Dignity: a human, health and aged care right

Development of a new Patient Reported Experience Measure based on the 10 Principles of Dignity in Care for use by older people (and their carers) in the hospital setting

by

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Abstract

Hospitalisation can be hazardous for older people, including from the harm of indignity; people with dementia are at increased risk. Multiple investigations revealing the abuse of older people, serve as a potent and perpetual reminder that health services need to enable older people to report on their experience of care. To do this, health services require measurement tools specifically designed and developed to meet the needs of older people. These tools also need to accommodate the older person's family / friends (referred to as their 'carer') if the patient is unable to report on their own experience of care.

There is compelling evidence, supported by concept analyses, policy, standards and rights, that the 10 Principles of Dignity in Care should be used to deliver and to evaluate the experience of care. Dignity is the word most prominent in rights and a word in common use in the community. To promote health literacy, there should be a shift away from the bureaucratic and poorly defined terms such 'person-centred' care and a shift toward the consumer empowering message contained in the 10 Principles of Dignity in Care.

The 10 Principles of Dignity in Care

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

The 10 Principles were generated from the feedback of hundreds of members of the public in the United Kingdom who were surveyed on their experience of dignity in care. The message 'Dignity in Care' has remained a powerful force for change in the provision of care in the United Kingdom. The 10 Principles are short, simple, easily understood and implementable statements, that can be used as a proxy for the more elusive 'person-centred' care.

Additionally, the 10 Principles cover content, important to older people, that is absent from the 'attributes' used to define 'person-centred' care.

My original contribution to knowledge was the development of a Patient Reported Experience Measure in the form of a Dignity in Care Questionnaire based on the 10 Principles of Dignity in Care. I have developed a patient version and a carer version of the Dignity in Care Questionnaire. The process of developing the patient and carer versions of the Dignity in Care Questionnaire was robust and resulted in achievement of each of the three aims of the study.

The first aim was to gain consensus from a panel of experts on the content to be used to measure each of the 10 Principles of Dignity in Care, for the patient and carer versions of the questionnaire that were to progress to the pilot study. This aim was achieved by a Delphi panel of 57 experts, including 19 consumers, were able to reach consensus on 69 items to include in the pilot study version of the questionnaire.

The second aim was to assess the: face validity of the items, ease of administration, number of items, time demands on respondents, scoring and interpretation with patients and carers in the hospital setting. This aim was achieved through the completion of an in-hospital pilot study in which 52 patients and carers participated in a cognitive interview while they completed the questionnaire, and in doing so, helped to refine the items and scoring used in the revised 50-item questionnaire.

The third aim was to collect questionnaire data to commence the process of assessment of the psychometric properties of the instrument. This aim was achieved through the collection of 200 patient and 77 carer questionnaires, which allowed the preliminary analysis of unidimensionality, validity and internal reliability using 'modern methods' of Rasch analysis.

The Dignity in Care Questionnaire includes 13 items in common across the patient and carer versions of the instrument. These 13 items represent 8 (of the 10) Principles of Dignity in Care. The final patient version of the instrument included an additional 10 unique items, resulting in a 23-item instrument, which demonstrated robust fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability. The final carer version of the instrument included an additional 5 unique items, resulting in an 18-item instrument which demonstrated acceptable fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability, but the carer results should be considered exploratory and preliminary as the findings need to be verified with a larger sample.

Both the patient and carer versions of the Dignity in Care Questionnaire warrant further development. Measuring experience of care is difficult, many instruments are developed to this point and progress no further, thus perpetuating a gap in the research for sound instruments, to be filled by yet another instrument that does not reach its potential. A robust instrument cannot be developed to its final form in one research study. The case for a patient and carer questionnaire, based on the 10 Principles of Dignity in Care, is sound, and this preliminary assessment of validity and internal reliability indicates the basis of a sound instrument of measure. Further development of items and further analysis of validity and reliability for both the patient and carer versions of the instrument are required.

The items that constitute the 23-item patient version and the 18-item carer version of the Dignity in Care Questionnaire, herald the evolution of a new PREM that can be used to measure aspects of care that are important and relevant to older people (and their carers).

The items included in the questionnaire hold messages that can be used by health services to improve the experience of care for older people. They can be used, as designed, in the form of a questionnaire and they can be used as the foundation of a discussion about experience of care, with those unable to complete a questionnaire. The messages contained in the items can be used in education and training and to guide the implementation of quality improvement activities.

In Australia, in 2020, there were two Royal Commissions underway. The Interim Report of the Royal Commission into Aged Care in Australia was titled ‘Neglect’. Dignity in Care is an obvious and compelling response. The title of the Disability Royal Commission is ‘Violence, Abuse, Neglect and Exploitation of People with Disability’. Again, ‘Dignity’ needs to be the headline response. Dignity is not a fad, it is a human, health and aged care right.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Louise Heuzenroeder

22 April 2020

Human dignity is inviolable. It must be respected and protected

The Charter of Fundamental Rights of The European Union

Dedicated to Maureen Therese Heuzenroeder

Acknowledgements

> *In everyone's life, at some time, our inner fire goes out. It is then burst into flame by an encounter with another human being. We should all be thankful for those people who rekindle the inner spirit* [1]

My greatest thanks to the Dementia Australia Research Foundation who awarded me the 2017 Dementia Advocate's Priority PhD Scholarship. An investment that I hope will be of value to older people, including those with dementia. With thanks to the Australian Government for their support of doctoral students through fee subsidy.

The very best part of undertaking my doctoral research was the opportunity to experience the extreme generosity of people I met along the way. The 57 people who gave hundreds of hours of their precious time and expertise to make the Delphi panel process a great success – thank you. The 52 patients and carers who participated in the pilot study and the 277 patients and carers who participated in the major data collection stage of the study - it would have been easy to say no, you enthusiastically said yes, and for that – thank you.

Thank you to the hundreds of nurses who treated me with collegiality by sharing some of their precious time to help me identify potential patient and carer participants.

A special thank you to Professor Dick Ruffin and Mr Ian Tindall, (previous and current) Chair of the CALHN Ethics Committee, who generously shared their wisdom.

I would like to acknowledge the belief and support of Professor Lynn Chenoweth and Professor Brian Draper in the early stages of development of this work.

Thank you to Professor Alison Kitson, it was an honour and a privilege to have you as my Principal Supervisor. Thank you for including me as a member of your team and thank you to your team members Dr Tiffany Conroy and Dr Rebecca Feo for your collegiality and support.

I was immensely fortunate to be the recipient of the extreme generosity of Dr Mike Horton. Thank you Dr Jyoti Khadka, an expert and Dr Faizal Ibrahim, an inspiration.

To my friends and family who may be wondering where I have been these last three years, this is my fifth and final university degree. I promise.

Abbreviations

ACSQHC	Australian Commission on Safety and Quality in Health Care
AHPEQS	Australian Hospital Patient Experience Question Set
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CPC	Category Probability Curve
CTT	Classical Test Theory
DiCQ	Dignity in Care Questionnaire
DIF	Differential Item Functioning
IRT	Item Response Theory
ISI	Item Separation Index
LHN	Local Health Network
	CALHN Central Adelaide Local Health Network
	NALHN Northern Adelaide Local Health Network
	SALHN Southern Adelaide Local Health Network
MnSq	Mean Square
NRSOA	Never, Rarely, Sometimes, Often, Always
PCAR	Principal Components Analysis of the Residuals
PREM	Patient Reported Experience Measure
PSI	Person Separation Index
RSM	Rating Scale Model
UK	United Kingdom
Zstd	Standardized as a z-score

Glossary of Terms

A ‘**carer’** is a person the patient would want involved in their care; the ‘carer’ might be a family member, spouse, child, relative, friend, support person, person responsible, care partner.

Throughout the thesis I have written ‘(and their carer)’ in brackets to emphasise that, in the first instance and wherever possible, the patient’s perspective must be sought and, wherever possible, the patient should determine to what extent the carer is involved. Where the patient does not have capacity, the ‘person responsible’ represents the patient’s wishes.

Patient Reported Experience Measures (PREMs) collect information about the experience of care, as described by patients. PREMs can utilise qualitative and quantitative methods, including surveys, focus groups, patient stories and observation.

A ‘**survey’** is a method of gathering information from a sample of people. A survey requires an instrument of measure. Surveys are commonly undertaken using questionnaires.

An ‘**instrument’** is the tool of measurement.

A ‘**questionnaire’** is the user interface of the instrument, for use by participants.

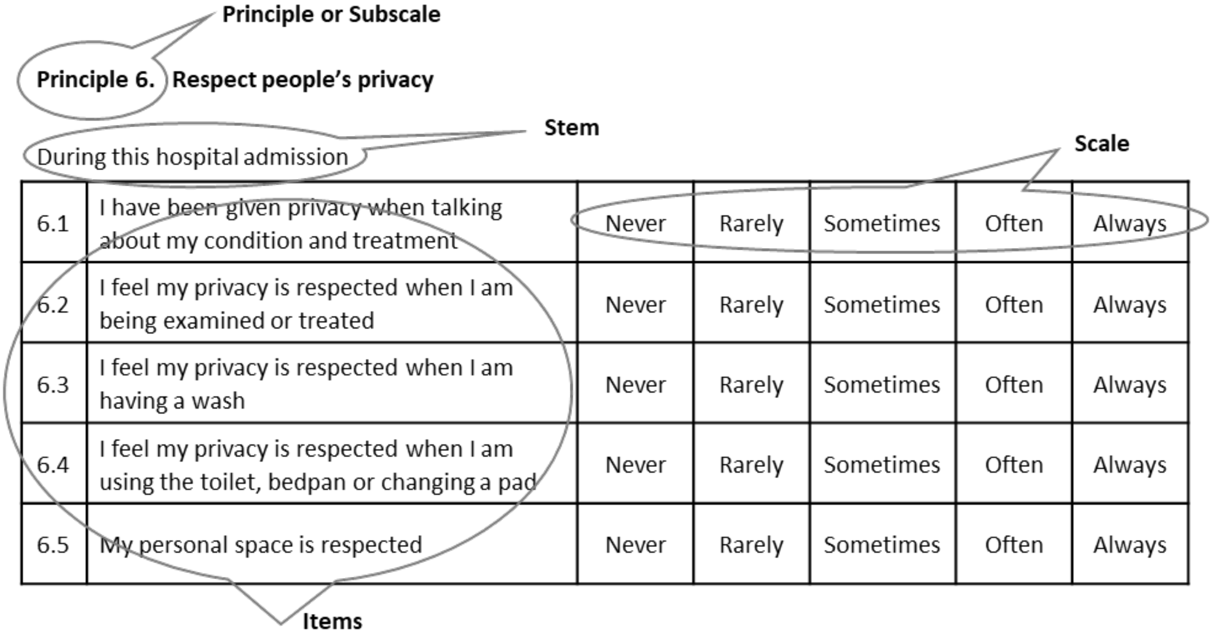
An ‘**item’** is the ‘question’ in the questionnaire.

The ‘**scale’** includes the options to answer to the question.

The ‘**stem’** is the introductory component of the item, used to place the item in context.

The ‘**subscales’** are the constituent parts of an overall subject composite scale. The 10 Principles of Dignity in Care were used as the subscales in this study.

An example of the terms in use in a questionnaire



Principle 6. Respect people's privacy

During this hospital admission

6.1	I have been given privacy when talking about my condition and treatment	Never	Rarely	Sometimes	Often	Always
6.2	I feel my privacy is respected when I am being examined or treated	Never	Rarely	Sometimes	Often	Always
6.3	I feel my privacy is respected when I am having a wash	Never	Rarely	Sometimes	Often	Always
6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Never	Rarely	Sometimes	Often	Always
6.5	My personal space is respected	Never	Rarely	Sometimes	Often	Always

1. Introduction

Our position, always, is not to bring a new scale into the world unless it is absolutely necessary [2]

1.1 Introduction

The Dignity in Care Campaign originated in the United Kingdom, in 2006, and grew in response to perceived systemic failures in the hospital care of vulnerable older people [3-6]. The Campaign has been supported by Dignity Champions who promote care according to the 10 Principles of Dignity in Care [7]. The Principles are statements about the expectations of care to be provided. Importantly, they were generated through feedback from a 2006 survey, conducted to allow the United Kingdom's Minister for Care Services to hear directly from the public about their own experiences of being treated with dignity, in care services [8].

The Dignity in Care Report (2006) [9] makes the recommendation that people should be surveyed on whether they were treated with dignity, so it was surprising, a Patient Reported Experience Measure, based on the 10 Principles of Dignity in Care, had never been developed. The purpose of this research study was to respond to that observation and see if it was possible to develop a Patient Reported Experience Measure based on the 10 Principles of Dignity in Care.

The Patient Reported Experience Measure I set out to develop took the form of two versions of a questionnaire. The Dignity in Care Questionnaire would include a patient version and a carer version. The carer is a family member or friend of the patient (defined in full in the Glossary of Terms). The main reason for the carer version was to capture patient experience of care, through the carer's perspective, when the patient was unable to report on their own experience of care. This is of great and increasing importance given the large proportion of patient's in hospital who are older and have cognitive impairment and are at greater risk of harm [10-12].

This research was undertaken in three stages. The first stage was a predominantly qualitative study utilising a modified Delphi technique designed to develop the content for the questionnaire. The second stage was a qualitative study utilising a cognitive interview to pilot test the questionnaire with older people and their carers in the hospital setting. The third stage, utilising quantitative methods, involved the collection of data and the analysis of the data to assess the validity and reliability of the newly developed questionnaire.

1.2 Chapter Outline

In this chapter I will introduce the research by explaining the background to the study. I explain my position in the research, the idea and the gap in research that the research question will answer. The conceptual framework and the stages of the study are explained through the methodological pathway. I present the scope of my doctoral research and acknowledge a Patient Reported Experience Measure (PREM) cannot be developed and finalised in one research study. Finally, I present my original contribution to knowledge and provide an outline of the thesis.

1.3 Background

Hospitalisation is hazardous for older people [13], and the evidence of that harm is well documented [5, 14]. A large proportion of the hospital population has cognitive impairment [12], placing them at greater risk of harm [11], including the harm of indignity [15, 16]. There are many messages used to describe how care should be provided. The different terms in use are confusing and have created definitional noise, which blurs the message.

For the past 40 years, the terms patient-centred [17] or person-centred [18] care have been extant in describing how health care should be provided. Other terms have also emerged, they include, but are not limited to, relationship-centred [19], individualised [20] and compassionate care [21]. As a collective, and for simplicity, these terms are referred to as ‘care concepts’.

The terminology for these care concepts varies by country and over time. The 2017 revision of the National Standards [22] used for hospital care in Australia referred both to ‘patient’- and ‘person’-centred care. In 2001, the Institute of Medicine’s Committee on the Quality of Health Care in America, identified the provision of ‘patient-centred’ care [23] as one of six aims for improvement. The Picker Institute Europe, prominent in producing reports and PREMs on care concepts, has shifted from ‘dignity in care’ in 2008 [24], to ‘person-centred care’ in 2016 [25] and ‘compassionate care’ in 2017 [26].

Publications exclusively using each care concept term imply these care concepts are each separate and different [19-21]. Other authors, however, have observed that the various care concepts cover similar territory and there are no agreed definitions for each [27-29]. The various terms contribute to definitional noise, making it difficult to understand the overall message of expectations around care to be provided and received.

The United Kingdom’s (UK) Dignity in Care Campaign has maintained a consistent message since 2006, which is, that care should be provided according to the 10 Principles of Dignity in Care (Figure 1. 1). The longevity of the Dignity in Care Campaign might be attributable to several factors. The Campaign has been resourced and supported through an independent National Dignity Council. The Campaign has harnessed the support of Dignity Champions [7]. Dignity has been the focus of many UK health policy documents, many of which are specific to the care of older people, including people with dementia, in hospital [15, 30]. The message ‘dignity in care’ is clear, and the words used in the message are clear ‘care should be provided according to the 10 Principles’.

The 10 Principles make short statements that can be used by clinicians to understand how to provide such care, and by patients (and carers) to know what to expect from the experience of care. Translating dignity in care into practice must include surveying people about their experience of dignity in care [9, 24]. The findings should be reported to, and monitored by, those accountable for the provision of care. A questionnaire is the tool required to undertake such a survey. Where people in care are unable to complete a questionnaire, a version of the questionnaire, adapted for use by the person’s carer (family/friend) should be used. A questionnaire is only a part of the process of implementation, but it is the important gap this research seeks to fill. The purpose of this research study is to develop a Dignity in Care Questionnaire (DiCQ) for use by older people (and their carer) for use in the hospital setting.

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people’s privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people’s loneliness and isolation.

Figure 1. 1 The 10 Principles of Dignity in Care

1.4 Patient Reported Experience Measures

Patient Reported Experience Measure (PREM) is a high-level term used to capture the ways a health service obtains a measure of patients' experience of care. A survey, using a questionnaire is the most common form of PREM. While questionnaires designed to measure 'satisfaction' and 'experience' have been used in health services for decades, the more recent shift to using the term PREM reflects the shift to being concerned about a patient's 'experience' (PREMs) and 'outcomes' (Patient Reported Outcome Measures) [31] and a shift away from measuring 'satisfaction'. However, a clear understanding of what is 'satisfaction' and what is 'experience' remains unclear.

The Australian Hospital Patient Experience Question Set (AHPEQS), which was revised in 2017 [32], is the generic hospital survey used for all adult inpatients. The AHPEQS is the most widely used PREM in Australia. My proposition is that the AHPEQS is necessarily generic, to meet the needs of all adult inpatient, and so not designed to meet the specific needs of older vulnerable people. As a result, such a generic questionnaire may not measure with accuracy the experience of care of older vulnerable people. As a consequence, there is a need for PREMs developed specifically for older people. Even more importantly, there is a need for PREMs to be developed that are based on a meaningful, implementable message about how care should be delivered and experienced.

1.5 My Position

My position is influenced by my experience in caring for my mother when she had advanced dementia, over the time period 2008 to 2014. As a carer for my mother, I experienced vastly different experiences of dignity in care when my mother attended two different hospitals. The experience made me wonder if anyone else knew about, or had experienced, this variation in care. There did not appear to be a systematic way for me to provide feedback on this experience. I could have initiated feedback through the complaints and compliments processes within each hospital, but I did not.

My experience made me feel that the provision of much dignity in care goes unrecorded. More terrifyingly for older people (and their carers), there is indignity which goes unrecorded, and is therefore sanctioned. There is little voice or power for patients (or their carers) if there are no systematic methods to measure and monitor dignity in care. This is profoundly unacceptable to anyone who has witnessed a person they love being treated with indignity.

1.6 The Idea

Geriatrician Dr Faizal Ibrahim introduced the Dignity in Care Campaign and the 10 Principles of Dignity in Care to South Australia when he commenced work at South Australia's The Queen Elizabeth hospital. In 2014, Dr Ibrahim formed a state-wide action group to expand interest in Dignity in Care [33]. I was a founding member of the action group.

As the work of the action group progressed, it struck me how easy it was for an organisation to state that it provided care according to the 10 Principles of Dignity in Care, but it was unclear exactly what had changed in organisations that made these claims. It was clear to me that the only way we could know if care was being provided according to the 10 Principles, was to ask those in receipt of care (and their carers). I was surprised to find the 10 Principles had never been developed into a questionnaire for use by consumers of care services. I was encouraged by the fact that a 2006 UK Department of Health report on dignity in care had recommended that people should be surveyed on whether they were treated with dignity [9].

It remains my most strongly held belief, that for change to occur, there needs to be commitment to implementation, measurement and monitoring of Dignity in Care by those with the highest levels of accountability in the hospital - the executive and the Board.

I articulated my original idea in an email addressed to the then Chair of the Dignity in Care Action Group (Andrew Larpent) on 15 October 2015, with a carbon copy to all members of the Action Group, which suggested developing a new consumer key performance indicator based on the 10 Principles of Dignity in Care.

I intentionally kept a hard copy of this email, and the generous responses I received from the action group members, in the hope that one day I would be able to reflect on the progress to implement this idea. I am proud of my progress to date, even more so because the original articulation of this idea did not reveal any understanding of the huge task ahead to develop the DiCQ.

Pleasing also that the core of what I wanted to achieve has remained over time. Despite the complexity of the task, I have not drifted from that which I set out to do.

1.7 The Gap

I am not the first to observe the disconnect between the dignity in care message and measurement of experience of dignity in care from the patient and carers' perspective [15 34 35 36 37 38 38]. In a concept analysis of care with dignity, Coventry (2006, p.42) noted 'Many institutions and organisations advertise dignified care and the importance of respect for human dignity as part of their philosophy and mission, but how this dignified care is accomplished or measured is not clearly stated.' [34] A similar conclusion was reached by Gallini (2011, p.144), in his thesis evaluating the response to the National Dignity in Care Campaign, he found 'The need for information on dignity to be able to be communicated from the wards to, and discussed at, Trust board was identified as a priority for the organization.' [39]

The gap my research is designed to fill is to create a PREM that can be used by organisations who wish to promote the 10 Principles of Dignity in Care as their organizational philosophy, to monitor the translation of that philosophy into practice.

1.8 The Research Question

The original idea translates well into the research question. 'Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting?'

1.9 Purpose

The purpose of my research study is to create a PREM that can be used to monitor older patients' (and carers') experience of Dignity in Care, the output of which can be reported in a form that is useful to hospital executives and Boards. The expectation being, if those with the highest level of accountability are aware of how patients' (and carers') experience Dignity in Care in their organisation, they will learn from and acknowledge great practice and improve unacceptable practice.

1.10 Aim

The aim of this research was to develop, and undertake a preliminary assessment of the unidimensionality, validity and internal reliability of, items that represent each of the 10

Principles of Dignity in Care that are relevant to older people (and their carers) when they are in hospital.

1.11 Ethical Questions

My research study sought to include vulnerable older people, including people with dementia (and/or their carers). These people have routinely been excluded from research studies. More recently, the ethics of exclusion have been questioned and there has been an acknowledgement that older people, including people with dementia need to be included in research [40].

Ethical approval for the study was granted by The Queen Elizabeth Hospital/Lyell McEwin Hospital/Modbury Hospital Human Research Ethics Committee and Central Adelaide Local Health Network Research Governance Office (HREC/17/TQEH/91) (All documents relating to ethics and governance approval are included in Appendices A1-A10).

1.12 Conceptual Framework

Development of PREMs in the absence of a clear conceptual framework has been identified as a common design fault [41]. Use of the 10 Principles of Dignity in Care as the conceptual basis of the design for this study gave structure to the item generation process and serves as a great strength of this study.

1.13 Methodological Pathway

The study utlised an exploratory sequential mixed method design to develop a survey instrument (Figure 1. 2). The methods included predominantly qualitative methods to develop the items and response categories and quantitative methods to test the psychometric properties of the instrument.

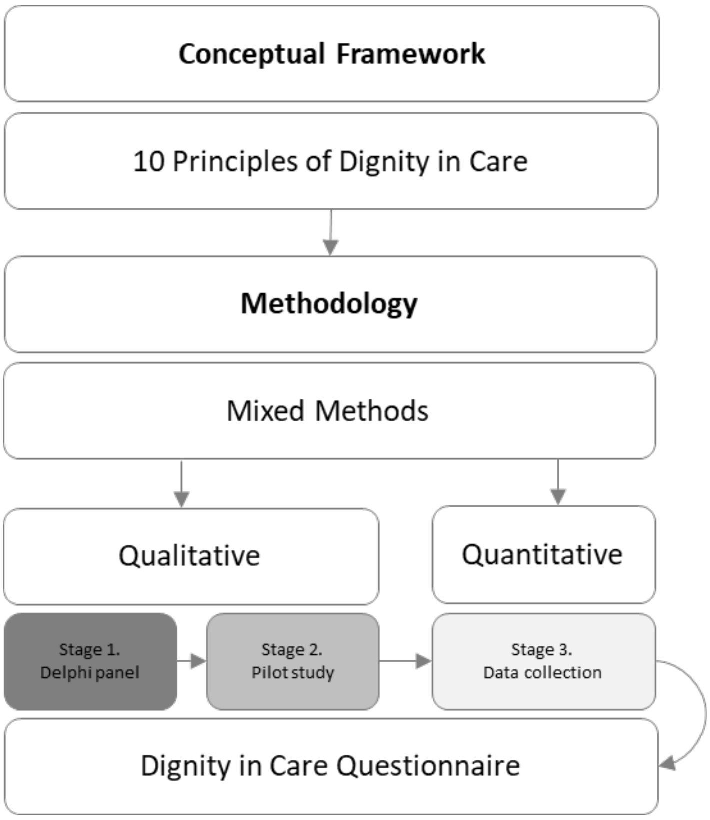


Figure 1. 2 Methodological Pathway

1.13.1 Stage 1. Delphi study

Aim: To gain consensus from a panel of experts on the content used to measure each of the 10 Principles of Dignity in Care, which will form the patient and carer versions of the questionnaire that will proceed to pilot testing.

Objectives:

i. To identify, recruit and consent the Delphi panel of experts.
ii. To prepare the initial item pool from policy, qualitative research and existing instruments, for use in the first round of Delphi panel deliberations.
iii. Conduct the required rounds of Delphi panel deliberations, preparing content for each round and providing feedback from each round to panel members.

1.13.2 Stage 2. Pilot study

Aim: To assess the: face validity of the items, ease of administration, number of items, time demands on respondents, scoring and interpretation with patients and carers in the hospital setting.

Objectives:

i. To identify, recruit and consent participants.
ii. To undertake a cognitive interview with patients and carers while they undertake the pilot questionnaire.

1.13.3 Stage 3. Preliminary Assessment of Validity and Internal Reliability

Aim: To collect questionnaire data to undertake a preliminary assessment of validity and internal reliability.

Objectives:

i. To identify, recruit and consent participants to complete the questionnaire
ii. Use Rasch analysis to undertake a preliminary assessment of the psychometric properties (including unidimensionality, construct validity and internal reliability) of the patient and carer versions of the questionnaire.

1.14 Scope

The scope of my doctoral research includes three stages (detailed in the previous sections 1.13.1, 1.13.2 and 1.13.3). It is acknowledged that a questionnaire cannot be development into its final form in one research study; it is expected that further research will be required. This may include further validity and reliability testing in the hospital setting. Further research will also be required to validate the questionnaire if there is support for its use in other settings, including disability services and aged care.

1.15 Original Contribution to Knowledge

My original contribution to knowledge has been the development of a PREM, in the form of a patient and carer version of a DiCQ based on the 10 Principles of Dignity in Care , for use by older people (and their carers) when they are in hospital.

The DiCQ could be used by hospitals as the message that translates the bureaucratic and poorly understood term ‘person-centred’ [42] care into 10 practical ways to deliver, measure, monitor and improve the experience of care.

1.16 Thesis Overview

This doctoral thesis is presented in eight chapters. Following this introductory chapter is the literature review (Chapter 2). The methodology (Chapter 3) prepares the reader for the three Stages of the research (presented separately in Chapters 4, 5 and 6, respectively). The findings of all three stages are presented in the discussion (Chapter 7) and finally, the conclusion (Chapter 8).

Chapter 1 introduces the research, setting out the research question, the scope of the research and the original contribution to knowledge. Chapter 2 explores the literature to commence the process of developing the content validity for the 10 Principles. The literature review also serves to develop the item pool for use in Stage 1 of the study. The conceptual framework and theoretical underpinnings of the research are explored within the structure of the methodological pathway in Chapter 3. The three stages of the study, each covering the method, findings and discussion, are presented in Chapters 4, 5 and 6. Chapter 4 covers Stage 1 of the research study, which involved conducting a Delphi study to determine content for the questionnaire. Chapter 5 covers Stage 2 of the study, the pilot testing of the questionnaire with patients and carers in the hospital setting. Chapter 6 covers Stage 3 of the study, the data collection and preliminary assessment of unidimensionality, validity and reliability of the instrument. Chapter 7 includes the findings of each Stage of the study and an overall discussion of the limitations and potential of the research and Chapter 8 draws conclusions from the research, considers the strengths and limitations of the study and presents plans for further research to continue to the process of developing the DiCQ as a PREM.

1.17 Summary

This chapter introduced the research by explaining the background, the research question and the stages of the study through the methodological pathway. I have explained the scope of the doctoral research and my original contribution to knowledge. The content of each of the following chapters of the thesis has been introduced. The next chapter is the literature review, which serves to strengthen the justification for the research and allows the necessary preparation for Stage 1 of the research.

2. Literature Review

The basic notion of human rights lies in people's recognition of the need to protect and affirm every other person's individual dignity [43]

2.1 Introduction

The purpose of the Literature Review is to commence the process of developing content validity for the 10 Principles of Dignity in Care. Through the Literature Review, I will determine whether I have included all the relevant and excluded the irrelevant material in terms of content. I will do this by exploring how the 10 Principles of Dignity in Care align with key concepts used to promote expectations of how care should be delivered and experienced. By doing so I will determine if the 10 Principles provide strong coverage of important content and identify gaps that should be filled.

The Literature Review is presented in three parts. In Part 1 I will examine the prominence of 'dignity' in human rights, health and aged care rights, standards and clinical guidelines. In Part 2 I will examine how the 10 Principles of Dignity in Care represent the component parts of 'care concepts' (including patient-centred care, person-centred care, relationship-centred care, individualised care and compassionate care). My proposition is that these care concepts, despite their separate names, are in fact representing a similar set of component parts and that those component parts are well articulated by the 10 Principles. In Part 3 I will mine the literature for items in existing Patient Reported Experience Measures, qualitative research and policy, for use in creating the item pool necessary for Stage 1 of the study (Delphi Panel, Chapter 4).

2.2 Part 1 Dignity in health care rights and policy

2.2.1 Introduction to Part 1 of the Literature Review

The purpose of Part 1 of the literature review is to start to make the case for dignity in care as a robust concept that is important to measure consistently and accurately in healthcare settings. I will do this by demonstrating the prominent place dignity has in health care rights, aged care rights, policy and clinical guidelines. Part 1 of the literature review is not a definitive account of all rights, policy, reports and guidelines on the topic of dignity in care, but an account of the evidence that demonstrates dignity is not a fad. Dignity is fundamental to the experience of care.

2.2.2 Search strategy for Part 1 of the Literature Review

2.2.2.1. Rights

The starting point for searching for material for Part 1 of the literature review was the World Health Organization [44], whose webpage includes links to the charters of health care rights of many countries. Many of the links were no longer functional, however entering the name of the country and 'health care rights' into a search engine proved successful in locating the charters.

2.2.2.2. Policy

I accumulated health and aged care policy employing an iterative snowballing technique [45], as one policy or report provided references for many similar reports. Saturation was reached once new policy or reports were no longer identified.

2.2.3 Results of Part 1 of the Literature Review

According to the World Health Organization, it is the 1948 Universal Declaration of Human Rights [46] recognition of the 'inherent **dignity'** of people that serves as the basis for the development of patients' rights. Dignity is a common thread across the Charter of Patient's Rights of many countries, including: Australia 'Be treated as an individual, and with **dignity** and respect' [47], Canada 'Patients in Canada have the right to be treated with **dignity** and respect' [48], Hong Kong 'Right to choices - To have privacy, **dignity**, religious and cultural beliefs respected' [49], India 'The hospital management has a duty to ensure that its staff upholds the human **dignity** of every patient in all situations' [50], Ireland 'We will treat you, your family and carers with **dignity** …' [51], Israel 'You have the right that all care providers and all employees of the medical institution will retain your **dignity** …at all stages of treatment' [52], Malaysia 'Every patient shall be treated with … **dignity** without discrimination of any kind' [53], Scotland 'When …. receiving NHS care in Scotland, you can expect to be treated with **dignity** and respect in line with your human rights' [54] and South Africa 'A positive disposition displayed by health care providers that demonstrate … human **dignity'**[55]. The European Charter of Patients' Rights references the European Union Charter of

Fundamental Rights, which states ‘Human **dignity** is inviolable. It must be respected and protected’ [56].

The recognition of dignity as a health care right is reflected in extensive policy documents, published in the United Kingdom (UK), promoting dignity in care. Examples include Leveson’s 2007 report for Help the Aged titled ‘The challenge of dignity in care: upholding the rights of the individual’ [57], the Health Commission’s 2007 ‘Caring for Dignity. A national report on dignity in care for older people while in hospital’ [58] and Age UK’s 2012 ‘Delivering Dignity’ [30]. The message in UK policy has been consistent over time. Dignity in care is not a fad. Dignity in care is important.

Internationally dignity is extant in patient’s rights and in UK policy, and now has a prominent place in clinical guidelines. In Australia, the number one recommendation of the Clinical Guidelines for Dementia in Australia (2016) state ‘The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated’ [59]. Evidence that this recommendation has been implemented would surely support aged care providers to meet the requirements for Standard 1 ‘Consumer dignity and choice’ of the 2018 revision of the Australian Aged Care Standards [60]. The same evidence could be used to support Action 2.3 of the Australian National Safety and Quality Healthcare Standard ‘Partnering with Consumers’, which includes ‘Conducting surveys of patients to check …. whether the rights in the charter have been respected’ [22]. In Australia, dignity is not only a health care right, it is an aged care right ‘I have the right to be treated with dignity and respect’ [61].

Despite the clear message in patient’s rights, policy and clinical practice guidelines, revelations of the **indignity** evident in substandard care continues to be exposed. By way of example, the Francis report (2013) found ‘Large numbers of patients were left unprotected, exposed to risk, and subjected to quite unacceptable risks of harm and **indignity** over a period of years’ (p.25) [5]. The Andrews’ report (2014) found ‘variable or poor professional behaviour and practice in the care of frail older people’ (p. 2) [4]. In Australia, the 2017 report into the abuse of patients at Oakden, an older person’s mental health service, reported ‘there were consumers who were not treated with respect, left soiled and un-bathed, were not adequately fed and hydrated, confronted with a “show of force” to undertake routine tasks of daily living, mocked, ridiculed, spoken to as if they are children, dressed inappropriately, left unkempt, and treated with **little personal dignity**’ [14]. The response to the revelations of abuse at Oakden include a recommendation to adopt the Dignity in Care Principles.

Given the findings of the 2019 Interim report of the Royal Commission into Aged Care in Australia [62], titled ‘Neglect’, it does not appear the prominence dignity holds in rights, policy, standards and guidelines is being translated into practice. The extent of neglect is evident by the fact that in 2019/20 Australia also had a Disability Royal Commission [63] underway, the title of which is ‘Violence, Abuse, Neglect and Exploitation of People with Disability’. Dignity in care is, once again, an obvious and compelling response, but the focus of the response must be on the implementation of dignity in care into practice.

2.2.4 Mapping the 10 Principles of Dignity in Care to Australian health care rights and aged care rights

Translating dignity in care into practice must include surveying people about their experience of dignity in care [9, 24]. A questionnaire is only one part of the process of implementation, but it is the important gap this research seeks to fill. Australia has well-articulated Health Care Rights [47] and Aged Care Rights [61]. I will now examine the alignment between the 10 Principles and Australian Health Care and Aged Care rights in more detail. Figure 2.1 displays the intent of the exercise to examine the alignment between rights and the 10 Principles. It is possible there might be content from rights that does not map to any of the 10 Principles and it is possible there are Principles that might not map to any content covered in rights. Strong alignment between the 10 Principles and rights could be used as evidence that to translate dignity in care into practice, is to translate health care and aged care rights into practice.

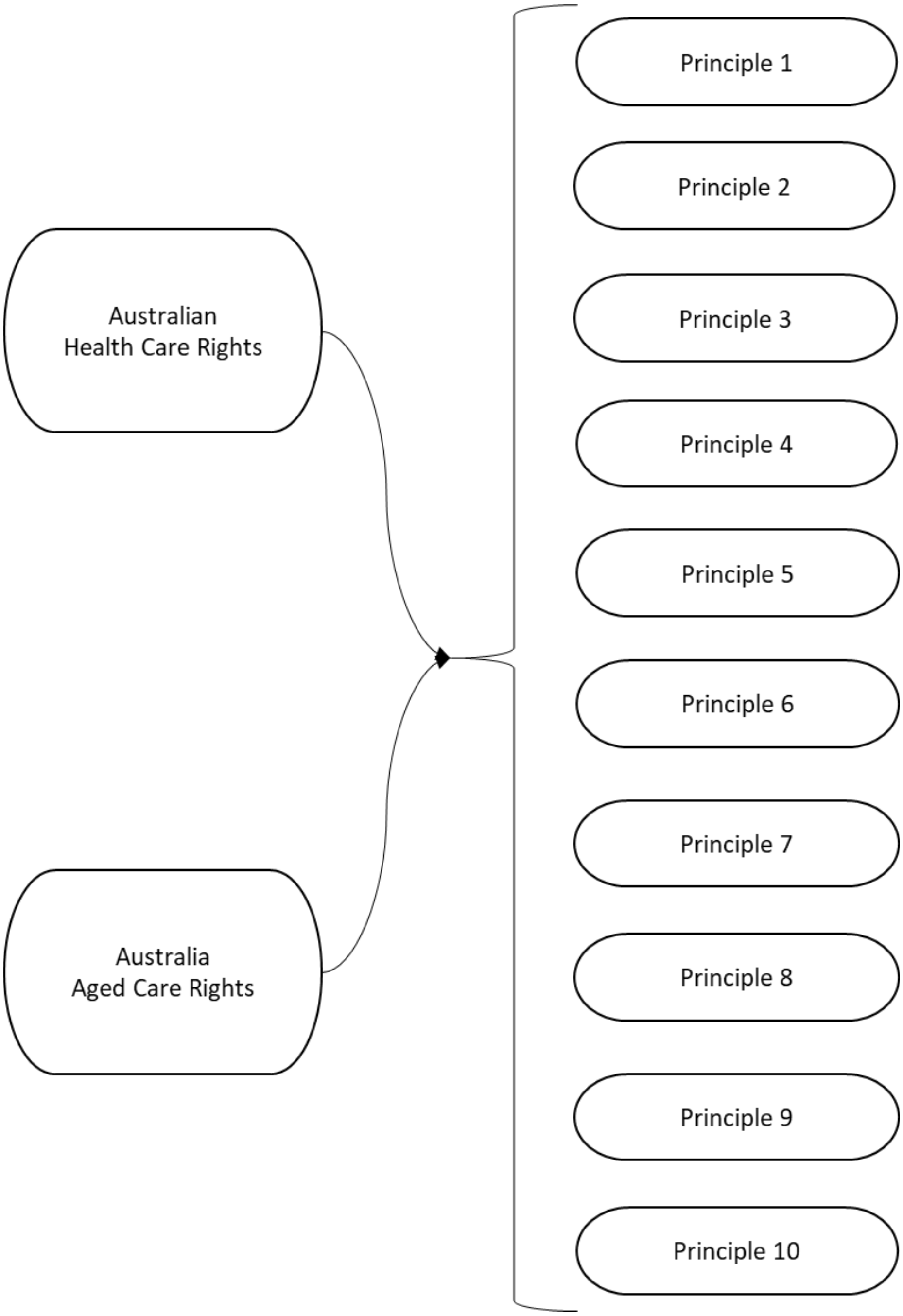


Figure 2. 1 Part 1 Mapping the Australian Health Care Rights and Aged Care Rights to the 10 Principles of Dignity in Care

Starting with Principe 1, the word used in the Australian health care rights is ‘safety’, which is far from the explicit statement ‘zero tolerance of all forms of abuse’. It seems ‘safe’ to use the word ‘safety’ despite the increasing volume of policy that uses the explicit terminology of ‘elder abuse’ [64] [65]. The 2019 revision of the Australian Charter of Aged Care Rights is moving in the necessary direction with the inclusion of ‘safe and high-quality care and services’ and the ability to ‘live without abuse and neglect’ [61] (Table 2. 1).

Table 2. 1 Australian Health Care Rights and Aged Care Rights mapped to Principle 1

Principle 1	'Zero tolerance of all forms of abuse' [7]
Health Care Rights	'Safety – Receive safe and high quality health care that meets national standards' [47] 'Safety – Be cared for in an environment that is safe and makes me feel safe' [47]
Aged Care Rights	'Safe and high-quality services – ability to live without abuse and neglect' [61]

The word 'respect' is common across Principle 2, health care and aged care rights. 'Respect' is an Australian Health Care right, described as 'Be treated as an individual, and with dignity and respect' and 'Have my culture, identity, beliefs and choices recognized and respected' [47]. To 'be treated with dignity and respect' is an Australian Aged Care Right [61] (Table 2. 2).

Table 2. 2 Australian Health Care Rights and Aged Care Rights mapped to Principle 2

Principle 2	'Support people with the same respect you would want for yourself or a member of your family' [7]
Health Care Rights	'Be treated as an individual, and with dignity and respect' [47] 'Have my culture, identity, beliefs and choices recognized and respected' [47]
Aged Care Rights	'Be treated with dignity and respect' [61]

The words 'individual' and 'identity' connect Principle 3 with health care rights and aged care rights. The Australian health care rights include, under the heading 'Respect', that people should 'be treated as an individual' [47]. Individuality is recognized in the 2019 revision of the Australian aged care rights, stated as to 'have my identity, culture and diversity valued and supported' [61] (Table 2. 3).

Table 2. 3 Australian Health Care Rights and Aged Care Rights mapped to Principle 3

Principle 3	'Treat each person as an individual by offering a personalised service' [7]
Health Care Rights	'Be treated as an individual' [47]
Aged Care Rights	'Have my identity, culture and diversity valued and supported' [61]

The Australian health care rights do not use the key words of Principle 4 'independence', 'choice' and 'control', rather they use the term 'partnership', described as 'ask questions and be involved in open and honest communication', 'make decisions with my healthcare provider, to the extent that I choose and am able to' [47]. The key words of Principle 4 are covered more explicitly by the Australian aged care rights, which include to ‘be informed about my care and services in a way I understand’, to be able to ‘access all information about myself, including information about my rights, care and services’, to ‘have control over and make choices about my care, personal and social life, including where choices involve personal risk’, to ‘have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions’ and to retain ‘my independence’ [61] (Table 2. 4).

Table 2. 4 Australian Health Care Rights and Aged Care Rights mapped to Principle 4

Principle 4	‘Enable people to maintain the maximum possible level of independence, choice and control’ [7]
Health Care Rights	‘Partnership - ask questions and be involved in open and honest communication, make decisions with my healthcare provider, to the extent that I choose and am able to… ’ [47]
Aged Care Rights	‘Be informed about my care and services in a way I understand’ [61] ‘Access all information about myself, including information about my rights, care and services’ [61] ‘Have control over and make choices about my care, personal and social life, including where choices involve personal risk’ [61] ‘Have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions’ [61] ‘My independence’ [61]

Principle 5 could be interpreted to align, to some extent, with ‘Information’, an Australian healthcare right, described as ‘clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent’, ‘receive information about services, waiting times and costs’, ‘be given assistance, when I need it, to help me to understand and use health information’, ‘access my health information’ and ‘be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe’ [47]. Principle 5 is far more closely aligned to the wording of the Australian aged care right ‘To be listened to and understood’ [61] (Table 2. 5).

Table 2. 5 Australian Health Care Rights and Aged Care Rights mapped to Principle 5

Principle 5	‘Listen to and support people to express their needs and wants’ [7]
Health Care Rights	‘Information - clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent, receive information about services, waiting times and costs, be given assistance, when I need it, to help me to understand and use health information, access my health information and be told is something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe’ [47]
Aged Care Rights	‘Be listened to and understood’ [61]

The word 'privacy' is common across Principle 6 and health care and aged care rights. 'Privacy' is an Australian healthcare right, described as 'Have my personal privacy respected' and 'have information about me and my health kept secure and confidential' [47]. 'Personal privacy and to have my personal information protected' is an Australian aged care right [61] (Table 2. 6).

Table 2. 6 Australian Health Care Rights and Aged Care Rights mapped to Principle 6

Principle 6	'Respect people's privacy' [7]
Health Care Rights	'Privacy - Have my personal privacy respected and have information about me and my health kept secure and confidential' [47]
Aged Care Rights	'Personal privacy and to have my personal information protected' is an Australian aged care right' [61]

The wording of Principle 7 is similar to the wording of health care and aged rights. 'Give Feedback' is an Australian healthcare right, described as 'provide feedback or make a complaint without it affecting the way I am treated', 'have my concerns addressed in a transparent and timely way', and 'share my experience and participate to improve the quality of care and health services' [47]. The ability to 'complain free from reprisal, and to have my complaints dealt with fairly and promptly' and the ability to 'exercise my rights without it adversely affecting the way I am treated' are Australian aged care rights [61] (Table 2. 7).

Table 2. 7 Australian Health Care Rights and Aged Care Rights mapped to Principle 7

Principle 7	'Ensure people feel able to complain without fear of retribution' [7]
Health Care Rights	'Give feedback - provide feedback or make a complaint without it affecting the way I am treated, have my concerns addressed in a transparent and timely way, and share my experience and participate to improve the quality of care and health services' [47]
Aged Care Rights	'Complain free from reprisal, and to have my complaints dealt with fairly and promptly' [61] 'Exercise my rights without it adversely affecting the way I am treated'[61]

The health care right 'Partnership … Include the people that I want in planning and decision-making' [47] and the aged care right 'To have a person of my choice, including an aged care advocate, support me or speak on my behalf' is an Australian aged care right [61] both align well to Principle 8 (Table 2. 8).

