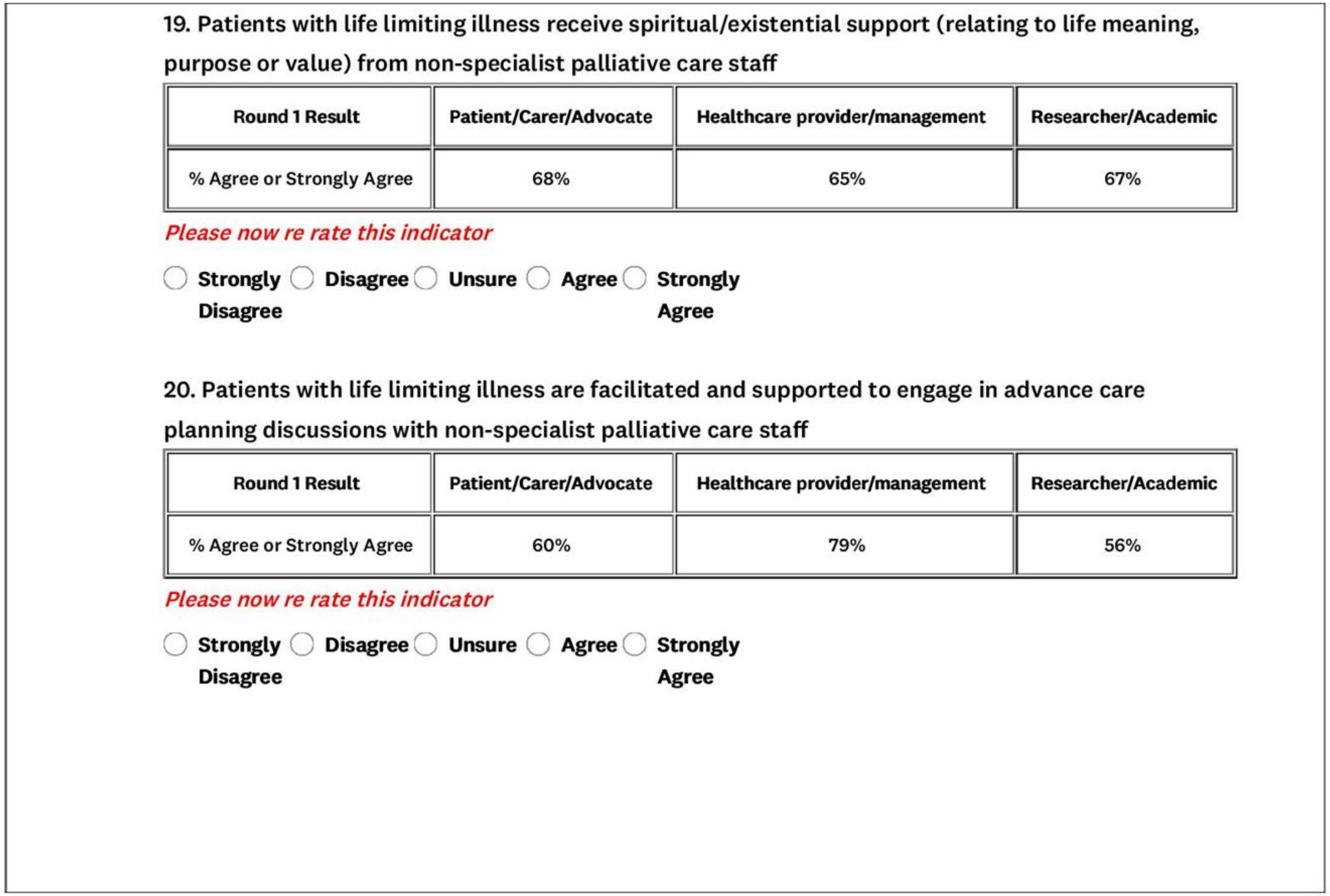
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

18. Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	73%	70%	78%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



19. Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	68%	65%	67%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

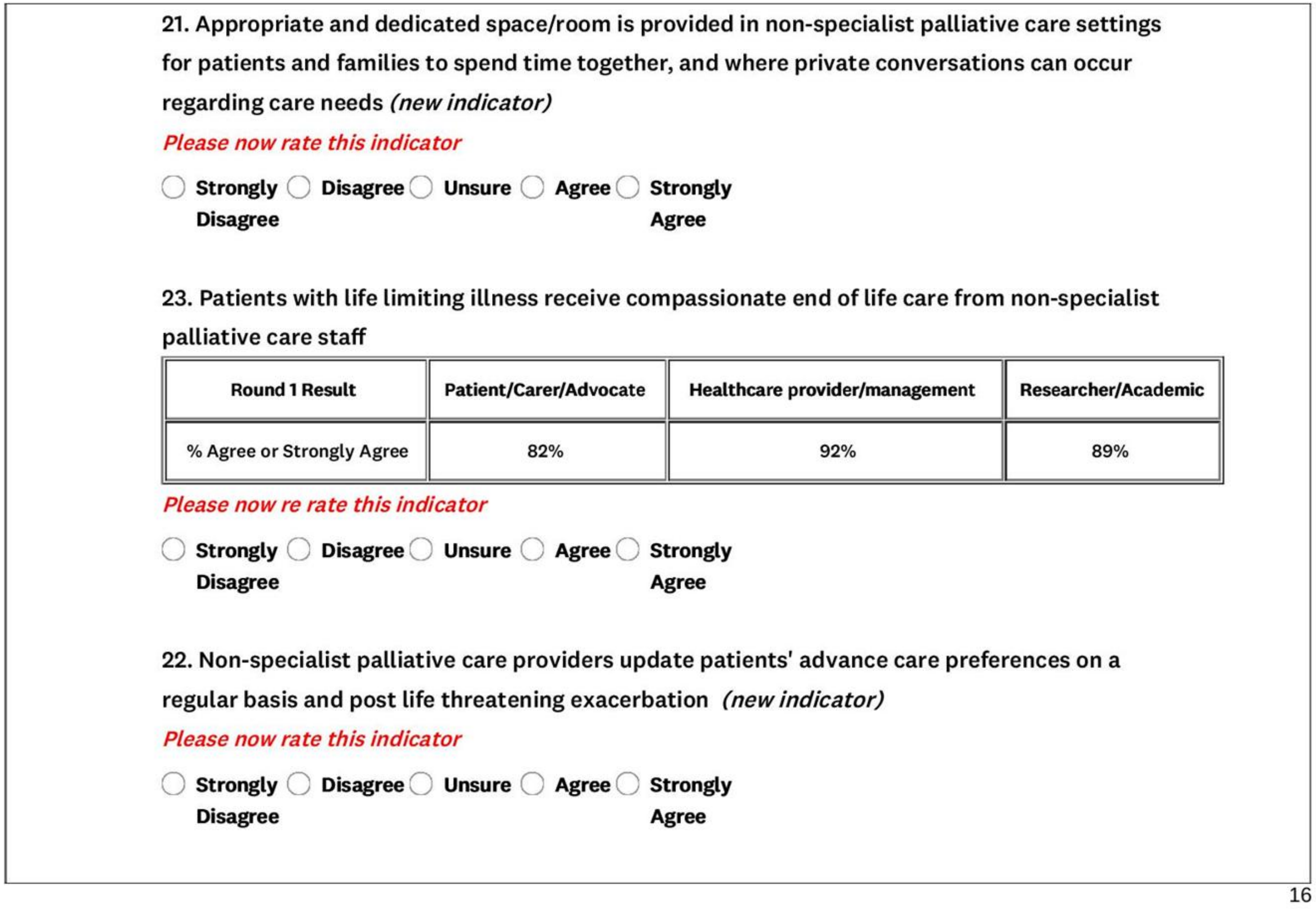
20. Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	60%	79%	56%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

15



21. Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs *(new indicator)*

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

23. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	82%	92%	89%

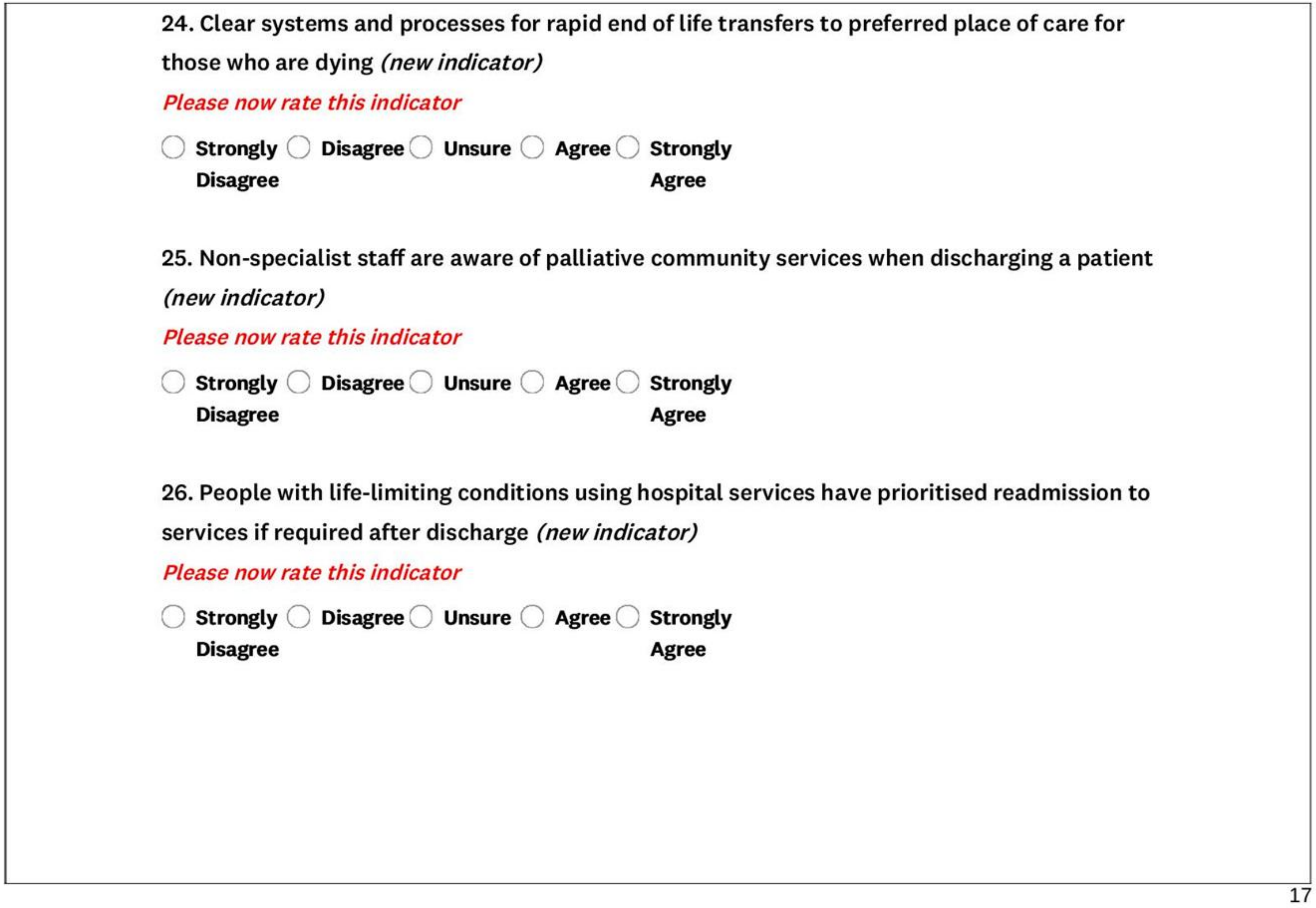
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

22. Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation *(new indicator)*

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



24. Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying ***(new indicator)***

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

25. Non-specialist staff are aware of palliative community services when discharging a patient ***(new indicator)***

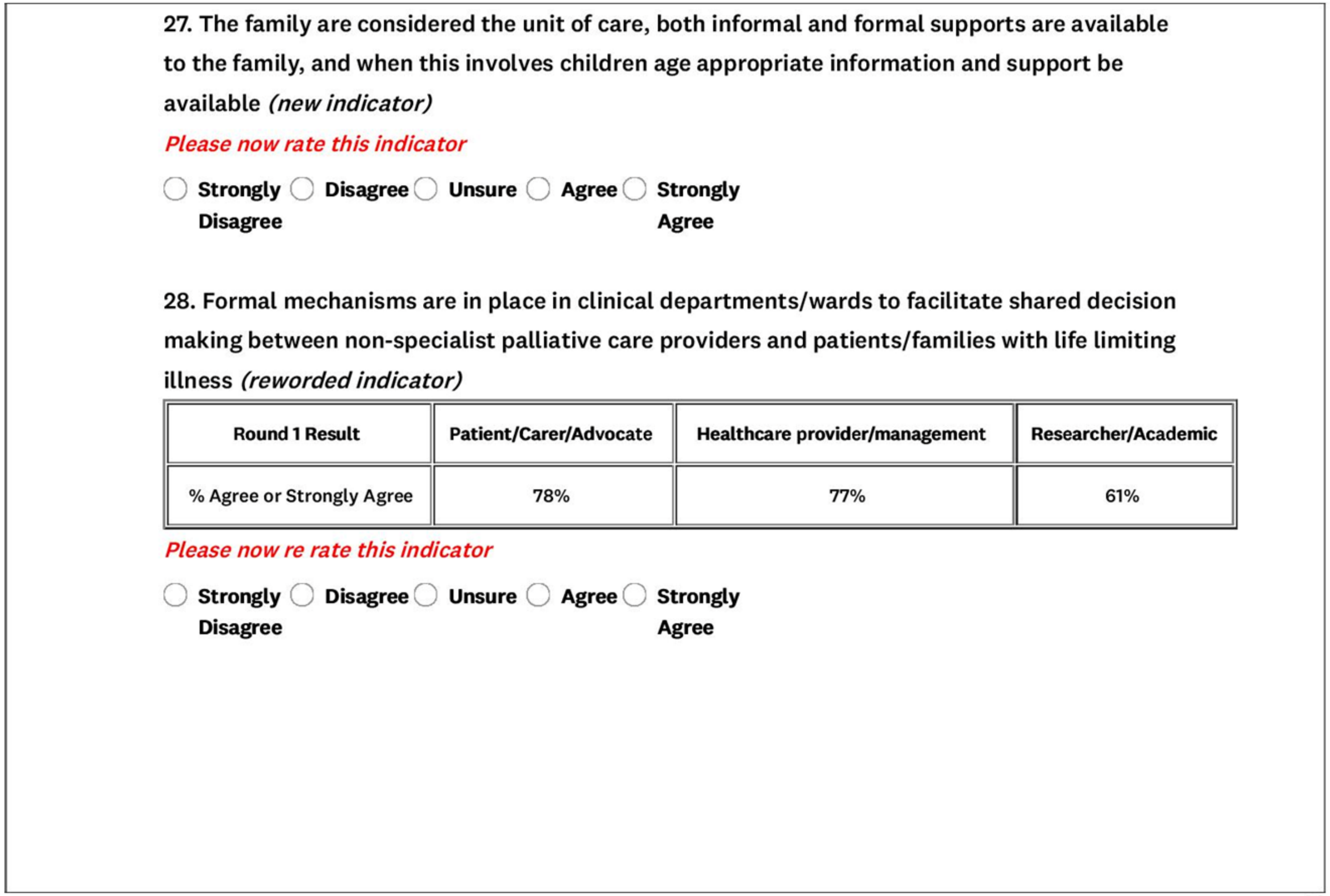
Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

26. People with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge ***(new indicator)***

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



27. The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available ***(new indicator)***

Please now rate this indicator

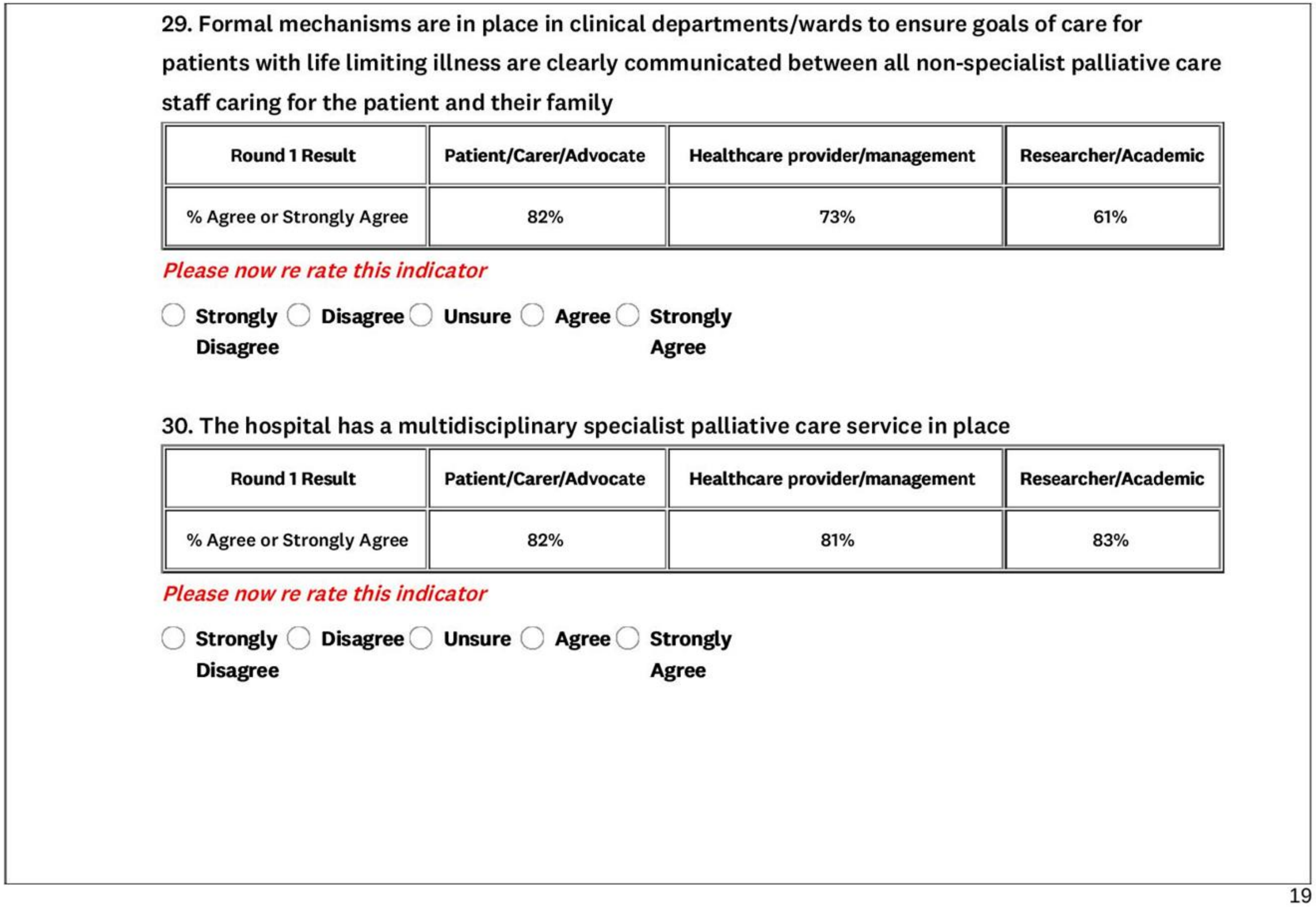
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

28. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness ***(reworded indicator)***

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	78%	77%	61%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



29. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	82%	73%	61%

Please now re rate this indicator

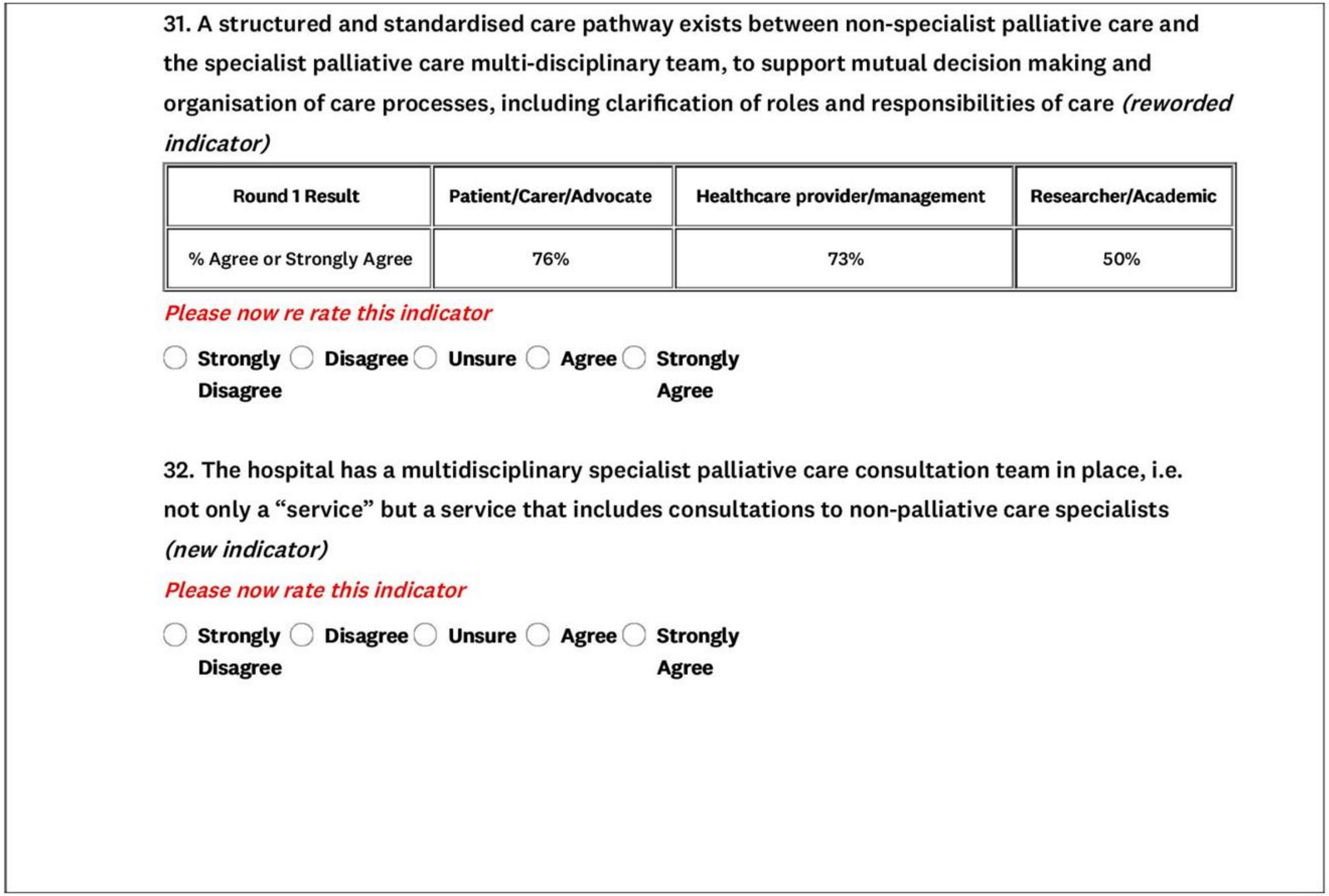
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

30. The hospital has a multidisciplinary specialist palliative care service in place

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	82%	81%	83%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