Table 2. 8 Australian Health Care Rights and Aged Care Rights mapped to Principle 8

Principle 8	'Engage with family members and carers as care partners' [7]
Health Care Rights	'Partnership… include the people that I want in planning and decision-making' [47]
Aged Care Rights	'Have a person of my choice, including an aged care advocate, support me or speak on my behalf' [61]

The breadth of the Principles is demonstrated by the fact that Principle 9 'maintaining confidence and self-esteem' and Principle 10 'alleviating loneliness and isolation' contain themes of importance to older people [15, 66], which are absent from Australian health care rights and aged care rights.

The only Australian healthcare right that does not map to any of the 10 Principles is 'Access', stated as 'I have a right to health care' [47].

2.2.5 Conclusion to Part 1 of the Literature review

Dignity is recognised internationally in health care rights. In Australia, dignity is recognised in health care rights and aged care rights. Dignity has a prominent place in health and aged care policy and clinical guidelines. A questionnaire based on the 10 Principles of Dignity in Care could be used to measure and monitor the translation of these rights, policy and the recommendations of guidelines and standards into practice.

2.3 Part 2 Mapping the definitions of care concepts to the 10 Principles of Dignity in Care

2.3.1 Introduction to Part 2 of the Literature Review

The purpose of Part 2 of the literature review is to continue to make the case for dignity in care. The literature on dignity in care is vast and includes many and varied definitions. I will map the various definitions of dignity in care to the 10 Principles of Dignity in Care in order to present the evidence that the 10 Principles are representative of the majority of content used to define dignity in care.

I will examine how the 10 Principles of Dignity in Care represent the component parts of 'care concepts' (including patient-centred care, person-centred care, relationship-centred care, individualised care and compassionate care). My proposition is that these care concepts, despite their separate names, are in fact representing a similar set of component parts and that those component parts are well articulated by the 10 Principles. If I can support my proposition with evidence, it strengthens the case that ‘The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated’ [59]. It follows, the 10 Principles should be used to measure patient’s and carer’s experience of care.

2.3.2 Search Strategy for Part 2 of the Literature Review

A search was undertaken through the Medline (OVID) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases. The literature on care concepts is vast and for this reason the search strategy was limited to concept analyses. I searched for articles with ‘dignity’, ‘patient-cent*’, ‘person-cent*’, ‘relationship-cent*’, ‘individuali*’ or ‘compassion*’ AND ‘concept analysis’.

Concept analysis is a formal and rigorous process by which an ambiguous concept is explored, made transparent, defined and differentiated from similar concepts [67]. According to Walker and Avant (2005), concept analysis is the first step toward building the foundations of nursing practice [68]. Walker and Avant modified Wilson's (1963) linguistic approach to concept clarification by tightening the process into eight discrete steps. Those steps include (a) selecting a concept, (b) stating the purpose of analysis, (c) describing uses of the concept, (d) determining the concept's defining attributes, (e) identifying a model case, (f) providing other associated cases, (g) enumerating antecedents and consequences, and (h) defining empirical referents [69].

The justification for concentrating on concept analyses is based on four arguments 1) the literature on care concepts is vast and had to be contained for access, understanding and interpretation 2) for a concept to be developed into a Patient Reported Experience Measure (PREM) it should have undergone rigorous conceptual and content development and this evidence should have been published. 3) I am seeking publications that include definitions with descriptions of the component parts of the care concept, this is identified as an ‘attribute’ in concept analyses and 4) Concept analyses are based on rigorous literature reviews of original research. I would duplicate content if I included concept analyses, original research and reviews of original research. This approach also seemed a fair way to represent the different care concepts as the concept analyses, almost exclusively, are based on the method of Walker and Avant [68].

2.3.3 Results of Part 2 of the Literature Review

There were ten concept analyses included for ‘dignity’, three conceptual analyses included for ‘compassion’, four conceptual analyses included ‘patient-centred’ care and two conceptual-analyses included for ‘person-centred’ care. No concept analyses could be identified for ‘individualised’ or ‘relationship-cnetred’ care. The reasons concept analyses that were identified in the results, but excluded from this review, are listed in Table 2. 9.

Table 2. 9 Search results for concept analyses across care concepts

Search terms	Result	Included	Why excluded
‘dignity’ and ‘concept analysis’	10	10	
‘compassion*’ and ‘concept analysis’	14	3	Most concept analyses for compassion were about compassion fatigue.
‘individuali*’ and ‘concept analysis’	3	0	One was for activities for people with dementia; one was for Neonatal Care and one was for ageing.
‘patient-cent*’ and ‘concept analysis’	5	4	One concept analysis was specific to ICU
‘person-cent*’ and ‘concept analysis’	2	2	
‘relationship-cent*’ and ‘concept analysis’	0	0	Nil results

There were no concept analyses located for individualised care or relationship-centred care, as a result these care concepts were not included in Part 2 of the Literature Review.

2.3.4 Presentation of Part 2 of the Literature Review

I presented each of the 10 Principles of Dignity in Care, one through to ten, with a table of ‘defining attributes’ (component parts of the definition) from each of the concept analyses across the different care concepts (as set out on the left hand side of Figure 2. 2) and provide commentary about how content does or does not map to each Principle. Figure 2.2 displays the intent of the exercise to examine the alignment between the attributes of care concepts and the 10 Principles. It is possible there might be content from the attributes of care concepts that does not map to any of the 10 Principles and it is possible there are Principles that might not map to any attributes of care concepts. Mapping the content to the 10 Principles is not an exact science, some definitional words map clearly, some map less clearly, some apply to more than one Principle and some do not map.

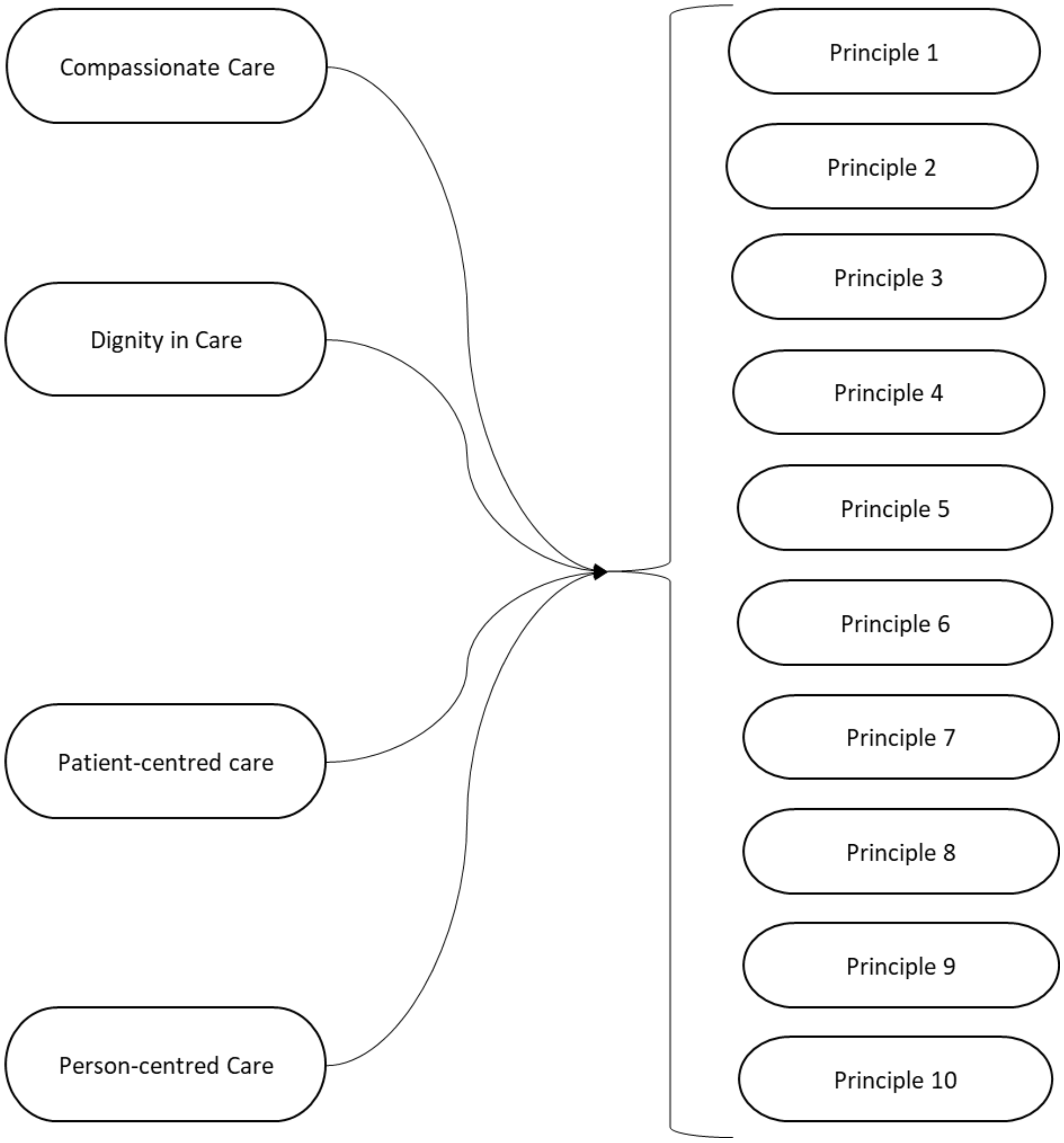


Figure 2. 2 Part 2 Mapping the content of care concepts to the 10 Principles of Dignity in Care

2.3.4.1. Principle 1. Zero tolerance of all forms of abuse

Much of the literature on care constructs has developed in response to the revelations of abuse of older people in care [4, 5, 14], yet there is no content relevant to Principle 1 in the concept analyses examined (Table 2. 10). The only reference that could be included was from Hemati's concept analysis of dying with dignity, which includes reference to pain.

Table 2. 10 Definitions of care concepts mapped to Principle 1

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Lack of pain' Hemati (2106, p. 1223)
Patient-centred Care	-
Person-centred Care	-

Undertaking this review of the 'attributes' used to define common care concepts has revealed a substantial gap in content relating to the right to be free from abuse. There appears to be a complete disconnect between the literature reporting on the abuse of older people in care [4, 5, 14] and the definitions available to guide staff about how care should be provided and what patients should expect from care. This is a gap the 10 Principles can fill with the plain and honest phrasing of Principle 1 'zero tolerance of all forms of abuse'. The language sets the tone of clarity and empowerment, both of which are much needed in the message and measurement of patient (and carer) experience of care.

2.3.4.2. Principle 2. Support people with the same respect you would want for yourself or a member of your family

The word 'respect' is well represented across the 'attributes' identified in concept analyses of dignity in care, patient-centred and person-centred care (Table 2. 11). Each includes several examples of how respect is 'attributed' to the experience of care, and there are some common themes which are relevant to other of the 10 Principles.

Respect is connected to Principle 10 (alleviate loneliness and isolation) "Showing respect also includes the social network around older people (Fenton&Mitchell 2002, Nordenfelt 2003a) [70]. Such a network gives meaning to an older patient and confirms self-respect (Stenbock-Hult 1993)" [70]. Respect is connected to Principle 6 (privacy) "Losing bodily functions threatens dignity (Edlund 1999, Nordenfelt 2003b) and it is important not to expose the body in front of others (Gallhanger & Seedhouse 2002, Woolhead et al. 2004)" [70]. Respect is associated with Principle 4 ('independence, choice and control) "The right to be treated with respect allows for individuals to be recognized as competent to make decisions about their own care (Leplege et al.,2007)" [71].

Table 2. 11 Definitions of care concepts mapped to Principle 2

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Respect' Anderberg (2007, p.639) [70] - Showing respect, according to older adults, implies the little things that make an older adult feel valued (Jacelon et al. 2004). - Older people link dignity and respect. They preserve self-respect through the respect communicated by people around them (Moody 1998, Woolhead et al. 2004). - Showing respect may imply giving older people a space of their own (Shotton&Seedhouse 1998). - This space should hold things serving as symbols of the older people's individuality (Gallhanger & Seedhouse 2002, Lee et al. 2002) and also allow for peace, silence and thoughts about life (Nystro¨m & Andersson-Segesten 1990, Nystro¨m 1995). - Showing respect also includes the social network around older people (Fenton&Mitchell 2002, Nordenfelt 2003a). Such a network gives meaning to an older patient and confirms self-respect (Stenbock-Hult 1993). - Even the bodies of older people need respect (Gallhanger & Seedhouse 2002, Woolhead et al. 2004). - Losing bodily functions threatens dignity (Edlund 1999, Nordenfelt 2003b) and it is important not to expose the body in front of others (Gallhanger & Seedhouse 2002, Woolhead et al. 2004). - Respecting older people's choices, such as choosing what clothes to wear, is important (Edlund 2003, Woolhead et al. 2004). 'Respect' Griffin-Heslin (2005, p.254) [72] - Self-respect, respect for others, respect for peoples' privacy, confidentiality, self-belief, belief in others [72]. 'Being respected' Hemati (2016, p. 1223) [73] - The body and beliefs of patients and their families (Cheraghi et al. 2014) [73]. 'Maintenance of Self Respect' [74] Mairis (1994, p.949)
Patient-centred Care	'Essential characteristics of the clinician' [75] - A set of attitudes towards the patient (e.g. empathy, respect, honesty) [75]. 'Caring Attitude' (Lusk, 2013, p. 94) [76] - Relationship development with respect for the patient is emphasized [76].
Person-centred Care	'Respectful' Morgan (2012, p. 9) [71] - Being respectful also is an important attribute of PCC and is frequently referred to as a "right" and the driving force behind this concept (McCormack, 2003). - The right to be treated with respect allows for individuals to be recognized as competent to make decisions about their own care (Leplege et al.,2007). Patients are increasingly regarded as active health care consumers and have the right to choices in their service and care (Mead & Bower, 2000).

	- Offering choices in care recognizes and respects the inherent value of each individual, supports a person's strength and abilities, and encourages human freedom (Rader & Lavelle, 2008). - Respect for basic choices in daily routines includes preferences about food and meal times, who visits and when, waking and sleep times, privacy, and bathing (Kantor, 2008).

Respect is a core attribute of dignity in care, patient-centred and person-centred care. The word respect is in common use across definitions of care concepts. It is a word that has not been subjected to rigorous definitional analysis (as has dignity) and appears to be written, used and understood without scrutiny [77]. It is not a word easily interchangeable with other words, but often appears alongside dignity [35, 78]. There is an interdependence between dignity and respect, and both are central to relationships between patients and carers and hospital staff.

2.3.4.3. Principle 3. Treat each person as an individual by offering a personalised service

Of all of the 10 Principles, the content covering Principle 3 'treat each person as an individual' is the most highly represented 'attribute' identified in concept analyses of dignity in care, patient-centred and person-centred care (Table 2. 12). The definitions are similar across dignity in care, patient-centred and person-centred. The concept of 'individuality' is often linked with Principle 4 (independence, choice and control) and to some extent, Principle 5 (listen and support/needs and wants). To demonstrate this point, Anderberg (2007, p.639) includes "Confirming individuality in caring implies encouraging the older person to take an active part in decisions and measures concerning their own care" and "Individuality is further confirmed when nurses listen carefully to older people's life experiences, life story and views of the future (SoS 1997a, Jacelon 2001, Berglund & Ericsson 2003, DOE n.d.)" [70].

The definitions identify the need to understand the individual cultural, spiritual and religious beliefs that are unique to each person, for example, Morgan identifies the 'attribute' of 'holistic' care, where "The whole person is described as the biological, social, psychological, and spiritual aspects of an individual (McCormack, 2003)" [71]. Hemati (2016, p. 1223) refers to "Having moral comfort and satisfying the spiritual needs with particular attention to religious and cultural characteristics" [73].

Table 2. 12 Definitions of care concepts mapped to Principle 3

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Individualised care' Anderberg (2007, p.639) [70] - Confirming individuality in caring implies encouraging the older person to take an active part in decisions and measures concerning their own care. - To be cared for in the way which older people prefer, in line with individual needs and choices, preserves dignity (Gallhanger 1995, SOU 1997, Stabell & Lindstrom 2003). - In several studies, older people stressed the importance of still being of value and, as far as possible, of being able to handle daily life activities on their own. They also stressed the importance of being useful and not being a burden (Nystro¨m & Segesten 1994, Edlund 1999, 2002). - Individuality is further confirmed when nurses listen carefully to older people’s life experiences, life story and views of the future (SoS 1997a, Jacelon 2001, Berglund & Ericsson 2003, DOE n.d.). - In this way, cultural and social norms from older people’s childhood and life will be expressed and confirmed (SoS 1997a, Ha¨ggstro¨m 2004). - Such norms include aspects of dignity related to self-esteem, habits and expectations (Edlund 2003). - Being confirmed may help older people to assume new values such as acceptance of help by others (Stabell & Lindstrom 2003) ‘Guidelines for how to respect individual diversity are set by each partner in the relationship’ Coventry (2006, p.44) [34]. ‘Individual dignity not affected by others’ Hasegawa (2019, p. 5) [79] ‘Having moral comfort and satisfying the spiritual needs with particular attention to religious and cultural characteristics’ Hemati (2016, p.1223) [73] ‘'Individual Dignity' Kadivar (2018, p.5) [80] - The concept of individual HD is characterized by those aspects of patient care that acknowledge patients’ individuality and integrity and respect their dignity as human beings throughout the life stages. ‘Appreciation of individual standards’ Mairis (1994, p.949) [74]
Patient-centred Care	‘Patient as a unique person’ Scholl (2014, p.5) [75] - Recognition of each patient’s uniqueness (individual needs, preferences, values, feelings, beliefs, concerns and ideas, and expectations). - A set of behavior that ensures physical support for the patient (e.g. pain management, assistance with daily living needs) ‘Patient as a unique person’ Castro (2016, p. 1929) [81] - Care that tries to see through the eyes of the patients and understand patients’ expectations, perceptions and experiences. - It is generally seen as an approach that meets the specific needs, values and beliefs of patients (Wolfe, 2001; Mead & Bower, 2000; Epstein et al, 2010). Several authors referred to it as ‘individualized care’ (Lusk & Fater, 2013; Scholl et al, 2014; Morgan & Yoder, 2012). The valued and essential characteristics of patient-centered

	care are empathy, listening and treating patients with dignity and respect, and regarding them as individuals (Scholl et al, 2014; Berghout et al, 2015) [81]. ‘Individualizing patient care’ Lusk (2013, p. 94) [76] - Individualizing patient care means collaborating with the patient when determining the goals of treatment and tailoring the plan of care to his/her specific needs (Wolf et al., 2008) [76]. ‘Individualized and relationship-based care’ Youn-Jung & Heun-Keung (2019, p. 61) [82]
Person-centred Care	‘Individualized’ Morgan (2012, p.8-9) [71] - The term individualized is the most frequently acknowledged attribute of PCC. In a PCC environment, the clinician considers the unique needs and the specific health concerns of the person to provide customized interventions (McCance, 2003) [71]. - Individualization cannot be achieved without understanding the person’s life situation in addition to his or her ability or desire to make decisions and take control of his or her care (Suhonen et al., 2002; Suhonen, Välimäki, & Leino-Kilpi, 2005) [71]. - Personal life situations include having knowledge about culture, beliefs, traditions, habits, activities, and preferences (Suhonen, Välimäki, et al., 2005) [71]. - According to Edvardsson, Koch, and Nay (2009), individualizing care demonstrates appreciation of the unique history and personality of people while recognizing their perspectives and customizing care that best meets their needs [71]. - Care should be organized by patients’ personal needs and preferences instead of institutional standards or routines, which Suhonen et al. (2002) argued is the opposite of individualized care because one size does not fit all (Leplege et al., 2007) [71]. ‘Holistic’ Morgan (2012, p.8) [71] - Holistic care is described as a behavior that recognizes and values whole persons as well as the interdependence of their parts (McEvoy & Duffy, 2008) [71]. - The whole person is described as the biological, social, psychological, and spiritual aspects of an individual (McCormack, 2003) [71]. - Providing holistic care allows the clinician to better understand how an illness affects the entire person and how to respond to the true needs of an individual (Mead & Bower, 2000). Care that focuses on biological illness without considering the psychological or social impact hampers healing and contributes to poor outcomes (Suhonen, Välimäki, & Katajisto, 2000) [71]. ‘Recognition of personhood’ Slater (2006, p.139) [83] - Barker (2001) maintains that personhood celebrates individuality [83]. ‘Respect for the individuality of the person’ Slater (2006, p.139) [83] - One of the most recognised attributes was respecting the person’s uniqueness and therefore their individuality (Coyle & Williams 2001; Downs 1997; Ericson et al. 2001; Fares 1997; Ford & McCormack 2000; Kitson 1999a; Kitwood 1993; Kitwood 1997; McCormack 2003b) [83]. ‘Acknowledgement of the person’s lived world’ Slater (2006, p.140) [83]

	- Each person comes to the health environment with their own lived experiences.

The coverage of 'individuality' across definitions and care concepts is extensive. The words 'individual', 'holistic', 'personhood' and 'unique' are used to explain the individual is more than their health problem. There is also a connection between culture, religion and 'individuality', as there is a connection between the rights of the individual to make decisions based on their own values.

2.3.4.4. Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

Consistent with the finding for Principle 3, being 'treated as an individual' and being able to maintain 'independence, choice and control' (Principle 4) are interconnected concepts. It follows, the coverage of content for Principle 4 across dignity in care, patient-centred care and person-centred care (Table 2. 13) is as extensive as that identified for Principle 3.

The words used to convey 'independence, choice and control' include 'control restored' [70], 'Advocacy' [70], 'Autonomy' [72] and 'Empowerment' [71, 83].

The ability to have 'control' is linked to Principle 9 'confidence and positive self-esteem', for example "By accepting a new level of capacity, older people strengthen their own self-esteem and gain control (Stabell & Lindstrom 2003)" [70]. Morgan (2012, p.9) adds "Self-confidence promotes self-determination, which facilitates the person's participation in decision making" [71].

A number of definitions note a power shift is required to achieve Principle 4, for example "The shift of power is relative to the amount of patient autonomy" [76] and "Person-centredness moves the onus of health care away from the paternalistic model (Barker 2001; Mansell & Beadle-Brown 2004). Instead it shifts power to the person (Barker 2001; Coyle & Williams 2001; Fares 1997; Kitson 1999b) by providing knowledge and the ability to make relevant decisions [83]" [83]. Slater (2006) refers to this power shift as a 'therapeutic' relationship and also that shared decision making reflects professional ethical standards [83].

Table 2. 13 Definitions of care concepts mapped to Principle 4

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Control restored' Anderberg (2007, p. 639) [70] - Supporting own control is brought to attention mostly when the older person has been through a period of turbulence related to health problems (Jacelon 2001, Lee et al. 2002) [70]. - The need to re-establish control over life and to accept being cared for becomes actualized. An older person may refer to previous social position or activities or to other relevant circumstances (Jacelon 2001) [70]. - By accepting a new level of capacity, older people strengthen their own self-esteem and gain control (Stabell & Lindstrom 2003). Control may also be gained by adjusting the environment and the situation to an older person's capability (Shotton & Seedhouse 1998) [70]. 'Advocacy' Anderberg (2007, p. 639) - Performing advocacy implies nurses' judging older adult patient's needs for support when their own ability to represent themselves wavers (Randers 2002) [70]. 'The patient's autonomy needs to be recognized' Coventry (2006, p. 44) [34] 'Dignity is promoted when individuals are enabled to exercise control, make choices and feel involved in the decision-making that underpins their care' Fenton (2002, p. 21) [84] 'Autonomy' Griffin-Heslin (2005, p. 254) - Having choice, giving choice, making decisions, being able to make decisions, competence, rights, needs, independence. - 'Gaining independence in all matters related to the disease. The right to participate in all decisions, especially decisions related to the disease process and treatment ' Hemati (2016, p. 1223)
Patient-centred Care	'Patient involvement in care' Scholl (2014, p. 6) [75] - A prominent dimension often described in the literature on patient-centeredness is the patient's active involvement in care. While older publications use terms like ''informed consent'' or ''sharing power and responsibility'', more recent publications define in more detail the importance of encouraging the patient to participate actively in the consultation and of engaging the patient in the decision making regarding his or her own health (shared decision making) [75]. 'Patient empowerment' Scholl (2014, p. 6) [75] - Acknowledging the patient's perceived ability to self-manage important aspects of his or her illness, activating and encouraging the patient to take responsibility to solve health related problems and to take actions to improve his or her health and becoming an expert regarding the management of his or her health condition [75]. 'Encouraging patient autonomy' Lusk (2013, p. 93-94) [76] - Power refers to the dominance of one over another and can be seen in the relationships of healthcare providers (as expert) and patients (Say, Murtagh, & Thomson, 2006) [76].

	- The shift of power is relative to the amount of patient autonomy. As power is shared and the patient’s ability to control the care increases, patient autonomy is enhanced (Lee & Lin, 2010) [76]. - Patient autonomy is also operationalized through the implementation of shared decision-making between the patient and the healthcare provider [76]. ‘Maintaining patient autonomy’ Youn-Jung & Heun-Keung (2019, p. 61) [82] ‘Shared decision-making’ Youn-Jung & Heun-Keung (2019, p. 61) [82]
Person-centred Care	‘Empowering’ Morgan (2012, p. 9) [71] - Empowerment is an equally important attribute. It encourages autonomy and self-confidence, two important factors when an individual is most vulnerable (Suhonen et al., 2000) [71]. - Self-confidence promotes self-determination, which facilitates the person’s participation in decision making. Participating in care decisions concerning treatment suggests that individuals have input into their own care (Suhonen et al., 2000) [71]. ‘Evidence of a therapeutic relationship between person and health care provider’ Slater (2006, p. 139) [83] - A partnership between the person and the carer ensures the person’s own decisions are valued [83]. ‘Provision of care that reflects professional ethical standards’ Slater (2006, p. 140) [83] - Person-centredness is professional care that also respects the autonomy, dignity and privacy of the person (Ford & McCormack 2000; McCormack 2003a; Nolan et al. 2001; Price 2004) [83]. ‘Empowerment for the person to make their own decisions about their own health’ Slater (2006, p. 140) [83] - Person-centredness moves the onus of health care away from the paternalistic model (Barker 2001; Mansell & Beadle-Brown 2004). Instead it shifts power to the person (Barker 2001; Coyle & Williams 2001; Fares 1997; Kitson 1999b) by providing knowledge and the ability to make relevant decisions [83].

The intent of Principle 4, across care concepts and using slightly different words, is best summarized in the frequently used adage attributed to Valerie Billinghurst (1998) ‘Nothing about me without me [85].

Ubiquitous across definitions of care constructs is the person’s ability to retain independence, choice and control. So far, respectful care, based on supportive relationships (Dignity in Care Principle 2), that identify and respond to the individual (Dignity in Care Principle 3), who retains the maximum level of independence, choice and control (Dignity in Care Principle 4) are themes common across patient-centred, person-centred, compassionate and dignified care. The need to ask patients and carers of their experience is highlighted by Barry (2012) who notes ‘although talk about patient-centred care is ubiquitous in modern health care, one of the greatest challenges of turning the rhetoric into reality continues to be routinely engaging patients in decision making’ [85].

2.3.4.5. Principle 5. Listen to and support people to express their needs and wants

It is stating the obvious to note that a patient cannot achieve Principle 4 (independence, choice and control) if not for Principle 5 (listen/support – needs/wants). Yet Principle 5 does not have the same volume of content across the concept analyses as Principle 4. Principle 5 is only represented by concept analyses of dignity in care and patient-centred care. Where ‘sensitive listening’ is specifically included as an ‘attribute’ of dignity in care [70] and ‘communicating and listening’ included under patient-centred care [76], the terms ‘communication’ [72] and ‘information’ [75] are also used to identify content that aligns with Principle 5 (Table 2. 14).

Table 2. 14 Definitions of care concepts mapped to Principle 5

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Sensitive listening' Anderberg (2007, p. 639) [70] - Listening carefully includes the entire communication between older patients and caregivers, the way they talk and the subjects they talk about (Caris-Verhallen et al. 1999, Walsh & Kowanko 2002, Randers & Mattiasson 2004) [70]. - Older persons are sensitive to the way they are addressed (Jacelon 2001). They often complain about being treated as children or being patronized (Woolhead et al. 2004) [70]. - Several studies have revealed that older patients want to talk about daily life, needs and limitations, thoughts about the future and about death (Nystro¨m 1995, SoS 1997a) [70]. - Caregivers need to be aware of the fact that older people may be inconsistent as they are in the process of reorientation and adaptation to being dependent on care (Jacelon 2001, Edlund 2002) [70]. - In that process, their inner values and perceptions of dignity will be adjusted and this will be expressed explicitly and implicitly (Edlund 1999, 2002) [70]. ‘Communication’ Griffin-Heslin (2005, p. 254) [72] - Time giving, explaining information, understanding information, comfort, non-verbal and verbal communication [72].
Patient-centred Care	‘Clinician-patient communication’ Scholl (2014, p. 3) [75] - A set of verbal and nonverbal communication skills. e.g. using open-ended questions, summarizing important information, asking the patient to repeat, making eye contact, nodding [75]. ‘Patient information’ Scholl (2014, p. 6) [75]

	- Provision of tailored information while taking into account the patient's information needs and preferences. The clinician should give tailored information (regarding all aspects of care from prevention to treatment, as well as information on how to access medical, psychosocial, physical, and financial support) while eliciting and respecting the patient's information needs and preferences [75]. ''Communicating and listening' Lusk (2013, p. 89) [76] - Behaviors fundamental to the provision of PCC include communicating and listening and responding to patient needs [76].
Person-centred Care	-

People must be recognised and treated as individuals (Principle 3) and listened to and supported to express their needs and wants (Principle 5) if we are to achieve patient involvement, choice and control (Principle 4). There is an obvious interdependency between Principle 3, 4 and 5. While there is comprehensive coverage of content across definitions for Principle 3 and Principle 4, the coverage is moderate and the words used to represent this content are highly variable for Principle 5.

2.3.4.6. Principle 6. Respect people's privacy

Across 16 conceptual analyses included in this mapping exercise, only one identified a specific 'attribute' relating to privacy (Table 2. 15).

Table 2. 15 Definitions of care concepts mapped to Principle 6

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Protecting the privacy of the patient in all aspects (privacy protection can have different meanings for patients with different cultures and religions)' Hemati (2016, p. 1223) [73]
Patient-centred Care	-
Person-centred Care	-

Privacy of the body and privacy of personal information are of importance to people when they are in hospital, where they are at particular risk of their privacy being breached [15, 16]. The word privacy is connected to activities of care, where privacy of the body is crucial to maintenance of dignity. The word privacy is connected to confidentiality when used in reference to the sharing and protection of personal information. Despite the importance of privacy to older people, privacy was (with only one exception) absent from the definitions of dignity in care, compassionate care, patient-centred care and person-centred care included in concept analyses. Undertaking this review of the 'attributes' used to define common care concepts has revealed a substantial gap in content relating to the need to 'respect people's privacy'.

2.3.4.7. Principle 7. Ensure people feel able to complain without fear of retribution

Given the revelations of abuse of older people in care [4, 5, 14], it would seem an obvious response to enable people to feel they can complain without fear of retribution if they experience abuse or unacceptable level of care, but that is unlikely if it is not identified as core to the definition of dignity in care, patient-centred care and person-centred care.

The description of 'feedback' in compassionate care appears to best align with Principle 7 [86].

Table 2. 16 Definitions of care concepts mapped to Principle 7

Care Concept	Details
Compassionate Care	-
Dignity in Care	-
Patient-centred Care	-
Person-centred Care	-

Evidence suggests there is fear among older people of making complaints [15]. According to Baillie (2009), the fear is real 'Patients related not complaining about upsetting incidents to avoid jeopardising relationships: I didn't do anything about it. I didn't want to upset anybody because I don't want anybody taking it out on me' (p.30) [66].

Undertaking this review of the 'attributes' used to define common care concepts has revealed a substantial gap in content relating to the need to Principle 1 (zero tolerance of abuse) and Principle 6 (Privacy) and Principle 7 (Ability to complain without fear of retribution).

2.3.4.8. Principle 8. Engage with family members and carers as care partners

Given a large proportion of hospital patients are older and many have cognitive impairment [87], Principle 8 (engaging with family/carers) is of great and growing importance [88-90], yet it has limited coverage across definitions and care concepts (Table 2. 17). Principle 8 is best represented by definitions of patient-centred care, Castro (2016, p. 1929) includes 'Mutually beneficial partnerships between the patient, his family and the health care provider, and is characterized by open communication of knowledge. There is an exchange of experiential knowledge and clinical knowledge' [81].

Table 2. 17. Definitions of care concepts mapped to Principle 8

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Dignity in relation to family members, friends, society, and other residents' Hasegawa (2019, p. 5) [79]
Patient-centred Care	'Involvement of family and friends' Scholl (2014, p. 5-6) [75] - Active involvement of and support for the patient's relatives and friends to the degree that the patient prefers [75]. - Besides involving the patient in care, some definitions describe the involvement of relatives and friends by providing them with information and involving them in decision making, depending on the patient's preference. It also includes offering support to caregivers and recognizing their needs [75]. 'Mutually beneficial partnerships between the patient, his family and the health care provider, and is characterized by open communication of knowledge. There is an exchange of experiential knowledge and clinical knowledge' Castro (2016, p. 1929) [81]
Person-centred Care	-

People involved with the patient need to be part of the patient's care, when and how the patient wants them involved. In this way, Principle 8 is connected to Principle 4 (independence, choice and control). Of significance is the involvement of carers (family/friends) of a person with cognitive impairment, carers who know the person, and need to be a part of the person's care when they are in hospital. Their knowledge and relationship to the patient must be respected.

2.3.4.9. Principle 9. Assist people to maintain confidence and positive self-esteem

Each of the care concepts dignity in care, patient-centred care and person-centred care, include at least one 'attribute' relevant to Principle 9. On dignity, Griffin-Heslin (2005, p. 252) includes 'Feeling important, valuable in relation to others, self-esteem, self-worth, modesty, pride [72]. Relevant to patient-centred care, Scholl (2014, p.5) includes 'Recognition of the patient's emotional state and a set of behavior that ensures emotional support for the patient' [75] and Younn-Jung & Heun-Keung (2019, p.61) have 'empowering self-care'.

Relevant to person-centred care Slater (2006, p.140) offers 'Identification and reinforcement of the person's strengths and positive aspects rather than the weaknesses and problems' [83].

Table 2. 18 Definitions of care concepts mapped to Principle 9

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Dignity is promoted when individuals are enabled to do the best within their capabilities' Fenton (2002, p. 21) [84] 'Empowerment' Griffin-Heslin (2005, p. 252) [72] - Feeling important, valuable in relation to others, self-esteem, self-worth, modesty, pride [72]. 'Maintenance of self-esteem' Mairis (1994, p. 949) [74] 'Bolstering self-esteem' Igai (2020, p.9)
Patient-centred Care	'Emotional support' Scholl (2014, p. 5) [75] - Recognition of the patient's emotional state and a set of behavior that ensures emotional support for the patient [75]. 'Empowering self-care' Youn-Jung & Heun-Keung (2019, p.61) [82]
Person-centred Care	'Identification and reinforcement of the person's strengths and positive aspects rather than the weaknesses and problems' (Slater (2006, p. 140) [83] - The person should feel inherently valued for who they are rather than being seen as the disease or illbeing (Downs 1997; Fares 1997; Kitwood 1997; Ericson et al. 2001) [83].

Assisting people to maintain confidence and a positive self-esteem cannot be achieved in isolation. Implementing care consistent with Principle 9 is contingent on the successful implementation of the preceding 8 Principles. Being free from abuse, being respected, being treated as an individual, having choice and control, being listened to and supported, having your privacy respected, being able to complain without fear…. the content of these Principles contributes to the building, rebuilding and maintenance of confidence and positive self-esteem.

2.3.4.10. Principle 10. Act to alleviate people's loneliness and isolation

Given the large proportion of older people in hospital, including those aged 80 years and older, and those with cognitive impairment, alleviating people's loneliness and isolation is a relevant aspect of providing an acceptable standard of care. Isolation and loneliness cause harm [15]. Yet there is no content in the 'attributes' identified in concept analyses that use the words 'loneliness' or 'isolation'. There is, however, at least some recognition of the need to recognise the 'social' aspect of people's lives, for example Scholl (2014, p.5) offers the need for ‘Recognition of the patient as a whole person in his or her biological, psychological, and social context’ [75].

Table 2. 19 Definitions of care concepts mapped to Principle 10

Care Concept	Details
Compassionate Care	-
Dignity in Care	'Behavioural dignity and older adults' Jacelon (2004, 79) [91] - Social roles were described as an important source of dignity for older adults: ‘Frail older people can give love and comfort [to another person]. It is this role of giving that can be a source of dignity for older people’ (Dobrof 1998, p. 154) [91]. 'Social Dignity' Kadivar (2018, p.6) [80] In the social domain includes attributes that reflect the social and cultural factors involved in human dignity.
Patient-centred Care	‘Biopsychosocial perspective’ Scholl (2014, p. 5) [75] - Recognition of the patient as a whole person in his or her biological, psychological, and social context’ [75]
Person-centred Care	-

Patients are carers who feel isolated and alone in hospital are not afforded the opportunity to build relationships, which are essential to the application of all 10 Principles of Dignity in Care. Tadd (2012), on dignity in care in hospitals, found ‘older people were bored through lack of communal spaces and activities’ (p.30) [73]. Content covering the words ‘loneliness and isolation’, and the implication that ‘alleviation’ is part of a caring role, is almost completely absent from the literature.

2.3.4.11. Content that does not map to the 10 Principles

None of the attributes of compassionate care mapped to any of the 10 Principles. The attributes identified across the three concept analyses were limited (Table 2. 20). Despite the extensive and growing literature on compassionate care [26, 92-95], clarity of the component parts of the concept remain unclear. A 2016 scoping review found studies ‘rely on pre-conceived theoretical definitions of compassion that lack specificity, clinical applicability, conceptual validity, and fail to adequately incorporate the understandings and experiences of patients’ [96]. A 2016 systematic review found ‘definitions of compassion abound, and the literature is both confused and confusing in the way that terms are used and often conflated’ [21] (p.138) and concludes the review with ‘this is a body of literature that seems to have little useful to say to nurses in practice’ [21] (p.153).

A number of attributes associated with dignity in care did not map to any of the 10 Principles, many were quite broad, for example 'Feelings of dignity can be affected by interactions with others' [34] and 'protecting patient's rights' [97] to quite specific 'Lack of financial concerns' [73].

The majority of attributes associated with patient-centred care that did not map to any of the 10 Principles were 'enablers' relating to access, integration and co-ordination of care, which are considered organisational components of care.

Of all the attributes that did not map to any of the 10 Principles, none appeared to present a clearly articulated component of care that could be considered an important addition to fill a gap in coverage in the 10 Principles.

Table 2. 20 Content that does not map to the 10 Principles

Care Concept	Details
Compassionate Care	'Defining Attributes' Galetz (2019, p. 450) [98] (None of the 3 defining attributes mapped to the 10 Principles) - External, passive feelings of concern about the situation of another person ("I am sorry it happened to you.") Projecting feelings of sensitivity, humanity, and kindness. Having a non-judgmental desire to help [98]. 'Critical attributes' Schantz (2007, p. 52-53) [99] (None of the 4 critical attributes mapped to the 10 Principles) - Acceptance, affirmation, enactment, and evaluation [99]. 'Defining Characteristics' Burnell (2009, p.321) [100] (None of the 7 defining characteristics mapped to the 10 Principles) - 'A dimension of caring' - 'Sympathetic consciousness of another's distress' - 'Sensitivity to the pain and brokenness of another' - 'Suffering alongside another' - 'A spiritual connection with another person' - 'Attempting to comfort or alleviate the suffering' - 'A demonstration of the fruit of the Holy Spirit' [100]
Dignity in Care	'Attributes' Coventry (2006, p. 44) [34] (4 of 6 attributes did not map to any of the 10 Principles) - Dignity is an inner feeling of well-being, personal worth, and self respect. - Feelings of dignity can be affected by interactions with others. - A covenant is agreed on in the form of the caregiver-patient relationship. - The patient does not have a decrease in the feeling of dignity related to the care provided. 'Themes' Hasegawa (2019, p.5) [79] (3 of 5 themes did not map to any of the 10 Principles) - Dignified care in a narrow sense. - Elements of the staff side.

	- Dignity in relation to nursing care facilities and the nursing care system. ‘Attributes’ Hemati (2016, p.1223) [73] (5 of 10 attributes did not map to any of the 10 Principles) - Lack of dependence on mechanical devices, machines and aids for survival in a way that life without them is not possible or that it decreases the independency and quality of life of the patient. - Not being a burden on family and friends. - Having a support system which may consist of financial and emotional support. - Having peace of mind and hope while being informed of the disease process. - Lack of financial concerns. ‘Attributes’ Jacelon (2004, p. 79) [91] - 'Philosophical' an example, Jacobs (2001) concluded that ‘dignity appears to be a conceptual something that all persons have and therefore can lose…that persons are born with and want to die with’ (p. 31). ‘Attributes’ Igai (2020, p.9) [97] (3 out of 4 attributes did not map to any of the 10 Principles) - ‘Reducing multi-faceted distress’ - ‘Continued relationship’ - ‘Protecting individual's rights’
Patient-centred Care	Dimensions Scholl (2014, p.5) [75] (6 of 15 Dimensions did not map to any of the 10 Principles) Principles ‘Essential characteristics of the clinician’ - A set of attitudes towards oneself (self-reflectiveness) as well as medical competency. ‘Clinician-patient relationship’ - A partnership with the patient that is characterized by trust and caring Enablers ‘Integration of medical and non-medical care’ - Recognition and integration of non-medical aspects of care (e.g. patient support services) into health care services. ‘Teamwork and teambuilding’ - Recognition of the importance of effective teams characterized by a set of qualities (e.g. respect, trust, shared responsibilities, values, and visions) and facilitation of the development of such teams. ‘Access to care’ - Facilitation of timely access to healthcare that is tailored to the patient (e.g. decentralized services) ‘Coordination and continuity of care’ - Facilitation of healthcare that is well coordinated (e.g. regarding follow-up arrangements) and allows continuity (e.g. a well-working transition of care from inpatient to outpatient) Attributes Castro (2016, p. 1929) [81] - 'The biopsychosocial perspective' A perspective combining biological, psychological and social dimensions is regarded as necessary to account for the full range of problems patients might experience. Providing care that considers the biopsychosocial

	perspective means exploring both the disease and illness experience, something that is also referred to as 'holistic care'. 'Creating a homelike environment' Youn-Jung & Heun-Keung (2019, p.61) [82]
Person-centred Care	-

2.3.5 Summary of findings from Part 1 and Part 2 of the Literature Review

Part 1 and Part 2 of the Literature Review covered extensive territory. Prior to concluding Part 2 of the Literature Review, I will provide a graphic representation of the findings thus far. Table 2. 21 provides a summary of the findings, identifying the amount of content identified in health and aged care rights and across the 'attributes' identified in concept analyses of care concepts that align to the 10 Principles. One green tick means some content was identified, two green ticks means good coverage and three green ticks mean comprehensive coverage of content was identified. A red cross means no content was identified and a red dash indicates no concept analysis was identified for that care concept (Table 2. 21).

Table 2. 21 Summary of findings from Part 1 and Part 2 of the Literature Review

10 Principles of Dignity in Care	Health Care Rights	Aged Care Rights	Concept Analyses					
			Dignity	Patient-centred	Person-centred	Compassionate	Individualised	Relationship-centred
P1. Zero Abuse	√	√	√	X	X	X	–	–
P2. Respect	√	√	√√	√√	√√	X	–	–
P3. Treat as Individual	√	√	√√√	√√√	√√√	X	–	–
P4. Independence Choice & Control	√	√√√	√√√	√√√	√√√	X	–	–
P5. Listen Support Needs Wants	√	√	√√	√√	X	X	–	–
P6. Privacy	√	√	√	X	X	X	–	–
P7. Complain Without Fear	√	√	X	X	X	X	–	–
P8. Involve Family (Carers)	√	√	√	√√	X	X	–	–
P9. Confidence & Self Esteem	X	X	√	√	√	X	–	–
P10. Loneliness & Isolation	X	X	√	√	X	X	–	–

Content from Australian health care and aged care rights aligned to Principle 1 through to Principle 8. Australian health care and aged care rights do not provide content relevant to Principle 9 ‘Confidence and Self-Esteem’ or Principle 10 ‘Loneliness and Isolation’.

There was strong alignment of care concept ‘attributes’ across the care concepts ‘dignity’, ‘patient-centred’ and ‘person-centred’ care for Principle 2 (Support people with the same respect you would want for yourself or a member of your family), Principle 3 (Treat each person as an individual by offering a personalised service) and Principle 4 (Enable people to maintain the maximum possible level of independence, choice and control).

There was good coverage of ‘attributes’ across the care concepts ‘dignity’ and ‘patient-centred’ care for Principle 5 (Listen and support people to express their needs and wants). There was some coverage of ‘attributes’ across the care concepts ‘dignity’ and ‘patient-centred’ for Principle 8 (Engage with family members and carers as care partners) and Principle 10 (Act to alleviate people’s loneliness and isolation). There was some coverage of ‘attributes’ across the care concepts ‘dignity’, ‘patient-centred’ and ‘person-centred’ care Principle 9 (Assist people to maintain confidence and a positive self-esteem).

There was no to scant coverage of ‘attributes’ across the care concepts ‘dignity’, ‘patient-centred’ and ‘person-centred’ for Principle 1 (Zero tolerance of all forms of abuse), Principle 6 (Respect people’s privacy) or Principle 7 (Ensure people feel able to complain without fear of retribution).

2.3.6 Conclusion to Part 2 of the Literature Review

The literature outlining the inability to agree a definition of dignity in care and related care constructs is abundant [20, 21, 29, 42, 92, 93, 101-110] and so it is not surprising that there are variable patterns of coverage of attributes that map to the 10 Principles of Dignity in Care.

The 10 Principles cover the attributes for which there appears to be consensus across the care concepts. But most importantly, the 10 Principles include reference to concepts that are important to older people that are absent from the attributes of commonly used care concepts. Of all of the attributes that did not map to any of the 10 Principles, none appeared to present a clearly articulated component of care that could be considered an important addition to fill a gap in coverage in the 10 Principles.

Part 2 of the literature review provides the evidence to support the Number 1. Recommendation of the Clinical Guidelines for Dementia in Australia [59] which state 'The 10 Principles of Dignity in Care should be the standard by which care is delivered and evaluated.

Continuing to refine and/or create new definitions/terms/concepts is not advancing the experience of care for patients and their family/friends/carers. There is certainly a need for ongoing research, but that should be focused on implementing a clear message of how care should be provided (articulated well by the 10 Principles), translating that message into practice and developing the tools required to measure the implementation of that message (10 Principles) into practice.

2.4 Part 3 Identifying items for each of the 10 Principles of Dignity in Care

2.4.1 Introduction to Part 3 of the Literature Review

Developing a questionnaire requires the preparation of an 'item pool' [111]. Items mined from a variety of sources maximises the content richness of the item pool. The purpose of Part 3 of the literature review was to identify content from existing instruments, qualitative research and policy (including content identified in Part 2 of the literature review) that map to the 10 Principles and which could be included in the item pool.

2.4.2 Scope and purpose of Part 3 of the Literature Review

The purpose of Part 3 of the literature review was to determine if there were any existing instruments that included items that represented the 10 Principles of Dignity in Care or content that could be identified from policy that could be drafted into an item that represented any of the 10 Principles, as these would contribute to the development of the item pool required for Stage 1 of the study (Delphi panel).

2.4.3 Search Strategy for Part 3 of the Literature Review

2.4.3.1. Existing instruments

The search strategy for Part 3 aimed to find original research articles describing the development, testing and use of instruments designed for use in hospital, to measure patient and/or carer experience of dignity, compassionate, individualised, relationship, patient and person-centred care. The search also included reviews of instruments and included instruments designed for use by nurses, based on the understanding that content could be adapted and rewritten from the patient and carer perspective, for this study. The search strategy was not limited to instruments designed specifically for older people as this would have reduced the available content for review and experience of care instruments designed for adults of all ages might include content that could be used in developing the item pool.

The search strategy used for the Medline (OVID) database (shown on the left of Table 2. 22), was developed with the advice and guidance of a research librarian and was used to develop the search strategy used for the CINAHL database (shown on the right of Table 2. 22).

Table 2. 22 Search strategy for care concept instruments in Medline and CINAHL

Medline (OVID) search strategy	CINAHL search strategy
1. (dignity or dignified).ti,ab. 2. Patient-Centered Care/ 3. ((person-cent* or patient-cent* or compassion* or individuali?ed or relation*) adj1 care).ti,ab. 4. 1 or 2 or 3 5. patient reported outcome measures/ or Psychometrics/ or exp ‘Surveys and Questionnaires’/ 6. (psychometric? or Measur* or tool* or instrument? or survey? or score? or scale? or questionnaire? or inventory or validity or reliability).ti,ab. 7. 5 or 6 8. 4 and 7 9. limit 8 to english language 10. hospital*.ti,ab. 11. hospitalization/ 12. 10 or 11 13. 9 and 12	TI ‘dignity in care’ or AB ‘dignity in care’ or TI ‘compassion* care’ or AB ‘compassion* care’ or TI ‘individual* care’ or AB ‘individual* care’ or TI ‘relationship cent* care’ or AB ‘relationship cent* care’ or TI ‘patient-cent* care’ or AB ‘patient-cent* care’ or TI ‘person-cent* care’ or AB ‘person-cent* care+’ AND TI ‘scale’ or AB ‘scale’ or TI ‘measure*’ or AB ‘measure*’ or TI ‘instrument*’ or AB ‘instrument*’ or TI ‘questionnaire*’ or AB ‘questionnaire*’ or TI ‘survey’ or AB ‘survey’ or TI ‘psychometric’ or AB ‘psychometric+’ AND TI ‘hospital*’ or AB ‘hospital*+’ With search filter ‘Exclude Medline’

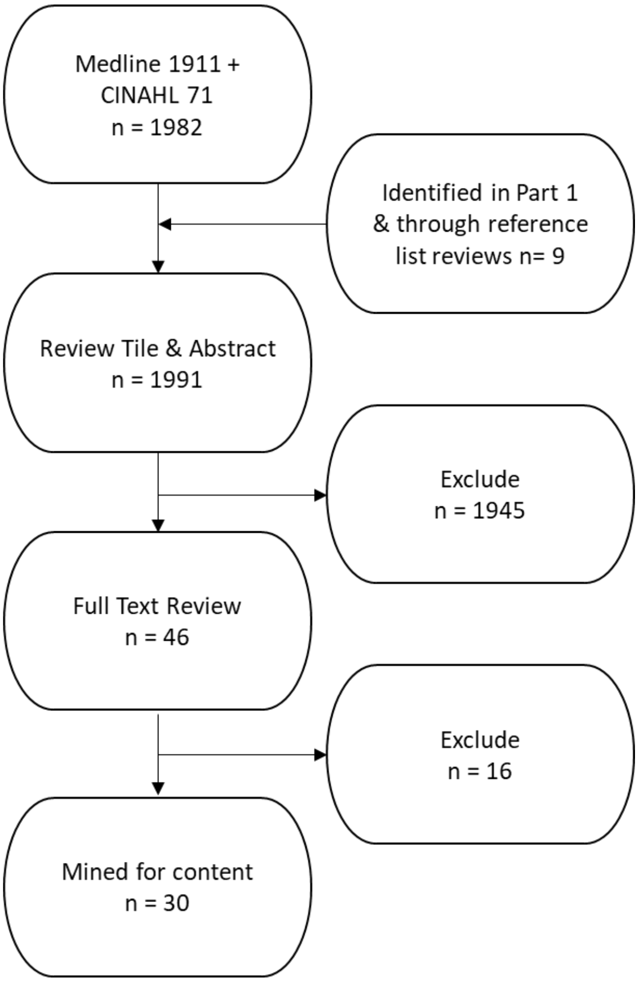


Figure 2. 3 Literature review search strategy

2.4.3.2. Qualitative research and policy

Content for the item pool is supplemented by content from qualitative research studies and policy documents, identified in Part 1 of the literature review.

2.4.4 Results of Part 3 of the Literature Review

2.4.4.1. Existing instruments

The initial database searches were undertaken in January 2018 and repeated and updated in June 2019. The Medline search returned 1911 records and with the 'Exclude Medline' filter on in CINAHL, 71 records were returned, resulting in a total of 1982 records. A further 9 records were identified in Part 1 of the literature review search and by hand searching the references of articles obtained from the database search. The title and abstract of 1991 records were reviewed for relevance. A total of 1945 records were excluded as they did not include reference to an instrument measuring experience of care. A full text review of the remaining 46 records, identified 30 records of unique instruments containing relevant content (Figure 2. 3).

The content of each of the 30 instruments was reviewed, and where relevant, mapped to each of the 10 Principles of Dignity in Care. Items were used from 15 of these 30 instruments. Items from each of the settings (hospital and community) and perspectives (patient, nurse/staff) were used and adapted. Items from instruments designed for generic experience of care, mental health services, client-centred care, communication assessment, compassionate care, individualised care and person-centred care were included (Table 2. 23).

I present each of the 10 Principles of Dignity in Care, one through to ten, with a table of items mined from existing instruments, with references (Figure 2. 4). I observe patterns in coverage of content across the Principles and how that reflects the coverage of content reviewed in Part 1 of the literature review.

There is a connection between each of the 10 Principles and so overlap between them is expected. The mapping of items to Principles, at this stage of instrument development, did not make their allocation fixed. A little overlap of content was expected to be clarified in future steps in the process of developing the item pool (Delphi Panel, Chapter 4).

To allow the reader to follow the development of items through the study, the identification of items in Part 3 of the literature review is consistent with the numbering used in Round One of the Delphi study (Chapter 4).

Table 2. 23 Instruments measuring experience of care by setting and perspective

Setting: Hospital / Perspective: Patient
*(Australian) National core common patient experience question set (AHPEQS) [32]
*Australian Mental Health Services - Your experience of service (YES) [112]
Caring Behaviours Inventory (CBI) [113]
*Client-centred Care Questionnaire (CCCQ) [114]
*Communication Assessment Tool (CAT) [115]
Compassionate Care Assessment Tool (CCAT) [116-118]
Dignity for older people (no name) [119]
*Hong Kong Inpatient Experience Questionnaire (HKIEQ) [120]
Hospital Consumer Assessment of Healthcare Providers and Systems Survey (HCAHPS) [121]
Inpatient Dignity Scale [122]
*National Health Service England Inpatient Survey [123]
*National Health Service Scotland Inpatient Experience Survey [124]
Norwegian Inpatient Experience Questionnaire (NORPEQ) [125, 126]
Patient Dignity Inventory (PDI) [127-129]
Patient Dignity Question (PDQ) [130]
*Patient experience of Compassionate Care [26]
Perception of dignity (no name) [131]
Person-Centred Climate Questionnaire – Patient (PCQ-P) [132]
Processes of Care for Adults (MPOC-A) [133]
*Quality from the Person's Perspective (QPP) [134]
*Schwartz Center Compassionate Care Scale (SCCCS) [135]
Setting: Hospital / Perspective: Nurse/Staff
Dignity in Care Scale for Nurses [136]
Geriatric In-hospital Nursing Care Questionnaire (GeriINCQ) [137]
*Individualized Care Scale (ICS) [138]
Person-centred care of older people with cognitive impairment in acute care (POPAC) [139, 140]
*Person-centred Practice Inventory (PCPI-S) [141]
*Person-Centred Health Care for Older Adults (PCHC) [142]
Setting: Primary or Secondary Care / Perspective: Patient/Person
Attributed Dignity Scale (ADS) [143]
*Person-centredness in secondary care [144]
*Suggested indicators of dignity in care [24]

*** Items from these instruments were included in the initial Delphi panel item pool**

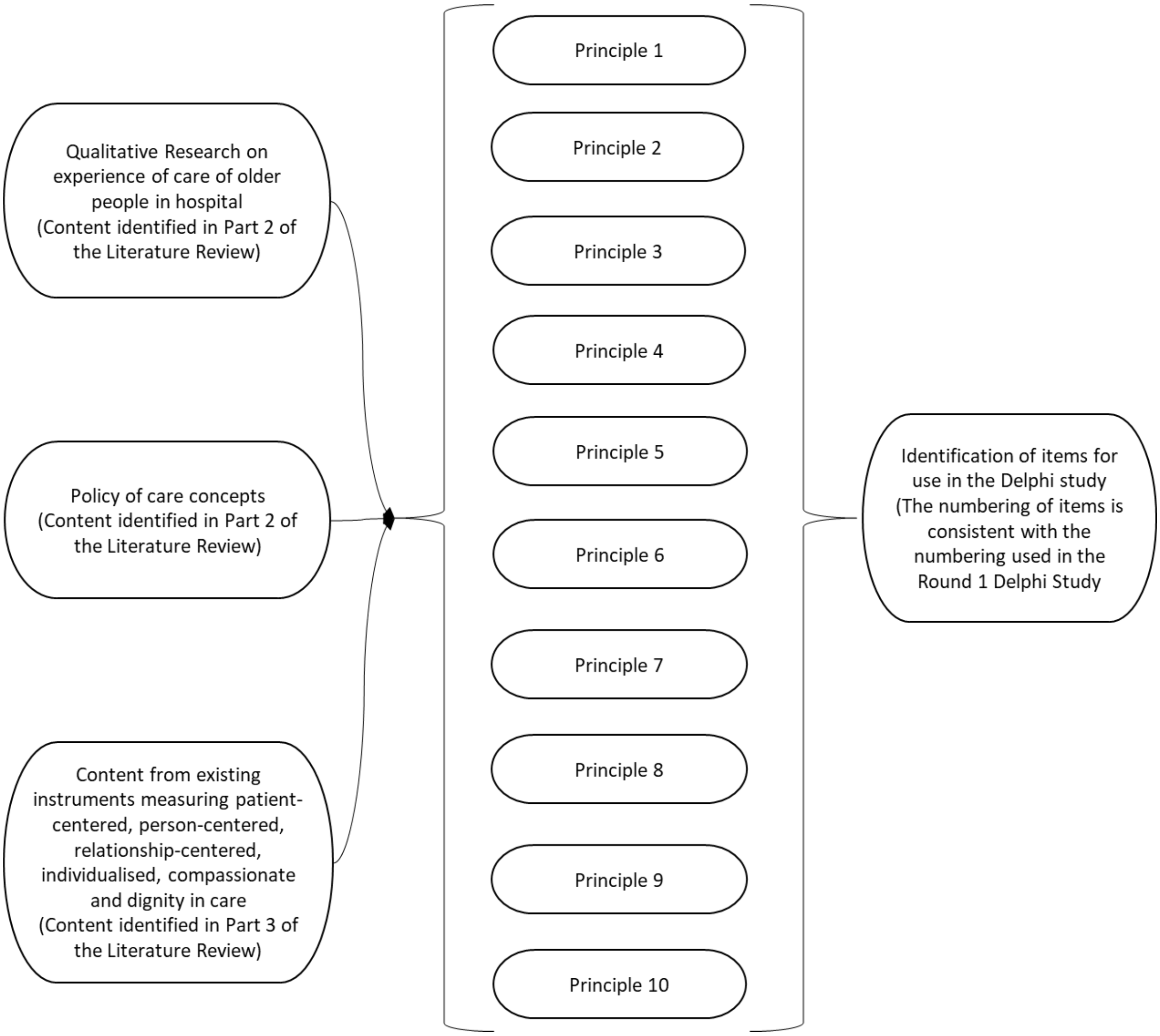


Figure 2. 4 Part 3 Content from existing instruments, qualitative research and policy mapped to the 10 Principles of Dignity in Care

2.4.4.2. Principle 1. Zero tolerance of all forms of abuse

There is sparse content in existing instruments that is relevant to Principle 1. This is consistent with the findings in Part 2 of the literature review. While policy and reviews have identified substantial and widespread abuse of older people in hospitals [4, 5, 14, 145], this finding is not reflected in the content and wording of items in care concepts. This is reflected in the absence of items that ask directly about a patient's experience of abuse. Principle 1 is making an important contribution to open the conversation about abuse. Patients and carers need to know the expectations (zero tolerance) and they need to be asked about their experience. Moving beyond using words such as 'safe' is entering new territory.

Only three items were identified that were relevant to Principle 1 (Table 2. 24). Item 1.14 was sourced from an experience of service questionnaire developed for mental health services (Table 2. 24). Mental health has, independently of general health, progressed to the point of being able to have the conversation about 'I have been given medication to restrain me' [112]. Given the chemical restraint of older people [146], and the issue of consent for chemical restraint [146], this is an important conversation for patients and their carers to have with hospital staff. The other two items (1.1 and 1.7 in Table 2. 24) identified use the word safe, which is a much softer approach that using the word 'abuse'.

Table 2. 24 Items from existing instruments mapped to Principle 1

Number	Item
1.1	'I felt safe' [112]
1.7	'The staff made me feel safe' [26]
1.14	'I have been given medication to restrain me' [112]

All three items identified from qualitative research (Table 2. 25) were sourced from Bridges 2010 review of studies of older peoples' and relatives' experiences in acute care settings. It is interesting to note, that when the content is generated from the patient and carer perspective, the language changes to 'worthless' (item 1.4) and 'fearful' (item 1.8), which goes beyond the softer word 'safe'.

Table 2. 25 Items from qualitative research and policy documents mapped to Principle 1

Number	Item
1.4	'I was made to feel worthless' [102]
1.5	'I was given care when I needed it' [102]
1.8	'I have felt fearful' [102]

Content available in existing instruments, qualitative research and policy was inadequate to fully represent Principle 1. Gaps in content are further supplemented by items I have drafted, based on my knowledge and experience, which are presented in Chapter 4 (Delphi Panel).

2.4.4.3. Principle 2. Support people with the same respect you would want for yourself or a member of your family

Several instruments include very broad items, for example 'I have been treated with dignity' (item 2.8), 'I have been treated with respect' (item 2.7). There is evidence that such high-level items yield overly positive responses [4]. These are included in the item pool, along with more specific items representing respect (Table 2. 26). Using respectful forms of address are core to the intent of Principle 2. The 'hellomyname' is campaign [147] is an excellent example of the power of name sharing in the experience of care (item 2.1 and 2.2). It would seem a name is an important ingredient for a 'friendly and warm' conversation' (item 2.6), which is required to 'learn about me as a person' (item 2.5).

Table 2. 26 Items from existing instruments mapped to Principle 2

Number	Item
2.1	'The staff introduced themselves by telling me their name' [24]
2.2	'The staff introduced themselves before treating or caring for me' [26]
2.5	'The staff have taken the time to learn about me as a person' [26]
2.6	'The staff made me feel at ease by being friendly and warm in conversation' [26]
2.7	'I have been treated with respect' [26, 115, 123]
2.8	'I have been treated with dignity' [26, 115, 123]

Given the dominance of the word 'respect' in the experience of care literature, it was surprising how difficult it was to find specific descriptions that represented the concept of respect. Being 'cared for in a courteous and considerate manner' (item 2.3) uses words other than 'respect' but is still very general (Table 2. 27).

Table 2. 27 Items from qualitative research and policy documents mapped to Principle 2

Number	Item
2.3	'I have been cared for in a courteous and considerate manner' [148]

There is a depth to Principle 2 that is not fully represented by items in existing instruments. It is a word that can be added to every interaction and action, as all need to be undertaken with respect, but it is a difficult to articulate, as a unique concept, in the form of items, for a questionnaire.

2.4.4.4. Principle 3. Treat each person as an individual by offering a personalised service

When trying to locate items that represent very broad words, such as 'respect', it is easy to drift into the territory of other Principles. It could be argued the item 'The staff took time to learn about me as a person' fits well in Principle 2 (item 2.5) and just as well in Principle 3 (item 3.3).

An extension of the sharing of names (covered in Principle 2) is item 3.1 'The staff asked me how I prefer to be addressed' (Table 2. 28). Greetings are a powerful acknowledgement of personhood that is at risk when people are referred to by their bed number and/or diagnosis. Everything that makes a person an individual should be considered, but major themes include language 'I have had access to an interpreter' (item 3.9) (Table 2. 28) and, from policy, 'my cultural beliefs have been considered and respected' (item 3.4) (Table 2. 29).

Table 2. 28 Items from existing instruments mapped to Principle 3

Number	Item
3.1	'The staff asked me how I prefer to be addressed?' [24]
3.2	'The staff greeted me in a way that made me feel comfortable' [115]
3.3	'The staff took time to find out more about me as a person' [26, 138]
3.9	'I have had access to an Interpreter when I needed one' [142]

Table 2. 29 Items from qualitative research and policy documents mapped to Principle 3

Number	Item
3.4	'My cultural beliefs have been considered and respected' [47]

There is good coverage of content for Principle 3 in the literature, as discussed in Part 2 of the literature review, but the content available in existing instruments to map to these Principles, is limited.

2.4.4.5. Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

It is not surprising that existing instruments offer good coverage of Principle 4. The concept of independence, choice and control had the greatest coverage in Part 1 of the literature review. The specific component parts of Principle 4 appear easy to represent in separate items. A total of seven existing instruments include the item 'I have been involved, as much as I wanted to be, in decisions about my care and treatment' (item 4.7). Time (item 4.4), understanding (item 4.5), the ability to ask questions (item 4.10) and being 'listened to and acted upon by staff' (item 4.11) appear to be core to Principle 4 (Table 2. 30).

Table 2. 30 Items from existing instruments mapped to Principle 4

Number	Item
4.4	'The staff have taken enough time to explain things to me' [149]
4.5	'The staff have explained what is happening to me in ways I understand' [115, 124]
4.7	'I have been involved, as much as I wanted to be, in decisions about my care and treatment' [24, 26, 32, 123, 124, 134, 135]
4.8	'I have felt in control of what was happening to me' [124]
4.10	'The staff encouraged me to ask questions' [115]
4.11	'My views have been listened to and acted upon by staff' [24]

The key words used in the Social Care Institute of Excellence's definition of dignity in care are broken down to create separate items representing Principle 4 (items 4.1, 4.2 and 4.3). Further to item 4.7 (above), which states the need to be involved in 'decisions', item 4.6 (below) states the need to be involved in 'discussions' (Table 2. 31).

Table 2. 31 Items from qualitative research and policy documents mapped to Principle 4

Number	Item
4.1	'I have been able to maintain the maximum possible level of independence' [148]
4.2	'I have been able to maintain the maximum possible level of choice' [148]
4.3	'I have been able to maintain the maximum possible level of control' [148]
4.6	'I have been involved, as much as I wanted to be, in discussions about my care and treatment' [47, 150]
4.12	'The staff have been open and forthcoming with information' [151]

Principle 4 has excellent coverage in existing instruments, which is further supported by policy. The need to maximise patients' and/or carers' independence choice and control are core to the experience of care.

2.4.4.6. Principle 5. Listen to and support people to express their needs and wants

Attention (item 5.7), time (items 5.1, 5.2 and 5.8), and opportunity (items 5.9 and 5.10) are components of Principle 5 that are well articulated in existing instruments (Table 2. 32).

Many of the definitions, identified in Part 1 of the literature review, use the word 'communication'. Interestingly, this word is absent from the items mapped to Principle 5. Breaking down the concept of 'communication' into component parts, including 'listening', is important. Good 'communication' in the hospital setting is at risk of being unidirectional. Listening is key to meeting patients' and carers' expectations of each of the 10 Principles.

Table 2. 32 Items from existing instruments mapped to Principle 5

Number	Item
5.1	'I was given enough time to explain what I needed' [142]
5.2	'I was given enough time to explain what I wanted' [142]
5.3	'The staff understood my main health concerns' [115]
5.6	'The staff showed interest in my ideas about my health' [115]
5.7	'The staff paid attention to me (looked at me, listened carefully)' [115, 135]
5.8	'The staff let me talk without interruption' [115]
5.9	'The staff have been available to help me when I needed them' [112]
5.10	'The staff made sure there was 'time to talk', and a chance to voice any concerns or simply have a chat' [135]
5.13	'The staff have given me an opportunity to discuss my wishes for care at the end of my life' [24]

Listening is required to avoid the error of making assumptions about what the patient and carer want and need (items 5.4 and 5.5). Critical to the experience of care is open and honest sharing of information (item 5.11), which is necessary for involvement in discussions and decisions (Principle 4) and planning of care (item 5.12) (Table 2. 33).

Table 2. 33 Items from qualitative research and policy documents mapped to Principle 5

Number	Item
5.4	'I felt the staff assumed they knew what I needed' [148]
5.5	'I felt the staff assumed they knew what I wanted' [148]
5.11	'I have been provided with clear information so I could make informed choices about my care' [148]
5.12	'The staff have been open to my opinions and allowed me to participate in planning my care' [148]

2.4.4.7. Principle 6. Respect people's privacy

Consistent with Part 1 of the literature review, privacy is core to the experience of care, but the content in existing instruments is limited (Table 2. 34). It is possible to expose the component parts of privacy by matching them with the main acts that risk a breach of privacy, during conversations (item 6.2), examination (item 6.3) and using the toilet (item 6.5).

Table 2. 34 Items from existing instruments mapped to Principle 6

Number	Item
6.1	'My privacy has been respected' [112, 142]
6.2	'I have been given privacy when discussing my condition or treatment' [120, 123]
6.3	'I have been given privacy when being examined or treated' [24, 120, 123, 124]
6.5	'I have been given privacy when using the toilet' [24]

Policy highlights the need for confidentiality of patient information (item 6.4). Item 6.7 links the breach of privacy to the indignity of embarrassment (Table 2. 35).

Table 2. 35 Items from qualitative research and policy documents mapped to Principle 6

Number	Item
6.4	'Information about me has been treated confidentially' [47]
6.7	'I have been given care in a way that ensured I have not felt embarrassed' [148]

Privacy is substantially influenced by higher-level health care decisions and actions. For instance, single room accommodation affords a great deal more privacy than multi-bed bays shared by men and women. Auditing of access to electronic medical records is a higher-level health care activity that could help protect the confidentiality of a patient's information. Regardless, as the items mapped to Principle 6 have identified, there is much, in every act of care, that can protect or breach a person's privacy.

2.4.4.8. Principle 7. Ensure people feel able to complain without fear of retribution

There was little content in existing instruments that mapped to Principle 7 (Table 2. 36). Three instruments include 'the staff have explained the process of making a complaint, or compliment, about my experience of care' (item 7.1), while two cover content related to the ability to make a complaint without fear of retribution (items 7.4 and 7.5).

Table 2. 36 Items from existing instruments mapped to Principle 7

Number	Item
7.1	'The staff have explained the process of making a complaint, or a compliment, about my experience of care' [112, 123, 124]
7.4	'I believe I would receive fair treatment if I made a complaint' [112]
7.5	'I felt I could make a complaint without it affecting my care' [24]

The policy content identified that is relevant to Principle 7 (items 7.2 and 7.3) is sparse (Table 2. 37).

Table 2. 37 Items from qualitative research and policy documents mapped to Principle 7

Number	Item
7.2	'I have been supported to raise any concerns or complaints with the appropriate person' [148]
7.3	'I have had my concerns and complaints treated with respect and dealt with in a timely manner' [47, 148]

There is an obvious and powerful relationship between Principle 1 and Principle 7. The lack of content in existing instruments about the ability to complain exposes the need to radically rethink what we are asking older people about their experience of care. It is difficult to imagine that a 'zero tolerance to all forms of abuse' will be achieved if people do not feel 'able to complain without fear of retribution'.

2.4.4.9. Principle 8. Engage with family members and carers as care partners

Principle 8 covers complicated territory. There is the balance between the patient's right to determine who is involved in their care (items 8.3, 8.6 and 8.7) and the desire of family members, who might have a substantial caring role, to continue to be involved when the patient is in hospital (item 8.4). The matter of the patient's mental (legal) capacity and the role of substitute decision maker is also important to Principle 8. It is very difficult to find items that succinctly capture every role a carer may hold (i.e., from a support role to being legally able to make decisions for the patient) (Table 2. 38 and Table 2. 39).

Table 2. 38 Items from existing instruments mapped to Principle 8

Number	Item
8.1	'The staff have taken enough time to explain things to my family/friends' [149]
8.2	'The staff explained what is happening in ways my family/friends could understand' [149]
8.3	'My family/friends been involved as much as I wanted them to be, in decisions about my care and treatment' [124, 141]
8.6	'My opinions, about the involvement of my family or friends in my care, were respected' [112]
8.7	'I had opportunities for my family and carers to be involved in my treatment and care, if I wanted' [112]

Table 2. 39 Items from qualitative research and policy documents mapped to Principle 8

Number	Item
8.4	'The expertise of my family/friends been recognised and valued by staff when working out how to provide my care' [102]

Given many older people in hospital have cognitive impairment, it is vital that family/carers are involved as care partners and are included in experience of care surveys.

2.4.4.10. Principle 9. Assist people to maintain confidence and positive self-esteem

Existing instruments offer light coverage of content that can be mapped to Principle 9 (Table 2. 40). It appears a difficult Principle to break down into component parts that are specific enough to form meaningful items. The item 'Staff spoke about me, in front of me, as if I wasn't there' (item 9.2) was sourced from three different instruments. Inclusion, articulated as 'Staff made me feel welcome' (item 9.1), is arguably necessary for confidence and a positive self-esteem. Having control (Principle 4) is also necessary (e.g., ‘I was given enough opportunity to do what I am capable of doing myself’, item 9.7).

Table 2. 40 Items from existing instruments mapped to Principle 9

Number	Item
9.1	‘The staff made me feel welcome’ [112]
9.2	‘Staff spoke about me, in front of me, as if I wasn’t there’ [24, 123, 144]
9.6	‘I was treated with less respect because of my age’ [24]
9.7	‘I was given enough opportunity to do what I am capable of doing myself’ [114]

Items 9.3 and 9.5, both from the Social Care Institute for Excellence, are more specific in that they relate to those requiring assistance, but nonetheless highlight the opportunity that exists, in every act of care, to help maintain confidence and a positive self-esteem (Table 2. 41).

Table 2. 41 Items from qualitative research and policy documents mapped to Principle 9

Number	Item
9.3	‘I have been given assistance with my meals in a way that helped me maintain my confidence and self-esteem’ [148]
9.5	‘I have been given assistance to maintain my personal appearance in a way that made me feel respected’ [148]

Principle 9 covers territory that is difficult to articulate in a short item, but it is no less important to include in experience of care questionnaires.

2.4.4.11. Principle 10. Act to alleviate people's loneliness and isolation

A singular item was identified in existing instruments that was relevant to Principle 10. Item 10.4 ‘Staff spent the right amount of time with me’ might be difficult to answer (Table 2. 42). Older people may be reluctant to speak openly about loneliness and their expectations of company. It is nonetheless important to try, and there is much work to do to bring these conversations into the expectations and understanding of experience of care. There were no items that could be derived from qualitative research or policy documents for Principle 10.

Table 2. 42 Items from existing instruments mapped to Principle 10

Number	Item
10.4	'The staff spent the right amount of time with me' [115]

2.4.5 Conclusion to Part 3 of the Literature Review

Existing instruments offered little content for Principles 1, 7 and 10. Existing instruments offered strong coverage of Principles 4 and 5. There was moderate coverage of the remaining Principles, 2, 3, 6, 8 and 9. Content from qualitative research and policy also contributed content for the item pool.

2.5 Conclusion

The Literature Review contributed to the development of content validity of the evolving Dignity in Care Questionnaire. Through exploring the component parts of health and aged care rights and the 'attributes' of commonly used care concepts, I have been able to demonstrate that I have included all the relevant (content that aligns to the 10 Principles) and excluded the irrelevant material (content that does not align to the 10 Principles and has no clearly articulated component that could be considered an important addition to fill a gap in coverage in the 10 Principles).

Through the literature review, I was able demonstrate that the 10 Principles cover content in common with Australian human rights and Australian aged care rights. Principles 1 to 8 are all aligned to component parts of human and aged care rights. Content relating to Dignity in Care Principle 9 (maintain confidence and positive self-esteem) and Principle 10 (alleviate loneliness and isolation) is absent from human and aged care rights.

Dignity in care has been subjected to rigorous definitional development, evident in the identification of ten concept analyses. In comparison, there were far fewer concept analyses identified for patient-centred care and person-centred care. The conceptual evidence for 'individualised' care and 'relationship-centred' care is poor, which suggests these terms require rigorous definitional development before they can be of use in improving experience of care. The literature review revealed the malalignment between the 'attributes' of compassionate-care and the 10 Principles. Where the 10 Principles are clear and specific (e.g., 'Zero tolerance of all forms of abuse'), attributes such as 'Suffering alongside another' [100] make the implementation and measurement of compassionate care more challenging.

The literature review revealed that the 10 Principles of Dignity in Care cover content in common with the ‘attributes’ of ‘dignity’, ‘patient-centred’ and ‘person-centred’ care as identified in a review of concept analyses. Common themes include being treated with respect (Principle 2), being treated as an individual (Principle 3) and having independence, choice and control (Principle 4). The literature review revealed that there is content important to older people, evident in their inclusion in the 10 Principles, that is absent from the ‘attributes’ of patient-centred care and person-centred care. The content described in Dignity in Care Principle 1 (Zero tolerance to abuse), Principle 6 (Privacy) and Principle 7 (Complain without fear of retribution) is almost entirely absent from the defining ‘attributes’ of patient-centred and person-centred care.

The literature review enabled definitions, policy, qualitative research findings and existing care concept PREMs to be mined for content to be included in the item pool, which will be further developed by a panel of experts in the content development phase of this research study (Stage 1, Delphi Panel, Chapter 4).

Before I write about the 3 Stages of my research (Stage 1, Delphi Panel, Chapter 4; Stage 2, Pilot Study, Chapter 5 and Stage 3, Preliminary Assessment of Validity and Internal Reliability, Chapter 6), I will firstly justify the methodology I have used to attempt to answer my research question.

3. Methodology

Be humble; no individual study can ever 'establish' or 'prove' the reliability or validity of an instrument [152]

3.1 Introduction

In the literature review I justified why this research should be pursued. In this chapter I justify the approach I have used to undertake this research. Methodology requires researchers to justify their particular research decisions [153]. Methodology is the theoretical justification for use of the methods the researcher believes are best suited to answering their research question. There are methods used in instrument development which are sound and uncontroversial. Those that I have employed include the use of a conceptual framework, harnessing the expertise of a broad range of people to develop the content for the questionnaire through a Delphi panel and testing and modifying the questionnaire through a pilot study, prior to the main data collection and analysis stage of the study. These require little justification and I will touch upon these lightly. There are also decision points in instrument development which are contested and without consensus, these are the decisions I will justify in greater detail. These include sample size and item order. The most contested area, however, is the theoretical approach to analysis. The debate exists between those who support the 'traditional' methods, referred to as classical test theory and those who support the 'modern' methods used in Item Response Theory, which includes Rasch analysis. I will conclude the chapter by explaining how the data analysis methods will be used to assess the validity and reliability of the instrument.

3.2 Methodological Pathway

The methodological pathway presented in Figure 3. 1, displays how the methodology connects the conceptual framework to the methods. Development of questionnaires in the absence of a clear conceptual framework has been identified as a common design fault [41]. McDowell (2006, p.706) notes '…as science ultimately tests theories, we must know what theoretical orientation each health index represents' [41]. Use of the 10 Principles of Dignity in Care as the conceptual framework for this study gave structure to the item generation process and serves as a great strength of the study. Justification for using the 10 Principles of Dignity in Care, as the conceptual framework for the research, was made in the Introduction (Chapter 1) and the Literature Review (Chapter 2).

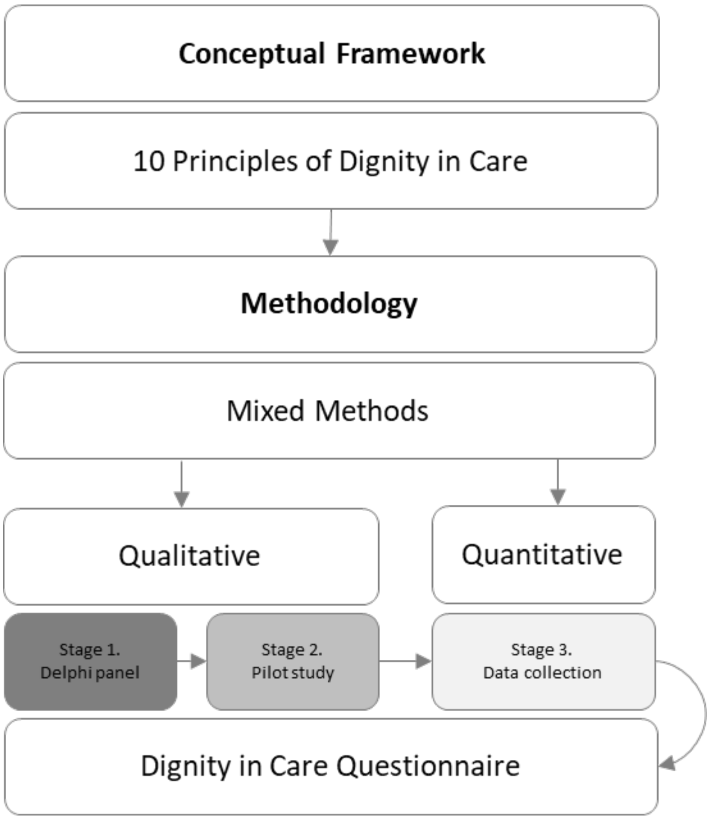


Figure 3. 1 Methodological Pathway

There have been many qualitative research studies, reviews and reports detailing older patients' (and to some extent, their carers') experience of care, under the various terms of 'dignity', 'compassion', 'individualised', 'person-centred', 'patient-centred' etc. I did not want to create, yet another, expansive report of interviews, relevant to a place and point in time, that is available for decision makers to read, if they choose to do so. In-depth interview reports are not presented in a usable form for executives and Boards of hospitals to use to measure and monitor patients' (and carers') experience of dignity in care [154]. Nor are they in a useable form to measure and monitor experience of care over time and across departments.

For an organisation to be able to monitor their performance in delivering dignity in care, information needs to be available in a form that is accessible to the hospital's executive and Board. This is the role of a Patient Reported Experience Measure (PREM), and a questionnaire is the instrument most commonly used to translate the experience of care into a reportable form for executives and Boards. Health service executives and Boards across Australia would mostly be relying on the Australian Hospital Patient Experience Question Set

(AHPEQS) [32] to monitor experience of care. My proposition is that the AHPEQS was not developed specifically for the needs of older people in hospital. A PREM is required that is based on a robust conceptual framework, that is relevant to the needs of older people.

Questionnaire development requires multimethodologies, which utilise both qualitative and quantitative methods [111]. Use of these methods is explained briefly below and in detail in the following chapters (Stage 1 Delphi Panel Chapter 4, Stage 2 Pilot Study Chapter 5 and Stage 3 Preliminary Assessment of Validity and Internal Reliability Chapter 6).

3.2.1 Stage 1 Delphi Panel

The key purpose of using the Delphi method is the collection of informed judgement on issues that are difficult to define [155]. I intended to ensure there was a substantial consumer voice involved in 'defining' the items to be included in the Dignity in Care Questionnaire (DiCQ).

Seeking feedback about their experience of care is intended to provide the consumer with a voice, yet an acknowledged inadequacy of many experience of care questionnaires is the failure to involve consumers in the process of development [110, 156-158]. My decision to use a Delphi panel (Figure 3. 1) to gain consensus on the items to be included in the questionnaire, allowed an intentionally large number of consumers to be involved, in acknowledgement of the value of the consumer voice. Other experts involved included clinicians, policy makers, academics and advocacy representatives.

Greater consumer participation was made possible because of the nature of how the Delphi panel process is conducted. The advantages of the Delphi panel technique include that participation was known only to the researcher, and as all participation was by email, participants were not restricted by the cost and time demands of face to face meetings and consumers could work with other people (family/friends) for support when completing their responses. Importantly, all participants have an equal voice as there is no dominant voice and perspective crowding out others' views, as can happen in face to face meetings [159].

As noted, the Delphi technique seeks to gain 'consensus' rather than 'agreement'. Consensus does not mean 100% agreement. Delphi consensus ranges from 55 to 100%, with 70% considered the standard [159]. This is helpful in providing further justification for the use of this method, given the literature review revealed that while there is a common core of items that are similar across care concepts (and map well to the 10 Principles of Dignity in Care) there is certainly no agreement on content.

The Delphi technique employed in the study utilised mostly qualitative techniques. Where the researcher's role in traditional qualitative research is as the 'instrument', Avella (2016) states the role of the researcher in the Delphi technique is to plan and facilitate the panel deliberations. It is the researcher's role to determine who should be invited to participate on the panel, and it is their role to develop, and analyse, the content for the panelists' deliberations. Fletcher (2014) notes that little has been written about the qualitative data processing within Delphi studies. The techniques used to process qualitative data in this study included 'binnowing' and 'winnowing'.

Binning [160] is a term used to describe the grouping of items according to meaning and construct (that is, which Principle (subscale) they represent). Winnowing [160] is a term used to describe the reduction of items. Items might be removed if: the item content does not represent the item construct (subscale/Principle); the item was too narrow or too broad; or the item was confusing [160].

Quantitative techniques used in the Delphi panel process were limited to using frequencies and means to analyse data panelists were asked to prioritise [161].

3.2.2 Stage 2 Pilot Study

Once the content (items and response categories) had been developed, the value of that content had to be judged by the target population: older patients and their carers in hospital. Justification for data collection in this population must be strong and clear. While the purpose of the study is to ultimately improve dignity in care, asking people to participate in research, in the context of hospitalisation, presents the risk of being burdensome for both the patient and carer.

A pilot study (Figure 3. 1) was justified. It was necessary to commence the process of testing the face and content validity of the items, to understand which items should be removed and why, and identify potential gaps that could be filled through the inclusion of other items. Obtaining this level of detail justified the use of cognitive interviews as part of the data collection process in the pilot study. The purpose of the cognitive interview was to explore respondents' understanding of the items, the scoring of the items and the ease of administration of the questionnaire. The verbal probing [162-164] method of cognitive interview was used to question participants as they considered their responses to the questionnaire.

As a researcher, the pilot study was a valuable opportunity for me to test and develop my processes of recruitment. Having worked as a clinical nurse for 15 years, I was familiar and comfortable in the hospital setting, but it is entirely different being a researcher of experience of care, a role none of the hundreds of nurses I spoke to during my data collection had ever encountered before.

3.2.3 Stage 3 Preliminary Assessment of Validity and Internal Reliability

Thus far, my methodology, including use of the Delphi technique and a pilot study involving cognitive interviews, was sound [2, 111]. But it was at that point, between the pilot study and the main data collection and analysis stage of my study that I encountered two of three methodological challenges. These were 1) sample size for the main data collection and 2) item order. The third methodological challenge arose after my data collection when I discovered the debate between the Classical Test Theorists and the Rasch measurement theorists.

3.3 Sample Size for Rasch Analysis

The implications for sample size in Rasch analysis are the same as any other statistical analysis; a small sample will provide 1) less precise estimates (bigger standard errors), 2) less powerful fit analysis and 3) less robust estimates (it is more likely that randomness in the data will distort them) [165]. Each time a set of items are calibrated on a different sample of participants, it is expected the results will be slightly different. In principle, as the size of the samples increases, the differences become smaller.

Linacre (2002) [166] proposes at least 10 observations per response category for polytomous models (i.e., models with more than two response categories) and notes a sample size of 50 would be a minimum requirement for polytomies, ranging upward to 500 for studies requiring robust confidence due to high stake outcomes. A sample size of 150 is required to have 99% confidence that no item calibration would be more than +/- ½ logit away from its stable value [165]. Based on Linacre’s evidence, I set a target sample size for this study of 150 patients and 150 carers.

Within the resource and time constraints of my doctoral research, my target sample size was dependent on many factors influencing recruitment. The Stage 2 Pilot study would provide a guide, and possibly a reality check, as to the sample size I was likely able to achieve in the Stage 3 data collection phase of my research.

3.4 Item Order

There is no dominant or agreed position on item order in instrument development. There are two options for the presentation of item order. The first is to present the items under the subscale headings, which for this study were the 10 Principles of Dignity in Care. The second is to intermix all items, which would necessitate removal of the subscale headings, and present the questionnaire as one list of items. Given the second option would require removal of the 10 Principles of Dignity in Care as the subheadings, I felt I needed to find compelling evidence to justify intermixing the items.

The literature on item order uses two terms, 'randomise' and 'intermix', the latter implies some purpose in the design of how items are mixed. It would not be feasible to randomise items in the DiCQ as some items are more challenging and require introduction through the completion of less challenging items. I was also concerned that if items were to be intermixed, would just one version of the intermixing be appropriate, or would the items need to be constantly intermixed into different order configurations? If so, I was concerned about the logistics of achieving multiple iterations of an intermixed questionnaire, particularly for use in a paper-based form.

On the topic of item order, the academic literature is scattered with articles offering inconclusive findings [167, 168]. Schurr and Henriksen (1983) found 'relatively few studies have been conducted which could serve as bases for recommendations' (p.9). Thirty years later, Schell and Oswald (2013) found 'the order in which items are presented or listed is not associated with any negative consequences' and helpfully, 'test builders are left to construct their instruments in the way that seems most logical to them, and at least based on these data, they are able to do so without having to worry a great deal about how that may impact the validity and reliability of the instrument itself' [167] (p. 320). In between times, published articles continue to report equivocal findings, some suggest randomisation/intermixing is required [169, 170], some suggest it is not required [171, 172] and many recommend further research [169-171, 173, 174].

Of the reviews of experience of care questionnaires [27-29, 156] I located as part of my literature review, I could find no reference to item order. Of the individual studies on instrument development, I could only find two that made reference to item order. Jacelon [143] intermixed items when pilot testing the Attributed Dignity Scale, 'by reorganising the items so seemingly like items were farther apart in the scale' (p.209)[143]. Reference was made to 'sequencing of items' in the guide to Your Experience of Service [112], which states 'Items are "banked" (grouped) in a pre-determined order to facilitate ease of completion and sequenced to reflect the consumer journey through a mental health service. As the order of the questions and how they are grouped or banked has an impact on the ratings provided, it is essential that the sequence is maintained in all uses of the instrument.' (p.7).