31. A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care *(reworded indicator)*

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	76%	73%	50%

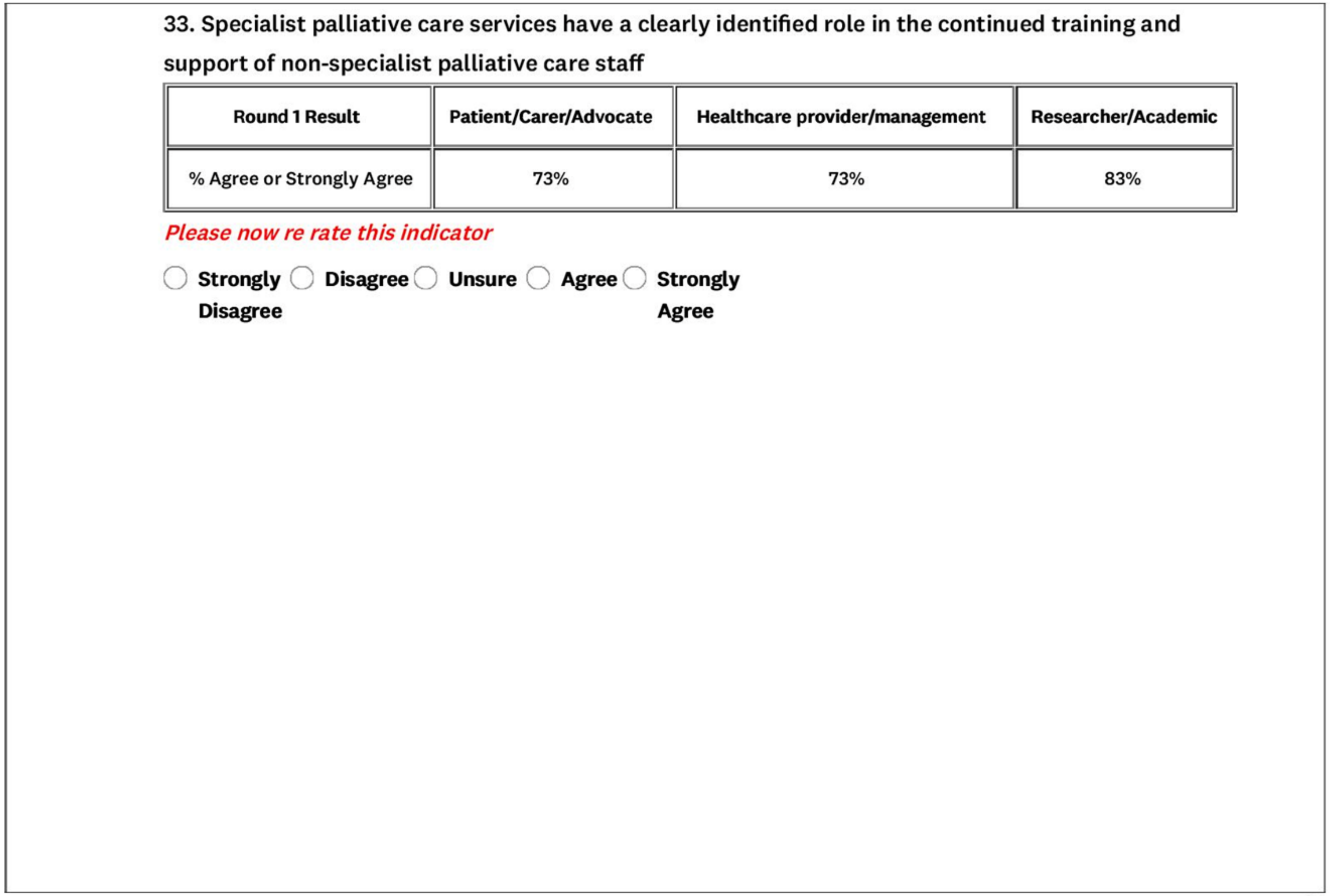
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

32. The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a "service" but a service that includes consultations to non-palliative care specialists *(new indicator)*

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

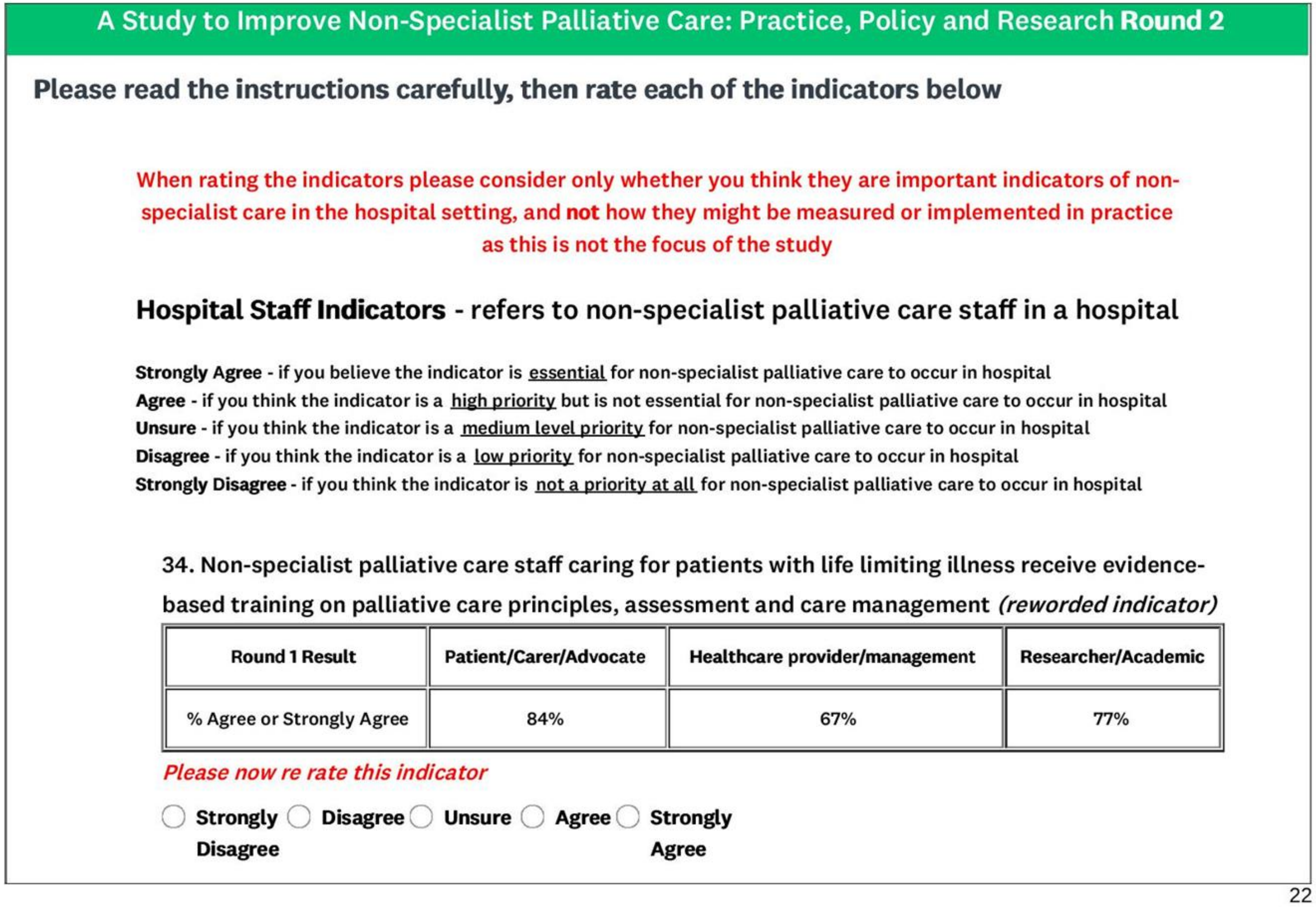


33. Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	73%	73%	83%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

Please read the instructions carefully, then rate each of the indicators below

When rating the indicators please consider only whether you think they are important indicators of non-specialist care in the hospital setting, and not how they might be measured or implemented in practice as this is not the focus of the study

Hospital Staff Indicators - refers to non-specialist palliative care staff in a hospital

Strongly Agree - if you believe the indicator is essential for non-specialist palliative care to occur in hospital
Agree - if you think the indicator is a high priority but is not essential for non-specialist palliative care to occur in hospital
Unsure - if you think the indicator is a medium level priority for non-specialist palliative care to occur in hospital
Disagree - if you think the indicator is a low priority for non-specialist palliative care to occur in hospital
Strongly Disagree - if you think the indicator is not a priority at all for non-specialist palliative care to occur in hospital

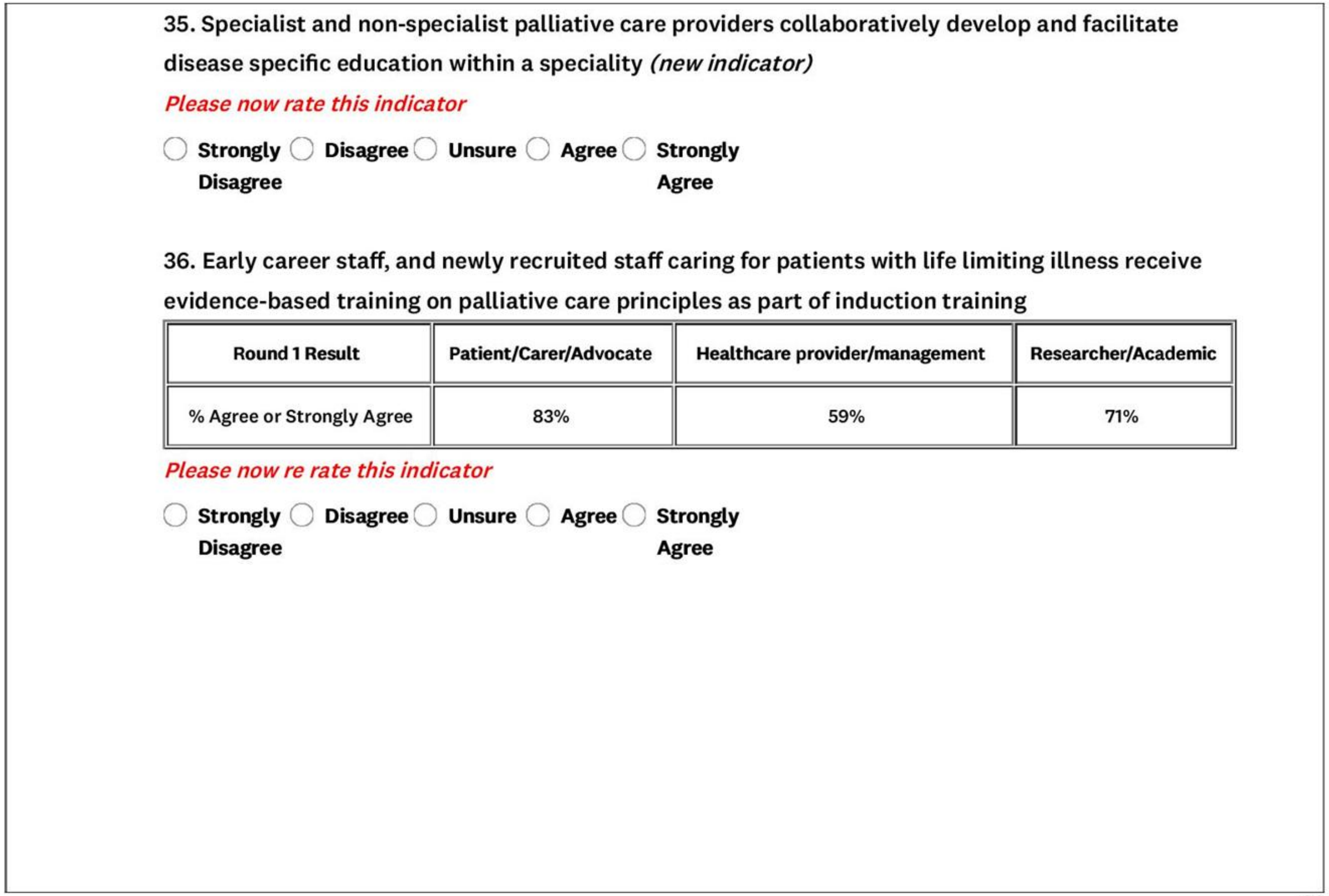
34. Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management *(reworded indicator)*

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	84%	67%	77%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

22



35. Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality ***(new indicator)***

Please now rate this indicator

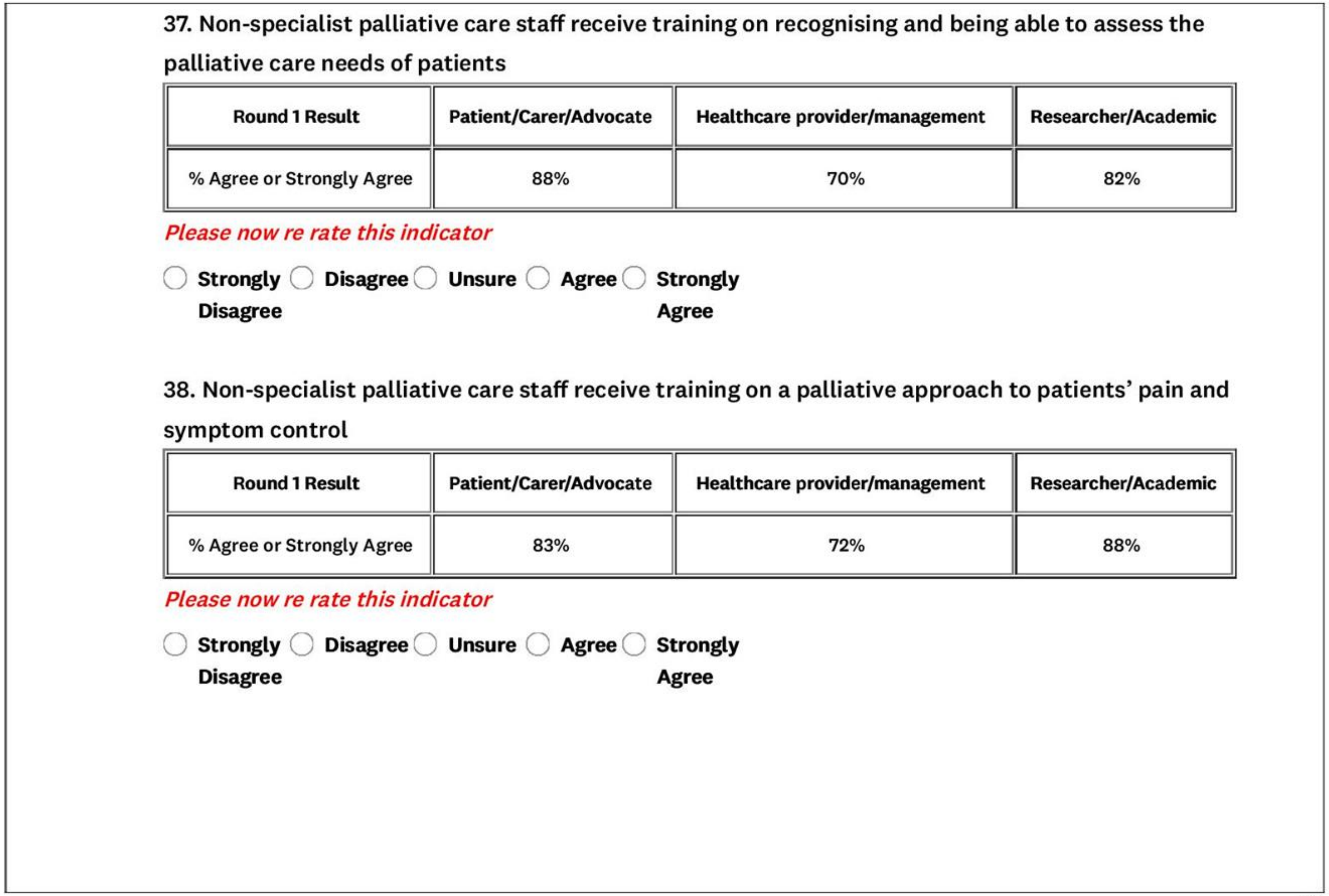
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

36. Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	83%	59%	71%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



37. Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	88%	70%	82%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

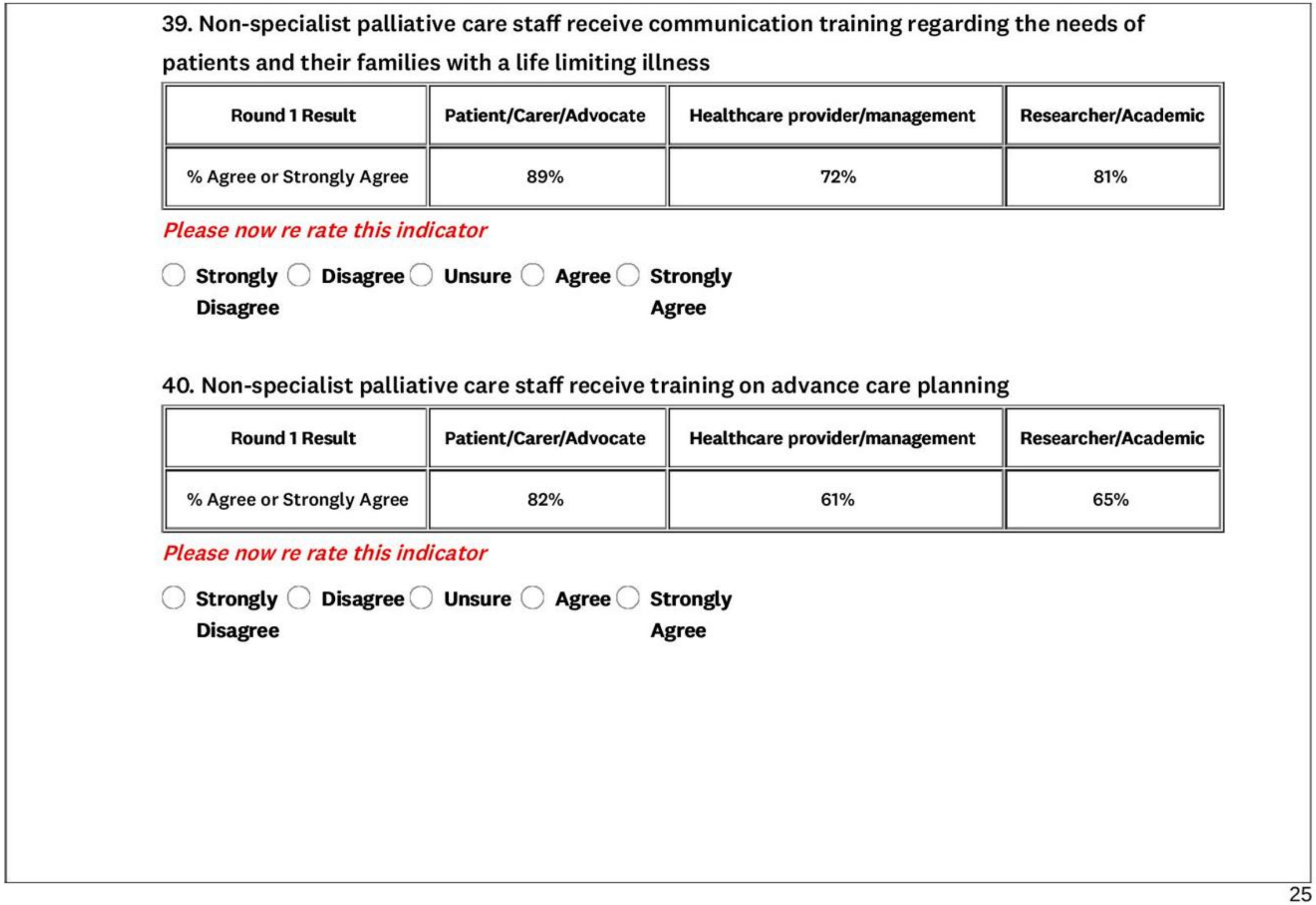
38. Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	83%	72%	88%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

24



39. Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	89%	72%	81%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

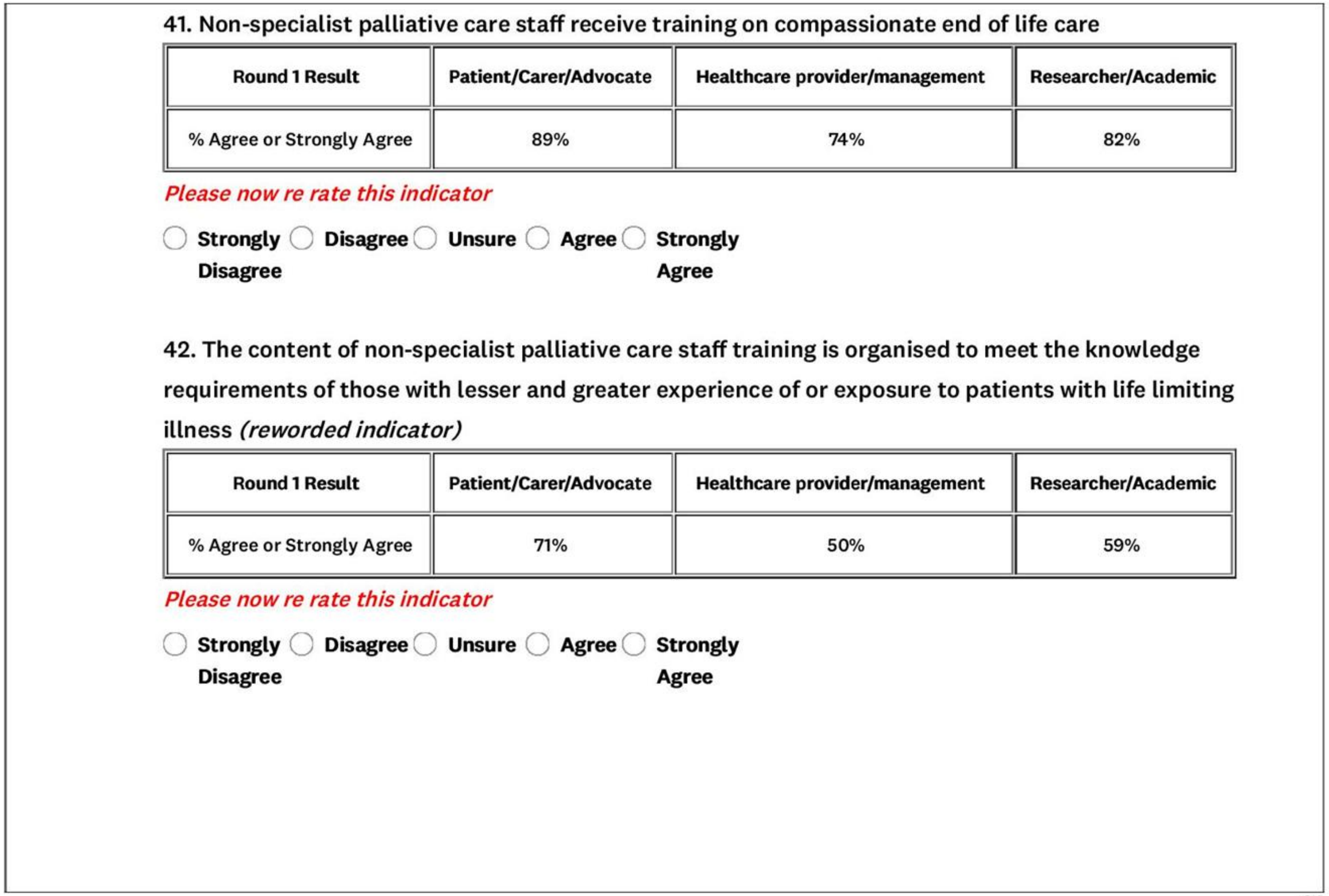
40. Non-specialist palliative care staff receive training on advance care planning

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	82%	61%	65%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

25



41. Non-specialist palliative care staff receive training on compassionate end of life care

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	89%	74%	82%

Please now re rate this indicator

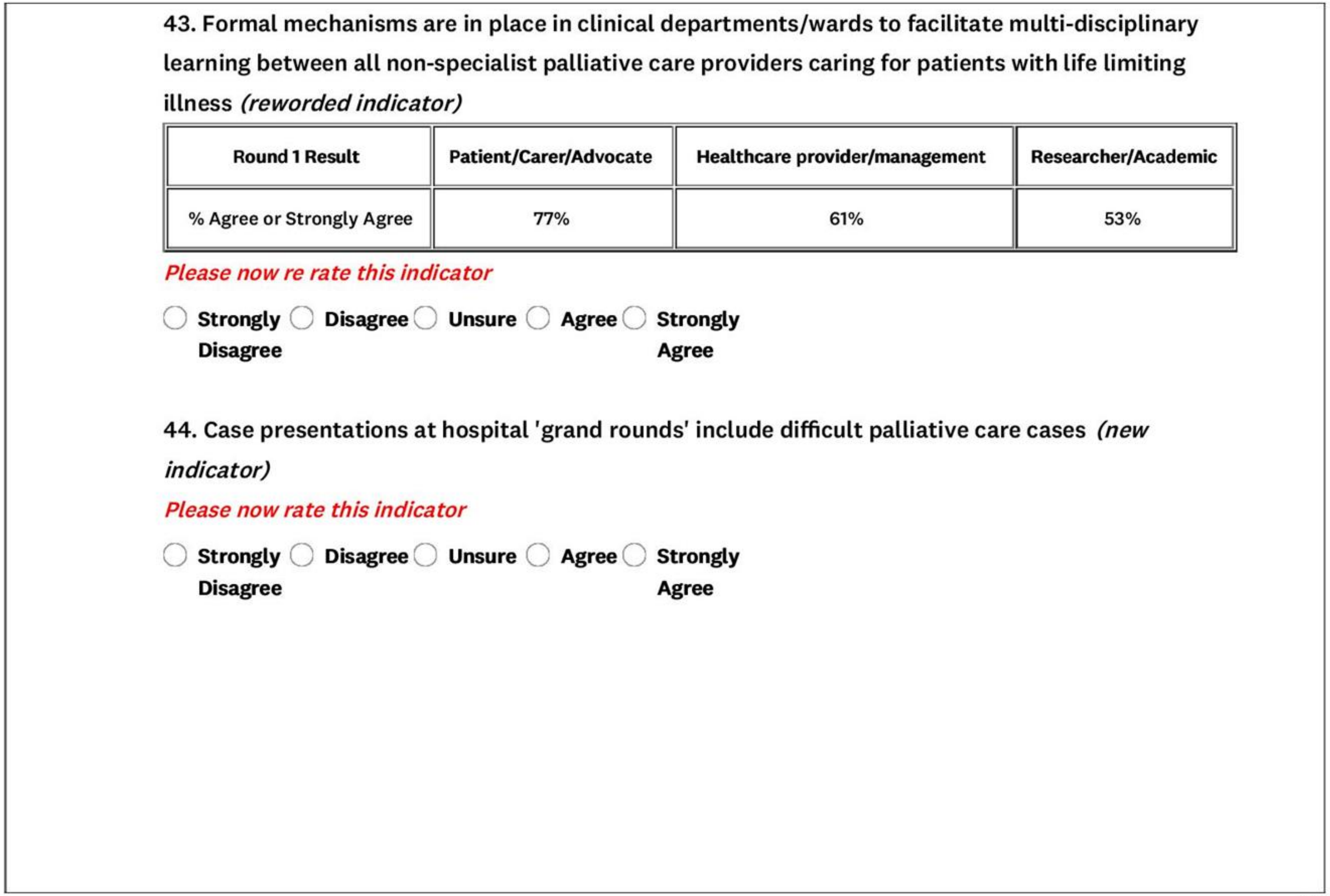
○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

42. The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with lesser and greater experience of or exposure to patients with life limiting illness ***(reworded indicator)***

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	71%	50%	59%

Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



43. Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness ***(reworded indicator)***

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	77%	61%	53%

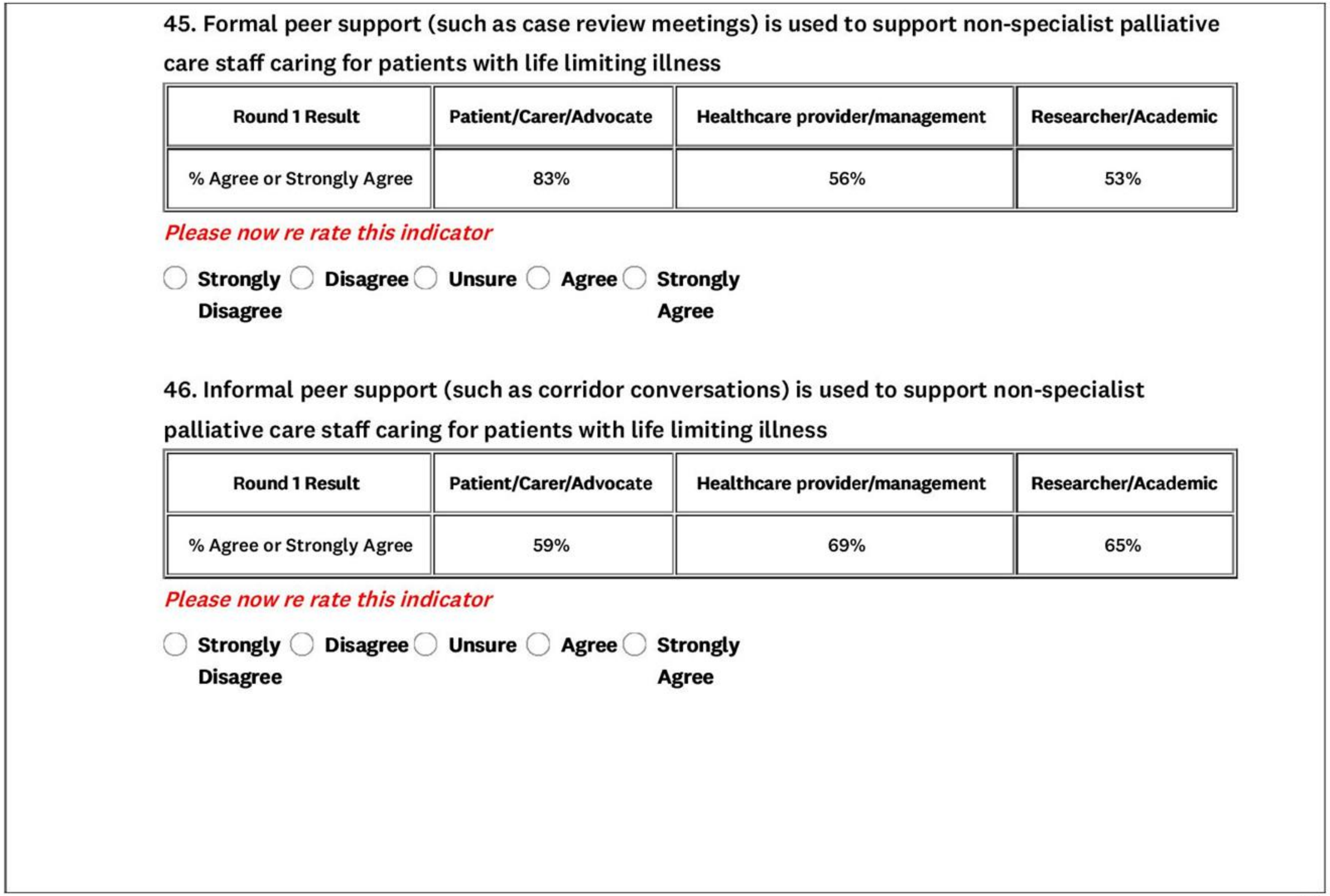
Please now re rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**

44. Case presentations at hospital 'grand rounds' include difficult palliative care cases ***(new indicator)***

Please now rate this indicator

○ **Strongly Disagree** ○ **Disagree** ○ **Unsure** ○ **Agree** ○ **Strongly Agree**



45. Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	83%	56%	53%

Please now re rate this indicator

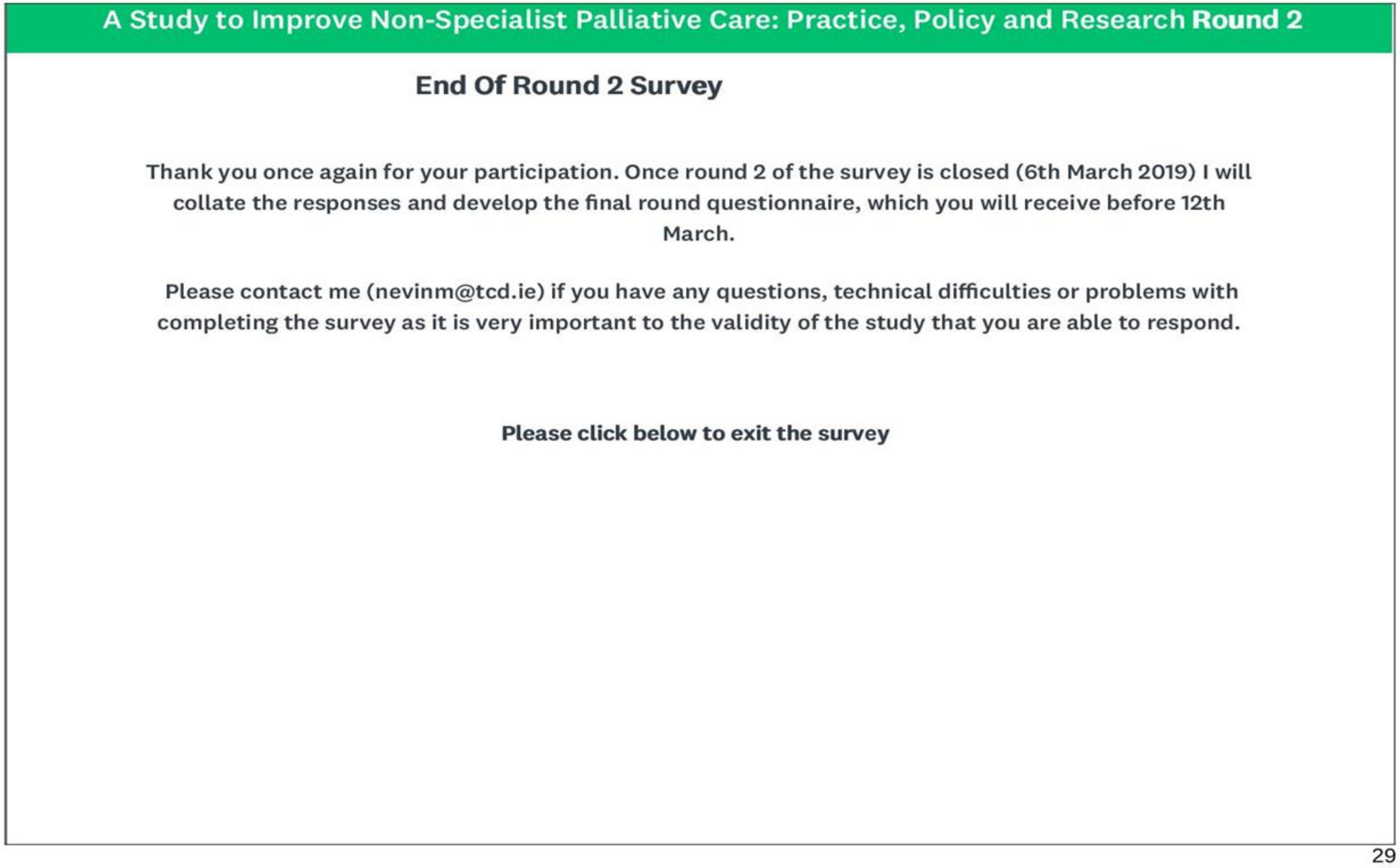
○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree

46. Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness

Round 1 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	59%	69%	65%

Please now re rate this indicator

○ Strongly Disagree ○ Disagree ○ Unsure ○ Agree ○ Strongly Agree



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research **Round 2**

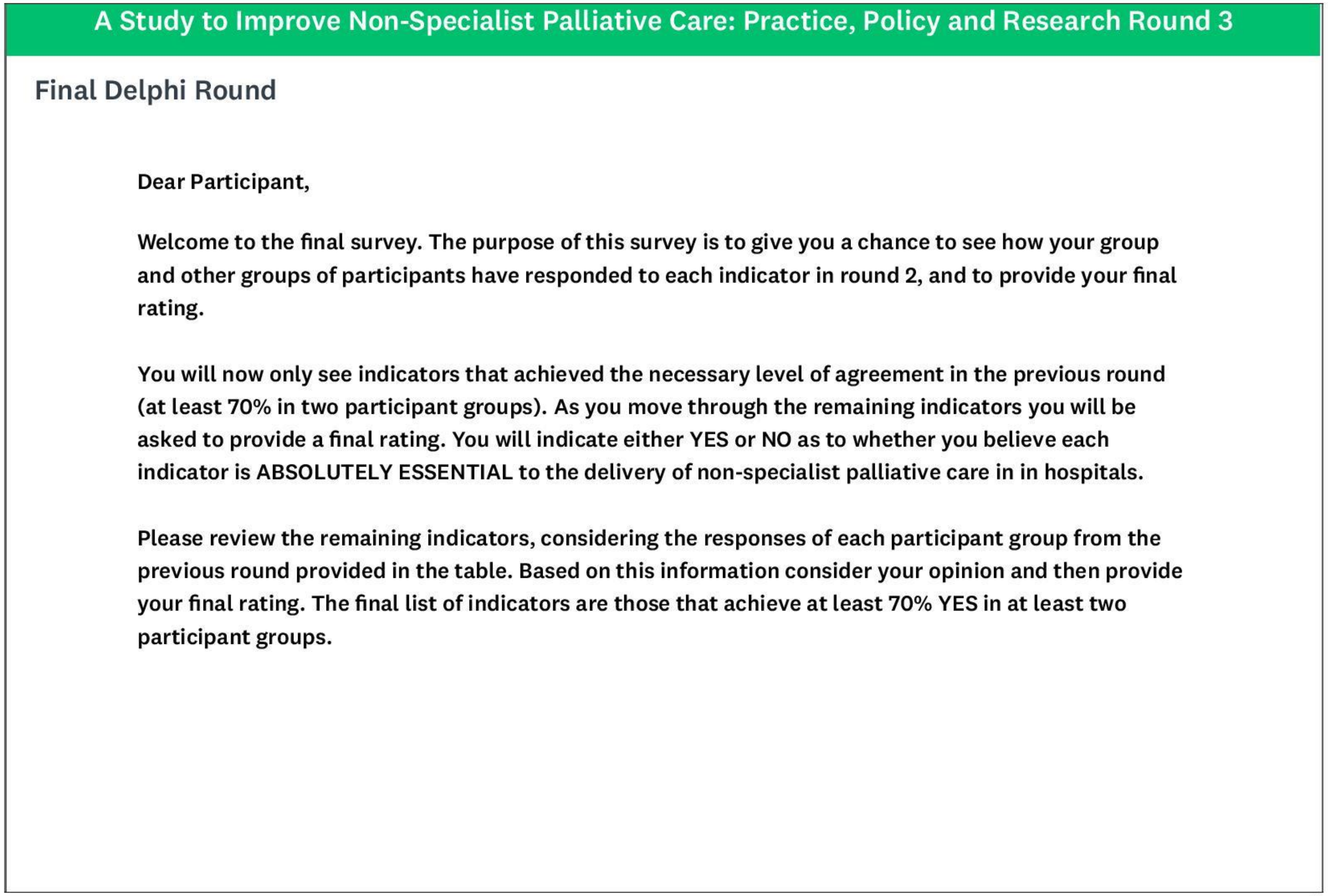
End Of Round 2 Survey

Thank you once again for your participation. Once round 2 of the survey is closed (6th March 2019) I will collate the responses and develop the final round questionnaire, which you will receive before 12th March.

Please contact me (nevinm@tcd.ie) if you have any questions, technical difficulties or problems with completing the survey as it is very important to the validity of the study that you are able to respond.

Please click below to exit the survey

Appendix 19 Round 3 Delphi survey



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

Final Delphi Round

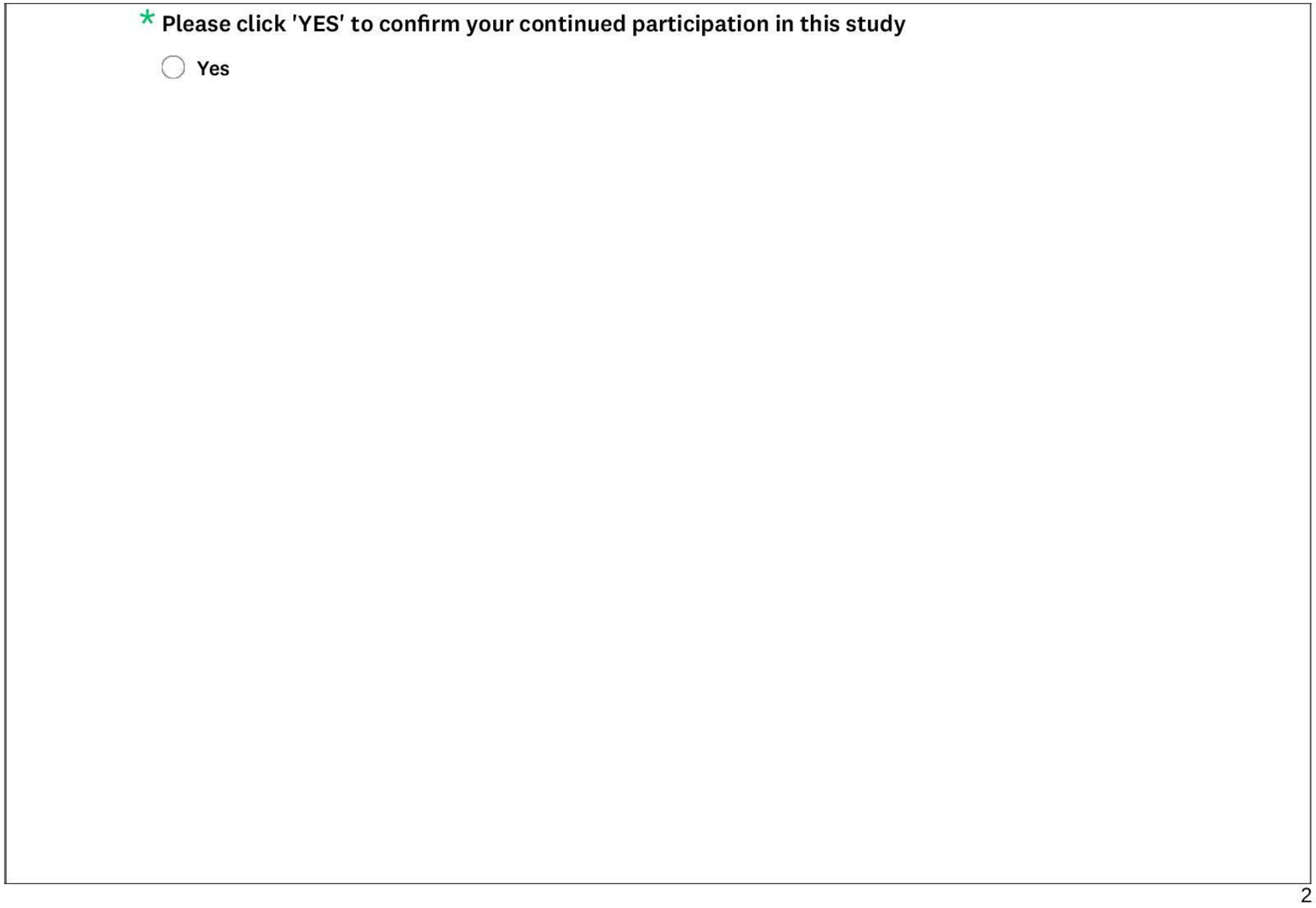
Dear Participant,

Welcome to the final survey. The purpose of this survey is to give you a chance to see how your group and other groups of participants have responded to each indicator in round 2, and to provide your final rating.

You will now only see indicators that achieved the necessary level of agreement in the previous round (at least 70% in two participant groups). As you move through the remaining indicators you will be asked to provide a final rating. You will indicate either YES or NO as to whether you believe each indicator is ABSOLUTELY ESSENTIAL to the delivery of non-specialist palliative care in in hospitals.

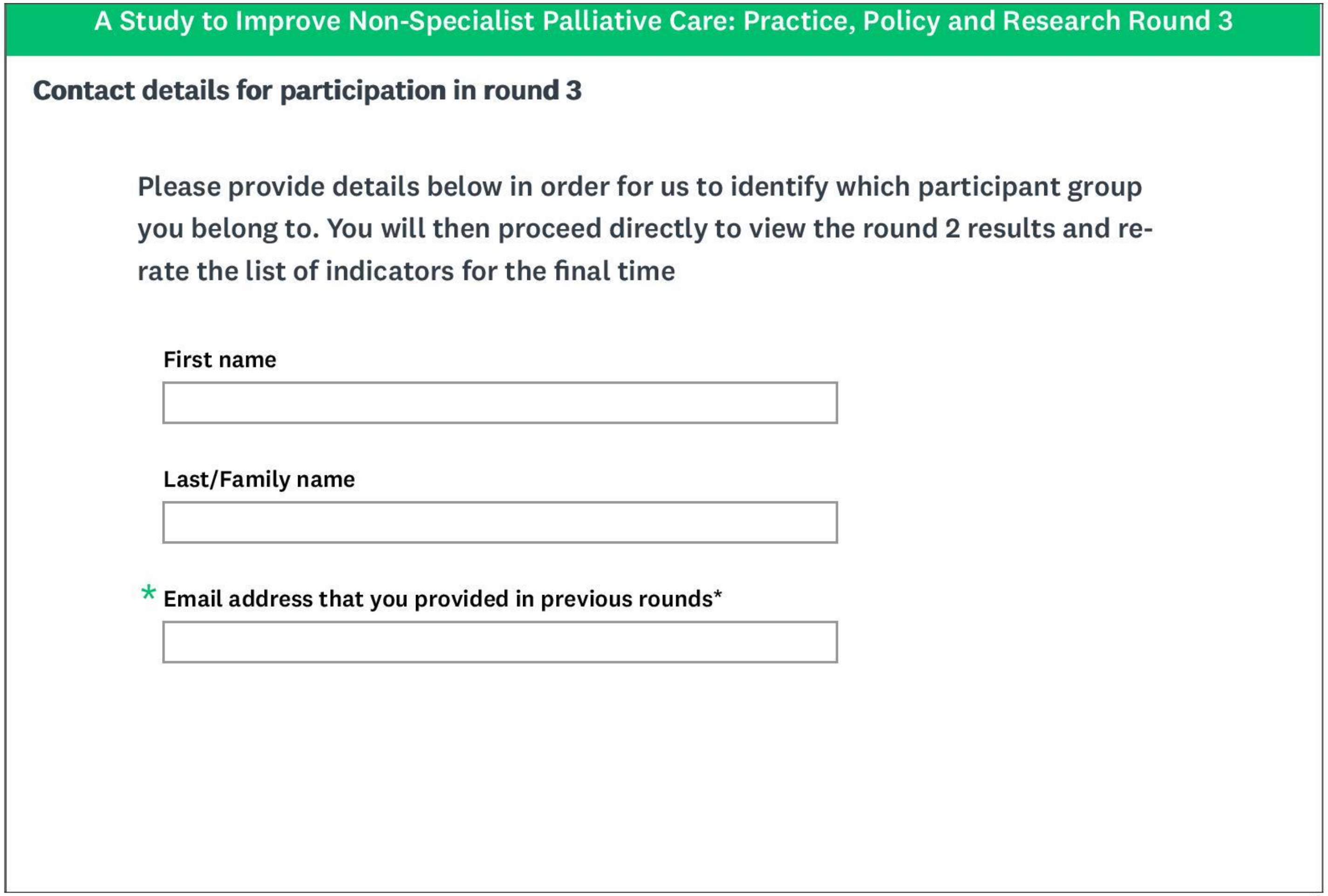
Please review the remaining indicators, considering the responses of each participant group from the previous round provided in the table. Based on this information consider your opinion and then provide your final rating. The final list of indicators are those that achieve at least 70% YES in at least two participant groups.