Having failed to find a dominant view of item ordering in the literature, I turned to the authors of the two scale development books I acquired and read with great enthusiasm when starting my doctoral studies. Professor David Streiner [2] was contacted for comment, and when asked if he had covered item order in his book Health Measurement Scales (2015), he replied 'I deliberately left it out because I couldn't find any evidence one way or the other', adding 'everybody has an opinion, but nobody has convincing data' (email communication 24 September 2018).

Professor Robert De Villis [111] was also contacted for comment, as I could not find coverage of item order in his book Scale Development Theory and Applications (2017). Professor De Villis provided a generous response, which included 'Once I've determined which items to retain, I can then order them, if I choose, in a way that helps the respondent focus on a single topic at a time because the items are categorically grouped and labelled' (email communication 24 September 2018).

I also contacted the COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) and received this response 'Item order as such is not included as a Standard in either … PROM development … or … Content Validity' (email communication 26 September 2018).

Based on the responses from these three authorities, I concluded that I did not have compelling evidence to justify the randomisation or intermixing of items. The evidence for intermixing the items (which necessitates removal of the subheadings, i.e., the 10 Principles) is neither strong nor clear. After considerable debate, consultation and reading, I made the decision to proceed, for the purpose of the doctoral research, with the items listed under the subheadings. In addition, given the instrument is being developed for use by older people in hospital, it is preferable that the questionnaire does not present unnecessary cognitive challenges and that is best achieved by anchoring each of the items to the relevant Principle of Dignity in Care.

I conclude the topic of item order by noting it is reasonable that the development of any questionnaire should consider testing item order, as further research is required to test whether item order has any effect on participant responses. However, researching the effect of item order was outside of the scope of this doctoral research.

3.5 Theoretical Approach to Analysis

3.5.1 Classical Test Theory and Rasch analysis

The role of quantitative data analysis in instrument development is to assess the unidimensionality (does it measure a single construct), validity (does it measure what it is intended to measure) and reliability (does it measure consistently) of the data collected from the sample of participants who have completed the questionnaire [175]. The challenge in measuring experience of care, is the requirement to measure the construct of dignity in care (known as the latent variable), because of the difficulty in measuring dignity in care directly [111]. The methods of analysis available fall into two groups 1) the 'traditional' methods used in classical test theory (CTT) and 2) the 'modern' methods used in Item Response Theory (IRT), including Rasch analysis.

Of the four reviews of experience of care questionnaires [27-29, 156] I referred to in my Literature Review (Chapter 2), not one study recorded the use of Rasch methods (which is a form of IRT) in the analysis of validity of the included studies. Even the most recently published instrument, 'the Dignity in Care Scale for Nurses', uses the methods of CTT [136]. This might make my decision to use Rasch analysis appear bold, misplaced or wrong. The justification for my decision is based on the argument that researchers, developing experience of care instruments, are continuing to use CTT in their data analysis, because that has been the predominant technique for a long time, not because it is the most robust method of analysis.

An extensive literature exists describing the debate between the use of 'traditional' versus 'modern' methods of analysis in instrument development [176-178]. At the heart of the debate is the criticism that the methods used in CTT, which include factor analysis and Cronbach's alpha, are based on inaccurate assumptions.

These assumptions stem from the practice of summarising the responses to the questionnaire into a total score. Allowing a summary score assumes the response options are equal distances apart on a scale and that items are of equal value (depicted by the bottom row of the ruler in Figure 3. 2 [179]. This assumes the data are on an interval scale. However, data from questionnaires using a Likert scale (i.e., with response categories: 'Never', 'Rarely', 'Sometimes', 'Often', 'Always') are on an ordinal scale, where the 'distance' between two consecutive unit points on the scale are not uniform and consistent across the entire range of the scale [175] (depicted by the top row of the ruler in Figure 3. 2). This assumption results in ordinal level categorical data being treated as interval level data in the analysis [177]. Interval level data are assumed to have parametric data structure: normal distribution, homogeneity (homogeneous groups within the data) and homoscedasticity (equal variance of the residuals) [180]. CTT methods then (inappropriately) employ parametric statistical techniques, including t-tests and analysis of variance, suitable for interval data [180].

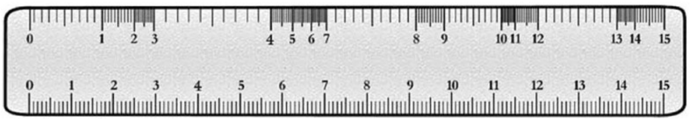


Figure 3. 2 Ordinal scale (top of ruler) and interval scale (bottom of ruler)

Image courtesy of Professor Alan Tennant, Leeds Psychometric Laboratory for Health Sciences, The University of Leeds

At this point I must introduce two terms 'Item difficulty' and 'person ability'. The terms arose from educational ability testing and make sense in that context. IRT has moved into the measurement of other constructs, but the language has been retained, and so must be explained. Item difficulty refers to the level of the attribute being measured that is associated with a transition from 'failing' to 'passing' (or endorsing) the item [111]. Items are constructed with different levels of difficulty. IRT has methods to calibrate the difficulty of an item that is independent of any characteristics of the person who happens to be completing the questionnaire [111]. The goal of determining item difficulty is to determine how much of the attribute is required to pass (endorse) the item. When this can be achieved, and the item receives a pass (endorsement), it has constant meaning (i.e., is invariant) for the construct being measured. This achieves a metric that is independent of a specific sample [111].

The assumption, that the data can be analysed with techniques suitable for interval level data, and that responses can be summed into a total score, are sources of criticism of CTT [177]. To explain further, the total score would represent, to use the topic of this study, the amount of the latent variable, the experience of dignity in care. By way of example, if there are 50 patients completing a 50-item questionnaire, with 5 response categories (0, 1, 2, 3, 4), the maximum score, representing the highest experience of dignity in care, would be 50 x 4 = 200. If 2 people had a score of 150, this would imply both people had an equal experience of dignity in care. This assumes all items exhibit the same quantity of the construct being measured [177]. However, one person might have answered 4 for 25 items and 2 on 25 items. The other may have scored 3 on all 50 items. Both add up to 150, but the items vary in 'difficulty', ranging from an item about being restrained to an item about being assisted to retain independence. One person might have scored higher on more difficult item (being restrained), but both share the same summary score. This is misleading as the total score does not take into consideration which items are more (or less) difficult or which persons have more (or less) ability [177].

Cronbach's alpha, routinely used in CTT, determines the correlation of every item in the instrument with every other item. If all the items are perfectly correlated, the alpha will be 1.0, if there is no relationship between the items, the alpha will be 0.0. For the purpose of research studies, an alpha of 0.7 or more is considered acceptable [181]. Massof (2002) notes that a measure of internal consistency should be independent of the number of items, and Cronbach's alpha is not [178]. Cronbach's alpha can be inflated by having too many items that are similar (and therefore highly correlated) but such items indicate redundancy [181]. The Cronbach's alpha does not assess validity, but poor reliability is an indicator of poor validity[178].

Item response theory evolved in response to the limitations of many of the methods used in CTT. De Villis (2017, p. 207-208) summarises the main differences between CTT and IRT. 1) Where CTT tends to emphasise characteristics of the entire instrument, IRT places greater emphasis on the properties of the individual items of the instrument. 2) IRT examines what level of the attribute being measured (i.e., low, moderate, high levels of the attribute) most strongly influences an item. 3) IRT makes use of graphical ways of representing the properties of individual items and the entire instrument [111].

Rasch analysis was developed independently of IRT [178], yet shares similarities as well as differences [178], such that IRT is considered part of the Rasch family [111]. The 'family' is made of up different models that include different numbers of parameters. Rasch considers only one parameter and that is item 'location' [111]. Where other IRT models are considered exploratory in that they describe the variance in the data, Rasch is a confirmatory model; that is, the analysis examines how the data fit the model [176] [182].

When the assumptions of the Rasch model are satisfied, the Rasch model can convert raw scores into linear and reproducible measurement [183]. It has separable person and item parameters and conjoint additivity [183]. These features allow objective comparisons of person and items and each set of model parameters can be conditioned out of the estimation procedure for the others [183]. With a grasp of the key terminology, the next section describes Rasch analysis in greater detail.

3.5.2 Rasch Analysis

Rasch analysis is a method for constructing, from categorical responses (i.e., Likert scales), linear systems within which item difficulty and person ability can be measured unambiguously [184]. This is achieved by positioning persons (completed questionnaires) and items (questions of the questionnaire) on a logit scale (log-odds unit), which represents the log odds ratio of the probability a person will select a particular response option of an item over 1-the same probability [176]. Through logarithmic transformation, Rasch analysis transforms ordinal categorical data into interval level data.

A 'valid' questionnaire should demonstrate unidimensionality, meaning the instrument measures a single underlying construct (the latent variable) and each item 'fits' the underlying construct[183]. If unidimensional, all items of the questionnaire can be summed to a single score as each item contributes to the measurement of a single construct [183]. The Rasch model assumes unidimensionality in an item set, the process of analysis, including examination of the Fit Statistics and an analysis of the Principal Components Analysis of the Residuals, will identify anomalies to a unidimensional structure.

To determine if the data fit the Rasch model, an assessment is made of Category Threshold Order, and recommendations for the Person Separation Index, Person Separation Reliability Coefficient, Item Separation Index and the Item Separation Reliability Coefficient, Fit Statistics, Response Dependency, Principal Components Analysis of the Residuals, Targeting and Differential Item Functioning are used as guidelines to assess the validity and internal reliability of the instrument [176].

Expert judgement is retained through the process of Rasch analysis [176], alongside the revelations of the data. When analysing data from a measure of a latent variable such as dignity in care, confirmation of a perfectly fitting model is not expected. Developing the DiCQ will be an ongoing enterprise. For my doctoral research, I have investigated how robust the questionnaire is in its current form and what immediate changes could be made to make the instrument more robust.

The Winsteps software (Linacre, J. M. (2019), Winsteps® Rasch measurement computer program, Beaverton, Oregon, version 4.4.5) was used to undertake the Rasch analysis.

There are two models that can be used in Rasch analysis, the Rating Scale Model (RSM) and the Partial Credit Model (PCM). The RSM specifies that a set of items share the same rating scale structure. It originates in attitude surveys where the respondent is presented the same response choices for several items. The partial credit model specifies that each item has its own rating scale structure. It derives from multiple-choice tests where responses that are incorrect, but indicate some knowledge, are given partial credit towards a correct response. The amount of partial correctness varies across items. Statistically, removing an item from a rating scale grouping and allowing it to define its own partial credit scale introduces extra parameters into the estimation. In general, more parameters mean a better fit of the data to the model. If misfit is reduced, then measurement appears to be better [185].

The justification for using the RSM for this study was based on the fact that the response categories used for analysis all shared the same rating scale (e.g., Likert agreement: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’, ‘Always’). Upon this basis, it is argued, the RSM is indicated, and it requires strong evidence to use a Partial Credit Model [185].

3.5.2.1. Subscale analysis

The Dignity in Care Questionnaire (DiCQ) was developed to have 10 subscales (the 10 Principles of Dignity in Care). A necessary step in the analysis is to determine if any of the subscales form their own separate measure. This is determined by undertaking Rasch analysis on each of the subscales. Where no subscale can form a separate measure, the analysis is undertaken to explore whether the instrument, as a whole, based on the content developed for all 10 Principles, can demonstrate construct validity.

I will now explain each of the steps in the Rasch analysis, which include examination of Category Threshold Order, Person Separation, Item Separation, Fit Statistics, Response Dependency, Principal Components Analysis of the Residuals, Targeting and Differential Item Functioning.

3.5.2.2. Category Threshold Order

Category Probability Curves (CPCs) are used to assess whether respondents use the response categories in an orderly manner. A threshold represents the transition between response options. It occurs when the likelihood of endorsing one category becomes the same as the likelihood of endorsing the next category [111]. If an item includes five response options (0 = 'Never', 1 = 'Rarely', 2 = 'Sometimes', 3 = 'Often', 4 = 'Always') of increasing difficulty, it has four thresholds (Figure 3. 3).

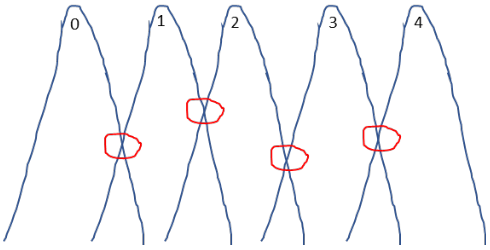


Figure 3. 3 Category threshold (circled red)

A minimum of 10 responses per category is recommended [176]. If persons completing the questionnaire do not use the full range of response categories, this can cause disordered thresholds. Items with disordered thresholds might misfit the unidimensional model. Response categories of items with disordered thresholds can be collapsed until threshold order is achieved. By way of example, the CPCs for item 2.1 in the patient version of the DiCQ *'Staff wear name badges large enough to read'* are shown in Figure 3. 4. The number of responses to this item, by response category, were 'Never' = 11, 'Rarely' = 17, 'Sometimes' = 46, 'Often' = 49 and 'Always' = 72.

The CPC has category probabilities on the y-axis plotted against the difference between person and item measures on the x-axis (Figure 3. 4). In this example, the higher the response option (i.e., 'Always'), the more likely it is to be endorsed by people who experienced staff wearing name badges large enough to read. To use the language of IRT, this is the most 'difficult' category to endorse. Those who experienced the highest level of 'staff wearing name badges large enough to read' are more likely to endorse this category over the alternative response options.

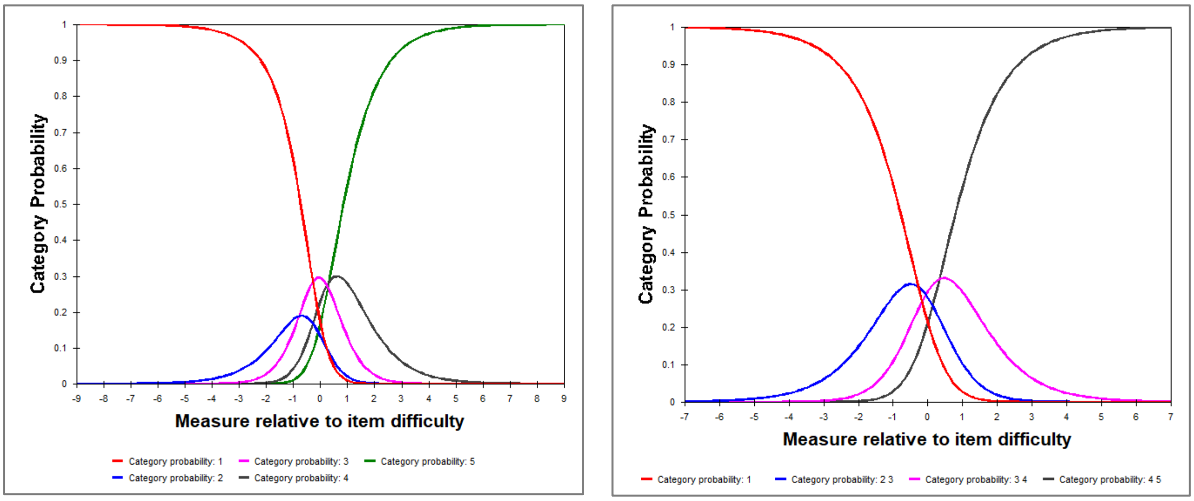


Figure 3. 4 Original (figure on left) and revised (figure on right) Category Probability Curves for Item 2.1

(Figure on left) Original disordered CPC (left) Red = category probability 1, blue = category probability 2, pink = category probability 3, grey = category probability 4 and green = category probability 5.
(Figure on right) Revised ordered CPC following collapse of 'Never' and 'Rarely' response categories Red = category probability 1, blue = category probability 2, pink = category probability 3 and grey = category probability 4.

A response category threshold step (i.e., separation between two adjacent categories) of between 1.4 and 5.0 logits is recommended [176]. Threshold values should be neither too close nor too far apart [176]. The steepness of the curves indicate the discrimination ability of the response category [176]. The response category threshold steps for the analysis of item 6.1 (Figure 3. 4, on left) were -1.12, 0.95 and 0.02 logits, which are consistent with disordered thresholds. These are most evident by the blue curve (category probability 2) which is flat (not steep) and completely within CPC 1 (red).

Categories can be collapsed to test if this will return order. Adjacent categories should be collapsed [176]. In this instance the categories 'Never' and 'Rarely' were combined and the CPC on the right (Figure 3. 4) demonstrates ordered categories, however the thresholds remained narrow (0.72, 0.58 logits). Revisions to the original data made as a result of the findings of iterative steps in Rasch analysis must consider other aspects of the analysis, including the effect of collapsing response categories on the person separation and the item misfits. These intertwined parts of the Rasch model are described in the following pages (Sections 3.1.5.3 to 3.1.5.9).

3.5.2.3. Person Separation

Optimally, an instrument should be able to stratify persons completing the questionnaire by ‘ability’. The more strata (which for this study, represent the perceived level of dignity in care) an instrument can distinguish, the greater the precision. In Rasch analysis, the person separation reliability coefficient is used to measure the number of strata. The higher the person separation reliability coefficient, the more strata, the greater the precision of the instrument. A person separation reliability coefficient of 0.8 can discriminate 3 strata and is recognised as the minimum acceptable level [186]. The Person Separation Reliability Coefficient can be used as a proxy for the Cronbach’s alpha coefficient. To fit the Rasch model, the person separation index should be greater than > 2.0 and the person separation reliability coefficient > 0.8 [186]. These results would indicate that the item distribution is adequate to reliably generate person hierarchy, that the persons have a wide range of abilities and the persons could be grouped into different strata of the latent construct (dignity in care) they have experienced.

3.5.2.4. Item Separation

The item separation index represents the replicability of the item hierarchy if the same items were endorsed by different groups of persons with similar ability distribution. Item reliability cannot be assessed if there are no persons at the same level as the item (to be examined further in section 3.1.2.6 Targeting and Figure 3. 5). To fit the Rasch model, the item separation index should be greater than 3.0 and the item separation reliability coefficient > 0.90 [186]. These results would indicate that the person distribution is adequate to reliably generate item hierarchy and that the items have a wide range of difficulties.

3.5.2.5. Fit Statistics

The Rasch model fit statistics report how well the observed data correspond to the measure estimates. The Winsteps software, used to undertake the Rasch analysis in this study, includes two ‘fit statistics’, the ‘Infit’ and the ‘Outfit’. The Infit, which means inlier-sensitive or information-weighted fit, is more sensitive to the pattern of responses to items targeted on the person [176]. The ‘Outfit’, which means outlier-sensitive fit, is more sensitive to responses to items with difficulty far from a person [176]. There are both unstandardized mean-square (MnSq) and standardised (Zstd) infit and outfit scores [176].

The ‘fit’ indicates the amount of distortion of the measurement system. Actual fit statistics can range from 0 to infinity. Items with MnSq infit or outfit statistic of 1.0 fit perfectly to the unidimensional scale [183]. Fit statistics between 0.6 MnSq and 1.4 MnSq are considered acceptable for rating scales such as Likert response categories [187]. Items with fit statistics of less than 0.6 MnSq indicate a high level of predictability in the responses and suggest redundancy [176]. Values higher than 1.4 MnSq indicate ‘noise’ in the responses. For example, an MnSq of 1.5 means 50% more variation in the observed data than the Rasch model predicted. For the standardised (Zstd) statistic, the expected value is close to zero [176]. Positive values indicate more variation, and negative values indicate less variation, than the model predicted. Acceptable values of Zstd are between -2.0 and 2.0 [176].

Items with fit statistics outside the acceptable range should be considered for removal. The decision requires both statistical and qualitative appraisal (i.e., ‘expert’ judgement). The mis-fitting items can be removed, one at a time, to test the effect on the model (examined by the effect of item removal on PSI/ISI). All items removed in the preliminary assessment undertaken in this study, should be considered for amendment and further testing in future (post-doctoral) development of the instrument.

3.5.2.6. Response Dependency

Local independence is a requirement of the Rasch model, it is achieved when items are only correlated through the latent trait the instrument is measuring [188]. The assumption of local independence can be violated through response dependency, which can occur when the item response on one item influences the response on another, because, for example, the items are similar in content and response categories [188] . The Q_3 test statistic can be used to detect response dependency. The Q_3 is calculated by the average of all residual item correlations and then add 0.2 [188]. Item pairs with residual item correlations greater than the calculated Q_3 test statistic are then reviewed and one of the item pairs removed. Individual items appearing in high residual correlations with multiple other items are targeted for removal. Expert judgment is required to determine which of the remaining highly correlated items should be retained and which should be removed. The items contributing to response dependency can be removed, one at a time, to test the effect on the model (examined by the effect of item removal on PSI/ISI). Noting, all items removed in the preliminary assessment undertaken in this study, should be considered for amendment and further testing in future (post-doctoral) development of the instrument.

3.5.2.7. Principal Components Analysis of the Residuals

Dimensionality is assessed by examining the Principal Components Analysis of the Residuals [183]. Residuals are the differences between observed data and the model estimates (expected data) [183]. For a unidimensional measure, most of the variance should be explained by the principal factor (construct). The observed raw variance explained by the first factor should approximate the expected [189]. Items clustered together with factor loadings for residuals significantly higher than zero (i.e., > 0.40) might indicate multidimensionality [190]. The eigen value is used to explain systematic variance [181]. It is the patterns (rather than the size) of the loadings that are important [190].

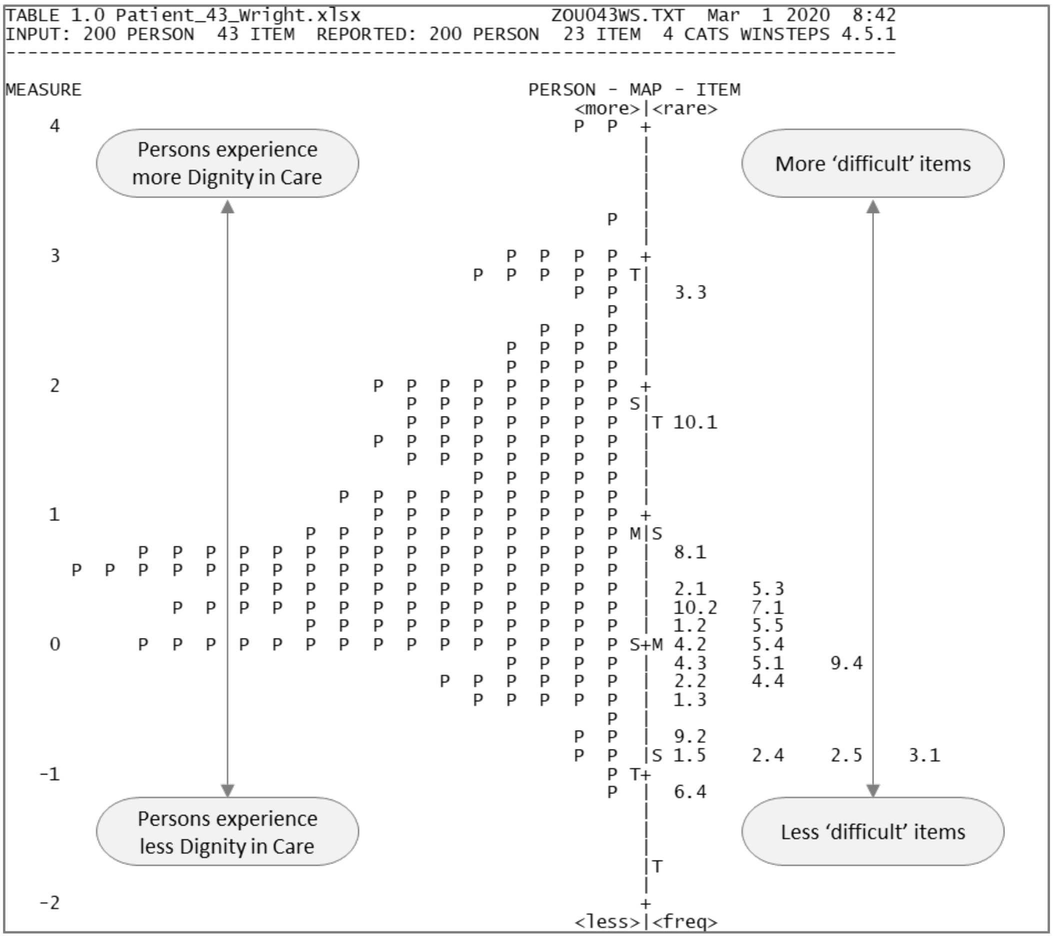
Where clusters of items are identified in the Principal Components Analysis of the Residuals, Linacre suggests disattenuated correlations > 0.7 between clusters indicates the clusters are simply groupings of items, which are all contributing to the same dimension [189]. Disattenuated correlations may be thought of as correlations between the latent variables measured by a set of observed variables. That is, what would the correlation be between two (unreliable) variables be if both variables were measured perfectly reliably [189].

3.5.2.8. Targeting

Targeting demonstrates how well the item-difficulty matches the person-ability. The person-item map (Figure 3. 5) allows analysis of targeting. The map displays the relative locations of items and persons along the same measurement continuum. In this analysis the latent variable being measured is dignity in care, persons with more of the latent variable are further from the mean and have a positive logit value and persons with less of the latent variable are further from the mean and have a negative logit value. The map has persons on the left and items on the right. Items that are further from the mean and have a positive logit value are more challenging to respond to with a high response category (i.e., obtain a higher score).

Optimally, there should be a match of persons to items, including a balance of easy and difficult items. Gaps along the item measurement continuum indicate gaps in the measurement continuum. Clusters of items indicates item (thresholds) that are at similar levels of ‘difficulty’. Items (thresholds) at the same point gives greater precisions and separation of persons. An instrument that has perfect targeting would have a difference between the person mean and item mean of 0. An instrument with a difference between the person and items means of more than 1 logit indicates poor targeting [191].

A brief examination of the person-item map (Figure 3. 5) makes it easy to see that the instrument lacks items of variable difficulty, particularly more difficult items. There is clustering of items (along rows). The difference in the means confirms the instrument does not display optimal targeting.



```
TABLE 1.0 Patient_43_Wright.xlsx                 ZOU043WS.TXT  Mar  1 2020  8:42
INPUT: 200 PERSON  43 ITEM  REPORTED: 200 PERSON  23 ITEM  4 CATS WINSTEPS 4.5.1
--------------------------------------------------------------------------------

MEASURE                                        PERSON - MAP - ITEM
                                                   <more>|<rare>
    4                                              P  P  +
                                                         |
                                                         |
                                                         |
                                                         |
                                                      P  |
                                                         |
    3                                        P  P  P  P  +
                                          P  P  P  P  P T|
                                                   P  P  |  3.3
                                                      P  |
                                                ★
                                                P  P  P  |
                                             P  P  P  P  |
                                             P  P  P  P  |
    2                            P  P  P  P  P  P  P  P  +
                                    P  P  P  P  P  P  P S|
                                    P  P  P  P  P  P  P  |T 10.1
                                 P  P  P  P  P  P  P  P  |
                                    P  P  P  P  P  P  P  |
                                          P  P  P  P  P  |
                              P  P  P  P  P  P  P  P  P  |
    1                            P  P  P  P  P  P  P  P  +
                           P  P  P  P  P  P  P  P  P  P M|S
            P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  |  8.1
      P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  |
                     P  P  P  P  P  P  P  P  P  P  P  P  |  2.1    5.3
               P  P  P  P  P  P  P  P  P  P  P  P  P  P  |  10.2   7.1
                           P  P  P  P  P  P  P  P  P  P  |  1.2    5.5
    0       P  P  P  P  P  P  P  P  P  P  P  P  P  P  P S+M 4.2    5.4
                                             P  P  P  P  |  4.3    5.1    9.4
                                       P  P  P  P  P  P  |  2.2    4.4
                                          P  P  P  P  P  |  1.3
                                                      P  |
                                                   P  P  |  9.2
                                                   P  P  |S 1.5    2.4    2.5    3.1
   -1                                                 P T+
                                                      P  |  6.4
                                                         |
                                                         |
                                                         |
                                                         |T
                                                         |
   -2                                                    +
                                                   <less>|<freq>
```

Figure 3. 5 Person-item map for the 43-item Dignity in Care Questionnaire (patient version)

Legend. The persons (each patient participant = 'P') are represented on the left of the scale and items, by item number, on the right of the scale (e.g., item 3.3 on the top right). The vertical dashed line represents the logit scale, M=mean; S= 1 standard deviation from the mean, T= 2 standard deviations from the mean. The M, S and T are shown for both items and persons. The more difficult items, and persons with a higher level of dignity, are placed at the top of the scale and vice versa.

3.5.2.9. Differential Item Functioning

Invariance is a statistical property of measurement that indicates that the same construct is being measured across some specified groups. Item and person invariance are violated when differential item functioning (DIF) exists. Differential item functioning, or item bias, occurs when subgroups of people with comparable levels of ability respond differently to an item, which implies a response to some characteristic other than item 'difficulty' [176]. In this study, differential item functioning was examined across gender, age and length of hospital stay prior to completing the questionnaire. Differential item functioning was measured by the DIF Contrast in Winsteps [192]. Parameters used to assess DIF Contrast in this study were defined as 1) it is optimal for all items to have DIF < 0.50 logits, 2) it is acceptable if some items are between 0.5 and 1.0 logits, and 3) it is unacceptable to have more than one item with DIF > 1.0 logits [191].

3.6 Validity, Reliability, Responsiveness and Interpretability

Thus far in this chapter, I have presented the justification for the approach to data analysis. I will now explain how my study complies with the COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) Taxonomy of Measurement Properties [145] (Figure 3. 6). I will also comment on the aspects of the Standards that will require consideration in future (postdoctoral) development of the instrument.

The assessment of validity is undertaken to determine the degree to which the instrument measures the construct it was designed to measure [145]. There is no single test that determines an instrument is valid. Validity is a concept that has many component parts. Each part contributes to the assessment of validity. Therefore several forms of validity assessment might be applicable [193]. The COSMIN Measurement Properties of Outcome Measurement Instruments [145] includes construct validity, content validity and criterion validity (Figure 3. 6).

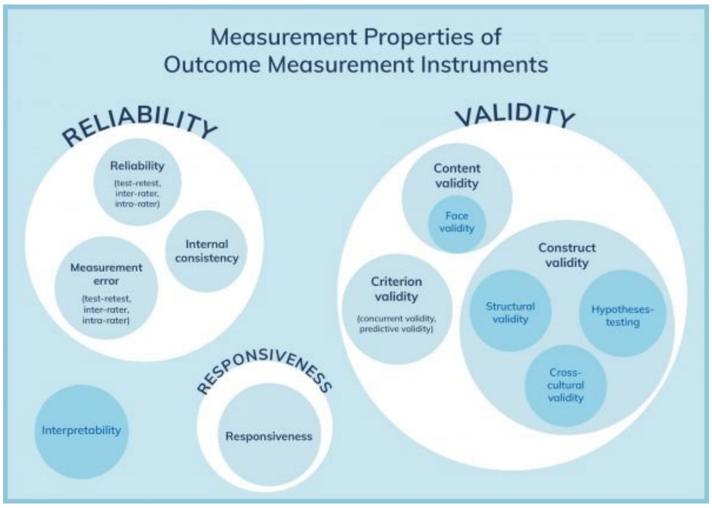


Figure 3. 6 COSMIN Taxonomy of Measurement Properties

Evident in Figure 3. 6, face validity is a component of content validity. Face validity is an assessment of whether an instrument looks reasonable, is relevant and understandable by the people who will be asked to complete the questionnaire [193]. Face validity is not tested using statistical procedures [193]. In this study, face validity was tested through Cognitive Interviews during the Stage 2 Pilot Study (Chapter 5).

Content validity considers whether an instrument has included all the relevant and excluded the irrelevant material in terms of its content [193]. Content validity is also the extent to which the items in the instrument reflect the entirety of the concept being measured [186]. The 10 Principles of Dignity in Care provided a powerful conceptual basis for guiding the development of content. Content validity cannot be formally assessed, however it is intrinsic to every decision made about how items should be written, which items to include, which items to retain and which items to remove; decisions made in each of the 3 Stages of this study and covered in detail in Chapter 4 (Delphi study), Chapter 5 (Pilot study) and Chapter 6 (Preliminary Assessment of Unidimensionality, Validity and Internal Reliability).

Criterion validity is assessed by comparing the instrument being developed with an existing instrument that has undergone robust assessment of validity [193]. This was not assessed in this study, as explored in the Literature Review (Chapter 2), there is instrument validated for use by older people, which is designed to measure dignity in care based on the 10 Principles of Dignity in Care.

Construct validity is the main form of validation for a test [193], its importance is reflected by its dominant size in Figure 3. 6, and includes hypothesis testing, structural validity and cross-cultural validity. The hypothesis I am testing forms the basis of the research question for this study 'Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting?'

Structural validity is assessed by examining how the data fits the Rasch model (detailed in Section 3.1.5). Cross cultural validity should be considered in future (postdoctoral) development of the instrument.

3.6.1 Reliability

Reliability refers to the degree to which the measurement is free from measurement error. It contains the measurement properties of internal consistency, reliability, and measurement error (Figure 3. 6) [145]. Internal consistency is a measure of the extent to which all the items in the outcome measure address the same underlying concept. This examined in the assessments of unidimensionality. In the Rasch model, reliability is estimated for both persons and items using the person reliability index and the item reliability index[176].

Test retest reliability is assessed by asking respondents to complete the questionnaire once and then again later, to test the assumption that no change will have occurred to the answers provided. It is possible a person's experience of dignity in care could change over a period of 1 to 2 days. The value and appropriateness of undertaking test retest will be considered in further (postdoctoral) development of the instrument.

3.6.2 Responsiveness

Responsiveness is defined as the ability of an instrument to accurately detect change when it has occurred [194]. It would be expected that a person would change their rating of the DiCQ if they were provided care in a hospital that did not have a commitment to implementation of the 10 Principles of Dignity in Care when compared to a hospital that did have a commitment to the implementation of the 10 Principles of Dignity in Care. Measuring responsiveness is outside of the scope of my doctoral research but should be included in further development of the DiCQ, with consideration given to measuring responsiveness over time, at the same site, prior to and following the implementation of the 10 Principles of Dignity in Care into practice.

3.6.3 Interpretability

Interpretability is the smallest change in rating the instrument, that is important to respondents. The DiCQ requires further development and testing before exploring interpretability (beyond the scope of this doctoral research).

3.7 Conclusion

In this chapter I have explained the relationship of the conceptual model to the methods by presenting the justification for decisions made in my research. These justifications represent my methodology. The methods I have used are mostly robust and uncontentious, however some are complicated, including sample size and item order, and I have justified my approach to these in my study. The methods used for data analysis are far more contentious, yet the argument for using 'modern' methods is justified by the science of statistics. The justification for examining how the data I have collected fits the Rasch model is sound. Rasch analysis contributes to the assessment of unidimensionality, construct validity and internal reliability. Further assessment of validity is covered in the Delphi panel (Chapter 4), the Pilot study (Chapter 5) and the Preliminary Assessment of Unidimensionality, Validity and Internal Reliability (Chapter 6).

4. Delphi Panel (Stage 1)

A word after a word after a word is power [195]

4.1 Introduction

The first stage of my doctoral research was a qualitative study utilising a modified Delphi technique designed to develop the content for the questionnaire. The content included both the items (i.e., the 'question' in the questionnaire) and the score (i.e., the response options to answer to the question). The content was developed for the patient version of the questionnaire and then adapted and adopted for the carer version, to ensure alignment of content across both versions.

The aim of the first stage of the study was to gain consensus from a panel of experts on the content used to measure each of the 10 Principles of Dignity in Care, to form the patient and carer versions of the questionnaire, that would progress to the pilot study. The objectives were to:

i. Identify, recruit and consent the Delphi panel of experts.
ii. Prepare the initial item pool from policy, qualitative research and existing instruments, for use in the first round of Delphi panel deliberations.
iii. Conduct the rounds of Delphi panel deliberations, preparing content for each round and providing feedback from each round to panel members.

This chapter presents the preparation, methods and results of Stage 1 of the study. The Delphi panel process establishes the foundation of the study, which is designed to answer the research question 'Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting?'

4.2 Methods

4.2.1 Study Design

The Delphi technique is a well-established method for the task of generating content for questionnaires [161]. The technique employs a panel of experts, who review and score content, through rounds of deliberations, with the goal of gaining ‘consensus’ on the topic under development. The Delphi technique seeks to gain ‘consensus’ rather than ‘agreement’ [161]. Where agreement might be defined as ‘the condition of having the same opinion’ [196], consensus is agreement of the majority. The definition of consensus is open to debate, but 70% is commonly stated as a working definition in the literature [159]. Using a consensus building technique is well suited to topics for which there is no clear agreement. The 10 Principles provide a useful conceptual framework, but no one has ever determined which items represent each of the 10 Principles. Approaching the task with a requirement of 100% agreement would be unrealistic. In this study, a priori, consensus was defined as 70% agreement [159]. The panellists participated in three rounds of deliberations. Only the researcher knew the identity and contributions of the panellists.

A ‘classical’ Delphi technique [159] would have started with a blank sheet and asked the panellists to define dignity in care. A ‘modified’ Delphi technique [159] can be used when a study has an advanced starting point. The definition of dignity in care had already been articulated through the 10 Principles, which were used as the conceptual basis of this study [41]. Given the questionnaire was to be designed using the 10 Principles as subscales, this allowed an ‘item pool’ of content to be provided to the panellists for consideration in their first round of deliberations.

4.2.2 Participants

According to Avella (2016), the number of participants on a Delphi panel is typically somewhere between 10 to 100, and there is no agreed standard [159]. The plan was to invite approximately 70 people, expect approximately 50 to consent, and of those, possibly 60% (or 30 people) to provide complete responses to the Delphi panel papers.

Consumers (representing the patient and carer voice) were identified through Local Health Network consumer committees. Consumers with dementia, identified through their involvement with Dementia Alliance International and Dementia Australia, were also invited to participate. To recruit additional consumers, including people living with dementia, an open invitation was sent through the author’s Twitter account #louheuzenroeder; through the Dementia Australia Research Foundation webpage and through the Consumers Health Forum of Australia.

Participants included representatives from the National Dignity Council in the UK, Aboriginal health workers and representatives from culturally and linguistically diverse communities. The Aboriginal member of the Delphi panel included their team of seven Aboriginal health workers when working on their response to the Delphi panel papers. The Chief Executive of Multicultural Communities SA supported recruitment of people representing ethnically diverse communities. The Delphi panel included representatives from the aged care sector and disability services to reflect the crossover in service use, and in recognition that the Dignity in Care Questionnaire (DiCQ) may, at some point in the future, be validated for use in aged care and disability settings.

Academic experts, predominantly from Australian universities, were identified by articles they had published on topics including dignity in care, older consumers' experiences of hospital care and questionnaire development. Clinicians, working in Australian Local Health Networks, were invited based on their experience and expertise in the care of older people in hospital.

I made direct contact with 74 potential participants. These people were sent, by email, a personal letter of invitation and the Delphi panel Participant Information and Consent form (Appendix A7).

4.2.3 Ethical approvals

Ethical approval for the study was granted by The Queen Elizabeth Hospital/Lyell McEwin Hospital/Modbury Hospital Human Research Ethics Committee and Central Adelaide Local Health Network Research Governance Office (HREC/17/TQEH/91) (Appendices A1, A6, and A7). Participants were required to read the Participant Information and Consent Form, sign the consent and return to me. I co-signed the consent and scanned and emailed it back to the participant.

4.2.4 Planned Timeframes

The panellists were informed that there would be three to four rounds of deliberations [159, 161], which would mean three or four papers for their review and comment and that responding to each paper may take approximately one hour. The panellists were informed that the rounds would take place over a period of four to five months, accounting for the two to three weeks for their response and the one to two weeks required to review participants' comments, provide feedback to panellists and construct the paper for the next round.

The Delphi panel process was intended to continue until there was consensus on a version of the questionnaire to be used in the pilot study. Panellists were informed that they would review the version of the questionnaires drafted following the pilot study, and at the point the Delphi panel process would close.

4.2.5 Communication with panellists

All communication with the Delphi panel took place by email. Communication within each round was undertaken by sending an email to the Delphi panel distribution list (that I created). Emails were sent as 'blind carbon copy' (bcc) to maintain confidentiality between panellists. The names of the panellists were known only to my Principal Supervisor and me.

4.2.6 Preparation for Round One

In preparation for Round One Delphi panel deliberations, an item pool was developed by undertaking a review of existing 'experience of care' questionnaires, qualitative research and policy.

In addition, I drafted items, based on my knowledge and experience, for Principles for which there was poor coverage in the literature. According to De Vellis (2017, p.109) it is 'often the case' that items must be drafted anew [111]. De Vellis' recommendations to 'think creatively about the construct you seek to measure' and to think of 'other ways the item can be worded so as to get at the construct' were heeded when drafting the items [111]. The number of items, by source, are summarized in Table 4. 1, Table 4. 2 and Table 4. 3 below.

Content included in the item pool from existing instruments are listed, by Principle (subscale) in Table 4. 1. Existing instruments provided the most content for Principle 5 (nine items: 5.1, 5.2, 5.3, 5.6, 5.7, 5.8, 5.9, 5.10 and 5.13) and the least content for Principle 10 (one item: 10.4). Noting a number of items, with identical wording were identified in a number of different instruments, for example, Item 4.7 'I have been involved, as much as I wanted to be, in decisions about my care and treatment' was identified in seven different instruments [24, 26, 32, 123, 124, 134, 135].

Table 4. 1 Round One items sourced from existing questionnaires

Principle 1	1.1[112]	1.7[26]	1.14[112]						
Principle 2	2.1[24]	2.2[26]	2.5[26]	2.6[26]	2.7[26, 115, 123]	2.8[26, 115, 123]			
Principle 3	3.1[24]	3.2[115]	3.3[26, 138]	3.9[142]					
Principle 4	4.4[149]	4.5[115, 124]	4.7[24, 26, 32, 123, 124, 134, 135]	4.8[124]	4.10[115]	4.11[24]			
Principle 5	5.1[142]	5.2[142]	5.3[115]	5.6[115]	5.7[115, 135]	5.8[115]	5.9[112]	5.10[135]	5.13[24]
Principle 6	6.1[112, 142]	6.2[120, 123]	6.3[24, 120, 123, 124]	6.5[24]					
Principle 7	7.1[112, 123, 124]	7.4[112]	7.5[24]						
Principle 8	8.1[149]	8.2[149]	8.3[124, 141]	8.6[112]	8.7[112]				
Principle 9	9.1[112]	9.2[24, 123, 144]	9.6[24]	9.7[114]					
Principle 10	10.4[115]								

Content included in the item pool that was adapted from qualitative research and policy documents are presented in Table 4. 2. Qualitative research and policy included the most content that could be matched to Principle 4 (five items: 4.1, 4.2, 4.3, 4.6 and 4.12) and no content that could be adapted for Principle 10.

Table 4. 2 Round One items sourced from qualitative research and policy documents

Principle 1	1.4[102]	1.5[102]	1.8[102]		
Principle 2	2.3[148]				
Principle 3	3.4[47]				
Principle 4	4.1[148]	4.2[148]	4.3[148]	4.6[47, 150]	4.12[151]
Principle 5	5.4[148]	5.5[148]	5.11[148]	5.12[148]	
Principle 6	6.4[47]	6.7[148]			
Principle 7	7.2[148]	7.3[47, 148]			
Principle 8	8.4[102]				
Principle 9	9.3[148]	9.5[148]			
Principle 10	nil				

Having sourced items from existing instruments and adapted content from qualitative research and policy, there were still Principles (subscales) with inadequate content. I drafted items for the Principles for which there was little content of use in the literature (Table 4. 3). I drafted eight items for Principle 1 (items 1.2, 1.3, 1.6, 1.9, 1.10, 1.11, 1.12 and 1.13) and ten items for Principle 10 (items 10.1, 10.2, 10.3, 10.5, 10.6, 10.7, 10.8, 10.9, 10.10 and 10.11).

Table 4. 3 Round One items drafted by the researcher

Principle 1	1.2	1.3	1.6	1.9	1.10	1.11	1.12	1.13		
Principle 2	2.4									
Principle 3	3.5	3.6	3.7	3.8						
Principle 4	4.9									
Principle 5										
Principle 6	6.6									
Principle 7										
Principle 8	8.5									
Principle 9	9.4									
Principle 10	10.1	10.2	10.3	10.5	10.6	10.7	10.8	10.9	10.10	10.11

4.2.7 Data Collection

4.2.7.1. Instructions for Round One

Panellists were instructed that the purpose of Round One was to shape the content provided in the item pool, by recording which of the 93 items they wanted to include, include with a change to wording or exclude. Panellists were able to add new items and were asked to reference new items they identified from other sources.

Round One included items from the patient's perspective (for the patient version of the questionnaire). Panellists were advised that the content for the carer version of the questionnaire would be adapted from the content of the patient version and would be provided in later rounds. Panellists were also advised the scale (the response category options) would also be provided in later rounds.

4.2.7.2. Instructions for Round Two

Panellists were instructed that the purpose of the Round Two deliberations was to prioritise and reduce the number of items listed under each Principle. For each Principle, the panellists were asked to rank the items they wished to retain from 1 to 7, with 1 being the most important to 7 being less important but important enough to retain. Panellists were also able to recommend rewording items they wished to retain and add new items.

The Round Two paper included the patient version with the rating scale. Most items in the questionnaire were suitable for use with a continuous rating scale [2]. For these items, five scale divisions were used with the following descriptors: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Frequently’ and ‘Always’.

4.2.7.3. Instructions for Round Three

The Round Three paper included both the patient and carer versions of the questionnaire, with the rating scale. The carer version matched the patient version content but was written from the carer perspective. Panellists were instructed that the purpose of the Round Three deliberations was to determine if the panel could reach consensus on the items and response categories to be included in the patient and carer versions of the questionnaire. Panellists were provided with two options. The first option was to record that they approved the questionnaires for use in the pilot study. The second option was to record that they approved the questionnaires for use in the pilot study with changes (which they were asked to detail).

4.2.8 Data analysis

Data analysis, undertaken for each round, reflected the purpose of each round. The purpose of Round One was to generate and interrogate content. Analysis was designed to classify and select content for which there was consensus. A priori, it was determined that content that did not reach 70% consensus would be removed. However, in order to reduce the volume of content of Round One responses, it was necessary to increase the cut off to 80% agreement for items marked ‘include or ‘include with change’. Items not reaching 80% consensus were removed. All remaining content was subjected to binning and winnowing.

Binning [160] is a term used to describe the grouping of items according to meaning and construct (that is, which Principle (subscale) they represent). For example, where numerous similar suggestions are provided as to how to reword an item, these were ‘binned’, and the item revised based on consideration of the content options and how they represent the construct (Principle/subscale) to be measured.

Winnowing [160] is a term used to describe the reduction of items. Items might be removed if: the item content does not represent the item construct (subscale/Principle); the item was too narrow or too broad; or the item was confusing [160]. For example, where numerous suggestions were provided for additional items, a review of items against these criteria would be used to determine whether the item should be removed.

The analysis of Round Two data examined both the frequency and mean of the priority panelists were asked to assign of 1 (highest priority) to 7 (lowest priority). Items were retained if they had:

1. The highest frequency of responses for item approval; and

2. The lowest mean (across the priority responses 1 to 7).

The mean was used as it proved to be a more sensitive discriminator across the items, allowing the identification of items to be included and items to be excluded. The median and interquartile range was not used as it did not help discriminate which items to include and exclude.

There was no data analysis required in Round Three, only changes to wording of items.

Rewritten items were reviewed to assess their capture of panellists' recommendations. All items were assessed for clarity and brevity and to ensure they contained only one keyword or concept.

4.3 Results

The number of people invited and consented to participate on the Delphi panel, by expert group, is listed in Table 4. 4. The table lists the person's predominant expertise, however, in practical terms, panellists are likely to represent multiple areas of expertise.

Table 4. 4 Number of Delphi panellists invited and consented by expertise

Expertise	**Invited**	**Consented**
Aboriginal health worker (Australia) *	1	1
Academic (Australia)	3	3
Academic (Sweden)	1	0
Academic (United Kingdom)	2	0
Academic (Instrument Development, Australia)	1	1
Advocate (Aged Care Rights, Australia)	1	1
Advocate (Carer, Australia)	1	1
Advocate (Consumer Advisor, Australia)	1	1
Advocate (Council on The Ageing, Australia)	1	1
Advocate (Mental Health Services, Australia)	1	0
Advocate (United Kingdom)	1	1
Aged Care Sector Management (Australia)	1	1
Aged Care Sector Policy (Australia)	1	0
Allied Health (Australia)	2	0
Consumer Representative (Australia)	2	2
Consumer Representative (Carer, Australia)	9	9
Consumer Representative (Dementia Alliance International)	6	5
Consumer Representative (Local Health Network, Australia)	8	7
Culturally and Linguistically Diverse Advocacy (Australia)	3	3
Dementia Key Worker (Australia)	2	1
Disability Sector Management (Australia)	1	1
Doctor (General Medicine Consultant, Australia)	1	1
Doctor (Geriatrician, Australia)	6	3
Doctor (Health Policy, Australia)	1	0
Doctor (Palliative Care Consultant, Australia)	2	2
Doctor (Psychiatrist, Australia)	2	1
Hospital Management (Australia)	2	1
Nurse (Health Policy, Australia)	1	0
Nurse (Hospital Management, Australia)	2	2
Nurse (Hospital, Geriatrics, Australia)	2	2
Nurse (Nurse Practitioner, Geriatrics, Australia)	1	1
Policy (Health Care, Australia)	1	1
Policy (Health Care, United Kingdom)	1	1
Policy (Older People's Health, Australia)	1	1
Policy (Safety and Quality, Australia)	1	1
Volunteer (Hospital, Geriatrics, Australia)	1	1
Grand Total	**74**	**57**

* One Delphi panel member worked with a team of seven Aboriginal health care liaison officers

4.3.1 Response Rate

The response rate for Round One was 86%, for Round Two 84% and for Round Three 79% (Table 4. 5). A slight reduction in the response rate occurred across the three rounds, but overall the response rate was excellent. One participant formally withdrew their consent prior to Round Two.

Table 4. 5 Response rate by expertise and by Round

Expert Group	Round One	Round Two	Round Three
Aboriginal and Torres Strait Islander	1	1	1
Academic	4	3	3
Advocate	4	4	4
Aged Care Sector	1	1	1
Allied Health	0	0	0
Consumer	19	19	19
Culturally and Linguistically Diverse	2	2	2
Dementia Key Worker	0	1	1
Disability Sector	1	1	0
Doctor	7	6	3
Hospital Management	1	1	1
Nurse	4	4	4
Policy	4	3	4
Volunteer	1	1	1
Grand Total (n)	**49**	**47**	**44**
Grand Total (%)	**86% ***	**84% ****	**79%**

* From 57 panellists who consented in Round one

** From 56 panellists in Round Two, following one withdrawal of consent

4.3.2 Actual Timeframes

The dates the Delphi panel papers were sent to participants, and the date set for return, are listed in Table 4. 6. The Delphi panel process was completed within approximately 3 months, well under the anticipated 4 to 5 months.

Table 4. 6 Delphi panel timeframes

Round	Paper Sent	Response Returned
One	5-Feb-18	23-Feb-18
Two	16-Mar-18	30-Mar-18
Three	20-Apr-18	4-May-18

4.3.3 Results for Round One

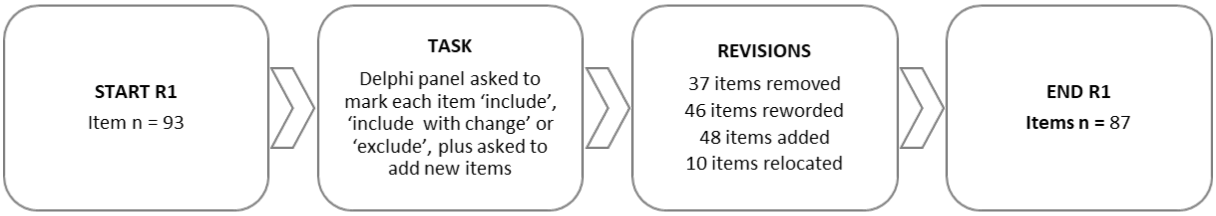


Figure 4. 1 Summary of content changes in Round One

Following the panellists Round One deliberations, the item pool was reduced from 93 to 87 items. The reduction was achieved through the process of binning and winnowing, which resulted in the removal of 37 items and the addition of 48 items. In addition, 46 items were reworded (and/or blended with new items) and 10 items were relocated to another of the 10 Principles. (Figure 4. 1). The full list of Round One item changes is available in the Delphi panel Round One Summary in Appendix B.

By way of example, the process of binning for item 1.1 is shown in Table 4. 7. Noting this is just one of 14 items included in the Round One item pool under Principle 1 'Zero tolerance of all forms of abuse'. All 14 items for Principle 1 can be found in the Round One Summary in Appendix B. As 94% of panellists marked the item 'include' or 'include with changes', the item was retained. Panellists (identified only by an identification code) made 11 recommendations for rewording the item. These suggestions were 'binned'. The revision reflects the suggestion, gained from the recommendations, that the item needed to be clearer in what aspect of safety the person is being asked to report on.

Table 4. 7 Example of an Item reworded from Round One to Round Two

Stem: Principle 1. Zero tolerance of all forms of abuse			
Item as presented in Round 1	Panellist recommendations for rewording item 1.1	ID*	Revised wording for Round 2
Item 1.1 I felt safe	I felt reassured	B	Item 1.1 I have felt safe when staff provide care to me
	I felt safe all of the time/some of the time	E,X	
	I have felt safe	M	
	I have felt safe at all times and for the duration of my care	O	
	I have felt safe within the hospital setting, when receiving treatment during daily hygiene care and when being physically active	P	
	I have felt emotionally safe	g	
	I have felt physically safe	g	
	I have felt safe all of the time	k	
	I have felt safe when receiving care and treatment	m	
	I have felt safe and supported	t	

* ID is the identification code given to each participant by the author to protect the identify of participants

4.3.4 Results for Round Two

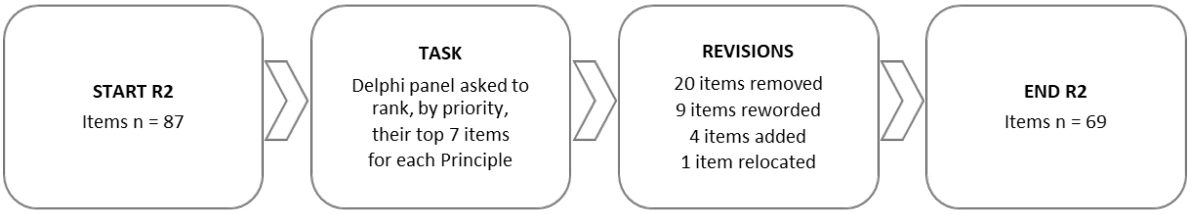


Figure 4. 2 Summary of content changes in Round Two

The Round Two task of ranking items by priority enabled the removal of 20 items, nine items were reworded, four items added, and one item was relocated to another of the 10 Principles. These changes resulted in a total of 69 items (Figure 4. 2). The full list of Round Two item changes in Appendix C.

By way of example, an excerpt from the full list (Appendix B), is provided for Principle 2 'Show people respect' in Table 4. 8, Table 4. 9 and Table 4. 10. The six items retained for Principle 2 'Show people respect' are detailed in Table 4. 8. Items 2.1, 2.2, 2.3, 2.4, 2.9 and 2.11 all scored the lowest means (and therefore deemed to have the highest priority). The item 'Staff rush me when providing care' was added as I considered the item represented the construct (Principle 2). The four items removed for Principle 2 are detailed in Table 4. 9. Items 2.5, 2.7, 2.8 and 2.10 all scored the highest means (and therefore deemed to have the lowest priority). The item relocated from Principle 2 to Principle 6 is detailed in Table 4. 10. This item was considered to more appropriately represent the construct of privacy.

Table 4. 8 Items retained in Round 2 for Principle 2 ‘Show people respect’

Principle 2. Show people respect			**Frequency by priority 1 to 7**							
Item		**Mean**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Total**
2.1	Staff wear name badges large enough for me to read	4.2	4	2	4	0	3	0	7	**20**
2.2	Staff introduce themselves by telling me their name and role	3.24	8	7	3	2	2	4	3	**29**
2.3	Staff introduce themselves before providing care	3.18	8	10	3	2	4	2	4	**33**
2.4	Staff have been respectful when they speak with me	2.73	15	8	8	1	4	2	3	**41**
2.9	Staff have spoken over me	4.55	0	2	1	2	2	3	1	**11**
2.11	Staff talk about me, in front of me, without including me	3.66	8	4	6	2	8	3	4	**35**
Add	Staff rush me when providing care	New item								

Table 4. 9 Items removed in Round 2 for Principle 2 ‘Show people respect’

Principle 2. Show people respect			**Frequency by priority 1 to 7**							
Item		**Mean**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Total**
2.5	Staff have made sure I have my hearing aid in, glasses on and teeth in on when I am awake	4.77	2	2	5	8	3	6	9	**35**
2.7	Staff respect my dignity when supporting me to eat and drink	4.77	1	1	4	10	6	9	4	**35**
2.8	Staff have spoken to me like I am a child	4.95	1	1	2	4	3	2	6	**19**
2.10	Staff have spoken to my family instead of speaking to me	4.65	1	3	1	4	5	7	2	**23**

Table 4. 10 Item relocated in Round 2 for Principle 2 ‘Show people respect’

Principle 2. Show people respect			**Frequency by priority 1 to 7**							
Item		**Mean**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Total**
2.6	Staff respect my dignity when supporting me to use the bedpan or bathroom (Moved to Principle 6)	3.63	6	5	9	10	6	6	1	**43**

4.3.5 Results for Round Three

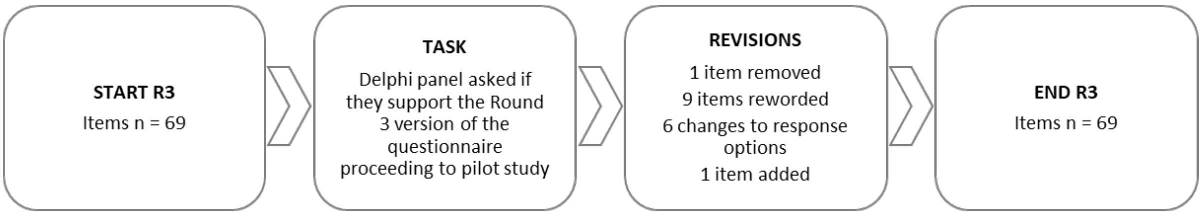


Figure 4. 3 Summary of content changes in Round Three

Of the 44 panellists who responded to the Round Three paper, 27 (61%) indicated the version presented should proceed to the pilot study and 16 (36%) agreed to proceed to pilot, if changes were made.

The suggested changes corrected unintended errors in language, errors in the scale, inconsistencies between the patient and carer versions and typographical errors. In summary, one item was removed, and one item added, nine items were reworded and there were six changes to response options. There were 69 items at the start and at the end of Round 3 (Figure 4. 3). The full list of Round Three item changes, for both patient and carer versions, is available in Appendices D1 and D2.

Of the 16 panellists who sought changes, 15 provided their support for the content to be included in the questionnaire, once the changes had been made. The revised Round 3 content achieved a 95% consensus.

An issue raised in the Round 3 deliberations was the suggestion that ‘In the Carer survey, I wonder whether it better to use a different term instead of patient. If all carers are family members, then perhaps you could say “relative” instead. For a dignity in care survey the word “patient” seems a little outdated.’ (Panellist C). There was also concern about the use of the word ‘carer’. Further, the issue of making the carer version of the questionnaire relevant to 1) whether the patient had capacity to make decisions or not and 2) the role of the carer as a substitute decision maker and 3) the language and legalities of these matters across jurisdictions, also proved challenging.

4.4 Discussion

The aim of this first stage of the study was to develop content (items and response categories) to be included in the DiCQ, for use by older people (and their carers) when they are in hospital. A Delphi panel of experts was able to achieve consensus on the content to be included in the patient and carer versions of the questionnaire after three rounds of deliberations.

The task given to panellists was to generate content for use in the questionnaire, using the 10 Principles as the subscales to guide content generation. The task was not to revise the 10 Principles. The volume of content received from panellists, in response to the Round One paper, was substantial across each of the 10 Principles (subscales). This finding confirms the relevance of the 10 Principles and suggests there is value in using them as the basis upon which to measure experience of care. There was, however, an argument put forward by panellists that the wording of Principle 2 did not reflect contemporary practice. Panellists who raised this were concerned that the wording of Principle 2 'Support people with the same respect you would want for yourself or a member of your family' implies an assumption that the care a staff member might consider is best for their own family, is best for the person (patient/carer) to whom they are providing care. There is a view that care providers who are too focused on what they would want, may not be tuned into listening to what the patient (and/orcarer) actually wants or needs [197]. Panellists noted the original wording of the Principle was at odds with the message of Principle 4 (independence, choice and control). As a result, Principle 2 was revised to 'Show people respect' for the remainder of this study.

All items retained from Round One were modified to improve brevity and clarity, based on suggestions from panellists, including writing items in the correct tense. Items were moved between Principles and items were separated into positive and negative statements. Consistent with the rules of good questionnaire design, items were reworded to include only one keyword or concept [2, 111]. This required some compromise in how items were written. Items that were perfectly worded, and completely inclusive of all options, were often too long and too complex.

Some changes proposed by panellists included words or phrasing that increased complexity of items; these changes were not made. One example is the use of the plural pronoun 'them', when grammatically it would be correct to use the singular pronoun 'him/her' (or 'her/him') in several items. In 2017, the Associated Press deemed use of the plural pronoun acceptable as a singular pronoun, 'when alternative wording is overly awkward or clumsy' [198]. When drafting the items, use of the 'him/her' (or her/him) pronouns were found to be tedious to read when repeated many times on the page. It was determined that it would be pointless to write grammatically perfect items, which were clunky to read and distract from the intent of the items. One of the most essential aspects of writing items for questionnaires is to make them short and precise [2, 111] so they are easy to read and understand. As a result, the questionnaire uses the plural pronoun ‘them’, rather than ‘him/her’.

Where Round One was designed to generate content, Round Two was designed to prioritise and reduce content. Using frequencies and means, items to be retained and items to be removed, were easily identified. A small number of items required my judgement as to whether to whether they should be retained (for example Item 2.9 ‘Staff have spoken over me’, which was retained).

Round Two introduced the proposed scoring for the patient version of the questionnaire. Most items were appropriate for use with a continuous response scale (‘Never’, ‘Rarely’, ‘Sometimes’, ‘Frequently’ and ‘Always’). These descriptors were used as they are simple and easy to understand, but also because there are few options for ‘frequency’ type responses [41]. Evidence suggests five scale divisions are appropriate [2]. More than five scale divisions may increase the cognitive load [41] when reading the questionnaire, which is to be avoided when designing a questionnaire for older people who are unwell in hospital. Panellists corrected the scale on several items for which a ‘yes’, ‘no’ and ‘unsure’ type response was more appropriate.

Round Three introduced the carer version of the questionnaire. The study was designed to create a carer version of the questionnaire that was adapted from the patient questionnaire. The reason for this approach was based on the understanding that the focus should on the patient’s experience. The carer should be able to provide feedback on the patient experience, when the patient is unable to do so, or when the patient would prefer the carer to do so. The intention was to include the same items in both versions but adapt the language of the carer version, so it made sense to the carer completing the questionnaire.

One challenge raised by adapting the patient version of the questionnaire for use by carers was how the language might change depending on the role of the carer. It made a difference in how the items were written if the patient has no mental (legal) capacity [199]. Addressing the nuances of language to reflect the legal role a carer might (or might not) have, had the potential to introduce great complexity into the wording of the carer questionnaire. Ultimately it was determined that specifying in language the role of the carer was not the role of the questionnaire. Both versions of the questionnaire include items related to legal capacity, including the use of Advance Care Directives [200].

Panellists raised concern about the use of two terms, much debated (informally) in the world of consumer advocacy. These words are ‘patient’ and ‘carer’. These words can be avoided, but only by using many more words, and complexity is to be avoided when writing items for questionnaires [2, 111]. Suggestions from panellists were to change use of the term ‘the patient’ to ‘relative’ or ‘person that I care for’. Both are difficult, given not all carers are relatives and not all people being asked to complete the carer version of the questionnaire see themselves as ‘carers’ [201]. Use of the word ‘patient’ is an efficient way to identify the patient, but the word is not empowering, as is evident from its origins, the Latin ‘patiens’, which means endure, bear or suffer, and refers to an acquired vulnerability and dependency [202].

The word ‘carer’ is extant in describing ‘the person you want by your side to support you when you are unwell’, but it is clumsy to describe all the potential relationships that person could hold. A description of a ‘carer’ (as relevant to this study) was added to the front of the carer version of the questionnaire. It states ‘A “carer” is a person the patient would want involved in their care; the “carer” might be a family member, spouse, child, relative, friend, support person, person responsible, care partner’. Use of the words ‘patient’ and ‘carer’ were retained. The ability to find the right words to describe these roles, while making the items clear and easy to understand, was considered larger than this study.

All items, including those sourced from other questionnaires, that were retained from Round One through to Round Three, underwent some change. The change might have been a minor word change or a major rewrite, based on the feedback of panellists and as analysed through the process of binning. The changes to items, including the removal, relocation and rewriting of items, reflects a thorough and robust process of content generation.

4.4.1 Strengths and limitations of the Delphi study

Development of questionnaires in the absence of a clear conceptual framework has been identified as a common design fault [41]. Using the 10 Principles of Dignity in Care as the conceptual basis of the design for this study gave structure to the item generation process and serves as a great strength of this study. Without the clarity of these Principles, it is unlikely the Delphi panel could have so efficiently reached consensus.

A common criticism of existing experience of care questionnaires is that it is often unclear if consumers were involved in the development of the questionnaire [156-158]. The recruitment process for this study was designed to identify and invite a broad range of consumers be involved.

A great deal of thought and work went in to planning the Delphi panel tasks and the panel was administered with timely, succinct and respectful communications. This might have influenced the ability to recruit and retain panellists, and the time and effort each panellist put into their responses.

The Delphi technique relies heavily on the background work of the person administering the Delphi panel rounds, thus potential exists for researcher bias [159, 203]. To reduce the potential for bias, all synthesis and analysis of data was reviewed, revised by my Principal Supervisor.

4.5 Conclusion

Use of the modified Delphi technique proved a successful method to generate content for the 10 Principles of the DiCQ. Over three rounds of deliberations, the panellists determined which items should be removed, reworded, relocated or added. The commitment of such a great proportion of panellists, per round, helped propel me into the next stage of the research study, with great confidence that the items to be pilot tested have been rigorously reviewed and revised. A large and diverse group of experts had reached consensus that the items are worthy of the time, effort and cost of continuing the development of the DiCQ. The consensus patient and carer questionnaires, inclusive of Round Three changes, are available in Appendices E1 and E2.

5. Pilot Study (Stage 2)

Do not take the risk. Pilot test first [204]

5.1 Introduction

A pilot study allowed testing of the feasibility of both the instrument (the pilot study questionnaire) and the process of data collection [205]. Modifications to the questionnaire and the processes, following the pilot, ensured the most efficient approach to the vastly more time-consuming major data collection stage of the study (Stage 3, Chapter 6).

The patient and carer versions of the Dignity in Care Questionnaire, that gained consensus from the Delphi panel for use in the pilot study, included 69 items (Appendices E1 and E2). This was far in excess of the ideal number of items to be included in the final version of the questionnaire. An excess of items allowed pilot study participants to influence which items to retain, which to rewrite and which to remove.

The aim of Stage 2, the pilot study, was to assess the face validity of the items, ease of administration, number of items, time demands on respondents, scoring and interpretation with patients and carers in the hospital setting. The objectives were to:

i. To identify, recruit and consent participants.
ii. Undertake cognitive interviews with patients and carers while they undertake the pilot questionnaire.

This chapter presents the preparation, methods and results of Stage 2 of the study. While the pilot study is a relatively small part of this research, its role in contributing to answering the research question ‘Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting?’ should not be diminished.

5.2 Methods

5.2.1 Study Design

The research study was undertaken in three sequential stages. This chapter reports on the second stage of the study, pilot testing of the questionnaire with patients and carer in the hospital setting. I undertook all data collection and analysis. I was present on the allocated wards, of the participating hospital, to recruit, consent, undertake the cognitive interviews and collect the questionnaires from participants.

5.2.2 Participants

The pilot study included participants who completed the patient version of the Dignity in Care Questionnaire (DiCQ) and participants who completed the carer version of the questionnaire. For the purpose of this study, the definition of 'carer', was written on the front of the carer version of the questionnaire (Refer to the Glossary of Terms). 'A "carer" is a person the patient would want involved in their care; the "carer" might be a family member, spouse, child, relative, friend, support person, person responsible, care partner.'

Patient participants for the pilot test of the research study were recruited from four general medical and geriatric wards in a major metropolitan hospital in South Australia. Patient participants had to be 65 years or older (50 years and older for Aboriginal and Torres Strait Islander people) and a current inpatient. The research sought to include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds. Funding to support the use of interpreters was available to the researcher. The research sought to include people who have dementia (including Alzheimer's Disease). All participants had to have capacity to provide informed consent.

The research excluded people who were unable to give consent and who did not have a carer who could legally give consent on their behalf. Patients requiring Personal Protective Equipment precautions [206] were excluded. The study also excluded people who were in the last days of life.

Carer participants were able to participate in three ways (1) if the patient was unable to participate, (2) if the patient preferred the carer to participate, or (3) both patient and carer agreed to participate.

5.2.3 Sample size

I set a sample size target of 25 patients and 25 carers [207], to be reviewed and revised if data saturation was evident. The pilot study was not designed to collect a sample of sufficient size to undertake psychometric or statistical tests on the completed questionnaires.

5.2.4 Ethical approvals

Ethical approval for the study was granted by The Queen Elizabeth Hospital/Lyell McEwin Hospital/Modbury Hospital Human Research Ethics Committee and Central Adelaide Local Health Network Research Governance Office (HREC/17/TQEH/91). Site specific approval was granted from the Local Health Network. Participants were required to read the Participant Information and Consent Form and sign the consent. I co-signed the consent and provided a copy to the participant. (All documents relating to ethics and governance approval are included in Appendices A1 to A10).

5.2.5 Timeframes

Stage 2 data collection took place every Wednesday, Thursday, Friday, Saturday and Sunday from 11am to 5pm during the time period 6 June to 8 July 2018.

5.2.6 Location

Stage 2 data collection was undertaken in medical and geriatric specific wards at one hospital in metropolitan South Australia. The site was chosen as it is the only major metropolitan hospital in South Australia with all single rooms, which supported the optimal environment for undertaking the cognitive interviews.

5.2.7 Process for data collection

On each data collection day, I would introduce myself to the Shift Co-ordinator of each participating ward and ask them to consider which patients (and/or carers) may be suitable to undertake the questionnaire. The Shift-Co-ordinator would provide me with a patient list and I would note which patients I could consider and which I should not approach.

I would then circulate through wards and ask the nurse, looking after the patients identified by the Shift Co-ordinator, if they would be happy for me to introduce myself to the patient (and/or their carer). If the patient (and/or carer) agreed, I would go ahead and speak with them. I would obtain their consent, undertake the cognitive interview and administer the questionnaire.

5.2.8 Materials

The Stage 2 version of the patient and carer versions of the DiCQ consisted of 69 items grouped under the subscales of the 10 Principles of Dignity in Care (Appendices E1 and E2). There were 7 items under each Principle, except Principle 8, which had 6 items.

The questionnaire was administered in paper format. I did not want the interaction, particularly given the use of cognitive interviews, to be consumed by the technical aspect of using an electronic tablet. The paper formatted questionnaire was printed in large font (14 for text and 18 for headings) to aid ease of reading for the older participants. Based on those font sizes, the items belonging to each Principle could be formatted onto one page. Participants were encouraged to write freely on the questionnaire; this may have been more difficult with an electronic form of the questionnaire, if a participant was not familiar with the use of an electronic tablet for typing.

5.2.9 Scoring

The Delphi panel achieved consensus on the items and the scoring to be used in the pilot study questionnaire. Most of the items in the questionnaire were suitable for use with a continuous response scale [2]. For these items, five scale divisions were used with the following descriptors: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Frequently’ and ‘Always’. These descriptors were used as they are simple and easy to understand. The use of 5-point scales is supported by the literature [2, 41].

Forty-four items used the scoring format ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Frequently’ or ‘Always’. A further 19 items used this scoring format with an additional response option. Of these 19, ten items include the option ‘Not Applicable’, four items include the option ‘I’d prefer not to answer’ and five items include a sixth scale option that is unique to the item. Six items have unique categorical responses (Table 5. 1). Three items (Item 1.3, 1.4 and 9.5) were negatively scored, that is, an ‘always’ response reflected a poor experience of dignity in care.

Table 5. 1 Scoring format groupings used with the instrument

n items (total = 69)	1	2	3	4	5	6
44	Never	Rarely	Sometimes	Frequently	Always	
10	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
4	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
5	Never	Rarely	Sometimes	Frequently	Always	Unique to item
6	Unique categorical response					

5.2.10 Item order

The pilot study DiCQ, that gained consensus by the Delphi panel, was presented to the Delphi panel with the 10 Principles used as subscales for the instrument. That is, the items were ordered under the 10 Principles, they were not randomised or intermixed. (refer Chapter 3, Methodology, Section 3.4).

5.2.11 Data collection

In addition to the questionnaire (completed by the patient or carer) and my notes from the cognitive interview, data were collected on the patient's age, length of stay prior to undertaking the questionnaire, usual accommodation, whether the participant was a patient or carer; and if a carer, their relationship to the patient.

I chose not to collect patient information which is routinely reported in the academic literature, such as level of education and marital status, because they are not considered to have any bearing on a patient's ability to report on their experience of care, if presented with a well-designed questionnaire.

Nor was information collected on diagnosis. The target audience for the questionnaire is older people who are likely to have multiple diagnoses, making the listing many diagnoses a meaningless task. There was no reporting on whether a patient had a diagnosis of dementia, as many older people have dementia, mild cognitive impairment or early dementia, without diagnosis [12]. The research did not seek to define people by their diagnosis. The research study enabled the inclusion of the patient's carer, if the patient could not participate. The patient's voice was not lost if they had a diagnosis preventing participation. But they did need a carer to provide their perspective.

More important than the recording of diagnoses, was to determine if the person could provide informed consent. A diagnosis of dementia does not automatically mean a person does not have capacity to provide informed consent [199].

5.2.12 Data storage

The participant's responses, recorded on the hard copy patient and carer questionnaires, were entered into a Statistical Package for the Social Sciences (SPSS) file (Version 25, Armonk, NY: IBM Corp.). Each record was de-identified using a simple code (P = patient or C = carer plus the sequential number of questionnaires collected). SPSS was used to present the demographic data, frequencies and summary statistics.

5.2.13 Cognitive Interview

While the participant was completing the pilot questionnaire, they also participated in a cognitive interview. The purpose of the cognitive interview was to explore respondents' understanding of the items, the scoring of the items and the ease of administration of the questionnaire. The verbal probing [162-164] method of cognitive interview was used to question participants as they considered their responses to the questionnaire. Given the questionnaire had 69 items, verbal probing was not pursued with every item, but only when the participant hesitated or raised their uncertainty about an item, the scoring, or the procedure for completing the questionnaire.

Verbal probing included techniques such as asking the participant to explain their understanding of an item, and if they thought the item should be retained, how could it be reworded or rewritten. Participants were also probed as to whether there were items they felt were repetitive and their preference for which item to retain and which to remove. As recruitment progressed, there were clear themes in the items and wording that prompted verbal probing and exploration with the participant.

Responses from the cognitive interviews underwent content analysis [208], which involved mapping each of the participant's comments to each of the 69 items of the questionnaire. The responses were categorised according to the participant's preferred outcome for the item; to reword, relocate or remove the item. I was aware that it was not optimal to fulfil the roles of both interviewer and data analyst, but this is a limitation of sole researcher studies.

5.3 Results

A total of 32 patients and 20 carers were recruited to participate in the pilot study (Table 5. 2). All 52 participants completed the questionnaire and the cognitive interview. Interviews took between 15 minutes and one hour. All patients and carers I recruited spoke English. I was unable to recruit any patients who did not speak English as their first language. A summary of the Pilot study data, for patient and carer participants, is included in Appendices F1 and F2.

Table 5. 2 Respondents by category

Respondent	**n**	**%**
Patient	32	61.5
Carer (daughter)	8	15.4
Carer (son)	7	13.5
Carer (Spouse)	4	7.7
Carer (Neighbour)	1	1.9
Total	**52**	**100**

It was not the intention of this study to make changes to the 10 Principles of Dignity in Care (Figure 1. 1, Chapter 1). However, it became evident, that the addition of one word, would increase the accessibility of Principle 8 (originally written as) ‘Engage with family members and carers as care partners’. Many participants in the pilot did not have family or did not have family involved in their life. Most, who did not have family, did have a friend involved in their life and wanted them involved in their care. ‘Family’ is a limiting term and despite including the definition of ‘carer’ on the front page, the word ‘carer’ does not have universal understanding and acceptance in the way it is being used in the questionnaire. The revised subscale (Principal) eight now reads ‘Engage with family members, *friends* and carers as care partners’. Increasing strings of words such as this, may reduce readability, but without the word ‘friends’ it appears confronting for those who do not have family.

A summary of item-level changes is presented (Figure 5. 1) to demonstrate the extent of change made as a result of the cognitive interview. Most of the changes recommended by participants fell neatly into the need to reword, relocate or remove the item and / or make changes to the response options for the item. Items are referred to as an ‘original’ item (present in the original 69-item pilot study questionnaire) or ‘revised item’ (present in the revised 50-item questionnaire) to enable transparency in tracking changes to the items.

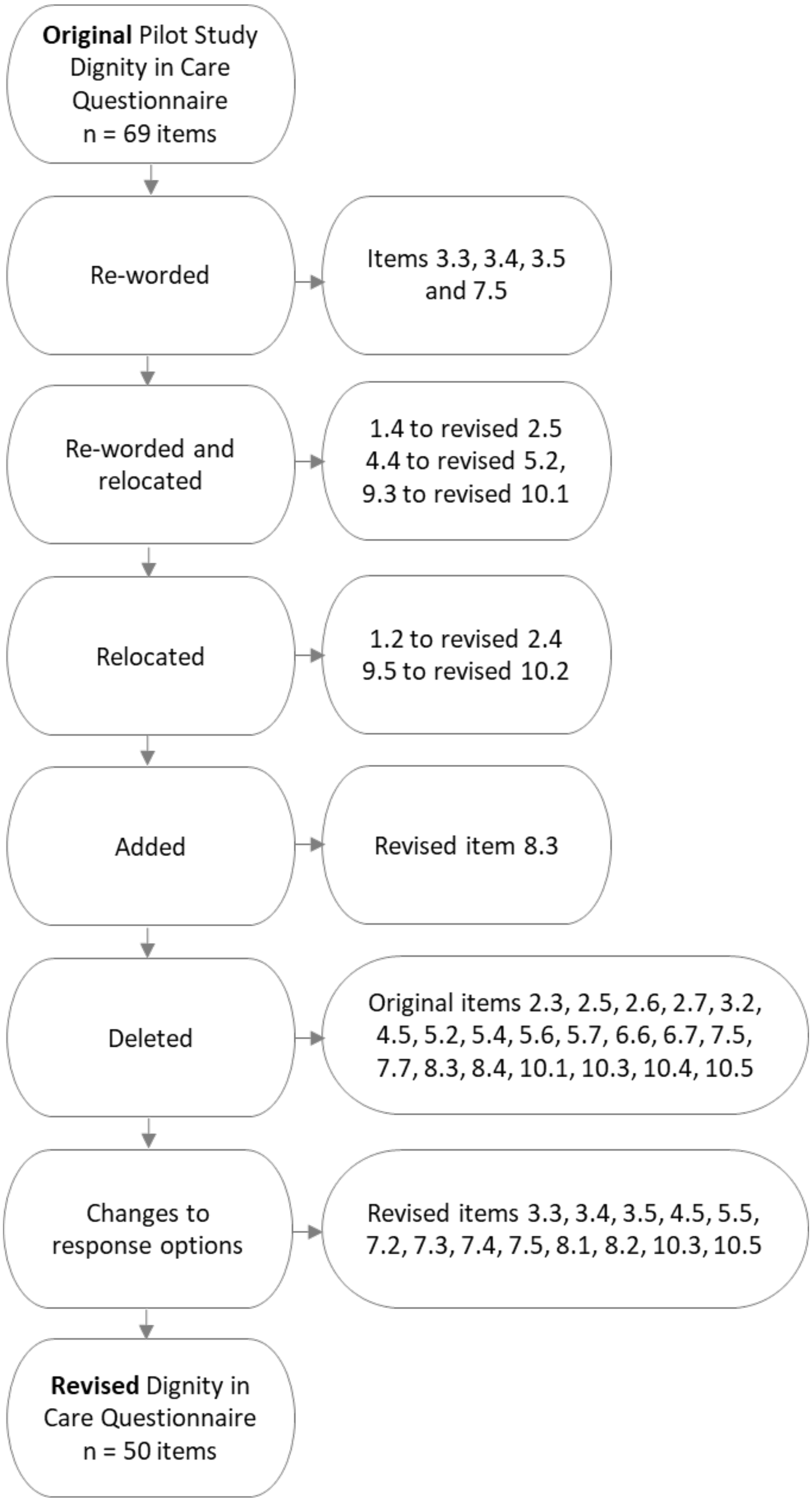


Figure 5. 1 Summary of changes made to the original pilot study questionnaire

5.3.1 Reworded items

To improve clarity, simplicity and meaning, several items were reworded. Respondents noted they had difficultly answering original items 3.4-3.6 ‘staff have provided care consistent with my cultural (3.4), religious (3.5) and spiritual beliefs (3.6)’ because they were ‘never asked’; that there had ‘been no discussion of cultural, religious or spiritual beliefs’. These three items were reworded into two, the first (revised item 3.3) ‘Staff have asked if I have cultural / religious / spiritual beliefs that are important to me’ and the second (revised item 3.4) ‘Staff have provided care consistent with my cultural / religious / spiritual beliefs’ (Table 5. 3).

Original item 7.6 ‘I made a complaint and I was satisfied with the outcome’ was changed to (revised) item 7.5 ‘I made a complaint and I was satisfied with the response’, a word change from ‘outcome’ to ‘response’ was made to reflect the fact that the complaint may not have yet reached an ‘outcome’ (Table 5. 3).

Table 5. 3 Summary of reworded items

Original item	Change	Revised Item
3.4 Staff have provided care consistent with my cultural beliefs	Original items 3.4, 3.5 and 3.6 reworded into two items. One item about being ‘asked’ and one item about ‘care consistent with … beliefs’	3.3 Staff have asked if I have cultural / religious / spiritual beliefs that are important to me
3.5 Staff have provided care consistent with my religious beliefs	As above	3.4 Staff have provided care consistent with my cultural / religious / spiritual beliefs
3.6 Staff have provided care consistent with my spiritual beliefs	As above	As above
7.6 I made a complaint and I was satisfied with the outcome	‘outcome’ to ‘response’	7.5 I made a complaint and I was satisfied with the response

5.3.2 Reworded and relocated items

Measuring the experience of dignity in care is not a precise science. Items developed for one Principle (of Dignity in Care), may well be more relevant to another Principle. Throughout the development of the items, during the Delphi panel process (Chapter 4), there had been movement of items between the subscales (Principles). Participants in the pilot study suggested five items should be relocated (summarised in Table 5. 4). Of these five, three items were reworded, as well as being relocated.

Item 1.4 was moved from the ‘zero abuse’ (Principle 1) subscale to the ‘respect’ (Principle 2) subscale, and was reworded, as the original wording ‘I have been given care when I need it’ was considered vague; the revised item is 2.5 and reads ‘my basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…).’

The wording of original Item 4.4 ‘Staff have explained what is happening to me in ways I understand’ was not considered consistent with the intent of the Principle ‘independence, choice and control’. The item was reworded to ‘Staff provide care that reflects an understanding of my needs…’ and relocated to the ‘Listen and Support’ subscale (Principle 5, item 5.2).

Original item 9.3 was moved from the ‘Confidence and Self-esteem’ subscale to the ‘Alleviate Loneliness and Isolation’ subscale and reworded from (9.3) ‘When talking about my care, the staff include me in the discussion’, which was considered vague, to (10.1) ‘Staff include me in the bedside discussion at shift handover’.

Table 5. 4 Summary of relocated and reworded items

1.4 I have been given care when I need it	Relocate from subscale 1 to 2, with change in wording	2.5 My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)
4.4 Staff have explained what is happening to me in ways I understand	Relocate from subscale 4 to 5, with change in wording	5.2 Staff provide care that reflects an understanding of my needs (such as my vision, hearing, memory, mobility, dietary needs)
9.3 When talking about my care, the staff include me in the discussion	Relocate from subscale 9 to 10, with change in wording	10.1 Staff include me in the bedside discussion at shift handover

5.3.3 Relocated, wording unchanged

Two items were relocated, wording unchanged (Table 5. 5). Original item 1.2 was moved from the ‘Zero Abuse’ subscale to the ‘Respect’ subscale, as revised item 2.4, with the original wording, ‘Staff have been considerate in how they provide care to me’. Original item 9.5 ‘Staff have supported me to stay physically and mentally active’ was relocated, with original wording, to the ‘Alleviate Loneliness and Isolation’ subscale (Principle 10, item 10.2).

Table 5. 5 Summary of relocated items

Original item	Change	Revised Item
1.2 Staff have been considerate in how they provide care to me	Relocate from subscale 1 to 2, with wording unchanged	2.4 Staff have been considerate in how they provide care to me
9.5 Staff have supported me to stay physically and mentally active	Relocate from subscale 9 to 10, with wording unchanged	10.2 Staff have supported me to stay physically and mentally active

5.3.4 Removed items

Twenty items were removed as a result of participant feedback from the pilot study. The most common reasons were that the item was redundant to a similar, superior item and the intent of the item was unclear. All items deleted and the reasons are detailed in Table 5. 6.

Table 5. 6 Summary of removed items

Original item that was deleted	Reasons
2.3 Staff introduce themselves before providing care	Redundant item. Preference to keep item 2.2 Staff introduce themselves by telling me their name and role
5.2 Staff have involved me in planning my care	Redundant item. Preference to keep item 4.1 I have been involved, as much as I wanted to be, in discussions about my care, and item 4.2 I have been involved, as much as I wanted to be, in decisions about my care
5.6 My preferences have been listened to and acted upon by staff	Redundant item. Preference to keep item 5.1 I have been given enough time to explain what I need
7.5 I made a complaint and it was taken seriously	Redundant item. Preference to keep (revised) item 7.5 I made a complaint and I was satisfied with the response
7.7 Staff treated me badly after I made a complaint	Redundant item. Preference to keep (revised) item 7.3 I believe I could make a complaint without it affecting my care
2.5 Staff have spoken over me	Many respondents did not understand this item. The intent of the item is unclear. ‘…but because they needed to’ (carer)
2.6 Staff talk about me, in front of me, without including me	Most respondents did not consider this a negative experience. The intent of the item is unclear.
2.7 Staff rush me when providing care	Many respondents thought being rushed may refer to receiving urgent care and so it was a positive experience. The intent of this item is unclear. ‘…it depends on too many factors’ (carer respondent)

3.2 Staff have asked the most important things they need to know about me	Most respondents found Item 3.2 to be vague and were unsure what it meant.
4.5 Staff have asked me if I have an Advance Care Directive	Most respondents did not know what an Advance Care Directive was (many thought it was either an Aged Care Assessment Team (ACAT) or the SA Health Resuscitation Plan 7 Step Pathway for health professionals). Having two items related to this poorly understood document was confusing. Retain 'I have discussed my Advance Care Directive with staff' with the response option 'I do not have an Advance Care Directive'.
5.7 Staff assume they know what I need, without asking me	Many respondents understood this Item to reflect a positive experience. The intent of the Item is unclear. '…sometimes he can't respond'. (Carer)
6.7 I have had access to my hospital medical record, when requested	Many respondents thought this was the discharge letter.
8.3 Staff talked to my family or carers about my care when I was unable to communicate	Respondents found this item unclear.
8.4 When I wanted my family or carers with me, staff supported them to be with me	Respondents found this item unclear.
10.1 I have been free to interact with other people	Most respondents found this unclear 'Did it mean just staff?' (Patient) Some responded 'Yes, of course, they interacted with staff'. Did it mean the patients with confusion who came into their room, which patients found frightening and so not a positive experience? Some people had infectious disease precautions. 'Silly question' (Patient)
5.4 Staff have given me a written plan of care for the time I am in hospital	It was clear the answer would always be 'no'.
6.6 Staff treat my information confidentially	The answer would never be known to the patient or carer.
10.3 I was able to access a tv by my bedside. 10.4 I have been able to listen to a radio. 10.5 I have had access to the internet, so I could use my telephone or tablet to stay in touch with people.	The items were not measuring the intent of the Principle.

5.3.5 Changes to the response options

The cognitive interviews revealed the need to make changes to the response options for several items. The response option 'I'd prefer not to answer' in the items (in subscale 3) relating to cultural, religious, spiritual beliefs and sexual identify, was found to be confusing to respondents. In the revised items the response option ‘Not Applicable’ was used (Table 5. 7).

Given many people sought this response, the option ‘Discharge has not yet been discussed’ was added to revised item 5.5 ‘Staff have encouraged me to be involved in planning my discharge from hospital’ (Table 5. 7).

The revised items 7.2, 7.3, 7.4 and 7.5 each have three response options, unique to each item. These were rewritten to make them clearer. The response option ‘Not Applicable’ was added to revised Item 8.1 and Item 8.2. The option ‘I have not been bored’ was added to revised Item 10.3.