1



* Please click 'YES' to confirm your continued participation in this study

○ Yes



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

Contact details for participation in round 3

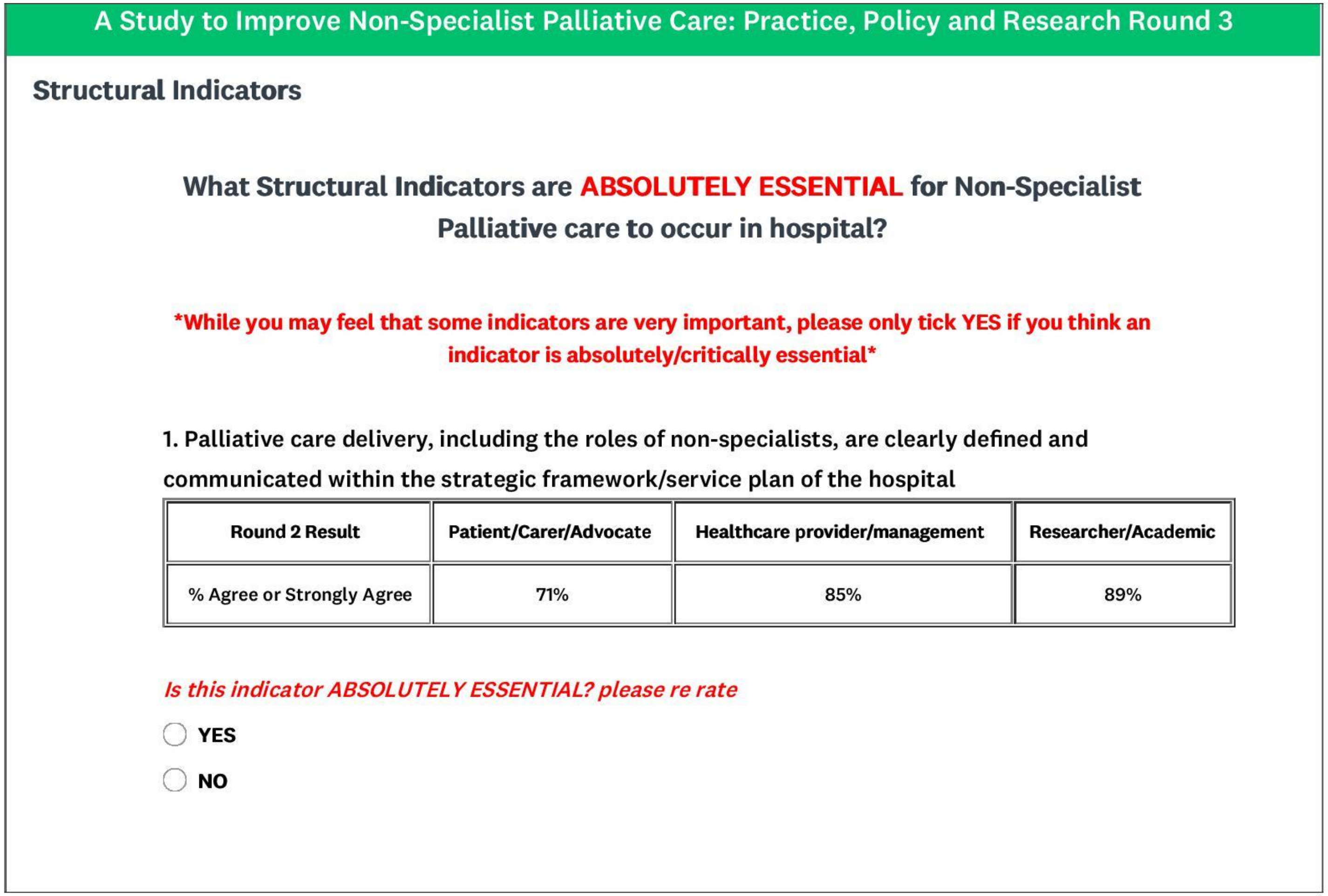
Please provide details below in order for us to identify which participant group you belong to. You will then proceed directly to view the round 2 results and re-rate the list of indicators for the final time

First name

Last/Family name

* Email address that you provided in previous rounds*

3



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

Structural Indicators

What Structural Indicators are ABSOLUTELY ESSENTIAL for Non-Specialist Palliative care to occur in hospital?

While you may feel that some indicators are very important, please only tick YES if you think an indicator is absolutely/critically essential

1. Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital

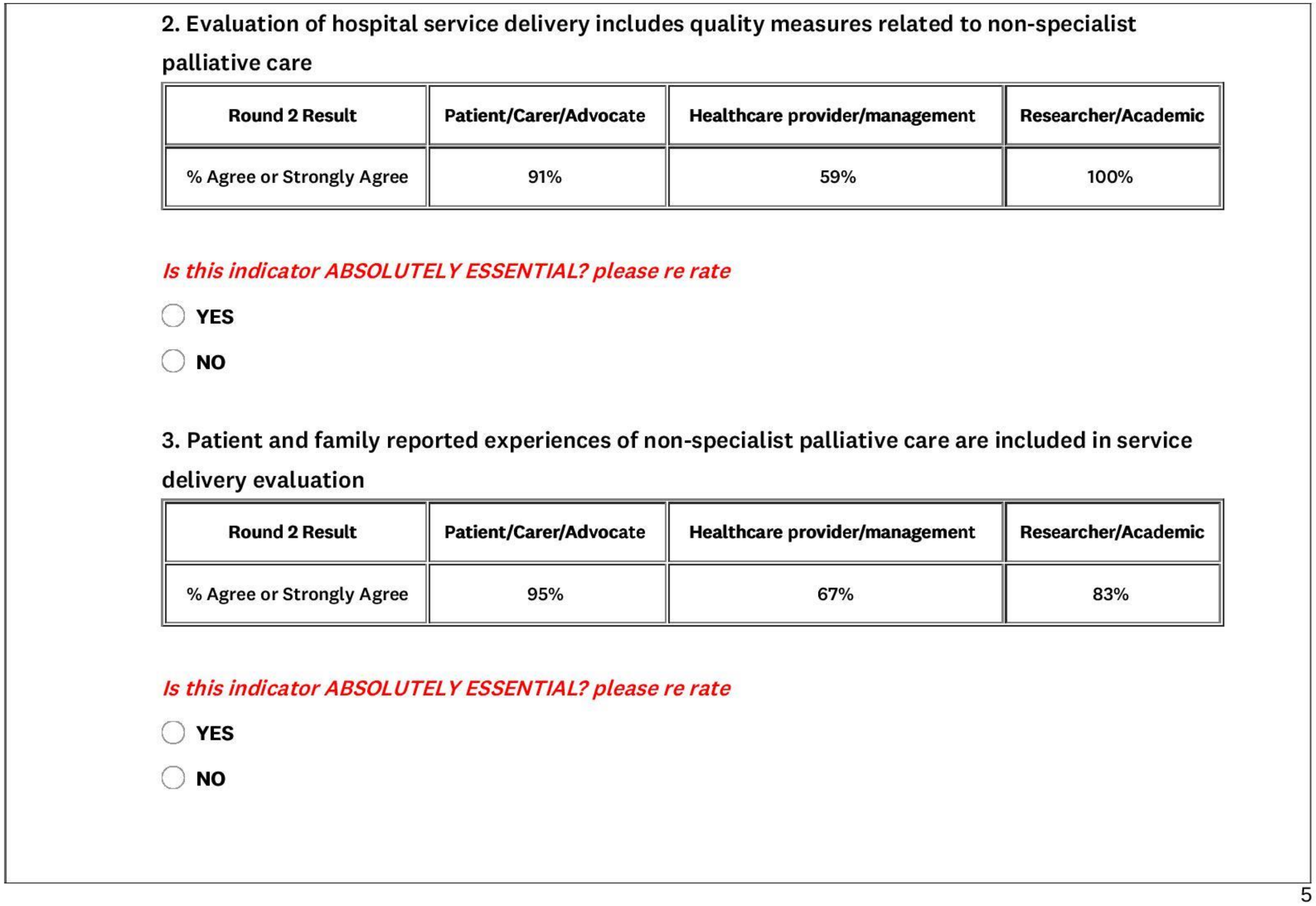
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	71%	85%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

4



2. Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	91%	59%	100%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

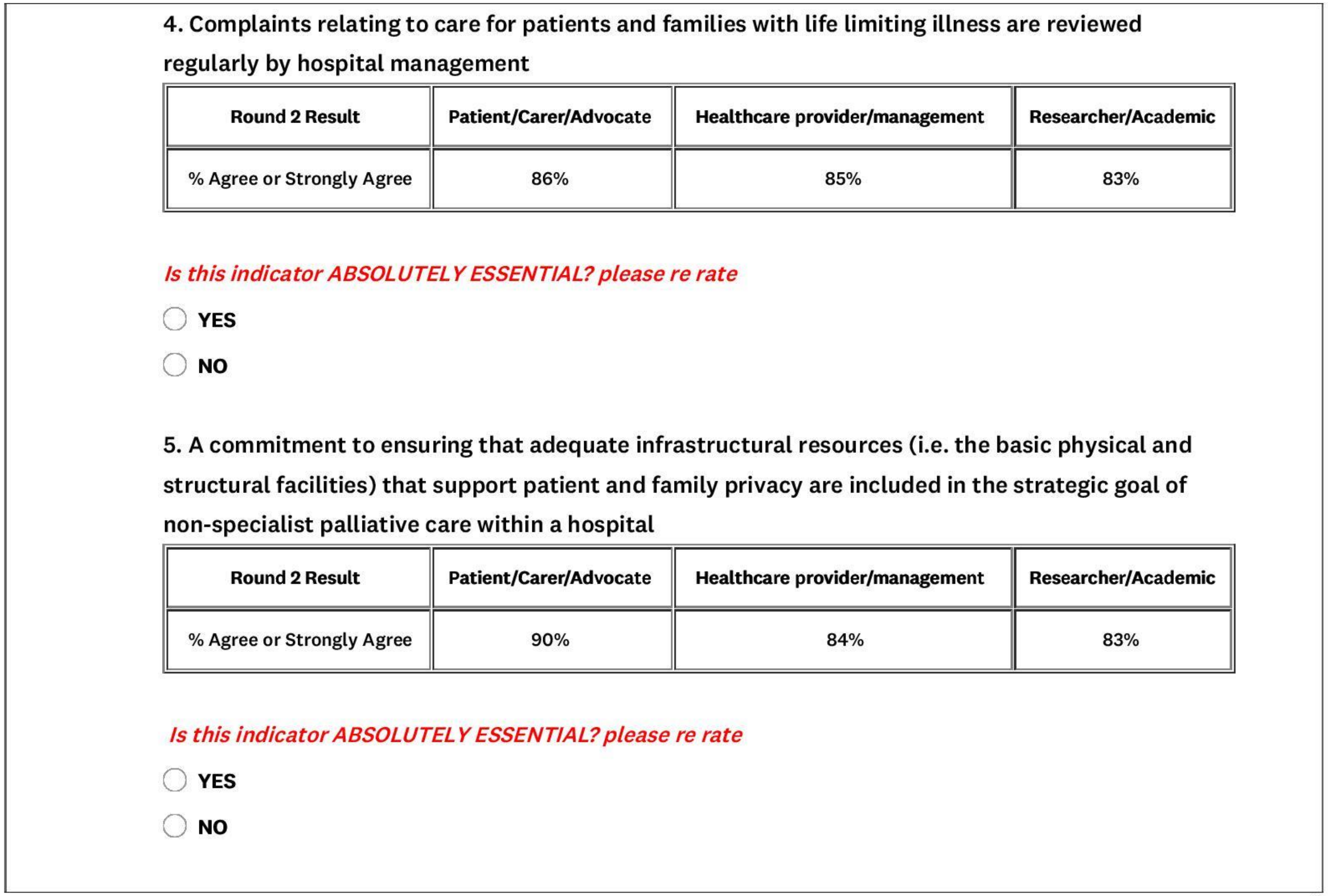
3. Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	95%	67%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



4. Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	86%	85%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

5. A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital

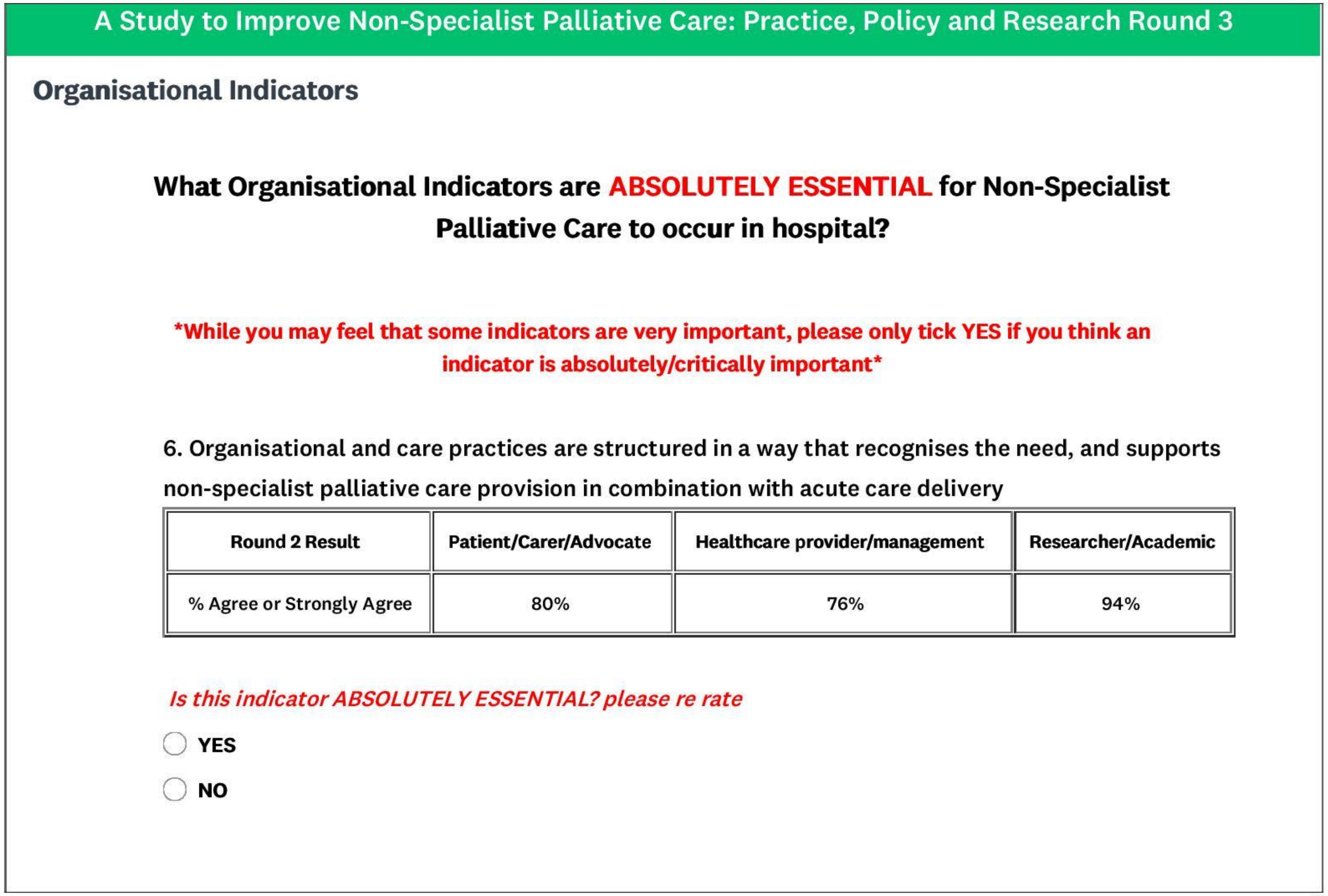
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	84%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

6



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

Organisational Indicators

What Organisational Indicators are ABSOLUTELY ESSENTIAL for Non-Specialist Palliative Care to occur in hospital?

While you may feel that some indicators are very important, please only tick YES if you think an indicator is absolutely/critically important

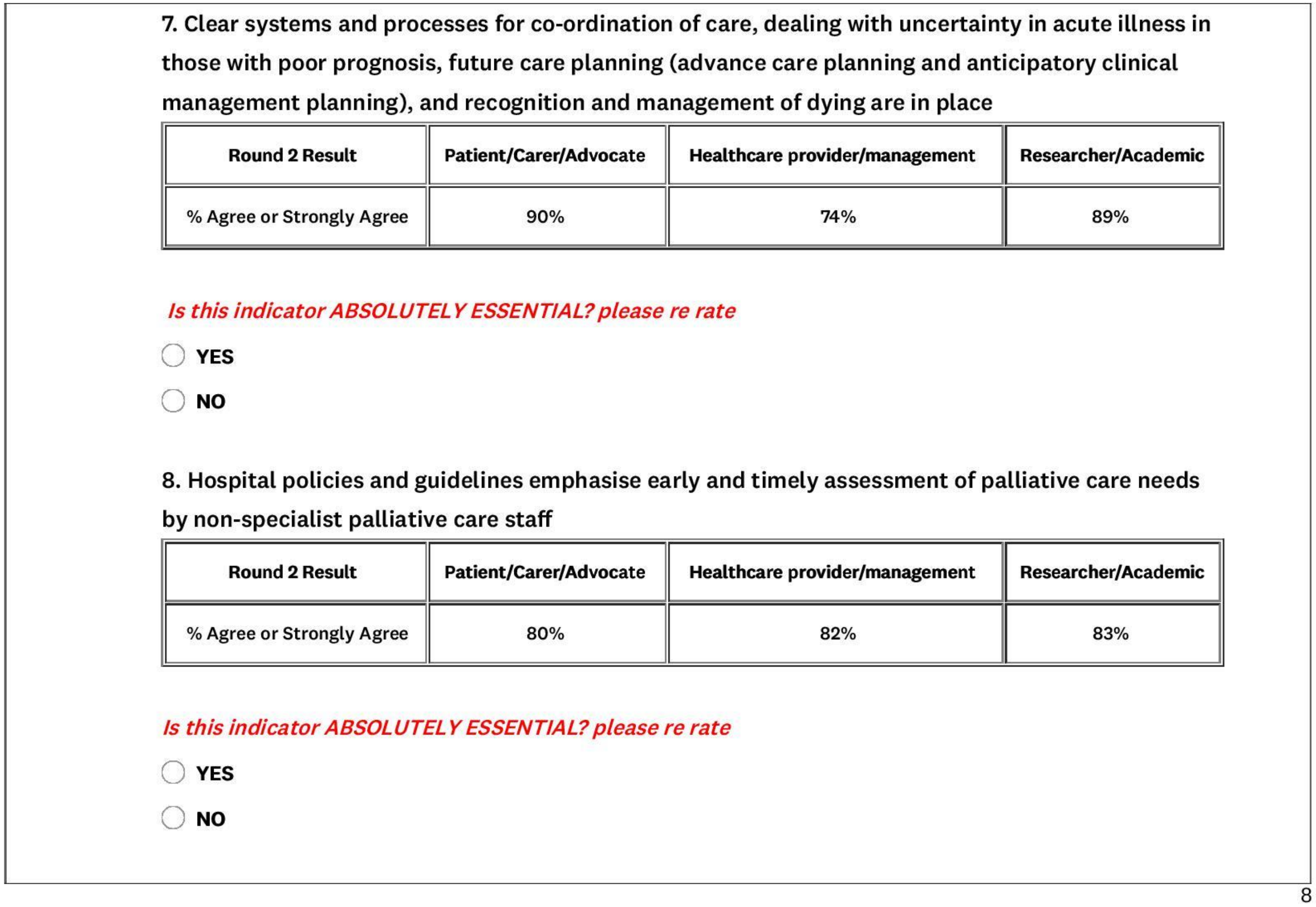
6. Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	76%	94%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



7. Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	74%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

8. Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff

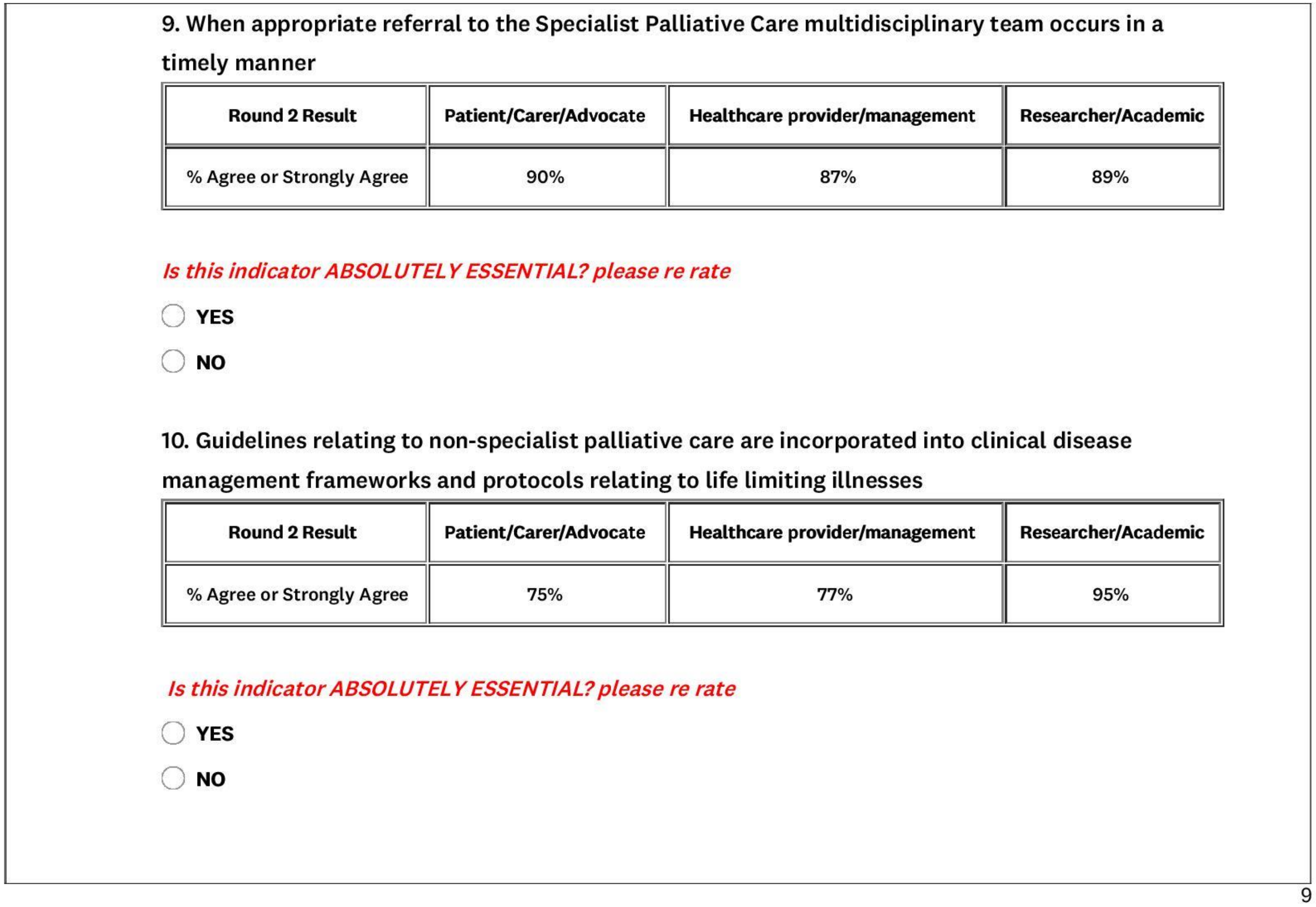
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	82%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