At the suggestion of a number of participants, the response option ‘frequently’ was changed to ‘often’ as it is shorter and was considered easier to understand.

Table 5. 7 Summary of revisions to response options

Revised Item	Revised response options
3.3 Staff have asked if I have cultural / religious / spiritual beliefs that are important to me.	Respondents found the response option ‘I’d prefer not to answer’ confusing. Revised to ‘Yes’, ‘No’ or ‘Not Sure’.
3.4 Staff have provided care consistent with my cultural / religious / spiritual beliefs.	Respondents found the response option ‘I’d prefer not to answer’ confusing. Revised to include the option ‘Not Applicable’.
3.5 Staff have respected my sexual identity.	Respondents found the response option ‘I’d prefer not to answer’ confusing. Revised to include the option ‘Not Applicable’.
5.5 Staff have encouraged me to be involved in planning my discharge from hospital.	Revised to include the option ‘Discharge has not yet been discussed’.
7.2 I have felt I could make a complaint if I needed to.	Revised to include the response options ‘I would never make a complaint, even if I felt I needed to’; ‘I would be reluctant to make a complaint, even if I felt I needed to’; and ‘I would always make a complaint, if felt I needed to’.
7.3 I believe I could make a complaint without it affecting my care.	Revised to include the response options ‘I would never complain, for fear it would affect my care’; ‘I would be reluctant to complain, for fear it would affect my care’; ‘I believe I could complain without it affecting my care’.
7.4 I know who to contact if I have a complaint.	The response options for item ‘I know who to contact if I have a complaint’ were changed to ‘No’; ‘Not sure’ and ‘Yes’.
7.5 I made a complaint and I was satisfied with the response.	Revised to include the response options ‘I did not make a complaint’; ‘I made a complaint and I was not satisfied with the response’ and ‘I made a complaint and I was satisfied with the response’.

8.1 Staff have asked me which family, friends or carers I want involved in my care.	Revised to include the option ‘Not Applicable’.
8.2 My family, friends or carers have been involved in decisions about my care.	Revised to include the option ‘Not Applicable’.
10.3 Staff have helped me to find things to do to keep me from being bored.	Revised to include the option ‘I have not been bored’.

5.4 Discussion

The pilot study provided the opportunity to 1) test how to recruit participants in the hospital environment and 2) test how participants understood the questionnaire. I have worked for decades in hospitals, so I am familiar with the environment. While my experience was hugely beneficial to my practice as a researcher, I found overwhelmingly, that having a person undertaking ‘care’ research in the clinical setting, was extremely novel. It is interesting that research is included in the Australian Code for Nurses:

> *Nurses recognise the vital role of research to inform quality healthcare and policy development, conduct research ethically and support the decision-making of people who participate in research* [209] *(p.5)*

However, I do feel there needs to be a much greater researcher presence, supported by PhD qualified senior management, for care research to be made a part, and a priority, of clinical practice. The issues associated with recruitment of older people into clinical research has been reported in the literature, but relates predominantly to clinical trials research [210-212], not ‘care’ research. There was no precedence I could find for how to conduct data collection, and I drafted my own processes.

The requirement from senior managers was clear, my presence was not to contribute in any way to the workload of the clinical staff. I was hoping to see if staff would write the name of potential participants in a large notebook I left under a Dignity in Care Research sign in the central staff area of each ward, but that approach was quickly abandoned as I realised all recruitment would need to be pursued through negotiation with staff. This was probably less efficient, but it meant I did not need to ask anything of the staff, and that was important. It meant I became highly skilled in giving a crystal clear and swift pitch to staff about who I was and what I was doing. These aspects of data collection should not be trivialised, they are vital to capturing the attention, and maintaining good relationships with the people you are completely reliant on for the success of your research. After two weeks, I found most staff knew who I was and what I was doing. I littered the tea rooms with chocolates, placed in Dignity in Care Research inscribed bowls, and I was hugely appreciative of everyone who helped me.

I could have hugged the first recruit who enthusiastically consented to participate. I will never forget this person. This appreciation grew and grew. Whilst I did not much enjoy the administrative work of getting to the point of talking to participants, I absolutely loved every second of the time I spent with patients and their carers. Their enthusiasm for the message of dignity was deeply reassuring.

There was a lot of time spent walking corridors, look for, and waiting for, staff to ask them if I could speak with their patients. There were a large proportion of patients, on the designated wards, who could not participate because they had cognitive impairment, no carer present and / or had infectious precautions. This meant recruitment was painfully slow. The pilot study gave me cause to question my ability to recruit adequate participants for the major data collection stage of my study (Chapter 6). I felt there was nothing I could do to be more efficient or speed up the process of recruitment. Appearing to be desperate or in a hurry to progress would have been extremely counterproductive.

I recruited my target of 50 participants within five weeks, but due to the inability to find carers, I recruited more patients than carers. Whilst I was in the hospital trying to recruit carers, I thought it better to continue recruiting patients as well, rather than walking about and waiting. The difficulty in recruiting carers raised an issue regarding Principle 8 ‘Engage with family members and carers as care partners’. It quickly became evident that many older patients do not have family involved in their lives. Principle 8 becomes inaccessible to those without family. I thought it important to revise the Principle to include ‘friends’. This also makes it consistent with the definition of ‘carer’ I used in the study, which includes ‘friends’.

Of all potential participants, identified by the Shift Co-ordinators, during the pilot study, there was only one who did not speak English. The patient was very unwell and I did not feel it appropriate to pursue, given I did not yet have experience in the process of using interpreters in my research (i.e., this was not an ideal participant to use as the first to trial use of interpreters).

Many people who participated were bored and welcomed a person to talk with, which was most beneficial to the content I was able to gather from the cognitive interviews. Most people were keen to talk about dignity; the word resonates with the target population of my research. It was my initial intention to tape record the cognitive interviews. However, I found the discussion about tape recording and the presence of a recording device, proved to be an unnecessary distraction. It did effect rapport with the participant. I felt people were more comfortable and open in their discussion without the presence of a recorder. The pattern of participants comments quickly became clear and I was able to record these in my notebook as we spoke. I felt this created a more relaxed and open atmosphere for a conversation.

The feedback provided was surprisingly consistent. Many participants found the same items were poorly worded or difficult to understand and were quick and clear about determining items that should be deleted. I felt participants were happy to be completely honest with me; this was important for the success of the cognitive interviews. However, I did find the way participants scored the questionnaire was, at times, inconsistent with the details they had provided me about their experience of dignity in care. This is not a new finding, ‘gratitude bias’ is understood to be a prevalent trait of older people [27]. This highlights the need for a comprehensive approach to understanding, measuring and monitoring patient and carer experience that goes well beyond the simple use of a questionnaire.

5.4.1 Limitations

The cognitive interviews were undertaken, analysed and interpreted by one person (the doctoral student).

5.5 Conclusion

The pilot study was undertaken with a 69-item questionnaire. Feedback from participants guided the revision of the questionnaire to 50 items. The revisions included the rewording of items, the relocation of items between subscales and the deletion of items deemed to be redundant, irrelevant or too difficult to understand. Conducting a pilot study was of vital importance to the progress of this research. I felt much more confident investing hundreds of hours of my time and the time of other generous participants, in the next stage of the study, knowing the instrument to be used had been well scrutinised and shaped by 52 more experts.

6. Preliminary Assessment of Unidimensionality, Validity and Internal Reliability (Stage 3)

No amount of belief makes something a fact [213]

6.1 Introduction

The patient and carer versions of the Dignity in Care Questionnaire used in the pilot study (Chapter 5) included 69 items (Appendices E1 and E2). The questionnaires were modified, and the number of items reduced, as a result of the findings of the pilot study. The patient and carer versions of the Dignity in Care Questionnaire, used for Stage 3 preliminary assessment of validity and internal reliability, included 50 items, presented under the subscales of the 10 Principles of Dignity in Care (Appendices G1 and G2).

The aim of Stage 3 of the study was to collect questionnaire data to undertake an assessment of validity and internal reliability. The objectives were to:

i. Identify, recruit and consent participants.
ii. Use Rasch analysis to undertake a preliminary assessment of the psychometric properties (including unidimensionality, construct validity and internal reliability) of the patient and carer versions of the questionnaire.

This chapter presents the preparation, methods and results of Stage 3 of the study, and explores the research question 'Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting?'

6.2 Methods

6.2.1 Study Design

This chapter presents the third (of three) stages of my doctoral research, which is the data collection and analysis required to commence the process of assessing the validity and reliability of the Dignity in Care Questionnaire (DiCQ). I undertook all data collection and analysis. I was present on the allocated wards, in the participating hospitals, to recruit, consent, facilitate administration of, and collect the questionnaires from participants.

6.2.2 Locations

Stage 3 data collection was undertaken in medical and geriatric-specific inpatient wards at four hospitals in metropolitan South Australia.

6.2.3 Participants

Participants were 65 years or older, or 50 years and older for Aboriginal and Torres Strait Islander people. Patients, and or their carers, could complete the questionnaire. Patients were excluded if they were unable to give consent. People requiring infectious precautions and people in the last days of life were also excluded.

It was my intention to include people who required an interpreter. The ability to include people who required an interpreter was reliant on my ability to cover the cost of the interpreters. I made a submission to the Hospital Research Foundation, who generously awarded me $4,000 to cover the cost of interpreters, thus allowing people who did not speak English to participate.

6.2.4 Sample size

A sample size for the Stage 3 data collection was of 150 patients and 150 carers. The theoretical argument for the proposed sample size was covered in detail in Chapter 3, Methodology. The study was designed to capture a broad range of patient and carer experiences across different hospitals and wards.

6.2.5 Ethical approvals

Ethical approval for the study was granted by The Queen Elizabeth Hospital/Lyell McEwin Hospital/Modbury Hospital Human Research Ethics Committee and Central Adelaide Local Health Network Research Governance Office (HREC/17/TQEH/91). Reciprocal approval was provided by the Southern Adelaide Local Health Network Ethics Committee. Site specific approval was granted by each participating Local Health Network. Participants were required to read the Participant Information and Consent Form and sign the consent. I co-signed the consent and provided a copy to the participant. (All documents relating to ethics and governance approval are included in Appendices A1 to A10).

6.2.6 Timeframes

Stage 3 data collection took place every Wednesday, Thursday, Friday, Saturday and Sunday from 11am to 5pm during the time period 31 October 2018 to 23 February 2019.

6.2.7 Process for data collection

Each day that I was collecting data I would introduce myself to the Shift Co-ordinator of each participating ward and ask them to consider which patients (and/or carers) might be suitable to undertake the questionnaire. The Shift-Co-ordinator would provide me with a patient list and I would note which patients I could consider and which I should not approach.

I would then circulate through wards and locate the nurse looking after the patients identified by the Shift Co-ordinator. If the nurse felt it was appropriate for me to speak with the patient (and/or their carer) the nurse would check with the patient (and/or carer) and, if the patient (and/or carer) agreed, the nurse would then introduce me to the patient (and/or carer). I would discuss the Research Project Information Sheet with the patient (and/or carer) and, if they agreed to participate, I would obtain their consent and administer the questionnaire.

6.2.8 Materials

The Stage 3 patient and carer versions of the DiCQ (Appendices G1 and G2) consisted of 50 items grouped under the subscales of the 10 Principles of Dignity in Care (five items under each Principle). The questionnaire was administered in paper (hard copy) format. The questionnaire was printed in large font (14 for text and 18 for headings) to aid ease of reading for the older participants. Based on these font sizes, the items belonging to each Principle could be formatted onto one page.

6.2.9 Mode of administration

I handed the paper questionnaire to each participant and collected the questionnaire when the participant had completed the questionnaire. Sometimes I sat with the person while they completed the questionnaire. I sensed the people who wanted me to sit with them were very keen for some company and a conversation. I was happy to help explain any aspect of the questionnaire, but I was clear my role was not to have any part in determining the response to the items.

6.2.10 Data Analysis

The participants' responses, recorded on the hard copy patient and carer questionnaires, were entered into a Statistical Package for the Social Sciences (SPSS) file (Armonk, NY: IBM Corp. version 25). Each record was de-identified using a simple code (P = patient or C = carer plus the sequential number of questionnaires collected). SPSS was used to present the demographic data (gender, age, length of stay), frequencies (by item and by response category) and descriptive statistics (skewness and kurtosis).

Rasch analysis, using Winsteps software (Linacre, J. M. (2019), Winsteps® Rasch measurement computer program, Beaverton, Oregon, version 4.4.5), was undertaken using the grouped Rating Scale Model (RSM) [176]. The RSM was used as response categories retained for analysis all shared the same rating scale (e.g., Likert agreement). The steps in the Rasch analysis were explained in detail in Chapter 3, Methodology, and so will not be explained again in this chapter, I will simply report the results and discuss the findings. The steps include examination of Person Separation Index (PSI), Item Separation Index (ISI), Category Threshold Order, Response Dependency, Fit Statistics, Principal Components Analysis of the Residuals, Targeting and Differential Item Functioning. In addition, Winsteps was used to rescale the DiCQ scores from a logit scale to a score from 0 to 100 (where a higher score represents a better experience of Dignity in Care). This was undertaken to make the presentation of the analysis of differences in scores (by gender, age, length of stay and data collection site) easier to understand.

6.2.11 Preparation of data for analysis

To ensure all items were consistent in the polarity of responses (so 'Always' equated to the optimal experience of care) items 1.3, 1.4 and 9.5 were reverse coded. This was undertaken as part of the preparation of the data in SPSS.

Of the 50 items included in the instrument used for the Stage 3 data collection (Appendices G1 and G2), seven items did not have scalable ordinal response categories and were deleted prior to the Rach analysis (Table 6. 1). Removal of the items does not reflect the importance of the content of the items. If the questionnaire progresses to implementation, these items could be considered for inclusion in the questionnaire, and responses counted, but not analysed or included in the overall score.

Table 6. 1 Items with non-scalable response categories removed prior to Rasch analysis

Item 4.5 I have discussed my Advance Care Directive with staff		
	1	I do not have an Advance Care Directive
	2	I do not know what an Advance Care Directive is
	3	Yes, I have discussed my Advance Care Directive with staff
	4	No, I have not discussed my Advance Care Directive with staff
Item 7.2 I have felt I could make a complaint if I needed to		
	1	I would never make a complaint, even if I felt I needed to
	2	I would be reluctant to make a complaint, even if I needed to
	3	I would always make a complaint, if I felt I needed to
Item 7.3 I believe I could make a complaint without it affecting my care		
	1	I would never complain, for fear it would affect my care
	2	I would be reluctant to complain, for fear it would affect my care
	3	I believe I could complain without it affecting my care
Item 7.4 I know who to contact if I have a complaint		
	1	No
	2	Not sure
	3	Yes
Item 7.5 I made a complaint and I was satisfied with the response		
	1	I did not make a complaint
	2	I made a complaint and I was not satisfied with the response
	3	I made a complaint and I was satisfied with the response
Item 10.4 I have been visited by a hospital volunteer		
	1	Unsure
	2	No, I have not had a visit from a hospital volunteer
	3	Yes, I have been visited by a hospital volunteer
Item 10.5 I have had access to an Aboriginal Liaison Officer		
	1	I am not an Aboriginal person
	2	I am an Aboriginal person, but I have not had access to an Aboriginal Liaison Officer
	3	I am an Aboriginal person and I have had access to an Aboriginal Liaison Officer

For the purpose of RSM, the data were analysed using the scalable response categories in common across all 43 items (‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’ and ‘Always’ (NRSOA). Thirty (of 43 items) in the patient questionnaire only included the response categories NRSOA. Six items (3.4, 3.5, 8.1, 8.2, 8.3 and 8.4) included NRSOA and ‘Not Applicable’ (N/A). One item (4.4) included NRSOA and ‘Unsure’. Six items (1.2, 1.5, 3.2, 5.5, 8.5 and 10.3) included NRSOA and an additional response category unique to that item. The additional response categories that were unique to each of the six items, are detailed in Table 6. 2.

Table 6. 2 Additional response categories ‘unique to item’

Item	Response categories
1.2	NRSOA plus ‘I have not used the call bell’
1.5	NRSOA plus ‘I had no pain’
3.2	NRSOA plus ‘I do not need an interpreter’
5.5	NRSOA plus ‘Discharge has not been discussed’
8.5	NRSOA plus ‘Interpreter not required’
10.3	NRSOA plus ‘I have not been bored’

Legend: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’ and ‘Always (NRSOA)

The non-scalable response options (‘N/A’, ‘unsure’ and the additional response category ‘unique to item’) were treated as ‘missing data’ [214] (Table 6. 3).

Table 6. 3 Response categories of the 43 items included in the Rasch analysis

		Scalable Response Categories					Non-scalable Response Categories
Items	**n**	**1**	**2**	**3**	**4**	**5**	**6**
1.1;1.3;1.4;2.1;2.2;2.3;2.4;2.5; 3.1;3.3;4.1;4.2;4.3;5.1;5.2;5.3; 5.4;6.1;6.2;6.3;6.4;6.5;7.1;9.1; 9.2;9.3;9.4;9.5;10.1;10.2	30	N	R	S	O	A	
3.4;3.5;8.1;8.2;8.3;8.4	6	N	R	S	O	A	N/A
4.4	1	N	R	S	O	A	Unsure
1.2;1.5;3.2;5.5;8.5;10.3	6	N	R	S	O	A	Unique to item

Legend: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’ and ‘Always (NRSOA)

The same process of data preparation was undertaken for the carer questionnaire. The patient and carer versions were analysed from separate control files in Winsteps. The Winsteps control files for both the patient and carer version, are provided in Appendix H.

The results of the analysis of the patient data are reported in section 6.3 (below) and the results of the carer data are reported in Section 6.4.

6.3 Results (Patient Data)

6.3.1 Demographic data (patients)

A total of 200 patient participants completed the patient version of the questionnaire. Recruitment exceeded the target sample size of 150, for patient participation (covered in Chapter 3, Methodology).

The patient participants were 52% female and 48% male. A greater proportion (n = 64; 62%) of the females were aged 80 years and over compared to males (n = 45; 47%) (Table 6. 4). On average patient participants were 81 years of age (standard deviation 8.4 years).

Table 6. 4 Gender and age (patient data)

Gender	Age (years)	n	%
Female	65 to 79	40	20.0%
	80 +	64	32.0%
Male	65 to 79	51	25.5%
	80 +	45	22.5%
Total		**200**	**100%**

One hundred and seventeen (58%) of patient participants had been in hospital for between one and five days and 83 (42%) of patient participants had been in hospital for 6 or more days, when they completed the questionnaire (Table 6. 5).

Table 6. 5 Length of stay of patient prior to undertaking the questionnaire (patient data)

Length of stay (days)	n	%
1 to 5	117	58.5%
6 +	83	41.5%
Total	**200**	**100%**

All patients I recruited spoke English. I was unable to recruit any patients who did not speak English as their first language.

6.3.2 Frequencies (patient data)

6.3.2.1. Floor and Ceiling effects (patient data)

The data in Table 6. 6 present the response category totals across all 43 items (calculated from the raw data presented in Appendices I1 and I2). Across all items there were fewer 'Never' (6%) and 'Rarely' (4%) responses, demonstrating a floor effect (Table 6. 6). The patient data demonstrated a substantial ceiling effect (48.2% of 'Always' responses, which equates to the highest experience of dignity in care) (Table 6. 6).

Table 6. 6 Response category totals (patient data)

	Missing	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**	**Additional Response**	**Total**
Totals	63	525	312	896	1,476	4,142	1,186	8,600
%	0.7%	6.1%	3.6%	10.4%	17.2%	48.2%	13.8%	100%

6.3.2.2. Missing data (patient data)

This study included two types of missing data. The first was data missing as a result of patient participants not responding to an item(s). The second was missing data created by treating the non-scalable response category in 13 items as 'missing data' (Table 6. 3).

There was very little missing data as a result of patient participants not responding to an item(s). Across all 43 items, there were only 63 (0.7%) missing responses (Table 6. 6 and Appendices I1 and I2). The low rate of missing data is possibly a result of my presence while patient participants completed the questionnaire. I would check the questionnaire and ask patient participants if they would like to complete items they had missed, occasionally patient participants missed a page and they were always willing to complete. The Rasch analysis was undertaken on all available data, without imputation.

The treatment of non-scalable response categories as 'missing data' created a lot of missing data. The missing data for the 13 items that included a non-scalable response category are detailed in Table 6. 7. Waterbury (2019) suggests consideration should be given to removing items from the Rasch analysis if they have missing data > 50% [214]. The content of the item is always considered prior to removing the item. Based on an assessment of the amount of missing data and the content of the items, four items were removed prior to the Rasch analysis. These were item 3.2 (185 patients (92.5%) selected the non-scalable response option

‘I do not need an interpreter’; item 8.3 (135 patients (67.5%) selected the response option ‘N/A’); item 8.4 (152 patients (76%) selected the response option ‘N/A’) and item 8.5 (189 patients (94.5%) selected the response option ‘Interpreter not required’ (Table 6. 7).

Table 6. 7 Number of patient participants who selected the non-scalable response option

Item	Response categories	Patient participants who selected the non-scalable response category (n,%)
1.2	NRSOA plus ‘I have not used the call bell’	15 patients (7.5%) selected the ‘I have not used the call bell’ response
1.5	NRSOA plus ‘I had no pain’	45 patients (22.5%) selected the ‘I had no pain’ response
3.2	NRSOA plus ‘I do not need an interpreter’	185 patients (92.5%) selected the ‘I do not need an interpreter’ response *
3.4	Item 3.4 NRSOA plus ‘N/A’	111 patients (55.5%) selected the ‘N/A’ response
3.5	Item 3.5 NRSOA plus ‘N/A’	101 patients (50.5%) selected the ‘N/A’ response
4.4	Item 4.4 NRSOA plus ‘Unsure’	27 patients (13.5%) selected the ‘Unsure’ response
5.5	NRSOA plus ‘Discharge has not been discussed’	75 patients (37.5%) selected the ‘Discharge has not been discussed’ response
8.1	Item 8.1 NRSOA plus ‘NA’	40 patients (20%) selected ‘N/A’ response
8.2	Item 8.2 NRSOA plus ‘NA’	45 patients (22.5%) selected the ‘N/A’ response
8.3	Item 8.3 NRSOA plus ‘NA’	135 patients (67.5%) selected the ‘N/A’ response *
8.4	Item 8.4 NRSOA plus ‘NA’	152 patients (76%) selected the ‘N/A’ response *
8.5	NRSOA plus ‘Interpreter not required’	189 patients (94.5%) selected the ‘Interpreter not required’ response *
10.3	NRSOA plus ‘I have not been bored’	66 patients (33%) selected the ‘I have not been bored’ response

Legend: ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’ and ‘Always (NRSOA). Not Applicable (N/A).
*** Items 3.2, 8.3, 8.4 and 8.5 were removed from the Rasch analysis due to the extent of missing data**

6.3.3 Descriptive Statistics (patient data)

6.3.3.1. Skewness and Kurtosis

The distribution of patient scores was assessed, by item, for skewness and kurtosis. Of the 39 items (43 minus four items with extreme ‘missing data’), nine items had skewness outside of acceptable parameters (> -2.00 to < +2.00) and 14 items had kurtosis outside of acceptable parameters (> -2.00 to < +2.00) [215] (Appendix J1).

6.3.4 Response rate (patient data)

A response rate was not calculated, the reasons are covered in the discussion.

6.3.5 Results of the Rasch analysis (patient data)

The steps in the Rasch analysis were explained in detail in Chapter 3 Methodology. In this section I report on the results of the Rasch analysis for the patient data, following the same steps, as detailed in Chapter 3, Methodology. The steps include examination of Person Separation Index (PSI), Item Separation Index (ISI), Category Threshold Order, Response Dependency, Fit Statistics, Principal Components Analysis of the Residuals, Targeting and Differential Item Functioning. (The carer data was analysed separately and is covered in section 6.4).

The starting point for the Rasch analysis was 39 items. These items are remaining (from the 50-item questionnaire used for the data collection, refer Appendix G1) after the removal of seven items (4.5, 7.2, 7.3, 7.4, 7.5, 10.4 and 10.5) with non-scalable ordinal response categories (detailed in Table 6. 1) and four items (3.2; 8.3; 8.4; 8.5) with extreme ‘missing data’ (detailed in Table 6. 7). Throughout this section, the figure below (Figure 6. 1) will be built on to assist the reader to keep track of the items removed and retained as the analysis progresses.

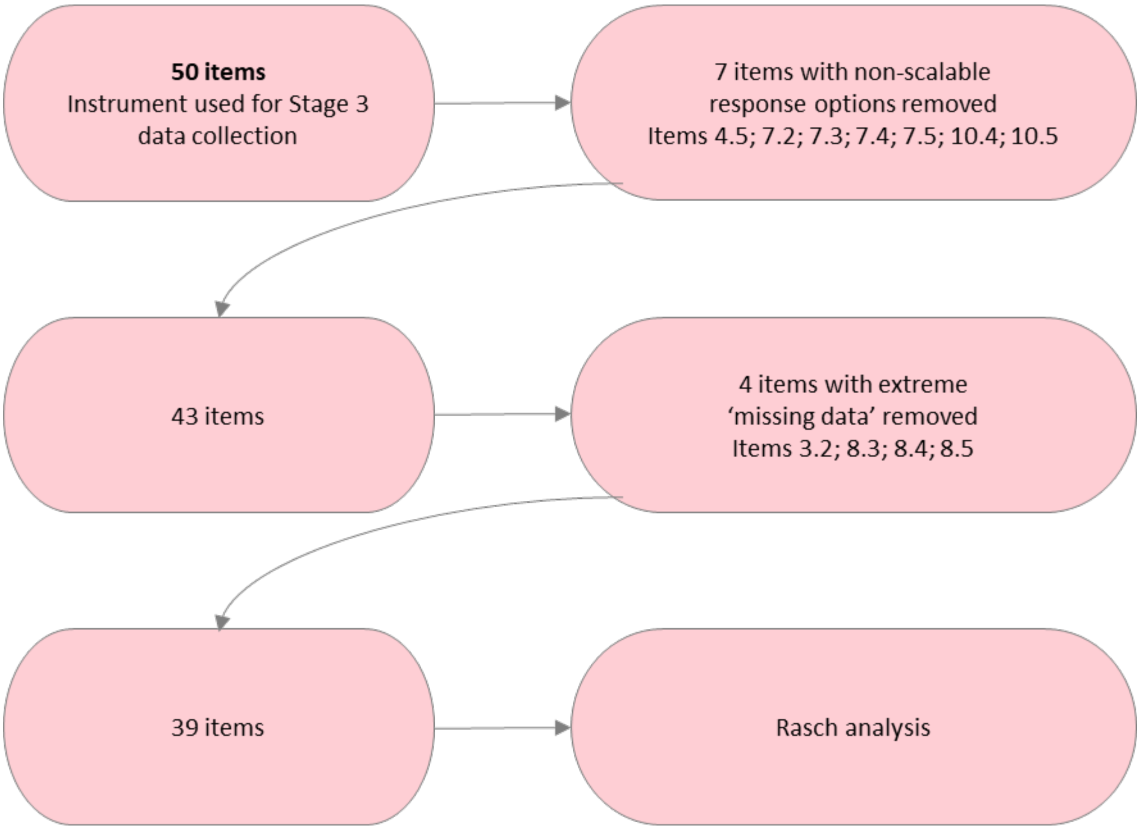


Figure 6. 1 Tracking items removed prior to Rasch analysis (patient data)

6.3.5.1. Person Separation and Item Separation (patient data)

The PSI and ISI for the 39-item instrument were all within acceptable parameters (Table 6. 8).

Table 6. 8 Person Separation and Item Separation (patient data)

Measured by	**Acceptable parameters**	**Output for 39-item instrument**
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.43 (0.86)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	4.60 (0.95)

6.3.5.2. Category Threshold Order (patient data)

The category probability curves were disordered for all 39 items. This finding was not surprising given the underutilised category (response option) of 'Rarely' which was selected by less than 10 people for three quarters (74%) of the items, as well as the substantial ceiling effect (Table 6. 6 and Appendix I1).

Collapsing of categories was undertaken to explore if this restored order. Usually only two response options are collapsed together, and they must be two categories next to each other in order, and optimally, the categories with the lowest responses. It was evident in the data (Appendix I1) that the ‘Never’ and ‘Rarely’ response options should be collapsed, this resulted in the thresholds becoming ordered for all 39 items. Collapsing the response categories is undertaken by making changes to the Winsteps code (Appendix H).

By way of example, for item 1.1, the original Category Threshold Curve is shown in Figure 6. 2, in the figure on the left, the blue line (category probability 2) is underneath category probability 3, indicating disordered categories. Collapsing the response categories ‘Never’ and ‘Rarely’ restored order (Figure 6. 2, figure on the right).

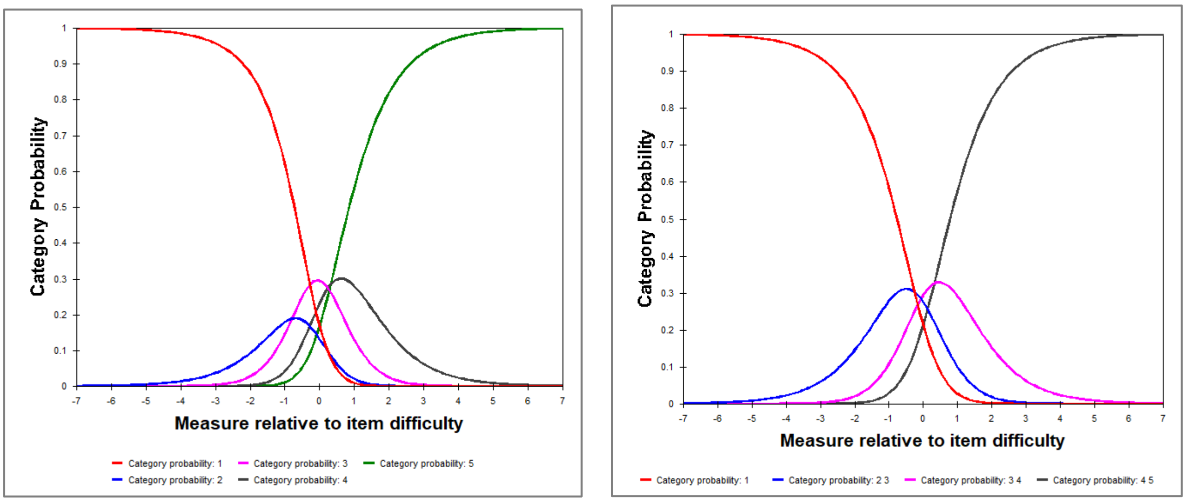


Figure 6. 2 Category Probability Curves for Item 1.1 (patient data)

Legend: Original Category Probability Curve (figure on left), collapse of ‘Never and Rarely’ (figure on right)

Following the collapse of the ‘Never’ and ‘Rarely’ response categories, the PSI and ISI remained within acceptable parameters (Table 6. 9).

Table 6. 9 Person Separation and Item Separation pre and post collapse of response categories (patient data)

Measured by	**Acceptable parameters**	**Output for 39-item instrument**	**Post collapse of ‘Never’ and ‘Rarely’**
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.43 (0.86)	2.71 (0.88)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	4.60 (0.95)	4.94 (0.96)

6.3.5.3. Subscale analysis (patient data)

The DiCQ was developed to have 10 subscales (the 10 Principles of Dignity in Care). Subscales must include more than one item to make subscale analysis possible. Subscale seven included only one item (7.1), this was excluded from the subscale analysis. Rasch analysis was undertaken on the remaining nine subscales, with a total of 39 items (after the response categories had been collapsed, but prior to removal of misfit items).

The Person Separation Index was well below the acceptable parameter of >2.00 and the Person Separation Reliability Coefficient was well below the acceptable ≥ 0.80 for all 9 subscales (Table 6. 10). Based on this finding, no subscale was able to demonstrate construct validity and no further subscale analysis was undertaken. The remainder of the analysis was undertaken to explore whether the instrument, as a whole, based on the content developed for all 10 Principles, can demonstrate construct validity.

Table 6. 10 Performance of the subscales (patient data)

Subscale (Principle)	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10
Items (n)	5	5	4	4	5	5	1	2	5	3
Misfitting items (n)	1	0	3	0	0	0		0	0	0
Person Separation Index	0.62	0.96	0.39	0.86	1.31	0.73		0.94	1.01	1.40
Person separation reliability coefficient	0.28	0.48	0.13	0.43	0.63	0.35		0.47	0.50	0.66
Mean person location	3.04	2.38	0.57	1.53	1.35	3.06		0.85	2.05	-0.28

6.3.5.4. Fit Statistics (patient data)

Out of the 39 items subjected to a single Rasch analysis, five items (1.4, 3.4, 3.5, 8.2 and 9.5) were removed because they had fit statistics outside of the acceptable parameters. Five items (3.3, 4.4, 8.1, 9.5 and 10.1) were retained despite having fit statistics outside of optimal parameters. Items were removed (or retained) iteratively, and after each item was removed, the fit statistics and the PSI and ISI were assessed for the remaining items. The PSI and ISI remained within acceptable parameters throughout each step of item removal (Table 6. 11).

Table 6. 11 Fit Statistics (patient data)

Fit Statistics	Item	Fit Statistics		Model Statistics	
		Infit MnSq (ZSTD)	Outifit MnSq (ZSTD)	PSI (PSRC)	ISI (ISRC)
Fit statistics sorted by highest Infit MnSq (Item 1.4) Baseline PSI/ISI (39 items)	1.4	2.96 (2.33)	2.46 (1.64)	2.71 (0.88)	4.94 (0.96)
Delete Item 1.4 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq (Now Item 3.3)	3.3 *	2.42 (7.06)	2.55 (5.49)	2.71 (0.88)	6.76 (0.98)
Item 3.3 retained * After Item 3.3 the next highest Infit MnSq is Item 3.4	3.4	2.01 (5.78)	2.21 (5.11)		
Delete Item 3.4 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq (Now Item 3.5)	3.5	1.77 (3.20)	1.97 (2.50)	2.73 (0.88)	9.94 (0.98)
Delete Item 3.5 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq (Now Item 8.1)	8.1*	1.75 (6.19)	1.85 (5.44)	2.72 (0.88)	7.27 (0.98)
Item 8.1 retained * After Item 8.1 the next highest Infit MnSq is Item 10.1	10.1*	1.66 (5.37)	1.76 (4.76)		
Item 10.1 retained * After Item 10.1 the next highest Infit MnSq is Item 8.2	8.2	1.66 (4.97)	1.81 (4.00)		
Delete Item 8.2 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq (Now Item 9.5)	9.5	1.58 (5.52)	1.97 (6.13)	2.72 (0.88)	7.46 (0.98)
Delete Item 9.5 Rerun PSI/ISI Re run Fit Statistics, sort by highest Infit MnSq (now Item 4.4)	4.4*	1.57 (4.23)	2.08 (4.66)	2.66 (0.88)	7.56 (0.98)
* Items 3.3, 4.4, 8.1, 10.1 retained (Refer to Discussion, Section 6.6) All remaining items have Infit < 1.5 MnSq					

Person Separation Index (PSI), Person Separation Reliability Coefficient (PSRC), Item Separation Index (ISI), Item Separation Reliability Coefficient (ISRC). * Items retained based on value of content

As noted in Chapter 3, Methodology, instrument development should not be driven by statistics alone [176]. Expert clinical / consumer / researcher judgement, based on sound qualitative assessment and argument, should contribute to decisions regarding the retention and removal of items. Examples are given, justifying the retention of items, in the Discussion (Section 6.6).

Following the removal of five misfitting items, there were 34 items that proceeded to the next step in the Rasch analysis. Figure 6. 3 shows the tracking of items as the Rasch analysis progresses to 34 items (for the patient data). A further review of the fit statistics for the final items remaining in the instrument will be presented in section 6.3.4.6, once all items have been removed, as a result of the findings, and expert opinion, at each step of the analysis.

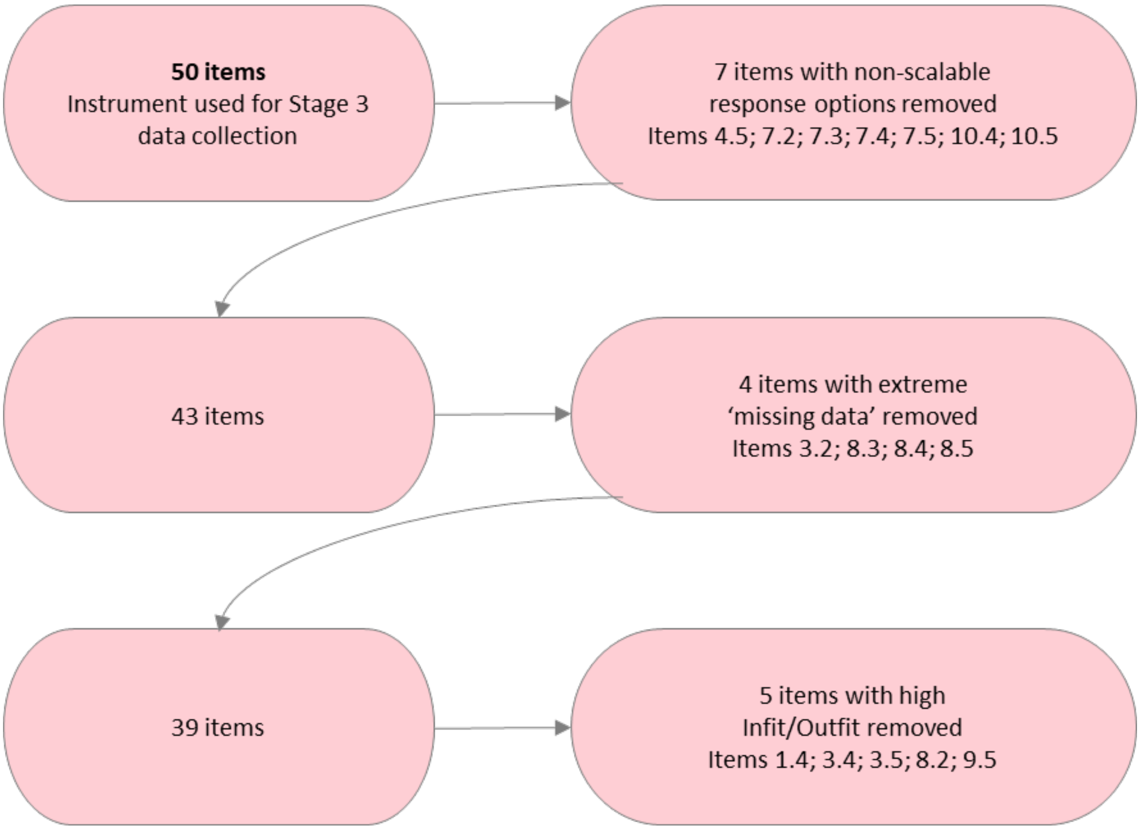


Figure 6. 3 Tracking items as the Rasch analysis progresses to 34 items (patient data)

6.3.5.5. Response Dependency

Of the 34 items remaining in the analysis, 25 pairs of items (Table 6. 12) had residual item correlations exceeding the acceptable parameter (calculated to be 0.18), suggesting response dependency. The acceptable parameter was determined by taking an average of all residual item correlations (which was -0.02) and adding 0.2 [188] (Refer section 3.1.5.5, Chapter 3, Methodology). The treatment of response dependency used in this study was to consider removing one of each of the item pairs with high residual correlations. 'Expert' judgement was employed to determine which items with high item correlations should be retained and removed. As a result, 12 items (1.1, 2.3, 4.1, 5.2, 6.1, 6.2, 6.3, 6.5, 9.1, 9.3 and 10.3) were removed (Table 6. 12).

Table 6. 12 Items with high Standardised Residual Item Correlations (patient data)

Item	Item	SRIC	Resolution
1.1	1.3	0.24	Remove Item 1.1
1.2	2.1	0.19	Both should be retained based on content
1.3	2.3	0.23	Remove Item 2.3
1.3	9.1	0.19	Remove Item 9.1
1.3	9.2	0.21	Both should be retained based on content
2.3	2.4	0.30	Remove Item 2.3
2.3	2.5	0.29	Remove Item 2.3
2.3	9.2	0.25	Remove Item 2.3
2.5	9.1	0.19	Remove Item 9.1
4.1	4.2	0.46	Remove Item 4.1
4.2	5.2	0.30	Remove Item 5.2
5.1	5.2	0.32	Remove Item 5.2
5.3	7.1	0.22	Both should be retained based on content
6.1	6.2	0.22	Remove Item 6.1 and Item 6.2
6.1	6.4	0.23	Remove Item 6.1
6.2	6.3	0.23	Remove Item 6.2 and Item 6.3
6.2	6.4	0.23	Remove Item 6.2
6.3	6.4	0.40	Remove Item 6.3
6.3	6.5	0.31	Remove Item 6.3 and Item 6.5
6.5	6.4	0.41	Remove Item 6.5
9.1	9.2	0.46	Remove Item 9.1
9.1	9.3	0.21	Remove Item 9.1 and Item 9.3
9.2	9.3	0.24	Remove Item 9.3
9.3	9.4	0.20	Remove Item 9.3
10.2	10.3	0.32	Remove Item 10.3

Legend: Standardised Residual Item Correlations (SRIC)

Thirteen items (1.2, 1.3, 2.1, 2.4, 2.5, 4.2, 5.2, 5.3, 6.4, 7.1, 9.2, 9.4 and 10.2) were retained based on ‘expert’ judgement.

Items 2.3 was removed as it appeared in high residual correlations with four other items (1.3, 2.4, 2.5 and 9.2). Item 9.3 was removed as it appeared in high residual correlations with three other items (9.1, 9.2 and 9.4).

A further nine items (1.1, 4.1, 5.2, 6.1, 6.2, 6.3, 6.5, 9.1 and 10.3) were removed based on ‘expert’ judgement. Examples are given, justifying the removal of items, in the Discussion (Section 6.6).

Following the removal of each of the 11 items, the PSI and ISI were examined to determine the effect of the item reduction on the model. A marginal decrease in PSI and marginal increase in ISI occurred as each item was removed (Table 6. 13).

Table 6. 13 Items with high residual correlations and model statistics (patient data)

Action	Model Statistics			
	PSI	PSRC	ISI	ISRC
Baseline	2.66	0.88	7.56	0.98
Delete 1.1 and re run PSI/ISI	2.64	0.87	7.64	0.98
Delete 2.3 and re run PSI/ISI	2.62	0.87	7.63	0.98
Delete 4.1 and re run PSI/ISI	2.56	0.87	7.69	0.98
Delete 5.2 and re run PSI/ISI	2.51	0.86	7.76	0.98
Delete 6.1 and re run PSI/ISI	2.48	0.86	7.87	0.98
Delete 6.2 and re run PSI/ISI	2.45	0.86	7.90	0.98
Delete 6.3 and re run PSI/ISI	2.43	0.85	7.90	0.98
Delete 6.5 and re run PSI/ISI	2.40	0.85	7.88	0.98
Delete 9.1 and re run PSI/ISI	2.36	0.85	7.89	0.98
Delete 9.3 and re run PSI/ISI	2.31	0.84	7.91	0.98
Delete 10.3 and re run PSI/ISI	2.23	0.83	7.70	0.98

Legend: Person Separation Index (PSI), Person Separation Reliability Coefficient (PSRC), Item Separation Index (ISI), Item Separation Reliability Coefficient (ISRC)

There were three item pairs (1.3, 4.2, 5.1, 5.3, 7.1 and 9.2) with standardised residual item correlations exceeding 0.18, that were retained based on their content (Table 6. 14). Examples are given, justifying the retention of items, in the Discussion (Section 6.6).

Table 6. 14 Items with high residual correlations that were retained for content (patient data)

	Item	Item	SRIC
Both items retained based on content	1.3	9.2	0.24
Both items retained based on content	4.2	5.1	0.19
Both items retained based on content	5.3	7.1	0.19

Legend: Standardised Residual Item Correlations (SRIC)

Following the removal of 11 items due to response dependency, there were 23 items that proceeded to the next step in the Rasch analysis. Figure 6. 4 shows the tracking of items as the Rasch analysis progresses to 23 items (for the patient instrument).

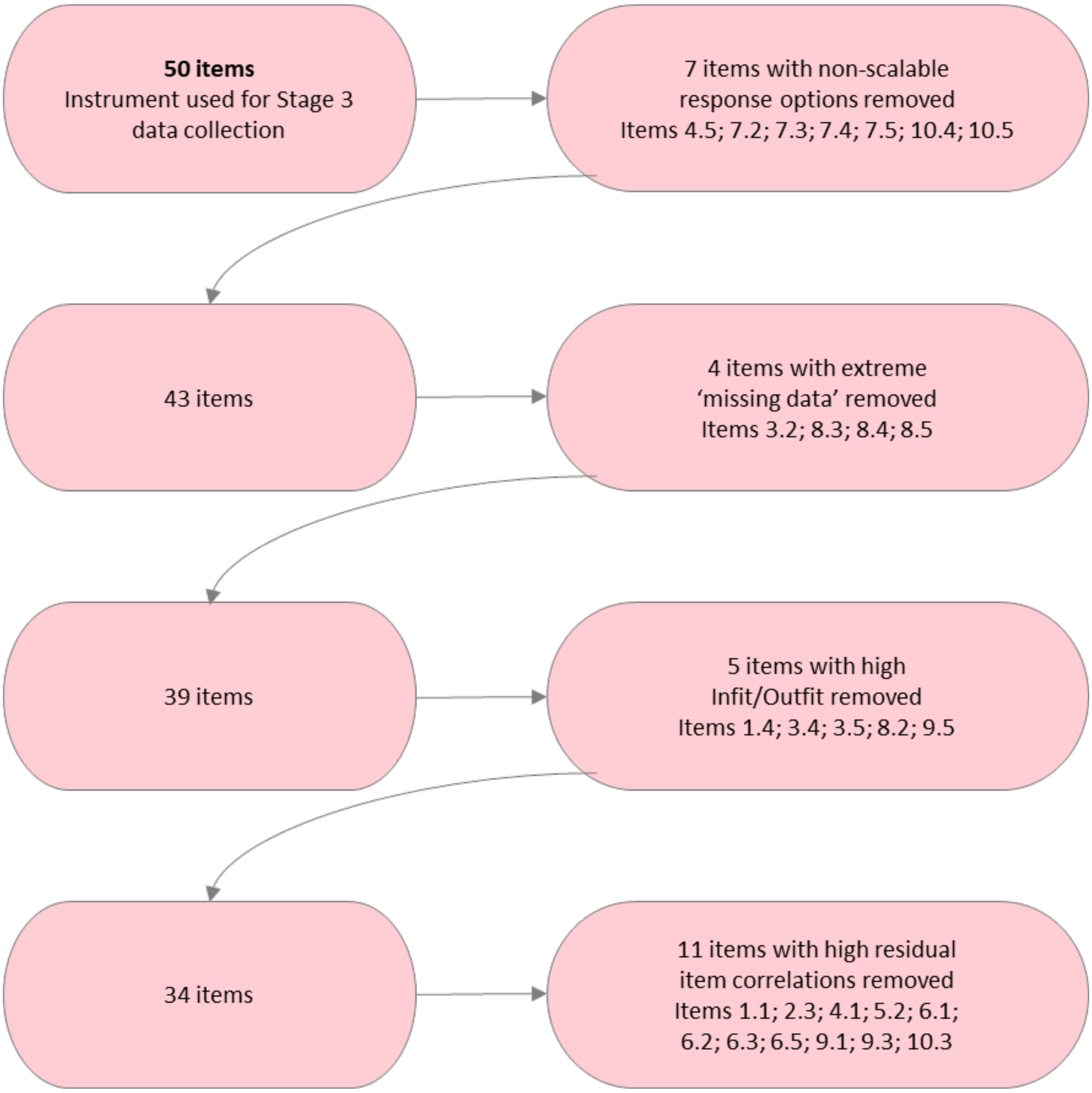


Figure 6. 4 Tracking items as the Rasch analysis progresses to 23 items (patient data)

6.3.5.6. Fit Statistics for the final 23 items

At this point, all decisions had been made about which items to retain and which items to remove. It is timely to review the fit statistics for the final 23 items, before I progress to the final steps in the analysis.

The fit statistics for the final 23 items in the instrument are presented in Table 6. 15. Three items (3.3, 8.1 and 10.1) have Infit and Outfit MnSq outside of optimal parameters. A further two items (2.1 and 4.4) have Outfit MnSq outside optimal parameters. Linacre (1994) observes that a MnSq of 0.5 to 1.5 is productive for measurement, a MnSq of between 1.5

and 2.0 is unproductive for construction of measurement, but is not degrading [187]. Justification for retaining item 3.3, despite its apparent misfit, is provided in detail in the discussion (Section 6.6.2.2).

Table 6. 15 Fit Statistics for the final 23 items (patient data)

Item	Infit MnSq (Zstd)	Outfit MnSq (Zstd)
Item1.2	0.80 (2.23)	0.89 (-0.74)
Item1.3	1.27 (2.15)	1.45 (2.29)
Item1.5	0.94 (-0.37)	1.26 (1.11)
Item2.1	1.30 (3.12)	1.66 (4.56)
Item2.2	0.86 (1.32)	0.75 (1.61)
Item2.4	0.67 (2.54)	0.76 (1.12)
Item2.5	0.80 (1.50)	0.74 (1.31)
Item3.1	1.05 (0.38)	1.02 (0.15)
Item3.3	2.26 (6.58)	2.43 (5.04)
Item4.2	0.85 (1.53)	0.98 (-0.08)
Item4.3	0.80 (1.94)	0.69 (2.13)
Item4.4	1.44 (3.39)	1.88 (4.15)
Item5.1	0.67 (3.65)	0.89 (-0.75)
Item5.3	0.85 (1.78)	0.79 (1.85)
Item5.4	0.75 (2.71)	0.70 (2.26)
Item5.5	1.01 (0.08)	0.98 (-0.06)
Item6.4	1.19 (1.12)	0.86 (-0.52)
Item7.1	0.66 (4.27)	0.58 (3.86)
Item8.1	1.67 (5.65	1.80 (5.30)
Item9.2	0.70 (2.49)	0.62 (2.22)
Item9.4	0.91 (-0.81)	0.82 (1.18)
Item10.1	1.64 (5.14)	1.61 (3.93)
Item10.2	0.87 (1.44)	0.85 (1.23)

Following the removal of items due to misfit and response dependency, the PSI and ISI for the final 23-item instrument remained within acceptable parameters (Table 6. 16).

Table 6. 16 Person Separation and Item Separation of the final 23-item instrument (patient data)

Measured by	Acceptable parameters	Final 23-items
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.23 (0.83)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	7.70 (0.98)

6.3.5.7. Principal Components Analysis of the Residuals (patient data)

The Principal Components Analysis of the residuals was examined using two measures: 1) Raw variance explained by measures and 2) Unexplained variance in 1st contrast (Table 6. 17).

Table 6. 17 Principal Components Analysis of the Residuals (patient data)

Measured by	Acceptable parameters	23 items
1. Raw variance explained by measures	Observed approximates expected [189]	Observed 49.2% Expected 50.3%
2. Unexplained variance in 1st contrast	<3.0 (< 5%)/High[190]	Eigen 2.26 Observed 4.9% Expected 9.8%

First, I reported on the raw variance explained by measures. Linacre argues [189] it is not the size of the variance, but rather whether the observed value is close to the expected value that is of importance. Based on the PCA of the 23-item instrument, the observed raw variance explained by the measure was 49.2%, which is close to the expected 50.3% (Table 6. 17).

Second, I reported on the unexplained variance in the 1st contrast. Based on the 23-item instrument, the eigen value was 2.26, an observed variance of 4.9% and an expected variance of 9.8%, which are all within acceptable parameters (Table 6. 17).

The PCA revealed that items were grouped into a pattern of three clusters (Table 6. 18). These clusters were identified in Winsteps Table 23.1 [189] based on their loading on the 1st contrast [189].

Table 6. 18 Clusters identified in the Principal Components Analysis of the Residuals by item (patient data)

Cluster 1	1.2	1.3	2.4	2.5	5.1	6.4	9.2	
Cluster 2	1.5	2.1	2.2	4.2	5.4	7.1	9.4	10.2
Cluster 3	3.1	3.3	4.3	4.4	5.3	5.5	8.1	10.1

Because of the number of items in each cluster [189] (i.e., more than two in each cluster), the clusters were investigated further to determine if they were simply, the same dimension measured differently [189], or indeed, representing different dimensions, which might suggest multidimensionality. The investigation involved examination of the Pearson correlation and the disattenuated correlation between each cluster. The Pearson correlations are all > 0.4 [190] and the disattenuated correlations are all above > 0.7, which suggests these three groups are simply groupings of items, which are all contributing to the same dimension [189] (Table 6. 19).

Table 6. 19 Between cluster correlations (patient data)

	Pearson Correlation	**Disattenuated Correlation**
Cluster 1 – Cluster 3	0.44	0.87
Cluster 1 – Cluster 2	0.70	1.00
Cluster 2 – Cluster 3	0.63	0.95

6.3.5.8. Targeting (patient data)

The person-item map demonstrates that the 23-item instrument has poor targeting (Figure 6. 5). The person-item map demonstrates that disproportionately more persons experienced more of the latent variable (located toward the top of the map) relative to the items, which were relatively less challenging to answer (located toward the bottom of the map). In other words, about 50% of the sample experienced higher dignity in care than could be measured with the set of items used [176].

The difference between the person and items means in the original analysis (of 23 items) was 0.94 logits, which is within the optimal parameter of 1 logit. The 23 items spanned a range from -1.198 to 2.67 logits, which is a reasonably broad range, but only two items (items 3.3 and 10.1) are located in the upper end of the range.

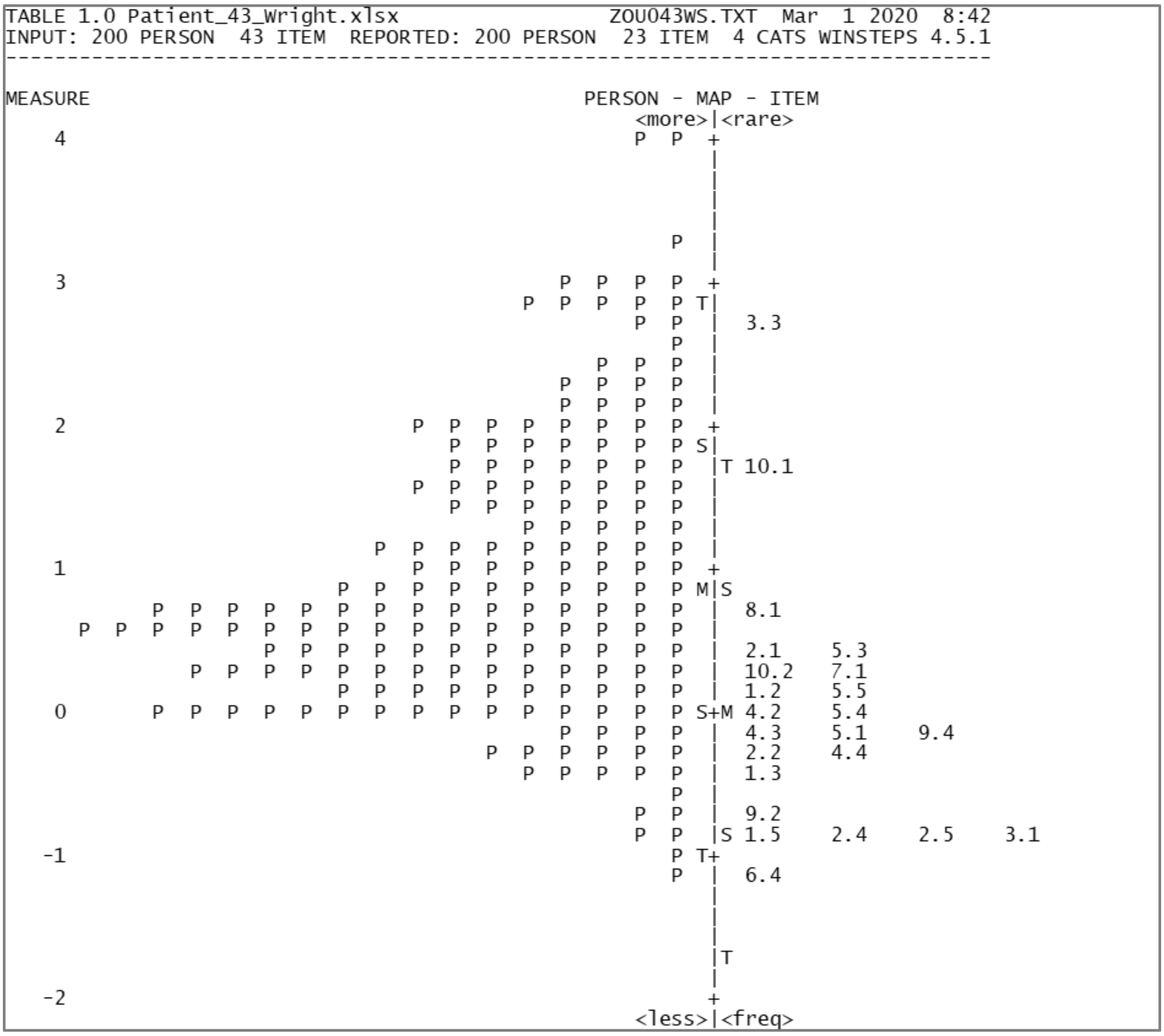


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TABLE 1.0 Patient_43_Wright.xlsx                 ZOU043WS.TXT  Mar  1 2020  8:42
INPUT: 200 PERSON  43 ITEM  REPORTED: 200 PERSON  23 ITEM  4 CATS WINSTEPS 4.5.1
--------------------------------------------------------------------------------