8



9. When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	87%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

10. Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses

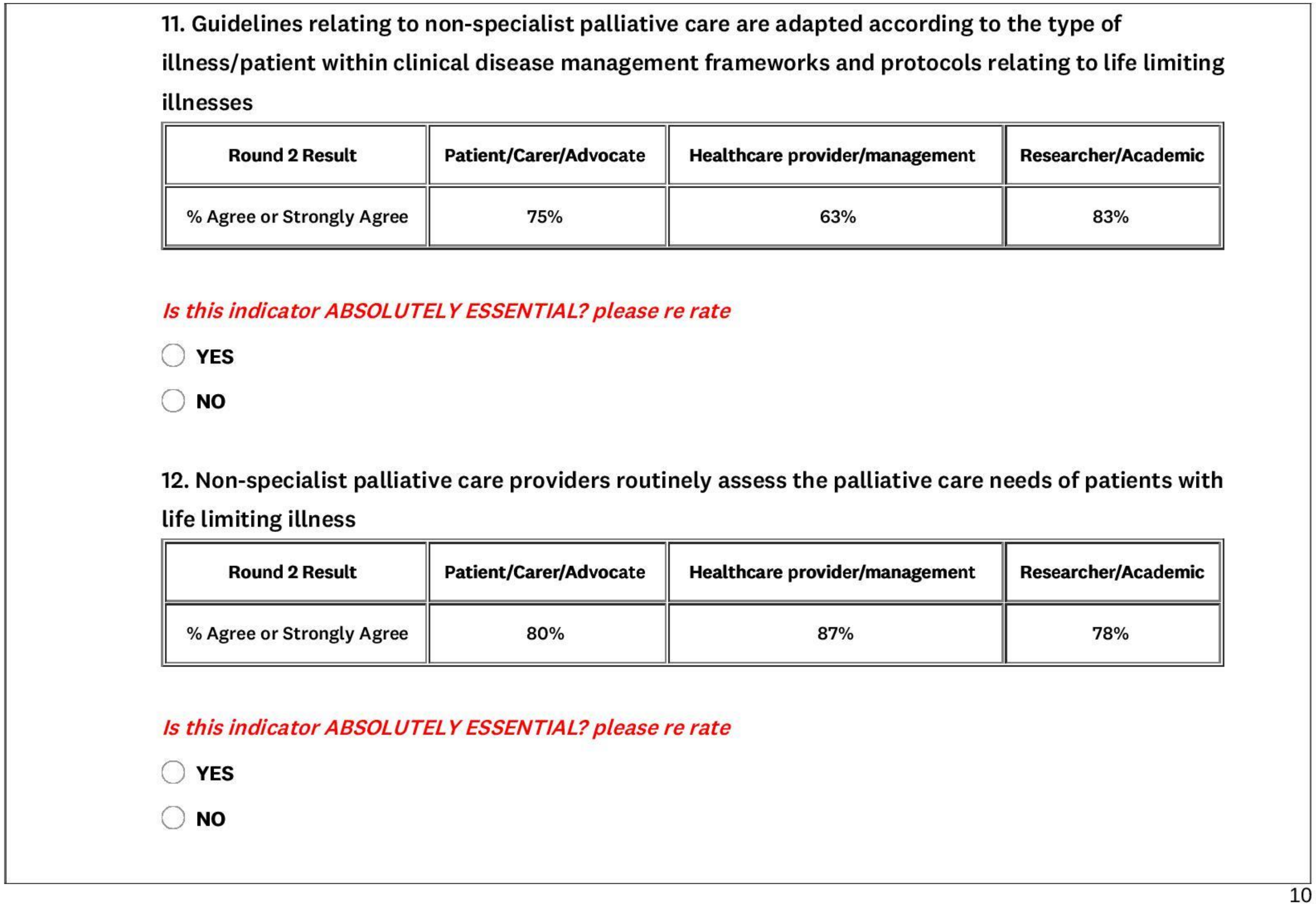
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	77%	95%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

9



11. Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	63%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

12. Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	87%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

13. Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	95%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

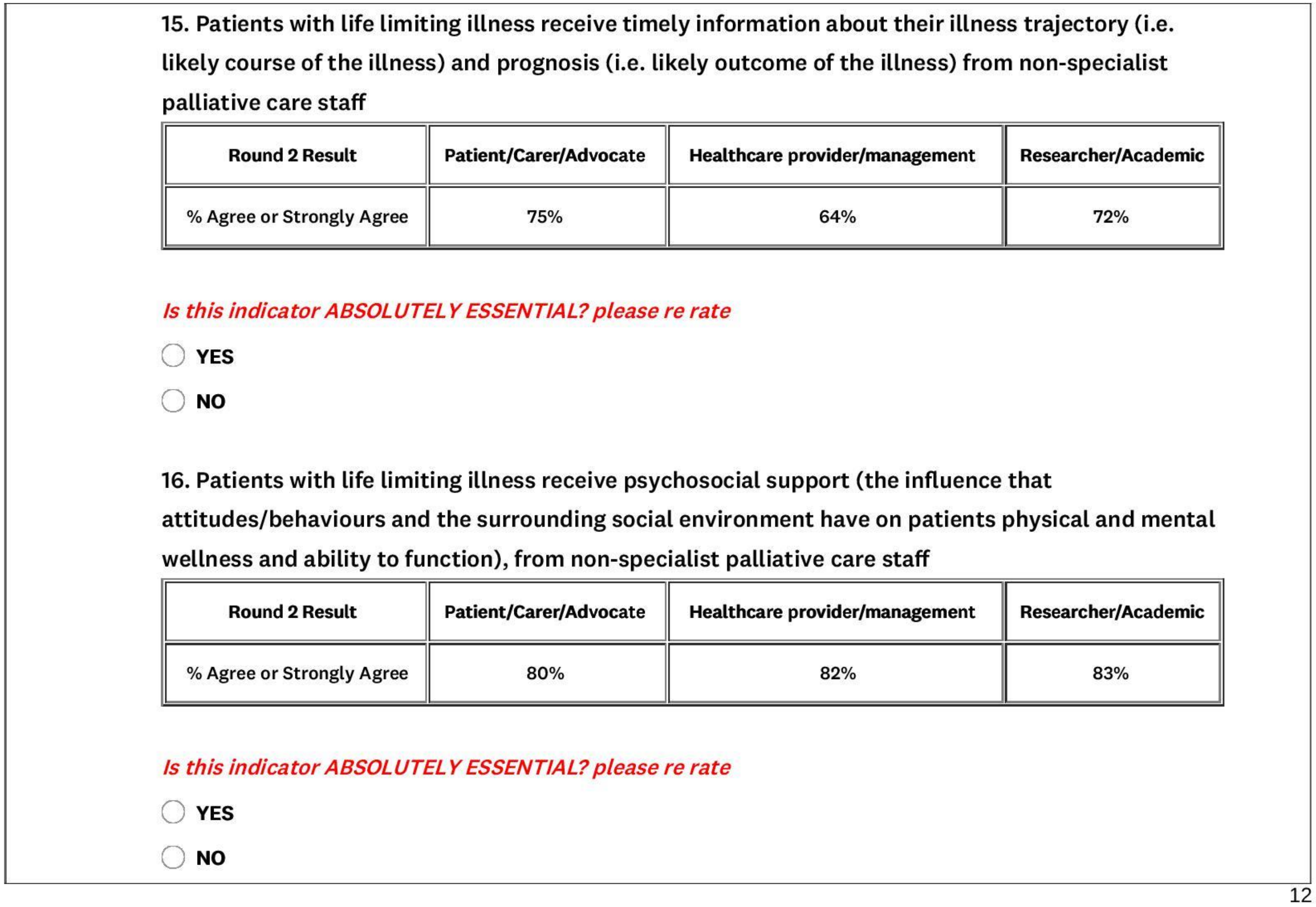
14. Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	82%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



15. Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff

Round 2 Result	**Patient/Carer/Advocate**	**Healthcare provider/management**	**Researcher/Academic**
% Agree or Strongly Agree	75%	64%	72%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

16. Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff

Round 2 Result	**Patient/Carer/Advocate**	**Healthcare provider/management**	**Researcher/Academic**
% Agree or Strongly Agree	80%	82%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

12

17. Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	63%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

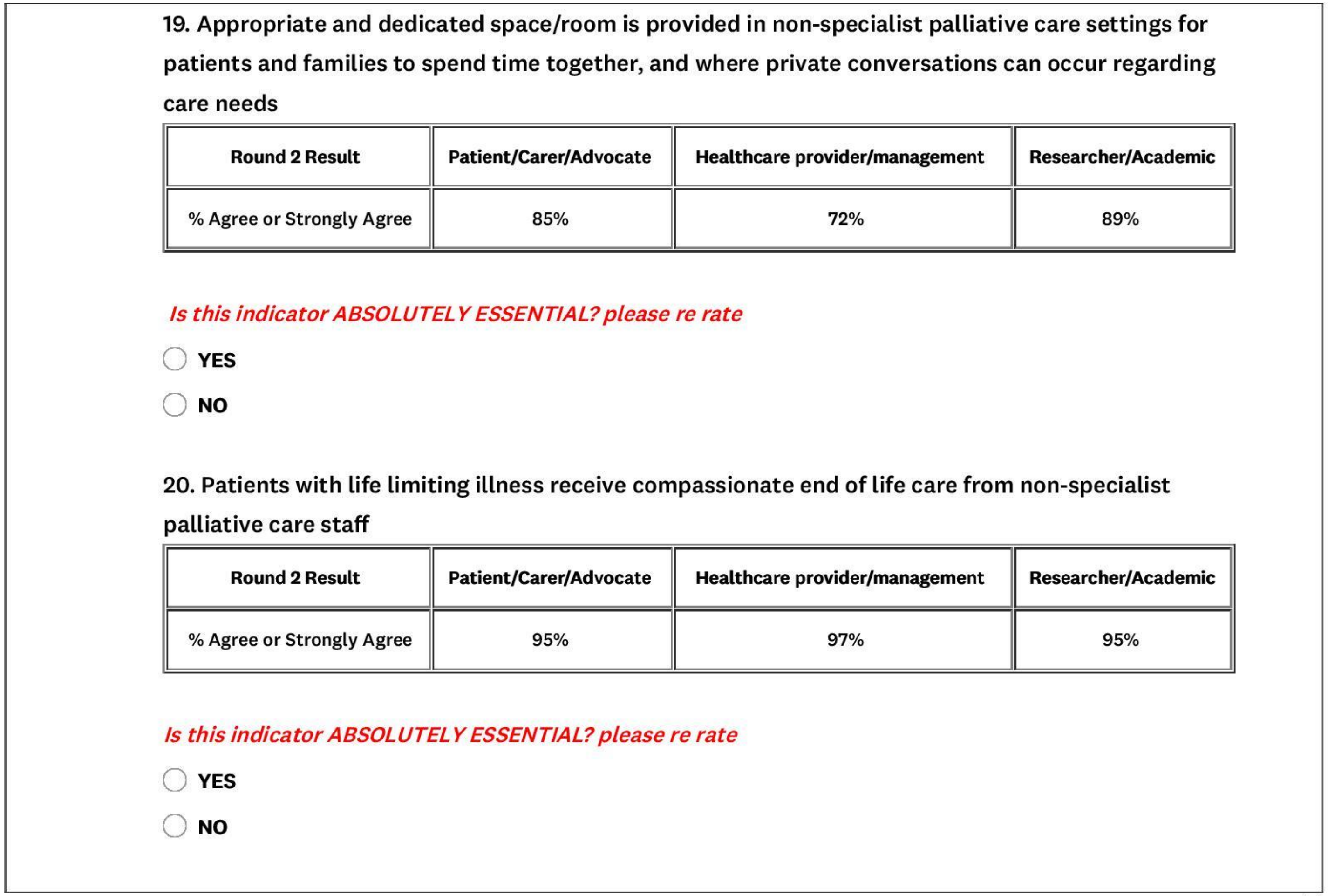
18. Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	72%	67%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



19. Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	72%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

20. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff

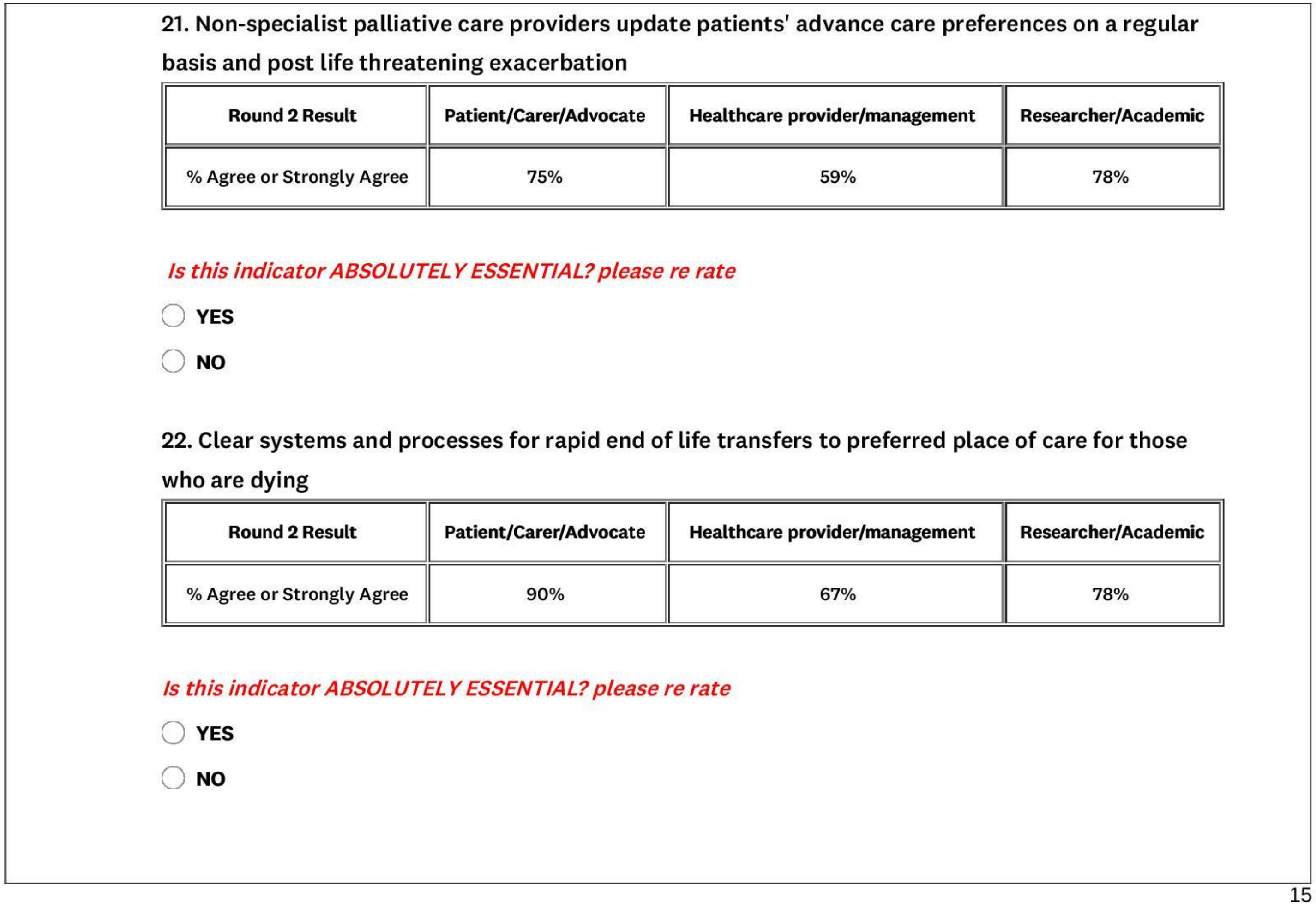
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	95%	97%	95%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

14



21. Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	59%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

22. Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying

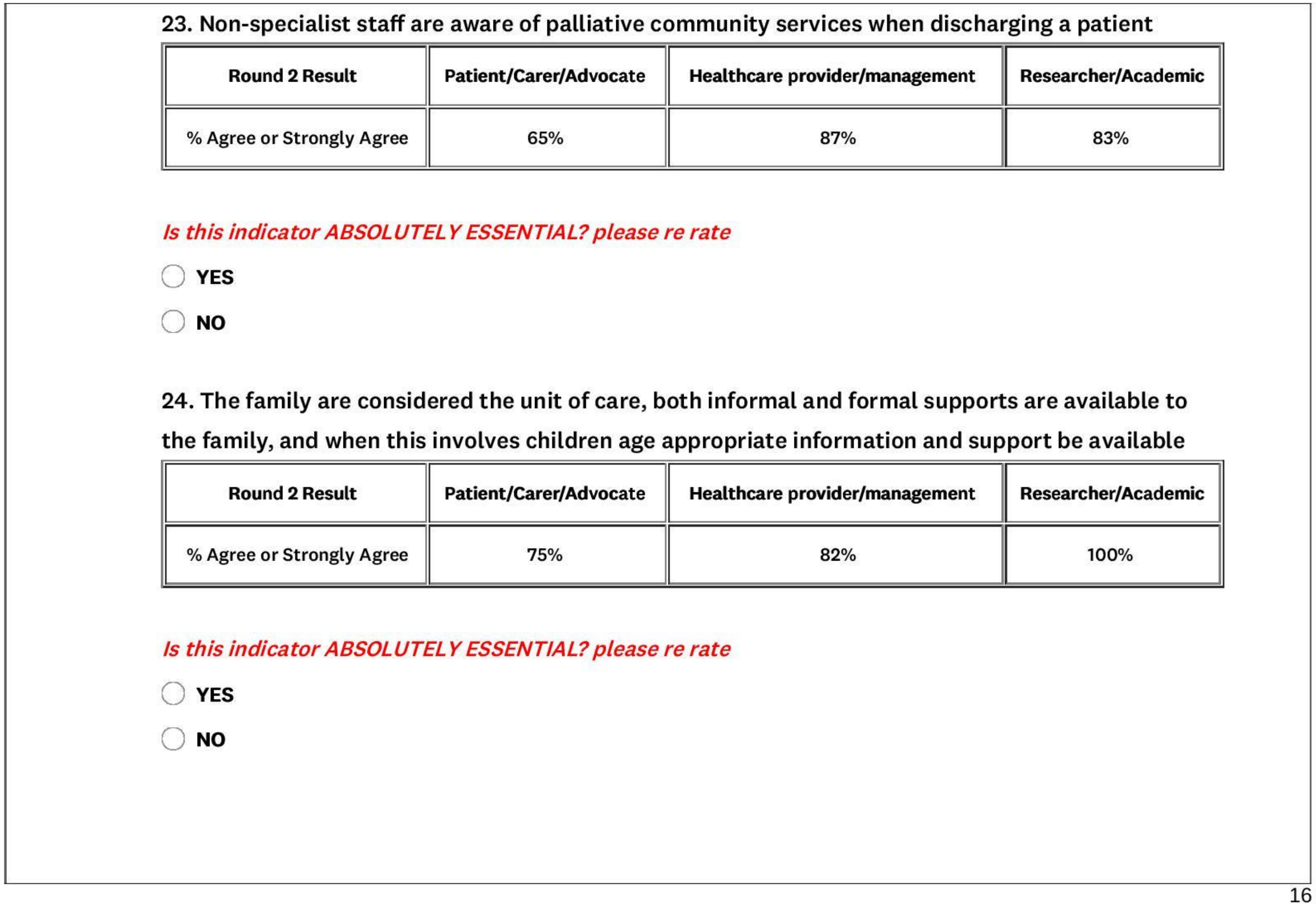
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	67%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

15



23. Non-specialist staff are aware of palliative community services when discharging a patient

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	65%	87%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

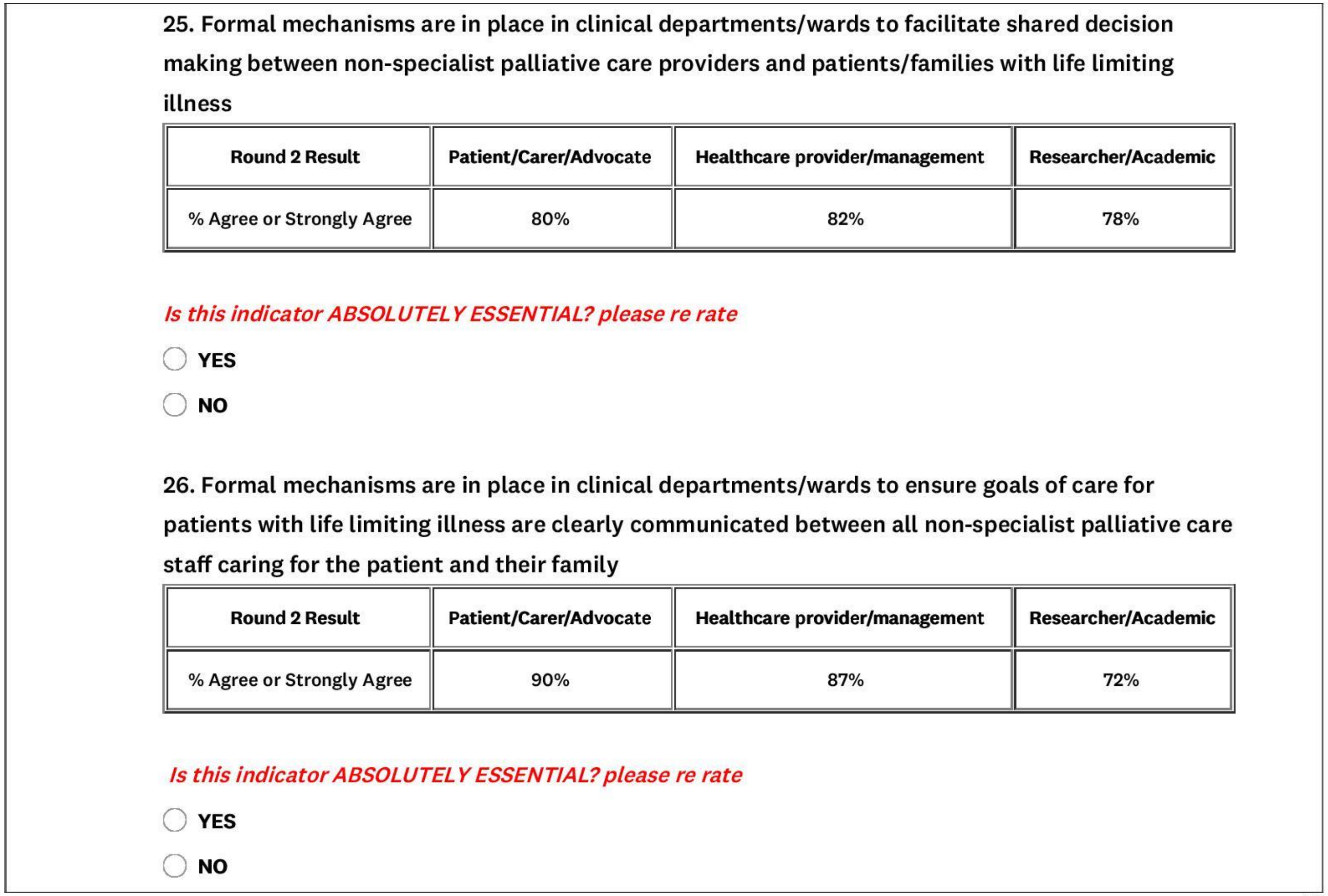
24. The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	82%	100%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



25. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	82%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

26. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	87%	72%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

27. The hospital has a multidisciplinary specialist palliative care service in place

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	98%	94%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

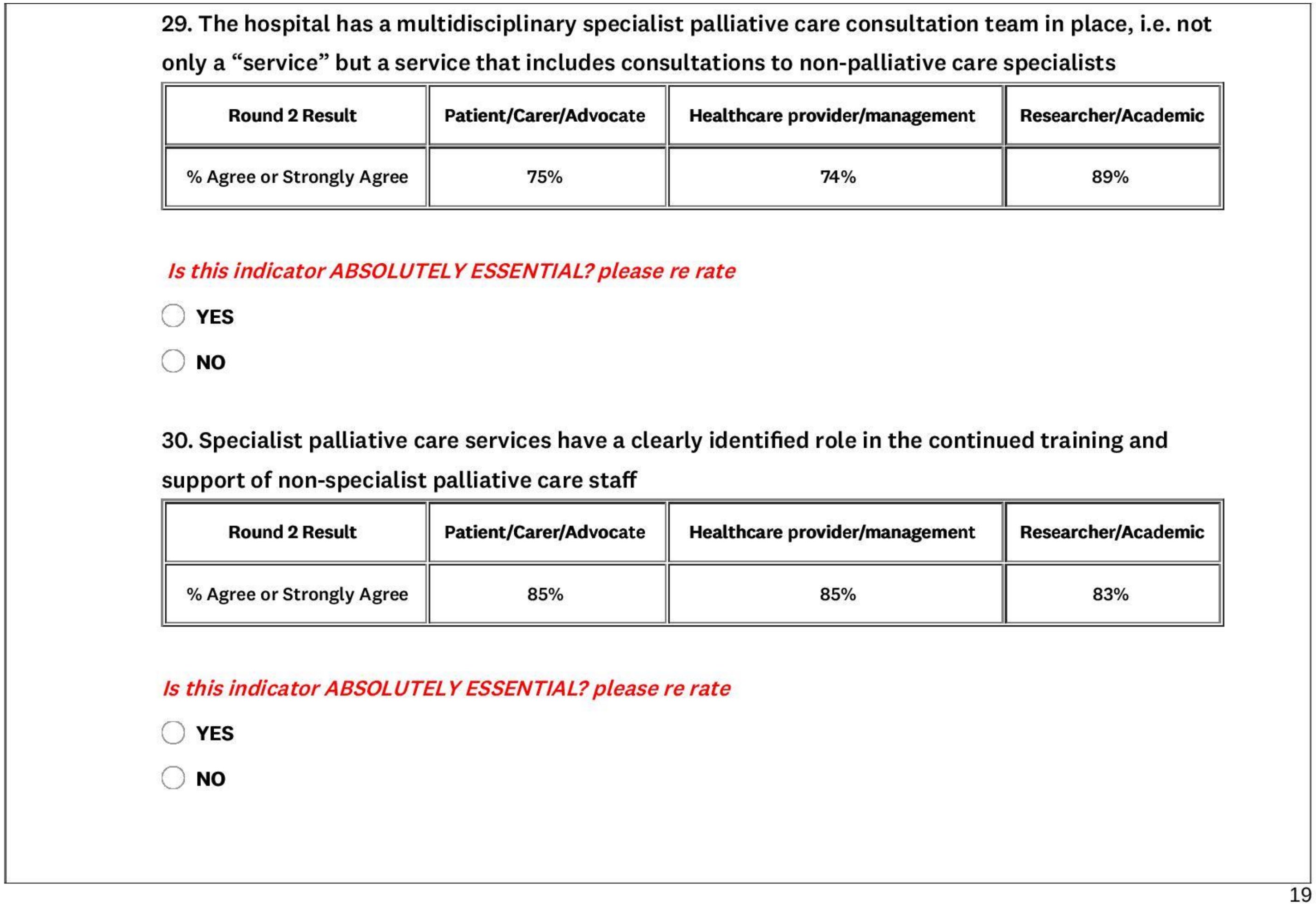
28. A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	82%	67%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



29. The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	75%	74%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

30. Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff

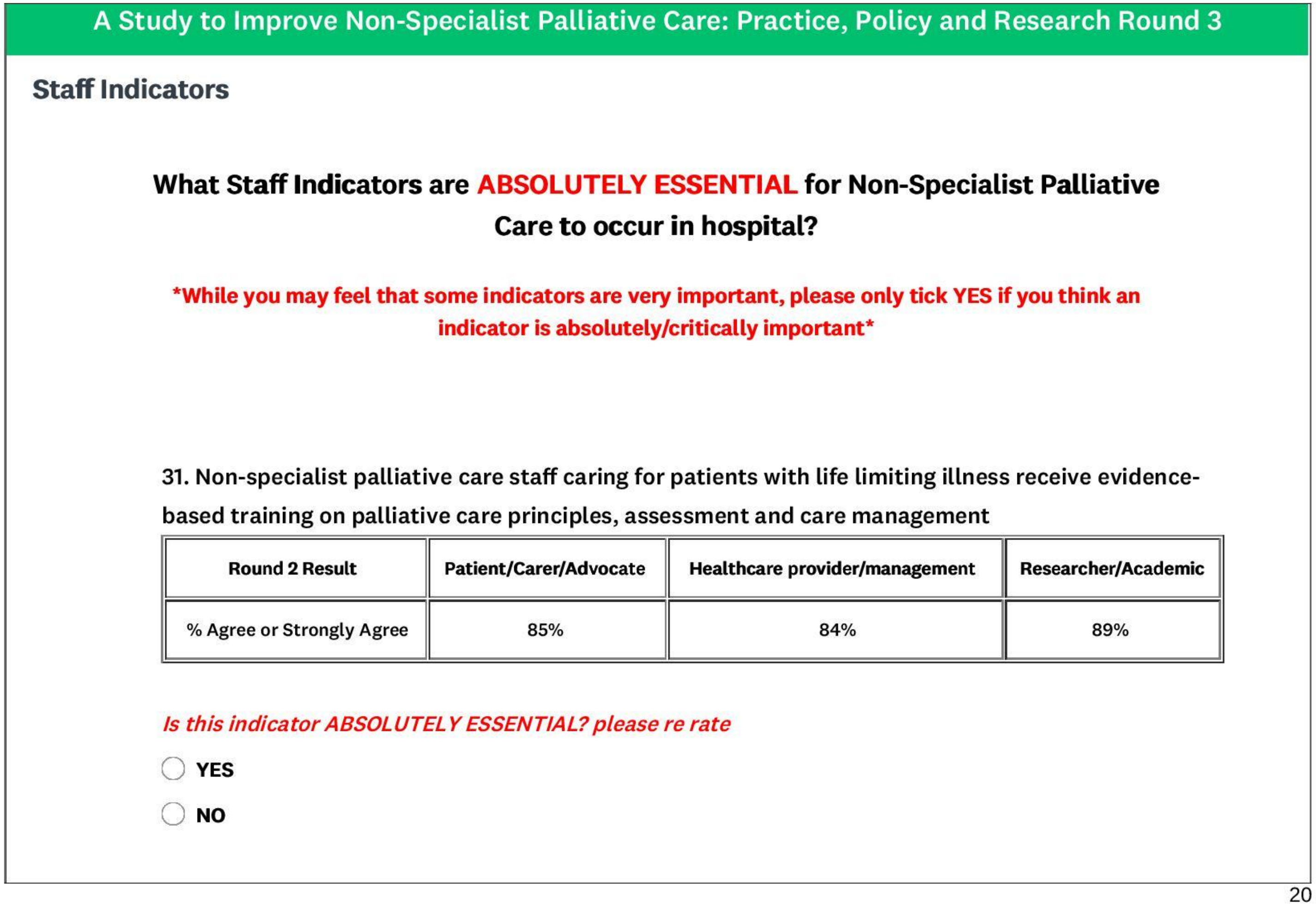
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	85%	83%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

19



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

Staff Indicators

What Staff Indicators are ABSOLUTELY ESSENTIAL for Non-Specialist Palliative Care to occur in hospital?

While you may feel that some indicators are very important, please only tick YES if you think an indicator is absolutely/critically important

31. Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management

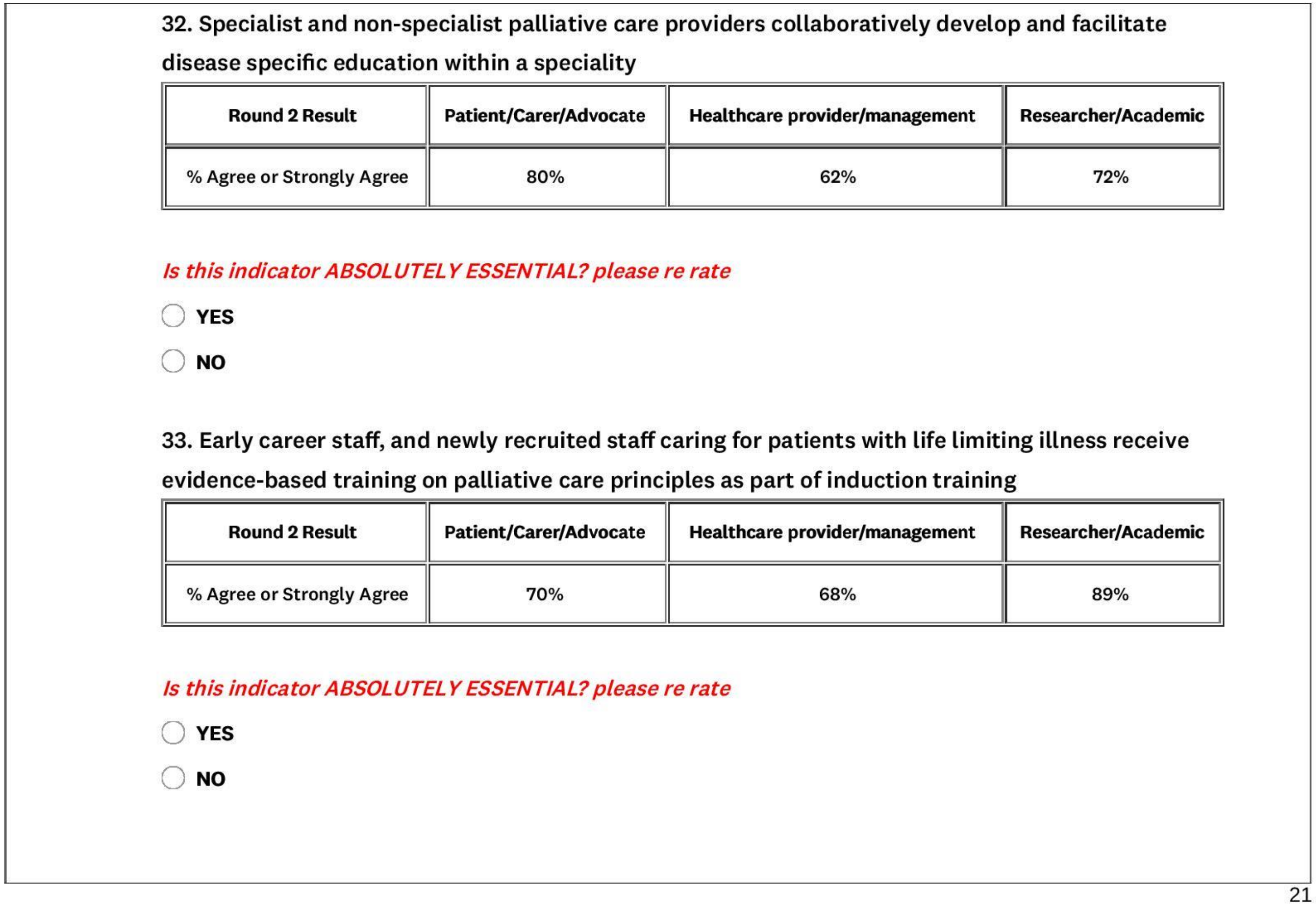
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	84%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

20



32. Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	62%	72%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

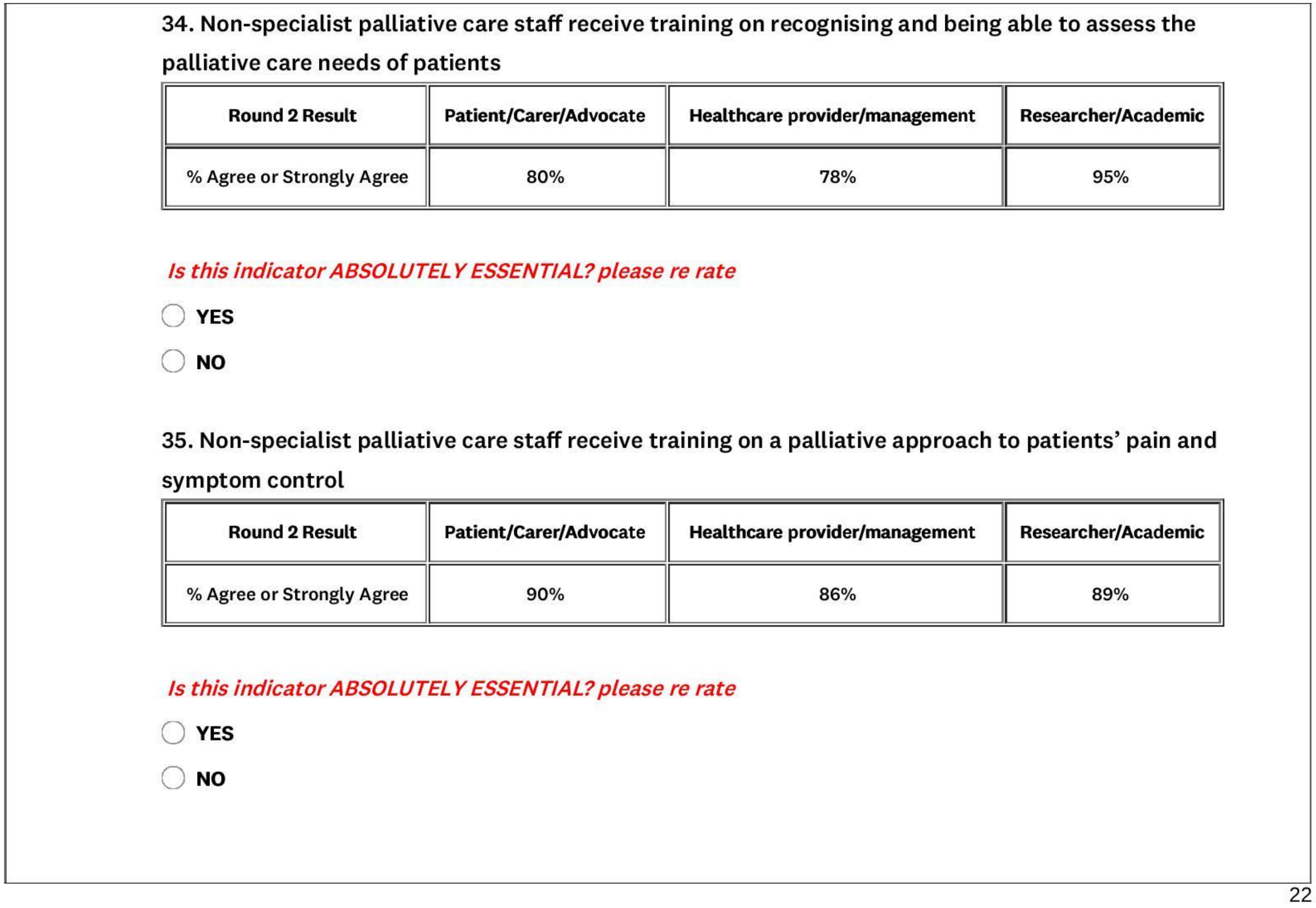
33. Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	70%	68%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



34. Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	78%	95%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

35. Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control

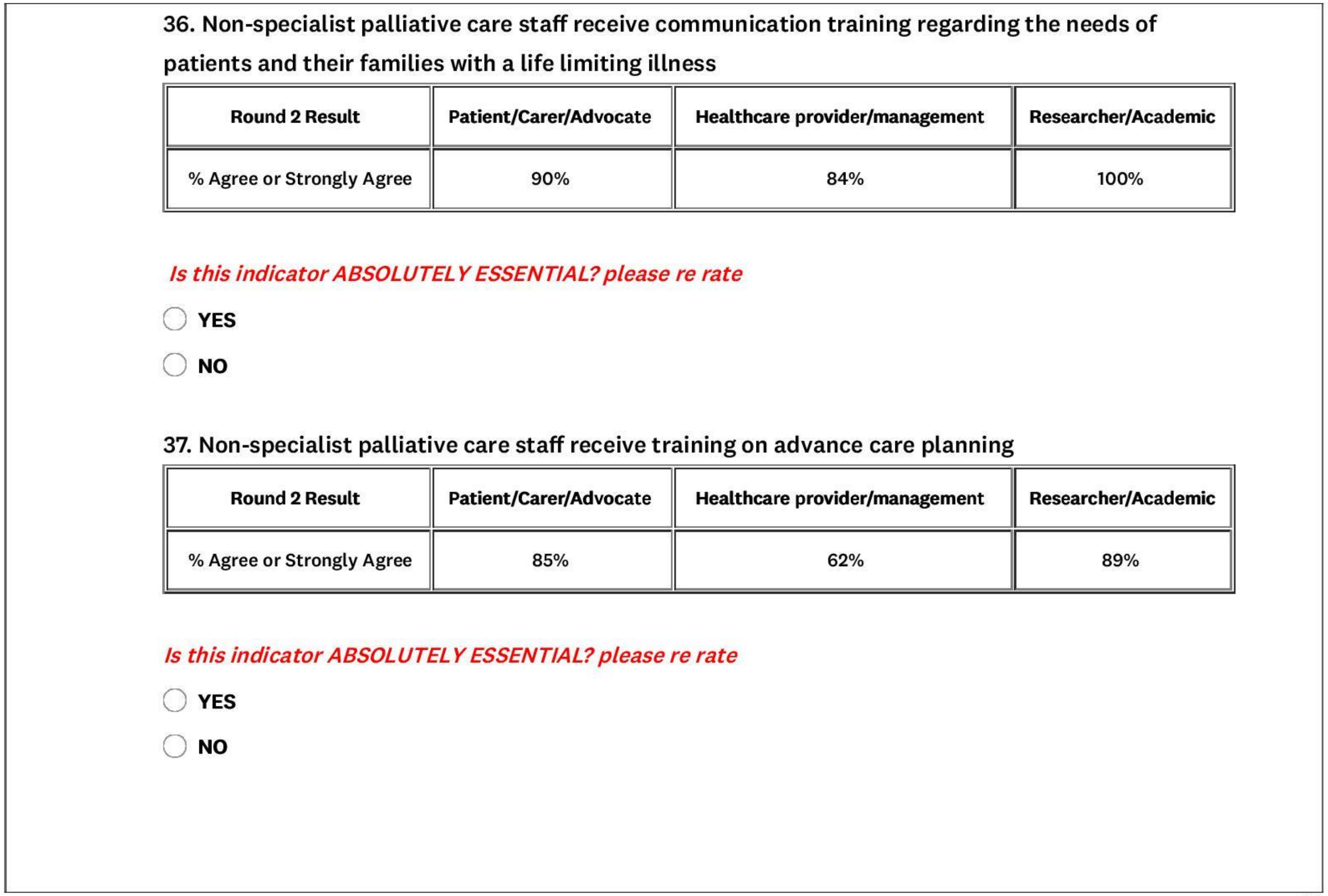
Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	86%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

22



36. Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	90%	84%	100%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

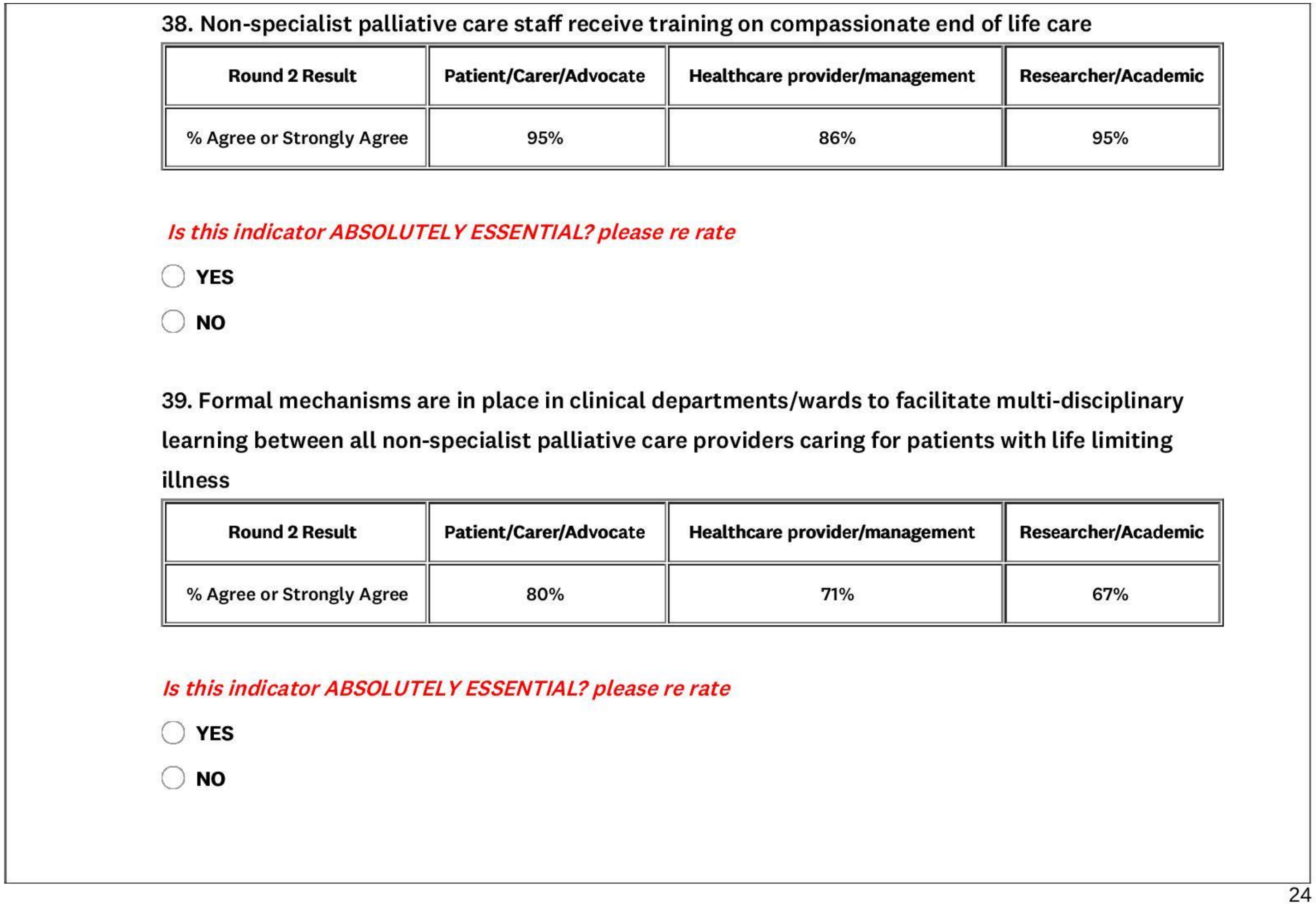
37. Non-specialist palliative care staff receive training on advance care planning

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	85%	62%	89%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



38. Non-specialist palliative care staff receive training on compassionate end of life care

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	95%	86%	95%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

39. Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	71%	67%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

24

40. Case presentations at hospital 'grand rounds' include difficult palliative care cases

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	50%	76%	78%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**

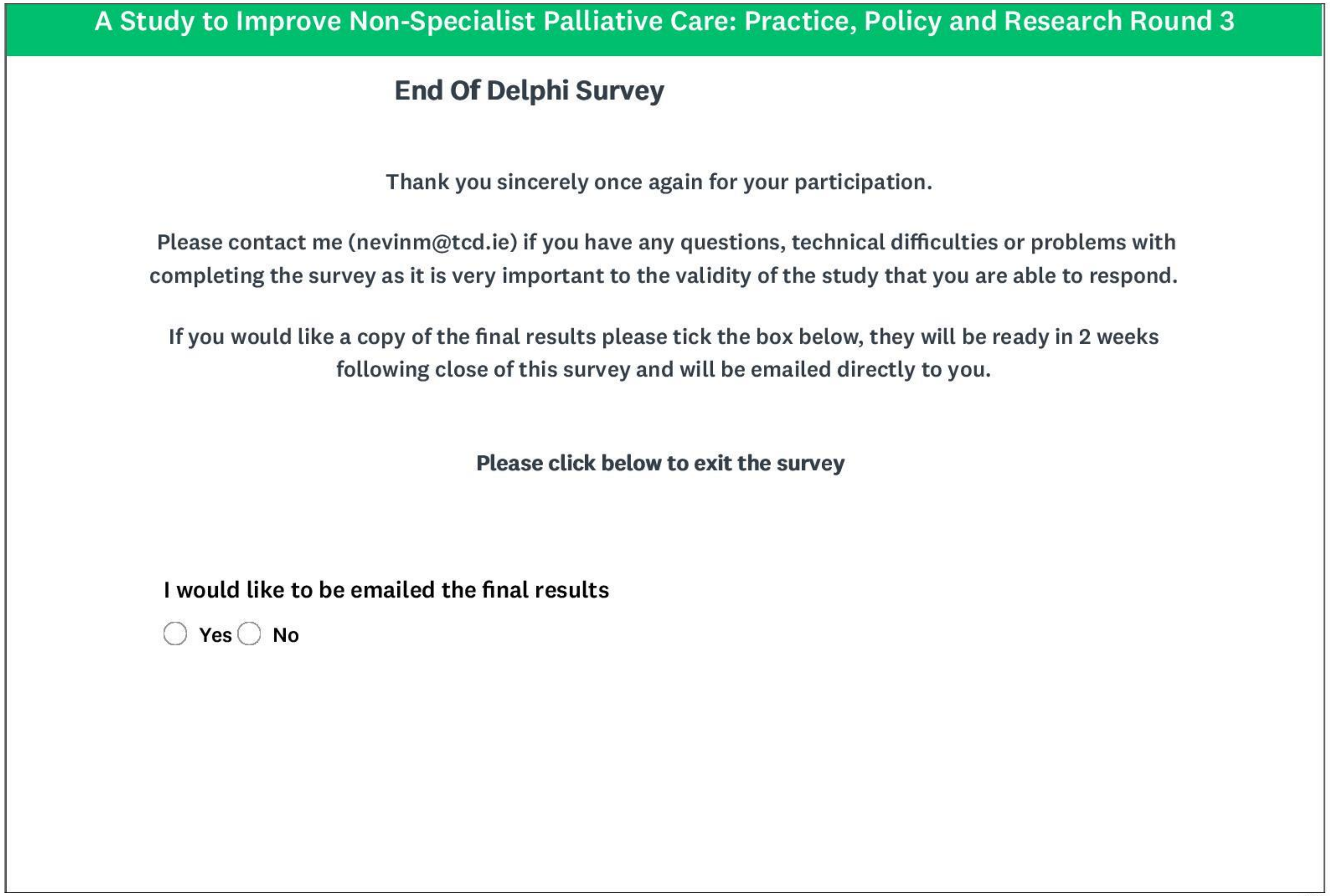
41. Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness

Round 2 Result	Patient/Carer/Advocate	Healthcare provider/management	Researcher/Academic
% Agree or Strongly Agree	80%	71%	67%

Is this indicator ABSOLUTELY ESSENTIAL? please re rate

○ **YES**

○ **NO**



A Study to Improve Non-Specialist Palliative Care: Practice, Policy and Research Round 3

End Of Delphi Survey

Thank you sincerely once again for your participation.

Please contact me (nevinm@tcd.ie) if you have any questions, technical difficulties or problems with completing the survey as it is very important to the validity of the study that you are able to respond.

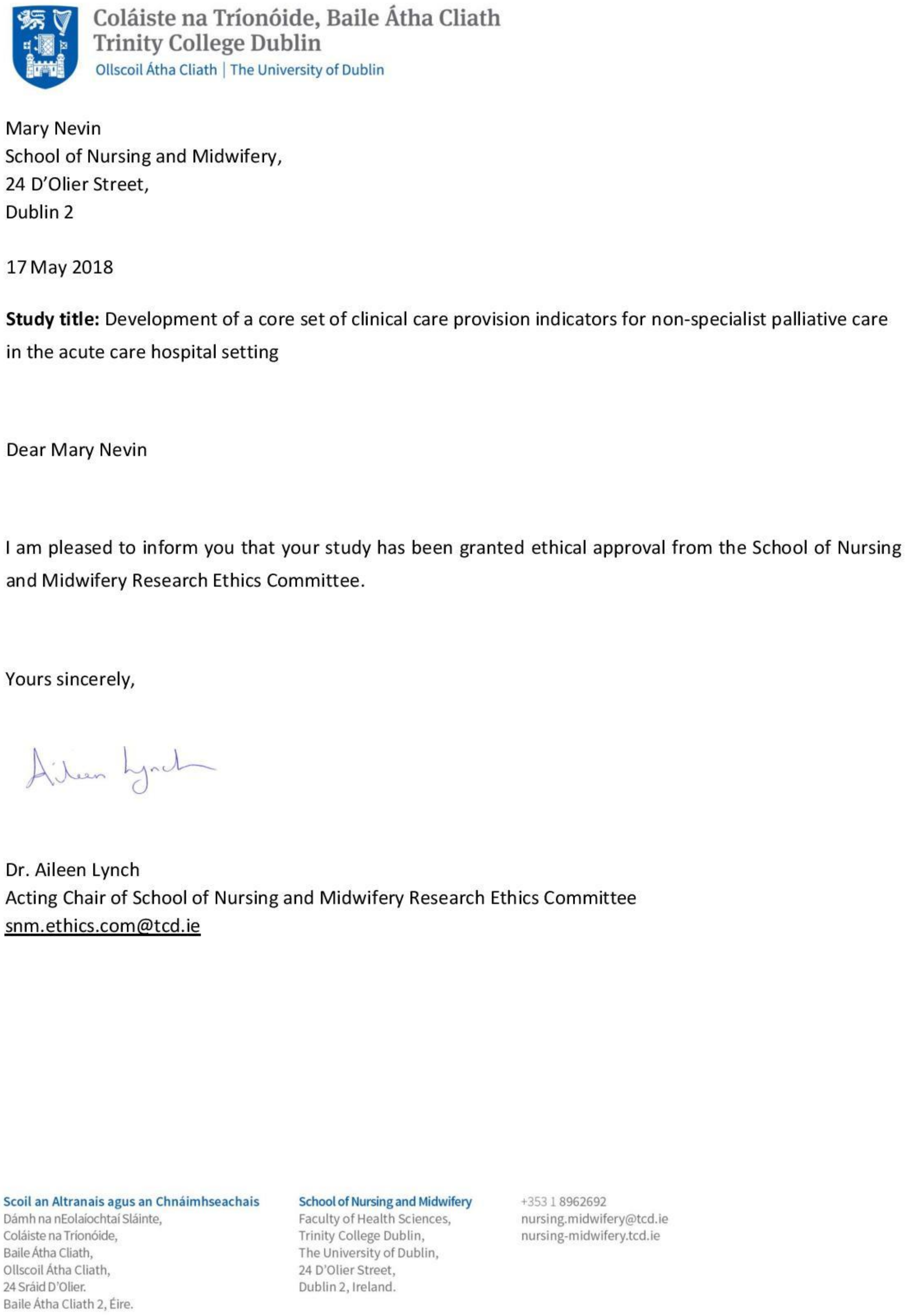
If you would like a copy of the final results please tick the box below, they will be ready in 2 weeks following close of this survey and will be emailed directly to you.

Please click below to exit the survey

I would like to be emailed the final results

○ Yes ○ No

Appendix 20 Confirmation of ethical approval for the Delphi study



Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Mary Nevin
School of Nursing and Midwifery,
24 D'Olier Street,
Dublin 2

17 May 2018

Study title: Development of a core set of clinical care provision indicators for non-specialist palliative care in the acute care hospital setting

Dear Mary Nevin

I am pleased to inform you that your study has been granted ethical approval from the School of Nursing and Midwifery Research Ethics Committee.

Yours sincerely,

Aileen Lynch

Dr. Aileen Lynch
Acting Chair of School of Nursing and Midwifery Research Ethics Committee
snm.ethics.com@tcd.ie

Scoil an Altranais agus an Chnáimhseachais
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Appendix 21 Delphi round 1 - Percentage responses

(SD=Strongly Disagree, D=Disagree, U=Unsure, A=Agree, SA=Strongly Agree)

Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Indicator		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
1. Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	**n**	0	2	4	10	9	2	10	5	16	13	0	5	3	2	8
	%	0.0	8.0	16.0	40.0	36.0	4.0	22.0	11.0	35.0	28.0	0.0	28.0	17.0	11.0	44.0
2. Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	**n**	0	1	4	11	9	1	12	6	17	10	0	5	2	4	7
	%	0.0	4.0	16.0	44.0	36.0	2.2	26.1	13.0	37.0	21.7	0.0	27.8	11.1	22.2	38.9
3. Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	**n**	0	2	4	5	14	1	9	8	18	8	0	4	1	4	9
	%	0.0	8.0	16.0	20.0	56.0	2.3	20.5	18.2	40.9	18.2	0.0	22.2	5.6	22.2	50.0
4. The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	**n**	0	2	6	8	9	2	11	7	12	12	0	3	3	6	6
	%	0.0	8.0	24.0	32.0	36.0	4.5	25.0	15.9	27.3	27.3	0.0	16.7	16.7	33.3	33.3
5. A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	**n**	0	2	4	9	9	2	8	5	14	15	0	3	5	3	7
	%	0.0	8.3	16.7	37.5	37.5	4.5	18.2	11.4	31.8	34.1	0.0	16.7	27.8	16.7	38.9
6. Organisational and care practices are structured in a way that supports non-specialist palliative care provision in combination with acute care delivery	**n**	0	3	5	4	11	1	3	3	12	18	1	3	0	6	8
	%	0.0	13.0	21.7	17.4	47.8	2.7	8.1	8.1	32.4	48.6	5.6	16.7	0.0	33.3	44.4

Participant Group	n	Patient/Carer/Advocate					Hospitalist					Researcher				
Indicator		SD	D	U	A	SA	SD	D	U	A	SA	SD	D	U	A	SA
7. Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	n	1	1	4	5	12	0	5	2	14	16	1	4	1	4	8
	%	4.3	4.3	17.4	21.7	52.2	0.0	13.5	5.4	37.8	43.2	5.6	22.2	5.6	22.2	44.4
8. Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	n	1	1	6	7	8	0	4	8	11	14	0	2	1	7	8
	%	4.3	4.3	26.1	30.4	34.8	0.0	10.8	21.6	29.7	37.8	0.0	11.1	5.6	38.9	44.4
9. Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	n	1	2	3	7	10	1	4	12	10	9	0	3	4	8	3
	%	4.3	8.7	13.0	30.4	43.5	2.8	11.1	33.3	27.8	25.0	0.0	16.7	22.2	44.4	16.7
10. Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	n	0	3	5	4	10	0	7	6	14	10	0	5	5	6	2
	%	0.0	13.6	22.7	18.2	45.5	0.0	18.9	16.2	37.8	27.0	0.0	27.8	27.8	33.3	11.1
11. Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	n	1	2	1	6	12	0	3	5	10	18	0	5	3	3	7
	%	4.5	9.1	4.5	27.3	54.5	0.0	8.3	13.9	27.8	50.0	0.0	27.8	16.7	16.7	38.9
12. Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	n	1	3	2	4	12	0	4	1	17	15	0	2	2	8	6
	%	4.5	13.6	9.1	18.2	54.5	0.0	10.8	2.7	45.9	40.5	0.0	11.1	11.1	44.4	33.3
13. Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	n	1	2	2	4	13	1	1	4	16	15	0	5	0	4	9
	%	4.5	9.1	9.1	18.2	59.1	2.7	2.7	10.8	43.2	40.5	0.0	27.8	0.0	22.2	50.0

Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Indicator		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
14. Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	**n**	1	2	3	6	10	1	5	3	13	14	1	5	1	4	7
	%	4.5	9.1	13.6	27.3	45.5	2.8	13.9	8.3	36.1	38.9	5.6	27.8	5.6	22.2	38.9
15. Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care	**n**	1	1	4	5	11	1	4	6	9	17	0	3	1	5	9
	%	4.5	4.5	18.2	22.7	50.0	2.7	10.8	16.2	24.3	45.9	0.0	16.7	5.6	27.8	50.0
16. Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	**n**	2	2	3	8	7	1	5	7	16	8	1	4	1	6	6
	%	9.1	9.1	13.6	36.4	31.8	2.7	13.5	18.9	43.2	21.6	5.6	22.2	5.6	33.3	33.3
17. Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	**n**	2	1	6	3	10	0	5	3	15	14	0	5	3	2	8
	%	9.1	4.5	27.3	13.6	45.5	0.0	13.5	8.1	40.5	37.8	0.0	27.8	16.7	11.1	44.4
18. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	**n**	0	2	2	4	14	0	1	2	7	26	0	0	2	5	11
	%	0.0	9.1	9.1	18.2	63.6	0.0	2.8	5.6	19.4	72.2	0.0	0.0	11.1	27.8	61.1
19. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care doctors and nurses caring for patients with life limiting illness	**n**	1	1	3	7	10	0	4	4	11	16	2	4	1	5	6
	%	4.5	4.5	13.6	31.8	45.5	0.0	11.4	11.4	31.4	45.7	11.1	22.2	5.6	27.8	33.3
20. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	**n**	1	1	2	6	12	1	6	3	9	18	1	4	2	4	7
	%	4.5	4.5	9.1	27.3	54.5	2.7	16.2	8.1	24.3	48.6	5.6	22.2	11.1	22.2	38.9

Participant Group	n	Patient/Carer/Advocate					Hospitalist					Researcher				
Indicator		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
21. The hospital has a multidisciplinary specialist palliative care service in place	**n**	1	0	3	3	15	1	3	3	4	26	1	1	1	4	11
	%	4.5	0.0	13.6	13.6	68.2	2.7	8.1	8.1	10.8	70.3	5.6	5.6	5.6	22.2	61.1
22. A structured and standardised care pathway exists between non-specialist palliative care and specialist palliative care, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	**n**	1	0	4	4	12	1	6	3	11	16	1	4	4	3	6
	%	4.8	0.0	19.0	19.0	57.1	2.7	16.2	8.1	29.7	43.2	5.6	22.2	22.2	16.7	33.3
23. Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	**n**	0	1	5	5	11	1	6	3	6	21	1	0	2	8	7
	%	0.0	4.5	22.7	22.7	50.0	2.7	16.2	8.1	16.2	56.8	5.6	0.0	11.1	44.4	38.9
24. Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	**n**	0	1	2	5	10	0	6	6	5	19	0	3	1	6	7
	%	0.0	5.6	11.1	27.8	55.6	0.0	16.7	16.7	13.9	52.8	0.0	17.6	5.9	35.3	41.2
25. Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	**n**	0	1	2	6	9	1	7	7	6	15	0	4	1	5	7
	%	0.0	5.6	11.1	33.3	50.0	2.8	19.4	19.4	16.7	41.7	0.0	23.5	5.9	29.4	41.2
26. Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	**n**	0	1	1	5	10	0	8	3	6	19	0	2	1	5	9
	%	0.0	5.9	5.9	29.4	58.8	0.0	22.2	8.3	16.7	52.8	0.0	11.8	5.9	29.4	52.9
27. Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	**n**	0	1	2	3	11	1	7	2	7	19	0	0	2	8	7
	%	0.0	5.9	11.8	17.6	64.7	2.8	19.4	5.6	19.4	52.8	0.0	0.0	11.8	47.1	41.2

Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Indicator		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
28. Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	**n**	0	1	1	3	12	1	5	4	12	14	0	2	3	4	8
	%	0.0	5.9	5.9	17.6	70.6	2.8	13.9	11.1	33.3	38.9	0.0	11.8	17.6	23.5	47.1
29. Non-specialist palliative care staff receive training on advance care planning	**n**	0	1	2	6	8	1	7	6	8	14	0	4	2	4	7
	%	0.0	5.9	11.8	35.3	47.1	2.8	19.4	16.7	22.2	38.9	0.0	23.5	11.8	23.5	41.2
30. Non-specialist palliative care staff receive training on compassionate end of life care	**n**	0	1	1	3	12	0	5	4	6	20	0	2	1	7	7
	%	0.0	5.9	5.9	17.6	70.6	0.0	14.3	11.4	17.1	57.1	0.0	11.8	5.9	41.2	41.2
31. The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with greater experience of or exposure to patients with life limiting illness	**n**	0	1	4	5	7	1	7	10	6	12	0	3	4	5	5
	%	0.0	5.9	23.5	29.4	41.2	2.8	19.4	27.8	16.7	33.3	0.0	17.6	23.5	29.4	29.4
32. Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between non-specialist palliative care doctors and nurses, caring for patients with life limiting illness	**n**	0	1	3	3	10	2	6	6	7	15	0	2	6	4	5
	%	0.0	5.9	17.6	17.6	58.8	5.6	16.7	16.7	19.4	41.7	0.0	11.8	35.3	23.5	29.4
33. Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	**n**	0	1	2	3	11	2	8	6	9	11	0	4	4	4	5
	%	0.0	5.9	11.8	17.6	64.7	5.6	22.2	16.7	25.0	30.6	0.0	23.5	23.5	23.5	29.4
34. Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	**n**	0	2	5	5	5	0	1	10	17	8	1	1	4	6	5
	%	0.0	11.8	29.4	29.4	29.4	0.0	2.8	27.8	47.2	22.2	5.9	5.9	23.5	35.3	29.4

Appendix 22 Audit trail of Delphi round 1 ‘New Indicator’ section

	‘New Indicator’ Text Round 1	Observations for round 2, any changes made to round 1 indicators	New Indicator Inserted
1	*“As palliative care is a team work, do not forget about other team members such as physiotherapists, occupational therapists, enrolled nurses and social workers.”*	Organisational Indicator #14 reworded to NSPC ‘providers’ rather than ‘doctors and nurses’ Staff Indicator #9 change to be more inclusive of MDT	No
2	*“My reflection is that some of the items were very similar; almost reflect the same meaning but were phrased differently, had slightly different emphasis. For this reason I agreed strongly to several items. I indicated disagree to #14 beacuse the shared decision-making was not said to include patients (and family members); thus I disagree that shared decision-making only include physicians and nurses/professionals. In the same way I disagree to #15 because I disagree to shared decision-making involving family members and excluding patients. I am not convinced about #17 because I am unsure about what a “structured and standardised care pathway” involves. If it could be a a multidisciplinary specialist palliative care consultation team it would be fine = I would agree. However, my association to “standardized care pathway” is more like the Liverpool care pathway for the dying, which I am not convinced about. I did not agree to #9 regarding hospital staff because “multi-disciplinary learning” was said to only include physicians and nurses, which hardly is multi-disciplinary; for example social workers, occupational therapists and other relevant professions.”*	Organisational Indicator #14 changed to reflect patients and family’s involvement in shared decision making Organisational Indicator #15 does not exclude patients Reservation noted about #17. Wording changed to be clear that it’s about the SPC MDT	No
3	*“Supporting relatives”*	Merged these two Added in **organisation** list	The family are considered the unit of care, both informal and formal supports are available to the
4	*“The family are considered the unit of care, both informal and formal supports are available to the*		

	family, when this involves children age appropriate information and support be available."		family, and when this involves children age appropriate information and support be available.
5	*"The specialist palliative care team acts as consultants in the ward on a regular basis"*	Merged these two added in **organisation** list	The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a "service" but a service that includes consultations to non-palliative care specialists
6	*"The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a "service" but a service that includes consultations to non-palliative care specialists."*		
7	*"Specialist and non-specialist staff collaboratively develop and facilitate disease specific education within a speciality"*	Added in **Staff** list	Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality
8	*"Non-specialist palliative care should include a requirement for nursing and medical staff to record and update patients' advanced care preferences on a regular basis including annual or post life threatening exacerbation whichever comes first"*	Added in **organisation** list	Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation
9	*"Structured/tiered programme of NSPC training to address needs of staff at all skill/experience levels"*	Staff Indicator #8 reworded to read more clearly	No
10	*"Need to define 'non-specialist' more clearly - does this include volunteers, community-based continuing care staff, gerontologists, family doctors?"*	This author emailed me this question and I clarified this in a return email, therefore I did not feel it needed further clarity in the participant information section of the survey	No
11	*"Non-specialist staff are aware of palliative community services when discharging a patient"*	Added in **organisation** list	Non-specialist staff are aware of palliative community services when discharging a patient
12	*"Systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning an anticipatory clinical management planning), recognition and*	Split into two new indicators in **organisation** list	Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning

	management of dying and rapid end of life transfers to preferred place of care for those who are dying need to be clear, cross boundary and supported by those who are familiar with them"		and anticipatory clinical management planning), and recognition and management of dying are in place Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying
13	*"Complaints about care for patients and families receiving palliative care are reviewed regularly by hospital board"*	As it is, it reads like a specialist palliative care indicator, so reworded to reflect NSPC provision, added in **structural indicator**	Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management
14	*"Availability of environment/facilities where private conversations can occur regarding care needs"*	Merged these added in **structural indicator**	Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs
15	*"Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to be together"*		
16	*"People with life-limiting conditions request service of non-specialist palliative care service in hospitals (i.e. own referral not just clinically led referral)"*	This is confusing NSPC with the requirement to need a referral to this type of care and is misleading	No
17	*"Palliative care need within the hospital is acknowledged at an organisational and service/ward level"*	Reworded Organisation indicator 1 to reflect the recognition aspect of NSPC in the hospital setting	No
18	*"Time allowed to care"*	This is not an indicator however it does reflect the nature of the challenges of integrating a palliative philosophy into acute care settings. All indicators should lead to a situation where NSPC is valued and supported within a hospital which recognises the time needed to provide many aspects of NSPC	No
19	*"should there be something about debriefing after care of palliative care patients for staff"*	Already addressed in peer support indicators	No
20	*"close working between critical care and those providing supportive and specialist palliative care*	Very similar to organisational indicator #17	No

	should ensure that escalation plans and ceilings of treatment include good parallel planning"		
21	*"When appropriate referral to the Specialist Palliative Care team occurs in a timely manner"*	Added in to **organisational** indicators	When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner
22	*"Case presentations at hospital 'grand rounds' include difficult palliative care cases"*	Added in **staff** indicators	Case presentations at hospital 'grand rounds' include difficult palliative care cases
23	*"people with life-limiting conditions using hospital services are prioritised readmission to services if required after discharge"*	Added to **organisation** list	people with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge

Appendix 23 Delphi round 2 - Results of the 46 Indicators

5 EXCLUDED, 41 RETAINED for round 3, RED denotes new indicators inserted from round 1

	Indicator	Pt/Carer/ Advocate	Hospitalist	Researcher	Decision for round 3
	Structural Indicators	**Percentage Level of Agreement**			
1	Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	71.4	84.6	88.9	Retained
2	Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	90.5	59	100	Retained
3	Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	95.2	66.7	83.3	Retained
4	Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management	85.9	84.6	83.4	Retained
5	The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	61.9	53.8	77.7	Excluded
6	A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	90.4	84.2	83.3	Retained
	Organisational Indicators				
1	Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery	80	76.3	94.4	Retained
2	Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place	90	73.7	88.9	Retained
3	Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	80	82.1	83.3	Retained
4	When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner	90	86.9	88.9	Retained
5	Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	75	77	94.5	Retained
6	Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	75	63.2	83.3	Retained

7	Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	70	56.4	55.6	Excluded
8	Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	80	87.2	77.8	Retained
9	Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	80	94.9	83.3	Retained
10	Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	85	82	88.9	Retained
11	Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	75	64.1	72.2	Retained
12	Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff	80	81.8	83.3	Retained
13	Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	80	63.2	77.7	Retained
14	Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	75	71.8	66.7	Retained
15	Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs	85	71.8	88.9	Retained
16	Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	95	97.3	94.5	Retained
17	Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation	75	59	77.8	Retained
18	Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying	90	66.7	77.7	Retained
19	Non-specialist staff are aware of palliative community services when discharging a patient	65	86.8	83.4	Retained
20	People with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge	80	52.3	55.6	Excluded
21	The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available	75	82.1	100	Retained
22	Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness	80	82	77.8	Retained
23	Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	90	87.1	72.2	Retained
24	The hospital has a multidisciplinary specialist palliative care service in place	85	97.5	94.1	Retained

25	A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	80	82	66.6	Retained
26	The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists	75	73.7	88.9	Retained
27	Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	85	84.6	83.3	Retained
	Staff Indicators				
1	Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	85	83.7	88.9	Retained
2	Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality	80	62.1	72.2	Retained
3	Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	70	67.5	88.9	Retained
4	Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	80	78.3	94.5	Retained
5	Non-specialist palliative care staff receive training on a palliative approach to patients’ pain and symptom control	90	86.4	88.9	Retained
6	Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	90	83.8	100	Retained
7	Non-specialist palliative care staff receive training on advance care planning	85	62.1	88.8	Retained
8	Non-specialist palliative care staff receive training on compassionate end of life care	95	86.1	94.5	Retained
9	The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with lesser and greater experience of or exposure to patients with life limiting illness	60	64.8	61.1	Excluded
10	Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness	80	70.3	66.7	Retained
11	Case presentations at hospital 'grand rounds' include difficult palliative care cases	50	76.3	77.8	Retained
12	Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	80	71.1	66.6	Retained
13	Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	45	81.6	61.1	Excluded

Appendix 24 Delphi round 2 - Percentage responses

Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Structural Indicators		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
1 Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	**n**	0	0	6	7	8	0	5	1	24	9	0	1	1	5	11
	%	0.0	0.0	28.6	33.3	38.1	0	12.8	2.6	61.5	23.1	0	5.6	5.6	27.8	61.1
2 Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	**n**	0	0	2	11	8	0	6	10	11	12	0	0	0	9	9
	%	0	0.0	9.5	52.4	38.1	0	15.4	25.6	28.2	30.8	0	0.0	0.0	50.0	50.0
3 Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	**n**	0	0	1	8	12	1	5	7	17	9	0	1	2	2	13
	%	0.0	0.0	4.8	38.1	57.1	2.6	12.8	17.9	43.6	23.1	0.0	5.6	11.1	11.1	72.2
4 Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management	**n**	0	0	3	7	11	0	0	6	12	21	0	0	3	5	10
	%	0	0	14.3	33.3	52.4	0	0	15.4	30.8	53.8	0	0	16.7	27.8	55.6
5 The strategic non-specialist palliative care service plan of the hospital details the resources, funding, staff training and support necessary to provide effective non-specialist palliative care for patients with life limiting illness	**n**	0	1	7	6	7	1	7	10	8	13	0	1	3	8	6
	%	0.0	4.8	33.3	28.6	33.3	2.6	17.9	25.6	20.5	33.3	0.0	5.6	16.7	44.4	33.3
6 A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	**n**	0	0	2	7	12	1	3	2	19	13	0	1	2	9	6
	%	0.0	0.0	9.5	33.3	57.1	2.6	7.9	5.3	50.0	34.2	0.0	5.6	11.1	50.0	33.3
Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Organisational Indicators		**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**	**SD**	**D**	**U**	**A**	**SA**
1 Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery	**n**	0	0	4	8	8	1	3	5	10	19	0	1	0	8	9
	%	0.0	0.0	20.0	40.0	40.0	2.6	7.9	13.2	26.3	50.0	0.0	5.6	0.0	44.4	50.0
2 Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and anticipatory clinical management planning), and recognition and management of dying are in place	**n**	0	1	1	9	9	1	6	3	7	21	0	0	2	4	12
	%	0.0	5.0	5.0	45.0	45.0	2.6	15.8	7.9	18.4	55.3	0.0	0.0	11.1	22.2	66.7
3 Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	**n**	0	1	3	8	8	0	4	3	17	15	1	0	2	6	9
	%	0.0	5.0	15.0	40.0	40.0	0.0	10.3	7.7	43.6	38.5	5.6	0.0	11.1	33.3	50.0
4 When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner	**n**	0	1	1	6	12	0	4	1	12	21	1	1	0	5	11
	%	0.0	5.0	5.0	30.0	60.0	0.0	10.5	2.6	31.6	55.3	5.6	5.6	0.0	27.8	61.1
5 Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	**n**	0	0	5	8	7	1	3	5	18	12	0	0	1	7	10
	%	0.0	0.0	25.0	40.0	35.0	2.6	7.7	12.8	46.2	30.8	0.0	0.0	5.6	38.9	55.6
	n	0	0	5	9	6	0	4	10	16	8	0	0	3	9	6

6 Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	**%**	0	0.0	25.0	45.0	30.0	0	10.5	26.3	42.1	21.1	0	0.0	16.7	50.0	33.3
7 Non-specialist palliative care delivery is structured to reflect the knowledge levels of those with greater experience and/or exposure to patients with life limiting illness	**n**	0	1	5	10	4	0	3	14	16	6	0	2	6	10	0
	%	0.0	5.0	25.0	50.0	20.0	0.0	7.7	35.9	41.0	15.4	0.0	11.1	33.3	55.6	0.0
8 Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	**n**	0	2	2	5	11	0	3	2	17	17	0	1	3	7	7
	%	0	10.0	10.0	25.0	55.0	0	7.7	5.1	43.6	43.6	0	5.6	16.7	38.9	38.9
9 Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	**n**	0	1	3	6	10	0	2	0	19	18	0	2	1	7	8
	%	0	5.0	15.0	30.0	50.0	0	5.1	0.0	48.7	46.2	0	11.1	5.6	38.9	44.4
10 Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	**n**	0	1	2	8	9	0	3	4	13	19	0	2	0	5	11
	%	0	5.0	10.0	40.0	45.0	0	7.7	10.3	33.3	48.7	0	11.1	0.0	27.8	61.1
11 Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	**n**	0	1	4	6	9	1	5	8	14	11	0	3	2	6	7
	%	0.0	5.0	20.0	30.0	45.0	2.6	12.8	20.5	35.9	28.2	0.0	16.7	11.1	33.3	38.9
12 Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff	**n**	0	2	2	4	12	0	6	5	17	11	0	2	1	6	9
	%	0	10.0	10.0	20.0	60.0	0	15.4	12.8	43.6	28.2	0	11.1	5.6	33.3	50.0
13 Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	**n**	0	3	1	12	4	2	6	6	18	6	0	2	2	8	6
	%	0.0	15.0	5.0	60.0	20.0	5.3	15.8	15.8	47.4	15.8	0.0	11.1	11.1	44.4	33.3
14 Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	**n**	0	2	3	9	6	2	5	4	14	14	1	3	2	7	5
	%	0.0	10.0	15.0	45.0	30.0	5.1	12.8	10.3	35.9	35.9	5.6	16.7	11.1	38.9	27.8
15. Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs	**n**	0	1	2	5	12	1	7	3	11	17	0	1	1	4	12
	%	0.0	5.0	10.0	25.0	60.0	2.6	17.9	7.7	28.2	43.6	0.0	5.6	5.6	22.2	66.7
16. Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation	**n**	0	1	4	9	6	1	6	9	12	11	0	1	3	7	7
	%	0.0	5.0	20.0	45.0	30.0	2.6	15.4	23.1	30.8	28.2	0.0	5.6	16.7	38.9	38.9
17. Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	**n**	0	0	1	5	14	0	0	1	14	23	0	1	0	3	14
	%	0.0	0.0	5.0	25.0	70.0	0	0.0	2.6	36.8	60.5	0	5.6	0.0	16.7	77.8
18. Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying	**n**	0	0	2	8	10	0	8	5	9	17	2	1	1	8	6
	%	0.0	0.0	10.0	40.0	50.0	0.0	20.5	12.8	23.1	43.6	11.1	5.6	5.6	44.4	33.3
19. Non-specialist staff are aware of palliative community services when discharging a patient	**n**	0	0	7	1	12	0	1	4	20	13	0	0	3	5	10
	%	0	0.0	35.0	5.0	60.0	0	2.6	10.5	52.6	34.2	0	0.0	16.7	27.8	55.6

20. People with life-limiting conditions using hospital services have prioritised readmission to services if required after discharge	**n**	0	0	4	6	10	2	5	11	9	10	1	1	6	5	5
	%	0.0	0.0	20.0	30.0	50.0	5.4	13.5	29.7	24.3	27.0	5.6	5.6	33.3	27.8	27.8
21. The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available	**n**	0	1	4	5	10	0	1	6	18	14	0	0	0	9	9
	%	0	5.0	20.0	25.0	50.0	0	2.6	15.4	46.2	35.9	0	0.0	0.0	50.0	50.0
22. Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness	**n**	0	1	3	8	8	0	2	5	22	10	0	2	2	9	5
	%	0	5.0	15.0	40.0	40.0	0	5.1	12.8	56.4	25.6	0	11.1	11.1	50.0	27.8
23. Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	**n**	0	1	1	9	9	0	2	3	21	13	0	1	4	6	7
	%	0	5.0	5.0	45.0	45.0	0	5.1	7.7	53.8	33.3	0	5.6	22.2	33.3	38.9
24. The hospital has a multidisciplinary specialist palliative care service in place	**n**	0	1	2	3	14	1	0	0	15	23	0	1	0	3	13
	%	0.0	5.0	10.0	15.0	70.0	2.6	0.0	0.0	38.5	59.0	0.0	5.9	0.0	17.6	76.5
25 A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	**n**	0	1	3	6	10	0	3	4	21	11	2	1	3	6	6
	%	0.0	5.0	15.0	30.0	50.0	0.0	7.7	10.3	53.8	28.2	11.1	5.6	16.7	33.3	33.3
26 The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists	**n**	0	0	5	6	9	2	0	8	16	12	0	0	2	7	9
	%	0	0	25.0	30.0	45.0	5.3	0	21.1	42.1	31.6	0	0	11.1	38.9	50.0
27 Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	**n**	0	1	2	7	10	1	1	4	13	20	1	1	1	4	11
	%	0.0	5.0	10.0	35.0	50.0	2.6	2.6	10.3	33.3	51.3	5.6	5.6	5.6	22.2	61.1
Participant Group	**n**	**Patient/Carer/Advocate**					**Hospitalist**					**Researcher**				
Staff Indicators		**SD**	**D**	**U**	**SD**	**D**	**U**	**SD**	**D**	**U**	**SD**	**D**	**U**	**SD**	**D**	**U**
1 Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	**n**	0	0	3	5	12	0	4	2	15	16	1	0	1	5	11
	%	0.0	0.0	15.0	25.0	60.0	0.0	10.8	5.4	40.5	43.2	5.6	0.0	5.6	27.8	61.1
2 Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality	**n**	0	1	3	9	7	1	4	9	14	9	0	1	4	8	5
	%	0.0	5.0	15.0	45.0	35.0	2.7	10.8	24.3	37.8	24.3	0.0	5.6	22.2	44.4	27.8
3 Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	**n**	0	0	6	5	9	1	6	5	16	9	0	0	2	9	7
	%	0.0	0.0	30.0	25.0	45.0	2.7	16.2	13.5	43.2	24.3	0.0	0.0	11.1	50.0	38.9
4 Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	**n**	0	0	4	4	12	1	2	5	16	13	0	1	0	5	12
	%	0.0	0.0	20.0	20.0	60.0	2.7	5.4	13.5	43.2	35.1	0.0	5.6	0.0	27.8	66.7

5 Non-specialist palliative care staff receive training on a palliative approach to patients’ pain and symptom control	**n**	0	0	2	5	13	0	1	4	18	14	0	1	1	5	11
	%	0	0.0	10.0	25.0	65.0	0	2.7	10.8	48.6	37.8	0	5.6	5.6	27.8	61.1
6 Non-specialist palliative care staff receive training on a palliative approach to patients’ pain and symptom control	**n**	0	0	2	5	13	0	3	3	20	11	0	0	0	6	12
	%	0	0.0	10.0	25.0	65.0	0	8.1	8.1	54.1	29.7	0	0.0	0.0	33.3	66.7
7 Non-specialist palliative care staff receive training on advance care planning	**n**	0	1	2	8	9	1	5	8	15	8	0	0	2	8	8
	%	0.0	5.0	10.0	40.0	45.0	2.7	13.5	21.6	40.5	21.6	0.0	0.0	11.1	44.4	44.4
8 Non-specialist palliative care staff receive training on compassionate end of life care	**n**	0	0	1	5	14	1	0	4	17	14	0	0	1	5	12
	%	0	0	5.0	25.0	70.0	2.8	0	11.1	47.2	38.9	0	0	5.6	27.8	66.7
9 The content of non-specialist palliative care staff training is organised to meet the knowledge requirements of those with lesser and greater experience of or exposure to patients with life limiting illness	**n**	0	1	7	7	5	1	2	10	14	10	0	3	4	9	2
	%	0.0	5.0	35.0	35.0	25.0	2.7	5.4	27.0	37.8	27.0	0.0	16.7	22.2	50.0	11.1
10 Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness	**n**	0	0	4	5	11	1	4	6	20	6	0	0	6	9	3
	%	0.0	0.0	20.0	25.0	55.0	2.7	10.8	16.2	54.1	16.2	0.0	0.0	33.3	50.0	16.7
11 Case presentations at hospital 'grand rounds' include difficult palliative care cases	**n**	0	1	9	5	5	0	6	3	17	12	0	1	3	4	10
	%	0	5.0	45.0	25.0	25.0	0	15.8	7.9	44.7	31.6	0	5.6	16.7	22.2	55.6
12 Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	**n**	0	0	4	7	9	2	4	5	21	6	0	3	3	6	6
	%	0.0	0.0	20.0	35.0	45.0	5.3	10.5	13.2	55.3	15.8	0.0	16.7	16.7	33.3	33.3
13 Informal peer support (such as corridor conversations) is used to support non-specialist palliative care staff caring for patients with life limiting illness	**n**	1	1	9	6	3	0	2	5	25	6	0	2	5	7	4
	%	5.0	5.0	45.0	30.0	15.0	0.0	5.3	13.2	65.8	15.8	0.0	11.1	27.8	38.9	22.2

Appendix 25 Indicators results in Delphi round 3

	Indicator		Pt/Carer/Advocate		Hospitalist		Researcher	
	Structural		**YES**	**NO**	**YES**	**NO**	**YES**	**NO**
1	Palliative care delivery, including the roles of non-specialists, are clearly defined and communicated within the strategic framework/service plan of the hospital	n	15	6	29	4	16	1
		%	71.4%	28.6%	87.9%	12.1%	94.1%	5.9%
2	Evaluation of hospital service delivery includes quality measures related to non-specialist palliative care	n	21	0	23	10	15	3
		%	100.0%	0.0%	69.7%	30.3%	83.3%	16.7%
3	Patient and family reported experiences of non-specialist palliative care are included in service delivery evaluation	n	21	0	22	11	15	3
		%	100.0%	0.0%	66.7%	33.3%	83.3%	16.7%
4	Complaints relating to care for patients and families with life limiting illness are reviewed regularly by hospital management	n	19	2	31	2	14	4
		%	90.5%	9.5%	93.9%	6.1%	77.8%	22.2%
5	A commitment to ensuring that adequate infrastructural resources (i.e. the basic physical and structural facilities) that support patient and family privacy are included in the strategic goal of non-specialist palliative care within a hospital	n	18	3	28	5	15	3
		%	85.7%	14.3%	84.8%	15.2%	83.3%	16.7%
	Organisational							
6	Organisational and care practices are structured in a way that recognises the need, and supports non-specialist palliative care provision in combination with acute care delivery	n	19	2	27	6	15	2
		%	90.5%	9.5%	81.8%	18.2%	88.2%	11.8%
7	Clear systems and processes for co-ordination of care, dealing with uncertainty in acute illness in those with poor prognosis, future care planning (advance care planning and	n	21	0	29	4	16	1

	anticipatory clinical management planning), and recognition and management of dying are in place	%	100.0%	0.0%	87.9%	12.1%	94.1%	5.9%
8	Hospital policies and guidelines emphasise early and timely assessment of palliative care needs by non-specialist palliative care staff	n	16	5	27	6	17	1
		%	76.2%	23.8%	81.8%	18.2%	94.4%	5.6%
9	When appropriate referral to the Specialist Palliative Care multidisciplinary team occurs in a timely manner	n	18	3	31	2	18	0
		%	85.7%	14.3%	93.9%	6.1%	100.0%	0.0%
10	Guidelines relating to non-specialist palliative care are incorporated into clinical disease management frameworks and protocols relating to life limiting illnesses	n	14	6	28	5	16	1
		%	70.0%	30.0%	84.8%	15.2%	94.1%	5.9%
11	Guidelines relating to non-specialist palliative care are adapted according to the type of illness/patient within clinical disease management frameworks and protocols relating to life limiting illnesses	n	14	6	14	19	10	7
		%	70.0%	30.0%	42.4%	57.6%	58.8%	41.2%
12	Non-specialist palliative care providers routinely assess the palliative care needs of patients with life limiting illness	n	19	2	26	6	15	3
		%	90.5%	9.5%	81.3%	18.8%	83.3%	16.7%
13	Non-specialist palliative care staff manage palliative pain and other symptoms experienced by patients with life limiting illness	n	18	3	32	1	17	1
		%	85.7%	14.3%	97.0%	3.0%	94.4%	5.6%
14	Patients with life limiting illness and their families receive timely and sensitive communication from non-specialist palliative care staff	n	20	1	33	0	18	0
		%	95.2%	4.8%	100.0%	0.0%	100.0%	0.0%
15	Patients with life limiting illness receive timely information about their illness trajectory (i.e. likely course of the illness) and prognosis (i.e. likely outcome of the illness) from non-specialist palliative care staff	n	15	5	18	15	9	8
		%	75.0%	25.0%	54.5%	45.5%	52.9%	47.1%

16	Patients with life limiting illness receive psychosocial support (the influence that attitudes/behaviours and the surrounding social environment have on patients physical and mental wellness and ability to function), from non-specialist palliative care staff	n	16	5	27	6	17	1
		%	76.2%	23.8%	81.8%	18.2%	94.4%	5.6%
17	Patients with life limiting illness receive spiritual/existential support (relating to life meaning, purpose or value) from non-specialist palliative care staff	n	11	10	18	15	9	8
		%	52.4%	47.6%	54.5%	45.5%	52.9%	47.1%
18	Patients with life limiting illness are facilitated and supported to engage in advance care planning discussions with non-specialist palliative care staff	n	14	7	23	10	10	6
		%	66.7%	33.3%	69.7%	30.3%	62.5%	37.5%
19	Appropriate and dedicated space/room is provided in non-specialist palliative care settings for patients and families to spend time together, and where private conversations can occur regarding care needs	n	19	2	26	7	14	4
		%	90.5%	9.5%	78.8%	21.2%	77.8%	22.2%
20	Patients with life limiting illness receive compassionate end of life care from non-specialist palliative care staff	n	18	3	32	1	18	0
		%	85.7%	14.3%	97.0%	3.0%	100.0%	0.0%
21	Non-specialist palliative care providers update patients' advance care preferences on a regular basis and post life threatening exacerbation	n	14	6	15	18	12	5
		%	70.0%	30.0%	45.5%	54.5%	70.6%	29.4%
22	Clear systems and processes for rapid end of life transfers to preferred place of care for those who are dying	n	21	0	24	9	13	4
		%	100.0%	0.0%	72.7%	27.3%	76.5%	23.5%
23	Non-specialist staff are aware of palliative community services when discharging a patient	n	19	2	27	6	15	2
		%	90.5%	9.5%	81.8%	18.2%	88.2%	11.8%
24		n	16	5	27	6	15	2

	The family are considered the unit of care, both informal and formal supports are available to the family, and when this involves children age appropriate information and support be available	%	76.2%	23.8%	81.8%	18.2%	88.2%	11.8%
25	Formal mechanisms are in place in clinical departments/wards to facilitate shared decision making between non-specialist palliative care providers and patients/families with life limiting illness	n	19	2	25	8	13	4
		%	90.5%	9.5%	75.8%	24.2%	76.5%	23.5%
26	Formal mechanisms are in place in clinical departments/wards to ensure goals of care for patients with life limiting illness are clearly communicated between all non-specialist palliative care staff caring for the patient and their family	n	19	2	26	7	16	1
		%	90.5%	9.5%	78.8%	21.2%	94.1%	5.9%
27	The hospital has a multidisciplinary specialist palliative care service in place	n	17	4	31	2	16	2
		%	81.0%	19.0%	93.9%	6.1%	88.9%	11.1%
28	A structured and standardised care pathway exists between non-specialist palliative care and the specialist palliative care multi-disciplinary team, to support mutual decision making and organisation of care processes, including clarification of roles and responsibilities of care	n	18	2	27	6	9	8
		%	90.0%	10.0%	81.8%	18.2%	52.9%	47.1%
29	The hospital has a multidisciplinary specialist palliative care consultation team in place, i.e. not only a “service” but a service that includes consultations to non-palliative care specialists	n	18	3	20	12	14	3
		%	85.7%	14.3%	62.5%	37.5%	82.4%	17.6%
30	Specialist palliative care services have a clearly identified role in the continued training and support of non-specialist palliative care staff	n	16	5	30	3	16	2
		%	76.2%	23.8%	90.9%	9.1%	88.9%	11.1%
	Staff Indicators							

31	Non-specialist palliative care staff caring for patients with life limiting illness receive evidence-based training on palliative care principles, assessment and care management	n	18	3	30	3	17	0
		%	85.7%	14.3%	90.9%	9.1%	100.0%	0.0%
32	Specialist and non-specialist palliative care providers collaboratively develop and facilitate disease specific education within a speciality	n	14	7	14	19	9	8
		%	66.7%	33.3%	42.4%	57.6%	52.9%	47.1%
33	Early career staff, and newly recruited staff caring for patients with life limiting illness receive evidence-based training on palliative care principles as part of induction training	n	17	4	22	11	15	2
		%	81.0%	19.0%	66.7%	33.3%	88.2%	11.8%
34	Non-specialist palliative care staff receive training on recognising and being able to assess the palliative care needs of patients	n	19	2	29	4	17	0
		%	90.5%	9.5%	87.9%	12.1%	100.0%	0.0%
35	Non-specialist palliative care staff receive training on a palliative approach to patients' pain and symptom control	n	19	2	30	3	17	1
		%	90.5%	9.5%	90.9%	9.1%	94.4%	5.6%
36	Non-specialist palliative care staff receive communication training regarding the needs of patients and their families with a life limiting illness	n	18	3	29	4	18	0
		%	85.7%	14.3%	87.9%	12.1%	100.0%	0.0%
37	Non-specialist palliative care staff receive training on advance care planning	n	13	8	18	15	13	4
		%	61.9%	38.1%	54.5%	45.5%	76.5%	23.5%
38	Non-specialist palliative care staff receive training on compassionate end of life care	n	18	3	32	1	18	0
		%	85.7%	14.3%	97.0%	3.0%	100.0%	0.0%
39		n	14	7	14	19	6	11

	Formal mechanisms are in place in clinical departments/wards to facilitate multi-disciplinary learning between all non-specialist palliative care providers caring for patients with life limiting illness	%	66.7%	33.3%	42.4%	57.6%	35.3%	64.7%
40	Case presentations at hospital 'grand rounds' include difficult palliative care cases	n	14	7	17	16	10	8
		%	66.7%	33.3%	51.5%	48.5%	55.6%	44.4%
41	Formal peer support (such as case review meetings) is used to support non-specialist palliative care staff caring for patients with life limiting illness	n	16	5	15	18	9	9
		%	76.2%	23.8%	45.5%	54.5%	50.0%	50.0%