MEASURE                                        PERSON - MAP - ITEM
                                                   <more>|<rare>
    4                                              P  P  +
                                                         |
                                                         |
                                                         |
                                                         |
                                                      P  |
                                                         |
    3                                        P  P  P  P  +
                                          P  P  P  P  P T|
                                                   P  P  |  3.3
                                                      P  |
                                                P  P  P  |
                                             P  P  P  P  |
                                             P  P  P  P  |
    2                            P  P  P  P  P  P  P  P  +
                                    P  P  P  P  P  P  P S|
                                    P  P  P  P  P  P  P  |T 10.1
                                 P  P  P  P  P  P  P  P  |
                                    P  P  P  P  P  P  P  |
                                          P  P  P  P  P  |
                              P  P  P  P  P  P  P  P  P  |
    1                            P  P  P  P  P  P  P  P  +
                           P  P  P  P  P  P  P  P  P  P M|S
            P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  |  8.1
      P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  P  |
                     P  P  P  P  P  P  P  P  P  P  P  P  |  2.1    5.3
               P  P  P  P  P  P  P  P  P  P  P  P  P  P  |  10.2   7.1
                           P  P  P  P  P  P  P  P  P  P  |  1.2    5.5
    0       P  P  P  P  P  P  P  P  P  P  P  P  P  P  P S+M 4.2    5.4
                                             P  P  P  P  |  4.3    5.1    9.4
                                       P  P  P  P  P  P  |  2.2    4.4
                                          P  P  P  P  P  |  1.3
                                                      P  |
                                                   P  P  |  9.2
                                                   P  P  |S 1.5    2.4    2.5    3.1
   -1                                                 P T+
                                                      P  |  6.4
                                                         |
                                                         |
                                                         |
                                                         |T
                                                         |
   -2                                                    +
                                                   <less>|<freq>
```

Figure 6. 5 Person-item Map for the 23-item instrument (patient data)

Legend. The persons (each patient participant = ‘P’) are represented on the left of the scale and items, by item number, on the right of the scale (e.g., item 3.3 on the top right). The vertical dashed line represents the logit scale, M=mean; S= 1 standard deviation from the mean, T= 2 standard deviations from the mean. The M, S and T are shown for both items and persons. The more difficult items, and persons with a higher level of dignity, are placed at the top of the scale and vice versa.

6.3.5.9. Differential Item Functioning (patient data)

Differential Item Functioning (DIF) was analysed by gender (Table 6. 20), by age (65 to 79 years versus 80 and over) (Table 6. 21) and by length of stay (one to five days versus six or more days) (Table 6. 22). To fit the Rasch model, it is optimal for all items to have a DIF Contrast < 0.50 logits, it is acceptable if some items are between 0.5 and 1.0 logits, and unacceptable to have more than one item with DIF Contrast > 1.0 logits [191]. Based on these guidelines, no items were removed as a result of DIF.

Table 6. 20 Items with greater than negligible DIF by gender (patient data)

Items with DIF Contrast < 0.50 logits	22 items
Items with DIF between 0.5 and 1.0 logits	1 item (Item 6.4, DIF Contrast = -0.76)
Items with DIF > 1.0 logits	nil

Table 6. 21 Items with greater than negligible DIF by age category (patient data)

Items with DIF Contrast < 0.50 logits	23 items
Items with DIF between 0.5 and 1.0 logits	nil
Items with DIF > 1.0 logits	nil

Table 6. 22 Items with greater than negligible DIF by length of stay category (patient data)

Items with DIF Contrast < 0.50 logits	23 items
Items with DIF between 0.5 and 1.0 logits	nil
Items with DIF > 1.0 logits	nil

6.3.6 Rescale Dignity in Care Summary Score (patient data)

Based on the final 23 items, the summary score for each of the 200 patients was rescaled in Winsteps, from measurement in logits (Winsteps output), to a 0 to 100 scale, useful for the presentation of comparative analysis. The rescaled patient summary scores for the 200 patients ranged from 33 to 92 (Figure 6. 6).

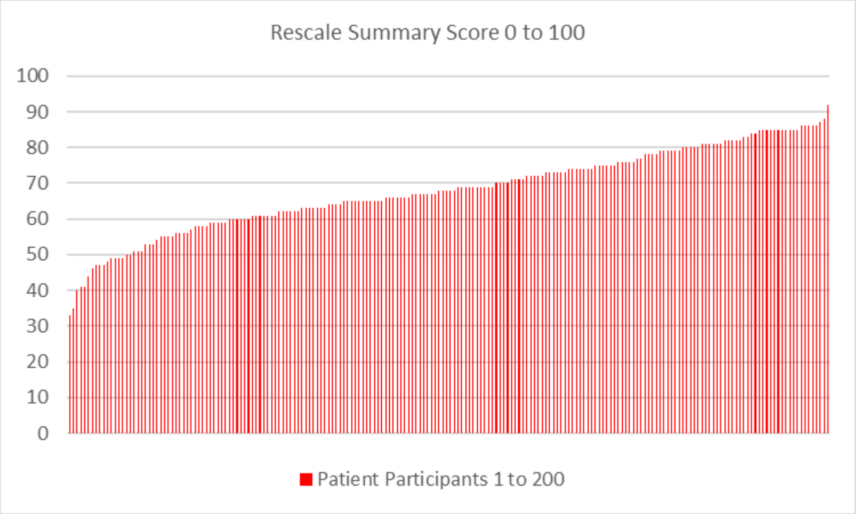


Figure 6. 6 Patient summary score rescaled from 0 to 100 for the 23-item instrument (patient data)

Legend: Each red line represents one (of the 200) patient participants

6.3.6.1. Summary Score by Gender, Age, Length of Stay and Data Collection Site (patient data)

Given the data were nonparametric, a Mann Whitney test was used to examine summary score by gender, age, length of stay and data collection site. There were no statistically significant differences between summary scores for patients based on gender, length of stay (0 to 5 days versus 6 or more days) and age (65 to 79 years versus 80 years and over) (Table 6. 23).

Table 6. 23 Test statistics by summary score for gender, length of stay and age (patient data)

	Gender	**Length of Stay**	**Age**
Mann Whitney U	4464.50	4838.00	4929.50
p. (2-tailed)	0.197	0.965	0.941

Data were examined to determine if there were any statistically significant differences in summary scores by data collection sites. Given the purpose of the data collection was instrument development (not hospital performance), the data collection sites have been intentionally de-identified. The analysis did not include ‘Site 2’ due to the small sample at that site. The difference between data collection sites was statistically significant between sites 1 and 3 (Table 6. 24).

Table 6. 24 Test statistics by summary score across data collection site (patient data)

Site		Site	Mann Whitney U	p. (2-tailed)
Site 1 (n = 93)	and	Site 3 (n = 66)	2362.00	0.013
Site 1	and	Site 4 (n = 34)	1376.00	0.264
Site 3	and	Site 4	991.00	0.340

Note: Site 2 data not presented due to small sample size

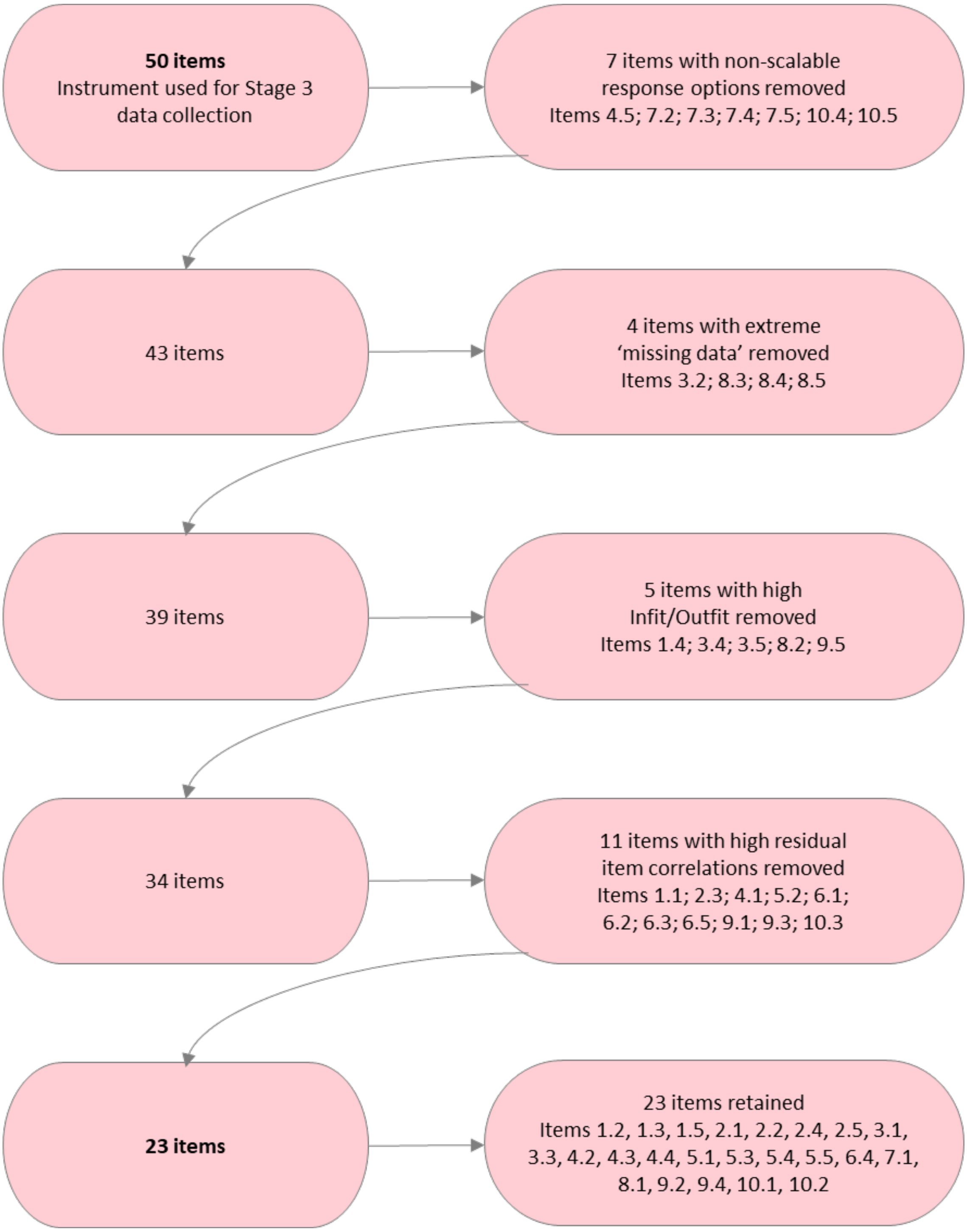


Figure 6. 7 Tracking items through the Rasch analysis to the final 23 items (patient data)

6.3.7 Summary of overall performance (patient data)

From the 50-item questionnaire used in the Stage 3 data collection, seven items were removed as they had non-scalable response options and four items were removed as they had excessive missing data. Rasch analysis was undertaken on 39 items, of these, five items were removed due to misfit and 11 items were removed due to response dependency (Figure 6. 7). Instrument development was guided by the findings of each step of the Rasch analysis, supplemented by 'expert' judgement, to maintain content validity.

The final 23-item patient version of the instrument (Appendix K1) was able to demonstrate unidimensionality, as assessed by the Fit Statistics and the Principal Components Analysis of the Residuals. Patient data fit the Rasch model as demonstrated by the sound PSI and ISI following the removal of misfitting items. The Principal Components Analysis of the Residuals confirmed the instrument (containing content developed across all 10 Principles) was measuring one dimension, the latent variable, Dignity in Care.

The final 23-item patient version of the instrument was able to demonstrate construct validity, as assessed by the final PSI, indicating the item distribution is adequate to reliably generate person hierarchy, that the persons (patients) have a wide range of abilities and the persons (patients) could be grouped into different strata of the latent construct (dignity in care) they have experienced. Targeting, however, was not satisfactory, with many patient participants experiencing more of the latent variable (dignity in care), than the items were able to measure. The final patient version of the instrument included one item with moderate (but within acceptable parameters) DIF, which was retained due to content value.

The final 23-item patient version of the instrument was able to demonstrate internal reliability, as assessed by the ISI, which indicates the person (patient) distribution is adequate to reliably generate item hierarchy and that the items have a wide range of difficulties.

Analysis of the patient data was undertaken on a robust sample and the findings suggest the instrument demonstrates unidimensionality, construct validity and internal reliability.

6.3.8 Moving from the analysis of the patient data to the carer data

In the next Section (6.4), I present the analysis of the carer data. At this point it is important to reflect on one aspect of the study design that has been core to the development of the DiCQ, from the Delphi panel (Chapter 4) through to the Pilot study (Chapter 5) and remains an influence in the Stage 3 data analysis (Chapter 6). This study was designed to develop an instrument to measure the patient experience of Dignity in Care. The patient version of the questionnaire has been adapted at each step of the study to make the language appropriate for a carer to complete the questionnaire, when the patient is unable to do so, or would prefer for the carer to do so. The study was not designed to allow the patient and carer questionnaires to develop separately with different items. There are two reasons for this design. The first is to support the priority of the patient perspective. When the carer undertakes the DiCQ, they are doing so to report, to the best of their ability, given the time they have spent with the patient while they have been in hospital, what is important to the patient. The patient might or might not contribute to the information the carer uses to determine their responses.

Developing the patient version of the questionnaire, and adapting it for carers had, to this point in the study, been quite straight forward. Upon reaching the Stage 3 analysis, it was necessary, and methodologically sound, to be guided by the data, which serves to indicate which items are of relevance and importance to carers. As a result, in final versions, there were items in common between the patient and carer versions, items unique to the patient version and items unique to the carer version.

6.4 Results (Carer Data)

6.4.1 Demographic data (carers)

A total of 77 carers completed the carer version of the questionnaire. Recruitment failed to reach the target sample size of 150 for carer participation (sample size was justified in Chapter 3, Methodology, Section 3.3).

Carers were recruited following the same process used to recruit patients. Carers were recruited if they were present with the patient, while I was also in the ward, during a data collection day.

Almost half of the carer participants were the daughter of the patient (n = 36; 47%) and approximately a quarter of carer participants were the spouse (n = 20; 25%). The relationship of the carers, who completed the questionnaire, to the patient, are listed in Table 6. 25.

Table 6. 25 Relationship of carer to patient

Relationship of carer to patient	n	%
Daughter	36	46.8%
Spouse	20	26.0%
Son	14	18.2%
Relative	6	7.8%
Friend	1	1.3%
Total	**77**	**100%**

The most frequent reasons why the carer completed the questionnaire was because the patient had cognitive impairment (n = 25; 36%) or because the patient wanted the carer to complete the questionnaire (n = 24; 31%). The reasons why carers completed the questionnaire are listed in Table 6. 26.

Table 6. 26 Reason carer completed questionnaire

Reason carer completed questionnaire	n	%
Patient has cognitive impairment	25	32.5%
Patient wants carer to do questionnaire	24	31.2%
Patient is too unwell	14	18.2%
Both patient and carer participated	12	15.6%
Patient does not speak English and does not want to use an interpreter	2	2.6%
Total	**77**	**100%**

For patients who had a carer completing the questionnaire, 54.5% of the patients were male (n = 42) and 45.5% female (n = 35). On average patients were 84 years of age (standard deviation 8 years) when the carer completed the questionnaire. The gender and age of the patient, when the carers completed the questionnaire, are listed in Table 6. 27.

Table 6. 27 Gender and age of the patient (when the carer completed the questionnaire)

Gender	**Age category**	**n**	**%**
Female	65 to 79	9	11.7%
	80 +	26	33.8%
Male	65 to 79	10	13.0%
	80 +	32	41.6%
Total		**77**	**100%**

Thirty-eight (49%) patients had been in hospital for between one and five days and 39 (51%) patients had been in hospital for six or more days, when the carer completed the questionnaire Table 6. 28.

Table 6. 28 Length of stay of patient (prior to carer undertaking the questionnaire)

Length of stay (days)	**n**	**%**
1 to 5	38	49.4%
6 +	39	50.6%
Total	**77**	**100%**

All carers who completed the questionnaire spoke English. I was unable to recruit any carers who did not speak English as their first language.

6.4.2 Frequencies (carer data)

6.4.2.1. Floor and Ceiling effects (carer data)

The data in Table 6. 29 presents the response category totals across all 43 items (calculated from the raw data presented in Appendix I2). Across all items there were fewer ‘Never’ (4.0%) and ‘Rarely’ (3.3%) responses, demonstrating a floor effect (Table 6. 29). The carer data demonstrated a substantial ceiling effect, with 45.4% of ‘Always’ responses, which represents the highest experience of dignity in care. The same pattern of floor and ceiling effects was seen in the patient data (Table 6. 6).

Table 6. 29 Response category totals (carer data)

	Missing	Never	Rarely	Sometimes	Often	Always	Additional Response	Total
Totals	81	134	110	347	687	1,503	448	3,310
%	2.4%	4.0%	3.3%	10.5%	20.8%	45.4%	13.5%	100%

6.4.2.2. Missing data (carer data)

This study included two types of missing data. The first was data missing as a result of carer participants not responding to an item(s). The second was missing data created by treating the non-scalable ordinal response category in 13 items as 'missing data' (Table 6. 30).

There was very little missing data as a result of carer participants not responding to an item(s). Across all 43 items, there were only 81 (2.4%) missing responses (Appendix I2). The treatment of non-scalable ordinal response categories as 'missing data' created a lot of missing data. There were 15 items that included a non-scalable 'additional response category'. The number of responses from carer participants selecting the non-scalable response option (identified as 'missing data' for the purpose of the analysis) is detailed in Table 6. 30. The items from the carer data with excessive 'missing data' as a result of the 'additional response category' being treated as 'missing data' were items 3.2, 3.4, 3.5 and 8.5. These four items were removed, leaving 39 items remaining for inclusion in the Rasch analysis.

Table 6. 30 Number of carer participants who selected the non-scalable response option

Item	Response categories	Participants who selected the non-scalable response category (n,%)
1.2	NRSOA plus 'The patient has not used the call bell'	17 carers (22.1%) selected the 'The patient has not used the call bell' response
1.5	NRSOA plus 'The patient has no pain or appears to have no pain'	10 carers (13.0%) selected the 'The patient has no pain or appears to have no pain' response
3.2	NRSOA plus 'The patient does not need an interpreter'	74 carers (96.1%) selected the 'The patient does not need an interpreter' response *
3.3	NRSOA plus 'Unsure'	16 carers (20.8%) selected the 'Unsure' response
3.4	Item 3.4 NRSOA plus 'N/A'	60 carers (77.9%) selected the 'N/A' response
3.5	Item 3.5 NRSOA plus 'N/A'	45 carers (58.4%) selected the 'N/A' response
4.4	Item 4.4 NRSOA plus 'Unsure'	11 carers (14.3%) selected the 'Unsure' response
5.5	NRSOA plus 'Discharge has not been discussed'	37 carers (48.1%) selected the 'Discharge has not been discussed' response
8.1	Item 8.1 NRSOA plus 'N/A'	9 carers (11.7%) selected 'N/A' response
8.2	Item 8.2 NRSOA plus 'N/A'	7 carers (9.1%) selected the 'N/A' response
8.3	Item 8.3 NRSOA plus 'N/A'	17 carers (22.1%) selected the 'N/A' response *
8.4	Item 8.4 NRSOA plus 'N/A'	36 carers (46.8%) selected the 'N/A' response *
8.5	NRSOA plus 'Interpreter not required'	75 carers (97.4%) selected the 'Interpreter not required' response *
9.5	NRSOA plus 'N/A'	5 carers (6.5%) selected the 'N/A' response
10.3	NRSOA plus 'The patient has not been bored'	23 carers (29.9%) selected the 'The patient has not been bored' response

Legend: 'Never', 'Rarely', 'Sometimes', 'Often' and 'Always (NRSOA). Not Applicable (N/A) *
Items 3.2, 8.3, 8.4 and 8.5 were removed from the Rasch analysis due to the extent of missing data

6.4.3 Descriptive Statistics (carer data)

6.4.3.1. Skewness and Kurtosis

The distribution of carer scores was assessed, by item, for skewness and kurtosis. Of the 39 items (43 items minus 4 items with extreme 'missing data'), five items had skewness outside of acceptable parameters (> -2.00 to < +2.00) and 11 items had kurtosis outside of acceptable parameters (> -2.00 to < +2.00)[215] (Appendix J2).

6.4.4 Response rate (carer data)

A response rate was not calculated, the reasons are covered in the discussion.

6.4.5 Results of the Rasch analysis (carer data)

The steps in the Rasch analysis of the carer data, followed the same steps undertaken in the Rasch analysis of the patient data. The steps include examination of Person Separation Index (PSI), Item Separation Index (ISI), Category Threshold Order, Response Dependency, Fit Statistics, Principal Components Analysis of the Residuals, Targeting and Differential Item Functioning.

The starting point for the Rasch analysis was 39 items. These items are remaining (from the 50-item questionnaire used for the data collection, refer Appendix G2) after the removal of seven items (4.5, 7.2, 7.3, 7.4, 7.5, 10.4 and 10.5) with non-scalable ordinal response categories (detailed in Table 6. 1) and four items (3.2, 3.4, 3.5 and 8.5) with extreme ‘missing data’ (detailed in Table 6. 30). Throughout this section, the figure below (Figure 6. 8) will be built on to assist the reader to keep track of the items removed and retained as the analysis progresses.

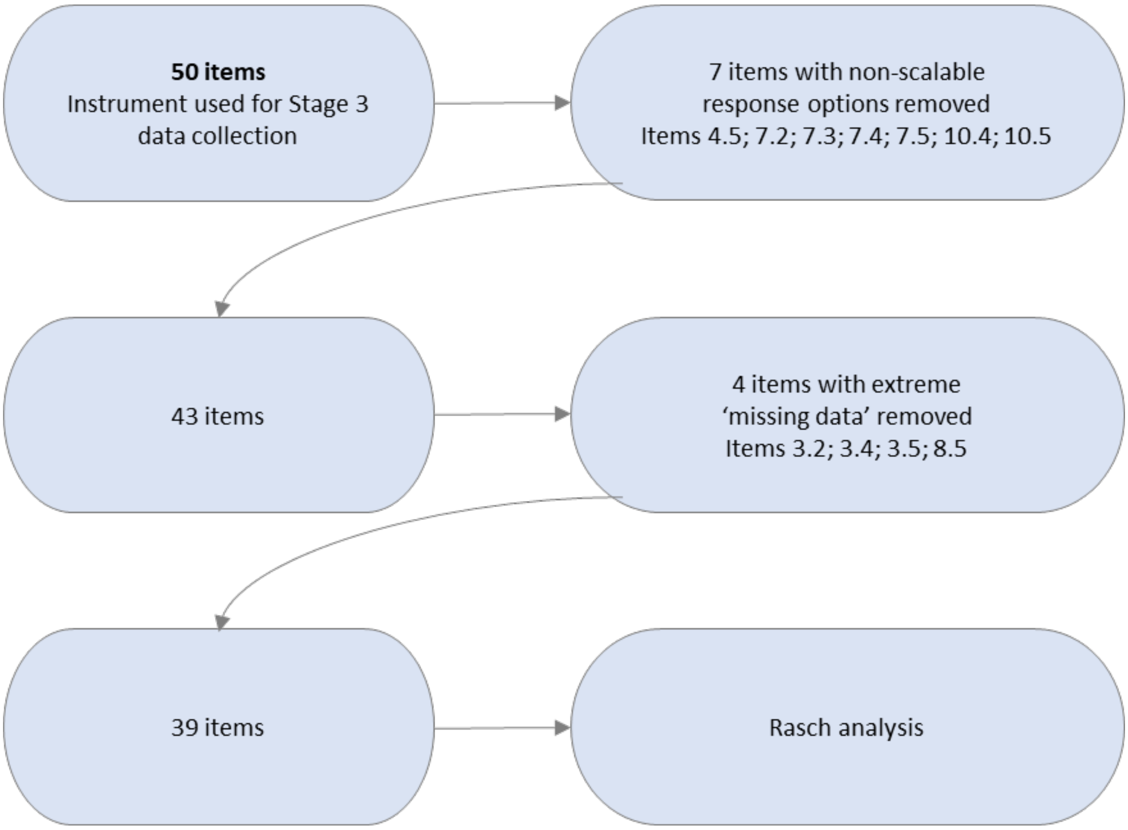


Figure 6. 8 Tracking items removed prior to Rasch analysis (carer data)

6.4.5.1. Person Separation and Item Separation (carer data)

The PSI and ISI for the 39-item instrument (43-items minus the four items with extreme 'missing data' 3.2, 3.4, 3.5, 8.5) were all within acceptable parameters (Table 6. 31).

Table 6. 31 Person Separation and Item Separation (carer data)

Measured by	**Acceptable parameters**	**39-item instrument**
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.52 (0.86)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	4.27 (0.95)

6.4.5.2. Category Threshold Order (carer data)

The category probability curves were disordered for all 39 items. This finding was not surprising given the underutilised category (response option) of 'Never' accounted for 4.0%, and 'Rarely' accounted for 3.3%, of all responses (Table 6. 29 and Appendix I2).

The 'Never' and 'Rarely' response options were collapsed, this resulted in the thresholds becoming ordered for all 39 items. Collapsing the response categories is undertaken by making changes to the Winsteps control files (Appendix H).

By way of example, for item 1.1, the original Category Threshold Curve is shown in Figure 6. 9, in the figure on the left, the blue line (category probability 2) is underneath category probability 3, indicating disordered categories. Collapsing the response categories 'Never' and 'Rarely' restored order (figure on the right).

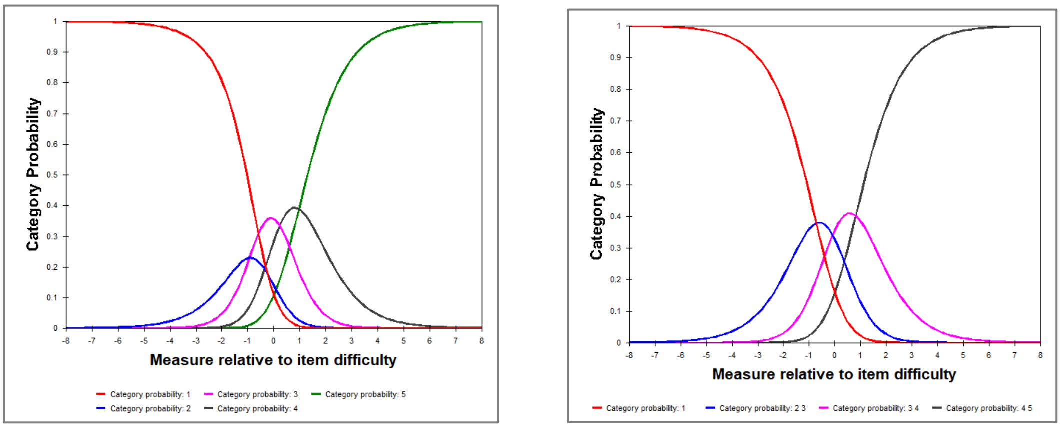


Figure 6. 9 Category Probability Curves for Item 1.1 (carer data)

Legend: Original Category Probability Curve (figure on left), collapse of 'Never and Rarely' (figure on right)

6.4.5.3. Person Separation (carer data)

Following the collapse of the 'Never' and 'Rarely' response categories, the PSI and ISI remained within acceptable parameters (Table 6. 32).

Table 6. 32 Person Separation and Item Separation pre and post collapse of response categories (carer data)

Measured by	Acceptable parameters	39-item instrument
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.72 (0.88)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	4.36 (0.95)

6.4.5.4. Subscale analysis (carer data)

The subscale analysis of the patient data (Table 6. 10) found no subscale had construct validity. There was no purpose or value in undertaking subscale analysis of the carer data.

6.4.5.5. Fit Statistics (carer data)

Four items (1.4, 2.1, 4.4 and 8.1) were removed because they had fit statistics outside of the acceptable parameters. Items were removed (or retained) iteratively, and after each item was removed, the fit statistics and the PSI and ISI were assessed for the remaining items (Table 6. 33). The PSI and ISI increased throughout the iterative process of item removal with one exception. Item 3.3 was retained despite having an Infit of 2.42 MnSq and an Outfit of 2.55 MnSq because removing the item had a detrimental effect on the model (PSI dropped from 2.71 to 2.29 and ISI dropped from 6.76 to 5.73). Item 10.1 was retained, with an acceptable Infit of 1.57 MnSq.

Table 6. 33 Fit Statistics (carer data)

Fit Statistics	Item	Fit Statistics		Model Statistics	
		Infit MnSq (ZSTD)	Outfit MnSq (ZSTD)	PSI (PSRC)	ISI (ISRC)
Fit statistics sorted by highest Infit MnSq (Item 3.3) Baseline PSI/ISI (39 items)	3.3*	2.23 (4.03)	2.29 (3.48)	2.72 (0.88)	4.36 (0.95)
Item 3.3 retained * After Item 3.3 the next highest Infit MnSq is Item 1.4	1.4	2.03 (1.68)	2.25 (1.39)		
Delete Item 1.4 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq	8.1	1.81 (3.96)	2.06 (4.01)	2.72 (0.88)	4.44 (0.95)
Delete Item 8.1 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq	4.4	1.81 (3.74)	2.09 (3.89)	2.76 (0.88)	4.54 (0.95)
Delete Item 4.4 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq	2.1	1.67 (3.54)	1.96 (3.94)	2.80 (0.89)	4.65 (0.96)
Delete Item 2.1 Rerun PSI/ISI Rerun Fit Statistics, sort by highest Infit MnSq	10.1*	1.57 (2.85)	1.47 (2.05)	2.83 (0.89)	4.73 (0.96)
* Items 3.3 and 10.1 retained (Refer to Discussion, Section 6.6) All remaining items have Infit < 1.5 MnSq					

Person Separation Index (PSI), Person Separation Reliability Coefficient (PSRC), Item Separation Index (ISI), Item Separation Reliability Coefficient (ISRC). * Items retained based on value of content

Following the removal of four misfitting items, there were 35 items that proceeded to the next step in the Rasch analysis. Figure 6. 10 shows the tracking of items as the Rasch analysis progresses to 35 items (for the carer data). A further review of the fit statistics for the final items remaining in the instrument will be presented in Section 6.4.5.7, once all items have been removed, as a result of the findings, and expert opinion, at each step of the analysis.

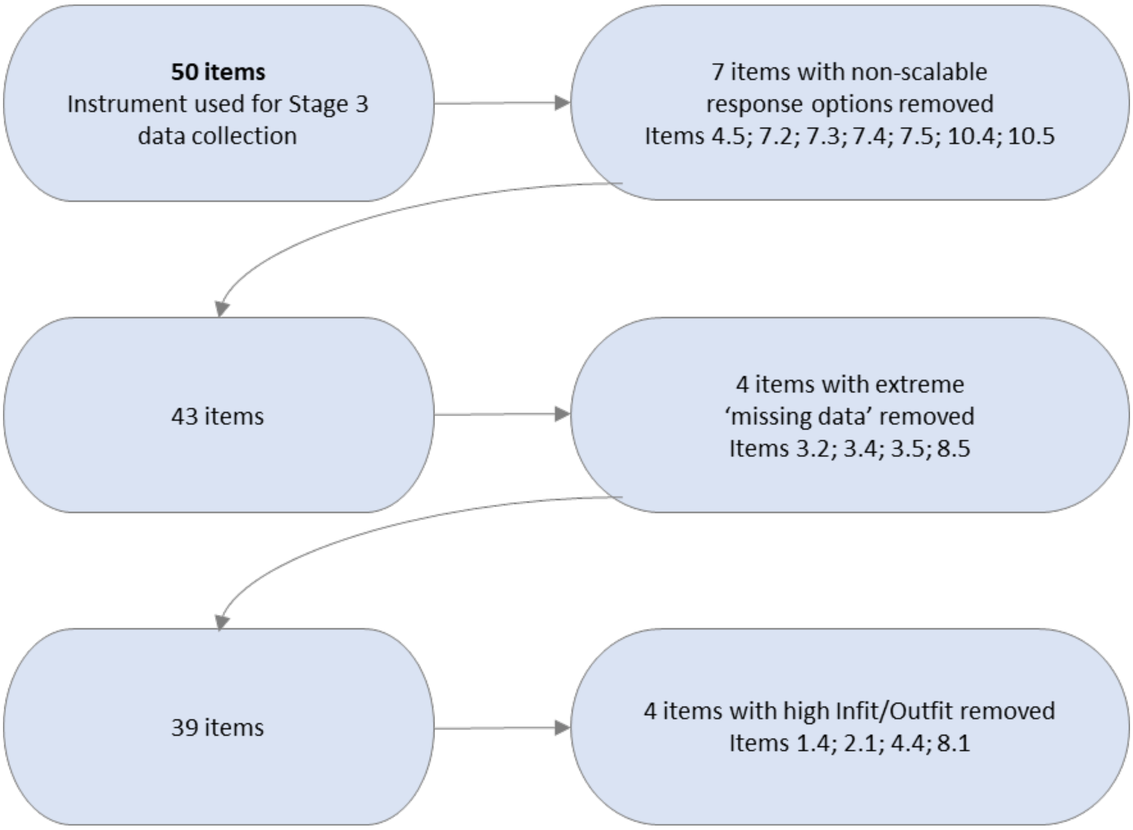


Figure 6. 10 Tracking items as the Rasch analysis progresses to 35 items (carer data)

6.4.5.6. Response Dependency (carer data)

Of the 35 items remaining in the analysis, 48 pairs of items (Table 6. 34) had residual item correlations above the acceptable parameter (0.18), suggesting response dependency (single items were represented multiple times in the item pairs). The acceptable parameter was determined by taking an average of all residual item correlations (which was -0.02) and add 0.2 [188]. (Refer Section 3.1.5.5, Chapter 3, Methodology). The treatment of response dependency, used in this study, was to consider removing one of each of the item pairs with high residual item correlations. Judgement as to which item (of the pair) to remove was made by first removing items which appeared frequently in pairs with high item correlations, and second, by using 'expert' judgement to determine which item should be retained and which removed (Table 6. 34). Examples are given, justifying the retention and removal of items, in the Discussion (Section 6.6).

Table 6. 34 Items with high standardized residual item correlations (carer data)

Item	Item	SRIC	Resolution
4.1	4.2	0.79	Remove Item 4.1
6.4	6.5	0.64	Remove Item 6.5
6.3	6.4	0.57	Remove Item 6.3
1.5	2.4	0.50	Remove Item 2.4
6.2	6.4	0.49	Remove Item 6.2
6.3	6.5	0.48	Remove Item 6.5
4.2	8.2	0.40	Remove Item 4.2
5.1	5.4	0.39	Remove Item 5.4
6.2	6.5	0.37	Remove Item 6.2
2.2	9.2	0.36	Remove Item 9.2
6.2	6.3	0.35	Remove Item 6.2
1.1	1.3	0.34	Remove Item 1.1
8.3	9.1	0.32	Remove Item 9.1
5.4	9.3	0.32	Remove Item 5.4
5.2	5.4	0.32	Remove Item 5.2
4.1	8.2	0.32	Remove Item 4.1
2.5	5.2	0.31	Remove Item 5.2
1.2	9.5	0.31	Remove Item 1.2
2.2	3.1	0.31	Both should be retained based on content
9.5	10.3	0.31	Remove Item 10.3
1.5	4.2	0.30	Remove Item 4.2
1.2	2.5	0.30	Remove Item 1.2
6.1	8.4	0.29	Remove Item 6.1
8.3	10.1	0.29	Remove Item 10.1
9.1	9.2	0.28	Remove Item 9.1
2.3	2.4	0.28	Remove Item 2.4
1.2	10.2	0.27	Remove Item 1.2
5.2	7.1	0.27	Remove Item 5.2
4.2	5.5	0.26	Remove Item 4.2
5.4	5.5	0.26	Remove Item 5.4
10.1	10.2	0.25	Remove Item 10.1
10.2	10.3	0.25	Remove Item 10.3
6.1	10.3	0.24	Remove Item 6.1
2.3	2.5	0.24	Remove Item 2.3
5.2	8.4	0.23	Remove Item 5.2
6.4	9.4	0.23	Remove Item 9.4
8.2	8.3	0.22	Both should be retained based on content
6.1	6.2	0.22	Remove Item 6.1
9.1	9.5	0.22	Remove Item 9.1

5.4	7.1	0.22	Remove Item 5.4
5.5	7.1	0.22	Both should be retained based on content
1.5	4.1	0.21	Remove Item 4.1
1.1	1.2	0.21	Remove Item 1.1
4.2	5.3	0.20	Remove Item 4.2
5.3	7.1	0.20	Both should be retained based on content
3.3	9.4	0.20	Remove Item 9.4
4.3	9.1	0.20	Remove Item 9.1
5.2	6.1	0.19	Remove Item 5.2

Legend: Standardised Residual Item Correlations (SRIC)

Eighteen items (1.3, 1.5, 2.2, 2.5, 3.1, 3.3, 4.3, 5.1, 5.3, 5.5, 6.4, 7.1, 8.2, 8.3, 8.4, 9.3, 9.5 and 10.2) were retained based on ‘expert’ judgement. Thirteen (1.3; 1.5; 2.2; 2.5; 3.1; 3.3; 4.3; 5.1; 5.3; 5.5; 6.4; 7.1 and 10.2) of those 18 items were retained as they were items also retained in the patient version.

Nine items (1.2, 4.2, 5.2, 5.4, 6.1, 6.2, 6.3, 6.5 and 9.1) were removed as they were identified multiple times in item pairs with high standardized residual item correlations.

Eight items (1.1, 2.3, 2.4, 4.1, 9.2, 9.4, 10.1 and 10.3) were removed based on ‘expert’ judgment.

Following the removal of each of the 17 items, the PSI/ISI was examined to determine the effect of the item reduction on the model. A marginal decrease in PSI and a marginal increase in ISI occurred as each item was removed.

Table 6. 35 Items with high residual correlations and model statistics (carer data)

Action	Model Statistics			
	PSI	PSRC	ISI	ISRC
Baseline	2.83	0.89	4.73	0.96
Delete 4.1 and re run PSI/ISI	2.82	0.89	4.76	0.96
Delete 6.5 and re run PSI/ISI	2.78	0.89	4.77	0.96
Delete 6.3 and re run PSI/ISI	2.75	0.88	4.71	0.96
Delete 2.4 and re run PSI/ISI	2.71	0.88	4.72	0.96
Delete 6.2 and re run PSI/ISI	2.69	0.88	4.78	0.96
Delete 4.2 and re run PSI/ISI	2.70	0.88	4.84	0.96
Delete 5.4 and re run PSI/ISI	2.64	0.87	4.89	0.96
Delete 9.2 and re run PSI/ISI	2.60	0.87	4.88	0.96
Delete 1.1 and re run PSI/ISI	2.56	0.87	4.90	0.96
Delete 9.1 and re run PSI/ISI	2.54	0.87	4.92	0.96
Delete 5.2 and re run PSI/ISI	2.47	0.86	4.97	0.96
Delete 1.2 and re run PSI/ISI	2.40	0.85	5.02	0.96
Delete 10.3 and re run PSI/ISI	2.35	0.85	4.79	0.96
Delete 6.1 and re run PSI/ISI	2.30	0.84	4.87	0.96
Delete 10.1 and re run PSI/ISI	2.24	0.83	4.68	0.96
Delete 2.3 and re run PSI/ISI	2.20	0.83	4.67	0.96
Delete 9.4 and re run PSI/ISI	2.14	0.82	4.76	0.96

Legend: Person Separation Index (PSI), Person Separation Reliability Coefficient (PSRC), Item Separation Index (ISI), Item Separation Reliability Coefficient (ISRC)

There were four item pairs with standardized residual item correlations, outside of the acceptable parameter (>0.18), that were all retained based on their content (Table 6. 36). These five items (2.5, 5.1, 6.4, 9.3 and 10.2) were retained, the reasons are as follows. Items 2.5, 5.1, 6.4 and 10.2 were retained in the patient version (refer Section 6.3.5.5). Item 9.3 was retained in the carer version as it only appeared in one high residual item correlation (with Item 5.4 which was removed because it appeared in multiple high residual item correlations).

Table 6. 36 Items with high residual correlations that were retained for content

	Item	Item	SRIC
Both items retained based on content	2.5	10.2	0.23
Both items retained based on content	6.4	10.2	0.23
Both items retained based on content	5.1	9.3	0.22

Legend: Standardised Residual Item Correlations (SRIC)

Following the removal of 17 items due to response dependency, there were 18 items that proceeded to the next step in the Rasch analysis. Shows the tracking of items as the Rasch analysis progresses to 18 items (for the carer instrument).

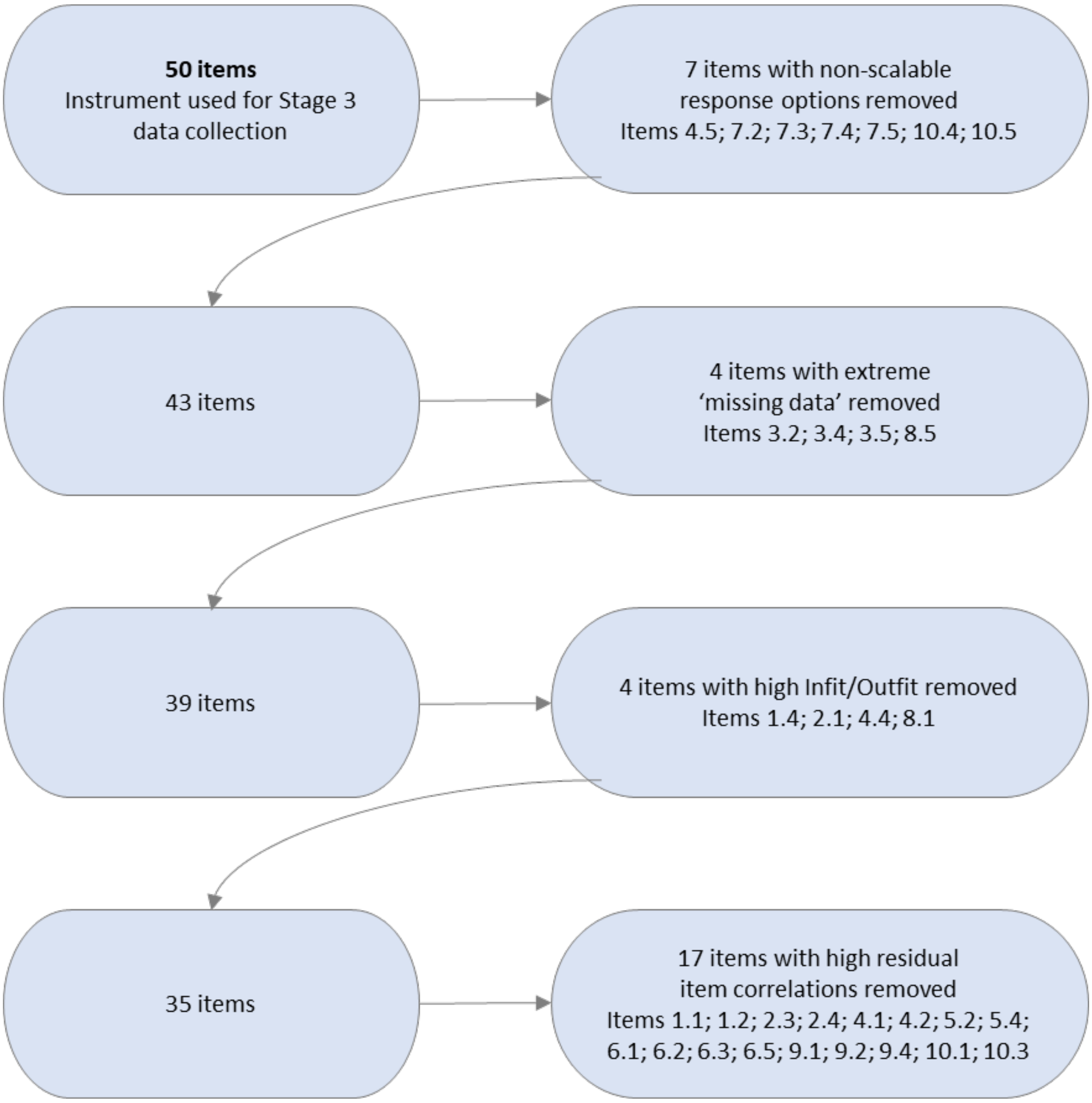


Figure 6. 11 Tracking items as the Rasch analysis progresses to 18 items (carer data)

6.4.5.7. Fit statistics for the final 18 items (carer version)

At this point, all decisions had been made about which items to retain and which items to remove. It is timely to review the fit statistics for the final 18 items, before I progress to the final steps in the analysis.

The fit statistic for the final 18 items in the instrument are presented in Table 6. 37. Item 1.3 has an Outfit MnSq (2.23) outside of the acceptable parameter but the item has an acceptable Infit MnSq (1.27). Item 3.3 has Infit and Outfit MnSq outside of acceptable parameters; justification for retaining item 3.3 was presented in Section 6.4.6.5.

Table 6. 37 Fit Statistics for the final 18 items (carer data)

Item	Infit MnSq (Zstd)	Outfit MnSq (Zstd)
1.3	1.27 (1.24)	2.23 (2.99)
1.5	1.10 (0.50)	1.39 (1.26)
2.2	1.20 (1.18)	1.07 (0.37)
2.5	0.69 (1.79)	0.83 (-0.60)
3.1	1.22 (0.90)	1.22 (0.67)
3.3	2.28 (4.20)	2.11 (3.07)
4.3	1.12 (0.70)	1.30 (1.19)
5.1	0.73 (1.64)	0.62 (1.76)
5.3	0.94 (-0.38)	0.88 (-0.67)
5.5	1.22 (0.99)	0.96 (-0.05)
6.4	0.57 (2.12)	0.56 (1.33)
7.1	0.58 (3.03)	0.54 (2.66)
8.2	1.20 (1.17)	1.10 (0.49)
8.3	1.29 (1.60)	1.11 (0.60)
8.4	0.60 (2.00)	0.52 (1.82)
9.3	0.57 (2.56)	0.52 (2.10)
9.5	1.29 (1.64)	1.33 (1.68)
10.2	0.80 (1.33)	0.79 (1.20)

Following the removal of items due to misfit and response dependency, the PSI and ISI for the final 18-item instrument remained within acceptable parameters (Table 6. 38).

Table 6. 38 Person Separation and Item Separation of the final 18-item instrument (carer version)

Measured by	Acceptable parameters	18-item instrument
Person Separation Index (Person Separation Reliability Coefficient)	> 2.0 (> 0.80) [176]	2.14 (0.82)
Item Separation Index (Item Separation Reliability Coefficient)	> 3.0 (> 0.90) [176]	4.76 (0.96)

6.4.5.8. Principal Components Analysis of the Residuals (carer data)

The Principal Components Analysis of the residuals was examined using two measures: 1) Raw variance explained by measures and 2) Unexplained variance in 1st contrast (Table 6. 39).

Table 6. 39 Principal Components Analysis of the Residuals (carer data)

Measured by	**Acceptable parameters**	**18-item instrument**
Raw variance explained by measures	Observed approximates expected [189]	Observed 53.7% Expected 54.2%
Unexplained variance in 1st contrast	<3.0 (< 5%)/High[190]	Eigen 2.11 Observed 5.4% Expected 11.7%

First, I reported on the raw variance explained by measures. Linacre argues [189] it is not the size of the variance, but rather whether the observed value is close to the expected value that is of importance. Based on the PCA of the 18-item instrument, the observed raw variance explained by the measure was 53.7%, which is close to the expected 54.2% (Table 6. 39).

Second, I reported on the unexplained variance in the 1st contrast. Based on the 18-item instrument, the eigen value was 2.11, which is within the acceptable parameter (<3.0). The observed variance of 5.4% is just outside the acceptable parameter (<5.0%) and the expected variance of 11.7% (Table 6. 39).

The PCA revealed that items were grouped into a pattern of three clusters (Table 6. 40). These clusters were identified in Winsteps Table 23.1 [189] based on their loading on the 1st contrast [189].

Table 6. 40 Clusters identified in the Principal Components Analysis of the Residuals by items (carer data)

Cluster 1	1.3	2.5	5.1	6.4	9.3	9.5	10.2
Cluster 2	1.5	2.2	5.5	7.1	8.4		
Cluster 3	3.1	3.3	4.3	5.3	8.2	8.3	

Because of the number of items in each cluster [189] (i.e., more than two in each cluster), the clusters were investigated further to determine if they were simply the same dimension measured differently[189], or indeed, representing different dimensions, which might suggest multidimensionality. The investigation involved examination of the Pearson correlation and the disattenuated correlation between each cluster. The Person correlations between each cluster were all >0.4 and the disattenuated correlations between Cluster 1 and 2 and between Cluster 2 and 3 were above >0.7, which suggests these are simply groupings of items, which are all contributing to the same dimension [189] (Table 6. 41). The disattenuated correlation between Cluster 1 and 3 was marginal at 0.68 (rounded to 0.7) and did not justify further investigation. Noting also, the marginal finding is likely the result of the inadequate sample size. Based on these findings, it is reasonable to assume the three clusters are simply groupings of items, which are all contributing to the same dimension.

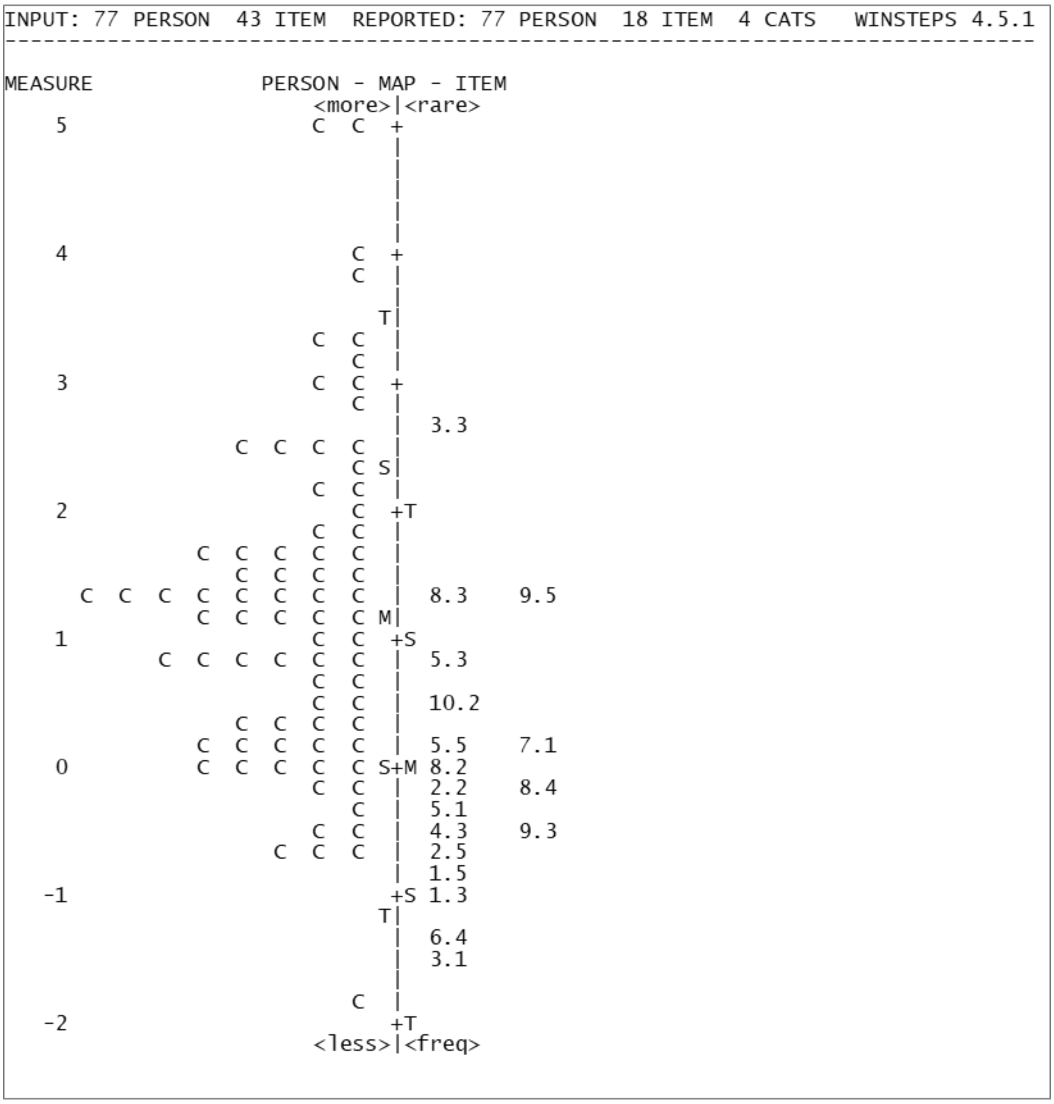
Table 6. 41 Between cluster correlations (carer data)

	Pearson Correlation	**Disattenuated Correlation**
Cluster 1 – Cluster 3	0.45	0.68
Cluster 1 – Cluster 2	0.62	1.00
Cluster 2 – Cluster 3	0.65	1.00

6.4.5.9. Targeting

The person-item map demonstrates that the 18-item instrument had poor targeting (Figure 6. 12). The person-item map demonstrates that disproportionately more carer participants experienced more of the latent variable (located toward the top of the map) relative to the items, which were relatively less challenging to answer (located toward the bottom of the map). In other words, about 50% of the sample experienced higher dignity in care than could be measured with the set of items used [176].

The difference between the person and items means was 1.25 logits, which is outside the optimal parameter of 1 logit. The 18 items spanned a range from -1.45 to 2.72 logits, which is a reasonably broad range, but only one item (item 3.3) is located in the upper end of the range.



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INPUT: 77 PERSON  43 ITEM  REPORTED: 77 PERSON  18 ITEM  4 CATS   WINSTEPS 4.5.1
--------------------------------------------------------------------------------

MEASURE             PERSON - MAP - ITEM
                        <more>|<rare>
    5                   C  C  +
                              |
                              |
                              |
                              |
                              |
    4                      C  +
                           C  |
                              |
                             T|
                        C  C  |
                           C  |
    3                   C  C  +
                           C  |
                              |  3.3
                  C  C  C  C  |
                           C S|
                        C  C  |
    2                      C  +T
                        C  C  |
               C  C  C  C  C  |
                  C  C  C  C  |
      C  C  C  C  C  C  C  C  |  8.3    9.5
               C  C  C  C  C M|
    1                   C  C  +S
            C  C  C  C  C  C  |  5.3
                        C  C  |
                        C  C  |  10.2
                  C  C  C  C  |
               C  C  C  C  C  |  5.5    7.1
    0          C  C  C  C  C S+M 8.2
                        C  C  |  2.2    8.4
                           C  |  5.1
                        C  C  |  4.3    9.3
                     C  C  C  |  2.5
                              |  1.5
   -1                         +S 1.3
                             T|
                              |  6.4
                              |  3.1
                              |
                           C  |
   -2                         +T
                        <less>|<freq>
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Figure 6. 12 Person-item Map for the 18-item instrument (carer data)

Legend. The persons (each carer participant = 'P') are represented on the left of the scale and items, by item number, on the right of the scale (e.g., item 3.3 on the top right). The vertical dashed line represents the logit scale, M=mean; S= 1 standard deviation from the mean, T= 2 standard deviations from the mean. The M, S and T are shown for both items and persons. The more difficult items, and persons with a higher level of dignity, are placed at the top of the scale and vice versa.

6.4.5.10. Differential Item Functioning (carer data)

Differential Item Functioning (DIF) was analysed by gender (Table 6. 42), by age (65 to 79 years versus 80 and over) (Table 6. 43) and by length of stay (one to five days versus six or more days) (Table 6. 44). Noting it was the patient's gender and age that was recorded (not the carer's). To fit the Rasch model, it is optimal for all items to have a DIF Contrast < 0.50 logits, it is acceptable if some items are between 0.5 and 1.0 logits, and unacceptable to have more than one item with DIF Contrast > 1.0 logits [191]. Given the small sample size, the number of items with DIF are not surprising. Further investigation of these items should be undertaken in any further development of the carer version of the instrument. In this preliminary analysis, no items were removed on the basis of DIF.

Table 6. 42 Items with greater than negligible DIF by gender (carer data)

Items with DIF Contrast < 0.50 logits	17 items
Items with DIF between 0.5 and 1.0 logits	nil
Items with DIF > 1.0 logits	1 item (Item 3.1, DIF Contrast = 1.32)

Table 6. 43 Items with greater than negligible DIF by age category (carer data)

Items with DIF Contrast < 0.50 logits	11 items
Items with DIF between 0.5 and 1.0 logits	6 items: Item 1.3, DIF Contrast -0.53 Item 2.2, DIF Contrast -0.80 Item 3.1, DIF Contrast -0.61 Item 5.3, DIF Contrast -0.60 Item 5.5, DIF Contrast 0.75 Item 6.4, DIF Contrast -0.63
Items with DIF > 1.0 logits	1 item (Item 1.5, DIF Contrast 1.12)

Table 6. 44 Items with greater than negligible DIF by length of stay category (carer data)

Items with DIF Contrast ≤ 0.50 logits	14 items
Items with DIF between 0.5 and 1.0 logits	4 items: Item 2.2, DIF Contrast -0.98 Item 3.3, DIF Contrast -0.68 Item 8.3, DIF Contrast -0.89 Item 9.5, DIF Contrast 0.69
Items with DIF > 1.0 logits	nil

6.4.5.11. Rescale Dignity in Care Summary Score (carer data)

Based on the final 18 items, the DiCQ score for each of the 77 carers was rescaled in Winsteps, from measurement in logits (Winsteps output), to a 0 to 100 scale, useful for the presentation of comparative analysis. The rescaled carer scores for the 77 carers ranged from 22 to 69 (Figure 6. 13).

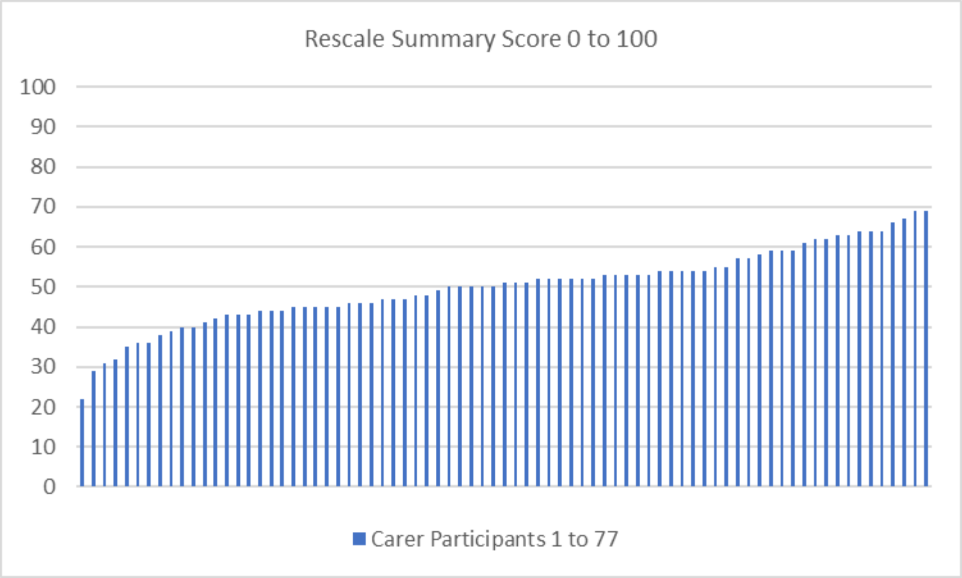

Figure 6. 13 Carer summary score rescaled from 0 to 100 for the 18-item instrument (carer data)

Legend: Each blue line represents one (of the 77) carer participants

6.4.5.12. Summary Score by Gender, Age, Length of Stay and Data Collection Site (carer data)

There were no statistically significant differences between summary scores for patient based on gender, length of stay (0 to 5 days versus 6 or more days) and age (65 to 79 years versus 80 years and over) (Table 6. 45).

Table 6. 45 Test statistics by summary score for gender, length of stay and age (carer data)

	Gender	Length of Stay	Age
Mann Whitney U	611	727.00	398.00
p. (2-tailed)	0.204	0.886	0.067

Analysis of carer data by summary score across data collection sites was not undertaken due to the small sample size across three of the four data collection sites.

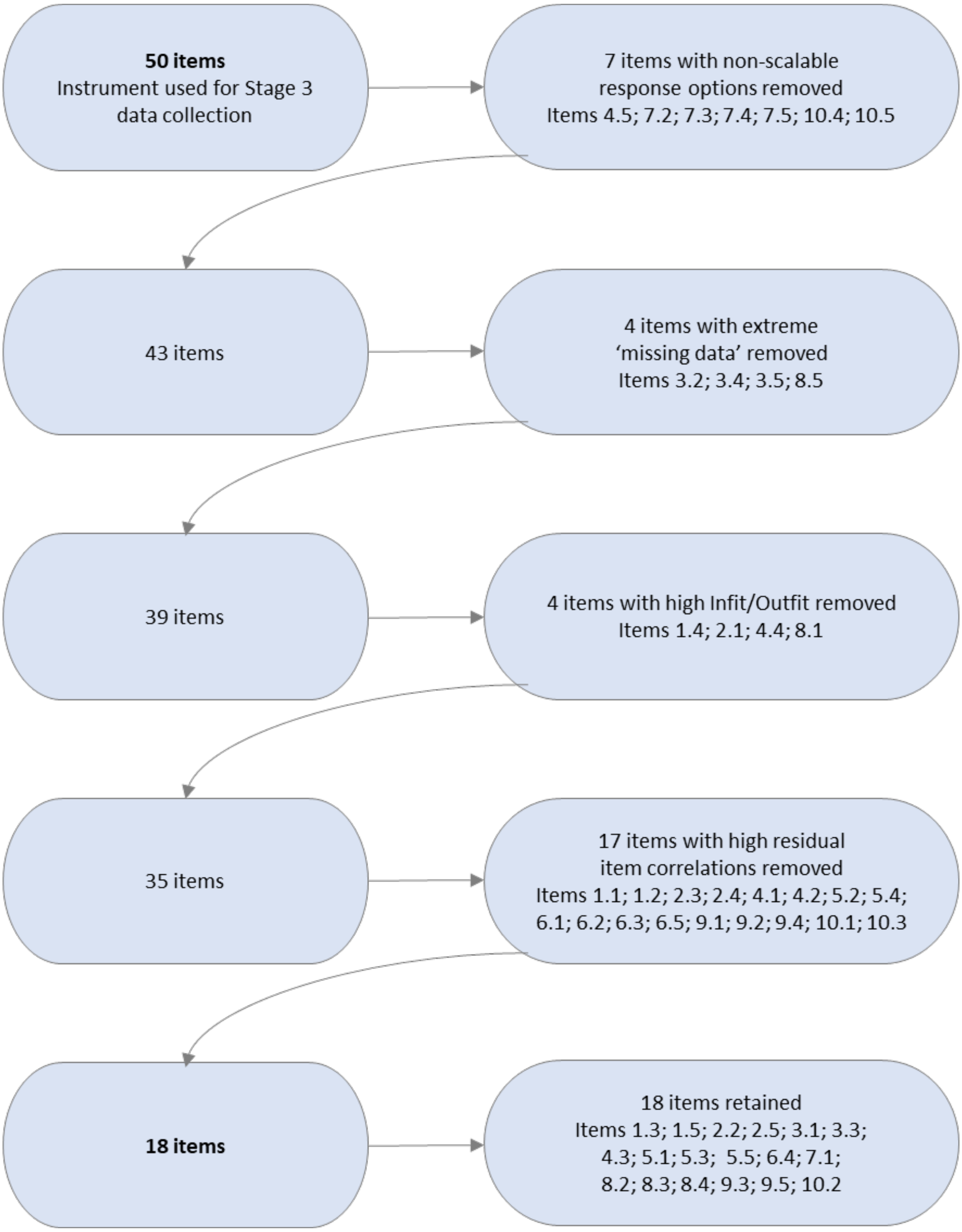

Figure 6. 14 Tracking items through the Rasch analysis to the final 18 items (carer data)

6.4.6 Summary of overall performance (carer version)

From the 50-item questionnaire used in the Stage 3 data collection, seven items were removed as they had non-scalable response options and four items were removed as they had excessive missing data. Rasch analysis was undertaken on 39 items, of these, four items were removed due to misfit and 17 items were removed due to response dependency (Figure 6. 14). Instrument development was guided by the findings of each step of the Rasch analysis, supplemented by ‘expert’ judgement, to maintain content validity.

The final 18-item carer version of the instrument (Appendix K2) was able to demonstrate unidimensionality, as assessed by the Fit Statistics and the Principal Components Analysis of the Residuals. Carer data fit the Rasch model as demonstrated by the acceptable PSI and ISI following removal of the misfitting items. The Principal Components Analysis of the Residuals confirmed the instrument (containing content developed across all 10 Principles) was measuring one dimension, the latent variable, Dignity in Care.

The final 18-item carer version of the instrument was able to demonstrate acceptable construct validity in some of the findings, while others indicated areas of concern. This uncertain finding was unsurprising given the inadequate sample size. The acceptable PSI indicated item distribution was adequate to reliably generate person hierarchy, that the persons (carers) have a wide range of abilities and the persons (carers) could be grouped into different strata of the latent construct (dignity in care) they have experienced. Targeting, however, was not satisfactory, with many carer participants experiencing more of the latent variable (dignity in care) than the items were able to measure. The final version of the instrument also indicated that there were a number of items demonstrating moderate to large DIF.

The final 18-item carer version of the instrument was able to demonstrate internal reliability, as assessed by the ISI, which indicated the person (carer) distribution was adequate to reliably generate item hierarchy and that the items have a wide range of difficulties.

Analysis of the carer data was undertaken on an inadequate sample size and the findings should be considered exploratory and preliminary. The findings requires confirmation with a larger sample.

6.5 Comparing the content of the final patient and carer versions of the instrument

The patient and carer versions of the instrument used in the Stage 3 data collection had 50 items in common, they were simply written from either the patient or the carer's perspective. As the Rasch analysis progressed, the findings suggested that some items should be dealt with differently in the patient analysis and the carer analysis. The item changes at each step of the analysis are shown in Figure 6. 15, the grey shapes indicate the common starting point, the red shapes show the patient version and the blue shapes show the carer version.

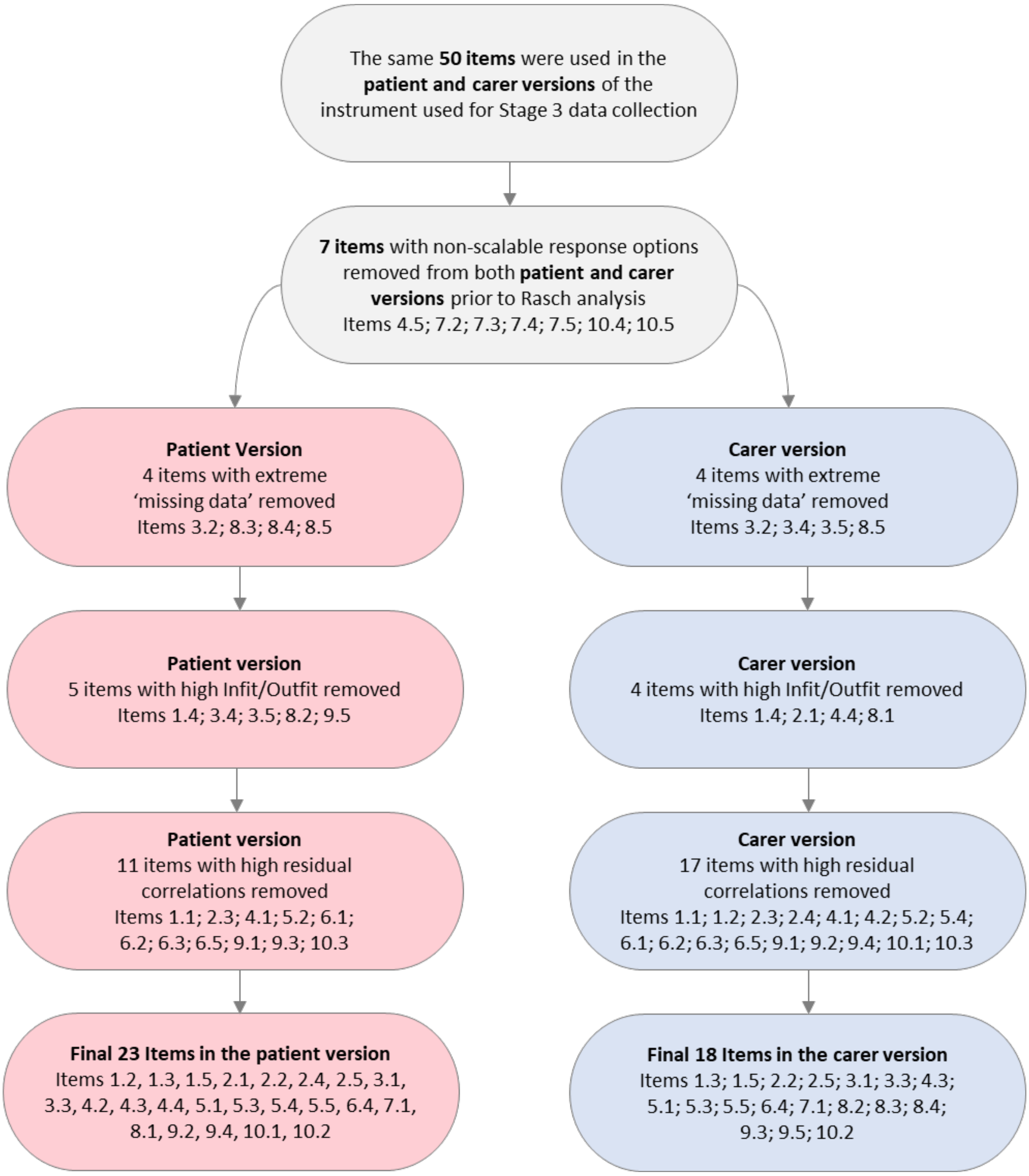

Figure 6. 15 Comparing the content of the final patient and carer versions of the instrument

The last step in Figure 6. 15 is repeated in Figure 6. 16 showing the final 23 items in the patient version and the final 18 items in the carer version. The central grey shape in Figure 6. 16 shows the 13 items in common across the patient and carer versions. There were an additional 10 items retained only in the patient version and 5 items retained only in the carer version (Figure 6. 16). Examples are given, justifying the retention and removal of items, in the Discussion (Section 6.6).

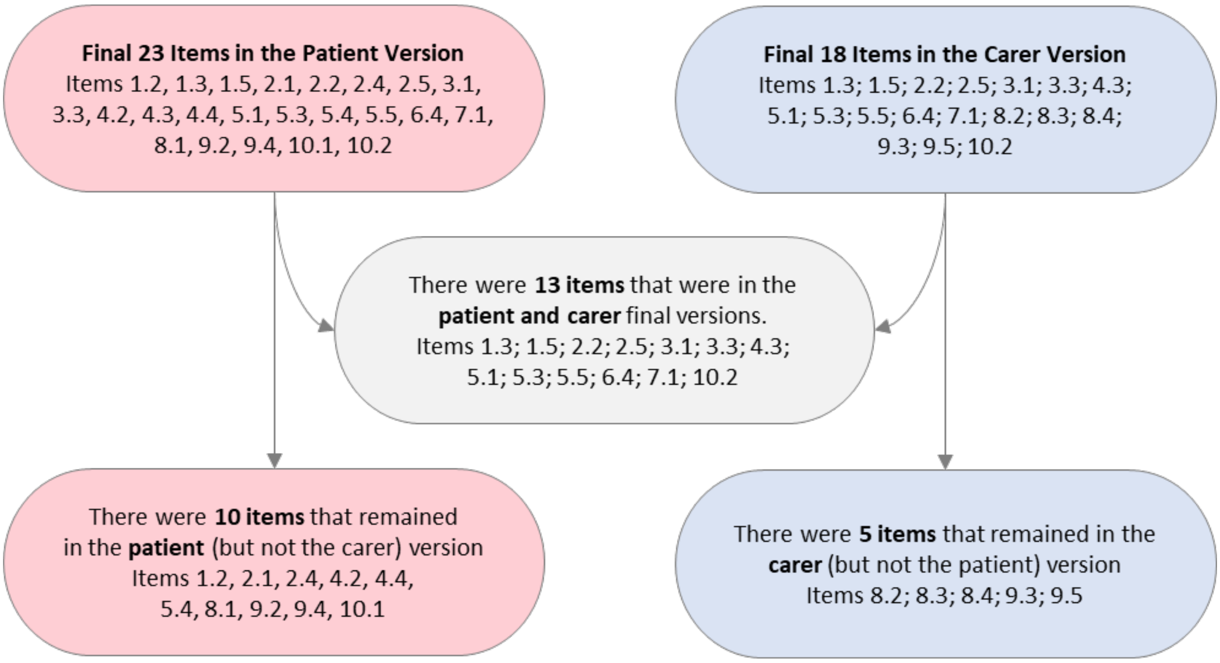

Figure 6. 16 Items in common and items unique to the patient and carer versions of the instrument

6.6 Discussion

The aim of Stage 3 of the study was to collect questionnaire data to undertake a preliminary assessment of validity and internal reliability of the patient and carer versions of the instrument. The aim was achieved by meeting both objectives. The first objective was to identify, recruit and consent participants. The second objective was to use Rasch analysis to assess the psychometric properties (including unidimensionality, construct validity and internal reliability) of the patient and carer versions of the instrument.

6.6.1 Recruitment

Success of the preliminary analysis of validity and internal reliability was dependent on the ability to identify, recruit and consent an acceptable sample of participants to complete the questionnaire. The sample size for patient respondents exceeded the target of 150, by 33% (n = 200). However, as anticipated from the Stage 2 Pilot Study (Chapter 5), recruitment of carers was more difficult and only 50% of the carer target sample size of 150 was achieved (n = 77).

The challenges of recruitment were many and complex. Hospital wards are extremely busy, and nurses have many competing priorities. I needed to spend a lot of time waiting to speak to nurses about which patients I could approach. Of the patients available on any of the recruitment wards, a large proportion could not be approached because they had infectious precautions, were confused, too unwell, or close to death. Routinely there would only be, on average, three to five patients on the ward, on any data collection day, that I could access. This number was highly variable and calculating a response rate for those I could access would be meaningless.

Of those I was able to approach, most were enthusiastic to participate because they were bored and were pleased to have someone to speak with, plus they thought the topic of value. Despite many people's enthusiasm for someone to speak with, there was an obvious 'survey' fatigue. This is not surprising given 'experience of service' surveys are extant in daily transactions and there is not always an obvious relationship between the excess of surveying and an improvement of services. Potential respondents were also hesitant to agree to undertake a lengthy questionnaire. I recall the most common question I had from potential participants was 'How long is the questionnaire?'.

Recruiting potentially vulnerable people increased the level of difficulty. Of note, wards do not include on their comprehensive patient lists, details of whether a patient has a 'person responsible' [216]. This information was difficult or impossible to find and I was reliant on the nurses to advise me. This contributed to the difficulty I experienced in recruiting people who did not speak English as a first language. I was unable to expend one dollar of the $4,000 of funds I received from the Hospital Research Foundation for the use of interpreters. Nurses would exclude patients, as suitable candidates to participate, who did not speak English. Negotiating the recruitment of vulnerable people, when you are an outsider to the organisation, you have a very brief period of time to explain your research, and you are operating in a position with almost no information about the patient, including whether they have family or a 'person responsible', is difficult and fraught with risk for the researcher.

I included Saturdays and Sundays in my data collection days as they presented greater opportunities to speak with nurses, patients and carers. The large proportion of patients without a carer present on the wards at any given day or time of data collection, severely restricted my ability to recruit carers.

6.6.2 Item level decisions contributing to unidimensionality, construct validity and internal reliability

In this section I will discuss examples of the numerous iterative decisions that needed to be made prior to, and during, each step of the Rasch analysis. It is the culmination of each of these decisions that contributes to the unidimensionality, construct validity and internal reliability of the final 23-item patient and 18-item carer versions of the instrument.

6.6.2.1. Items removed prior to Rasch analysis

Seven items were removed from both the patient and carer versions of the instrument prior to the Rasch analysis because they contained non-scalable response categories. For example, Item 4.5 ‘I have discussed my Advance Care Directive with staff’ included the response categories ‘Yes’, ‘No’, ‘I do not know what an Advance Care Directive is’ and ‘I do not have an Advance Care Directive’. However, all seven items contain valuable content and their removal does not reflect the importance of their content. Consideration should be given to modifying each of these items so they can be tested in the instrument, using scalable response categories (NRSOA), in any future (post-doctoral) developments of the questionnaire.

Several items included one non-scalable response category alongside the NRSOA ordinal response categories (for example, Item 1.5 ‘Staff have helped to control my pain’ included the response categories NRSOA plus ‘I had no pain’). While the NRSOA response categories were retained for the analysis, the additional response categories, which were non-scalable, were treated as ‘missing data’ because Rasch analysis should only be undertaken on items with scalable ordinal response categories (i.e., NRSOA). Further, selecting ‘Not Applicable’ or ‘Unsure’ (other examples of ‘additional response categories’) also indicates the item was not relevant to the respondent. If most respondents select ‘Not Applicable’ or ‘Unsure’ then the item is not relevant to the sample population. An example includes Item 3.2 ‘I have had access to an interpreter’, which was removed from both the patient and carer versions due to excessive ‘missing data’ as a result of the majority of respondents selecting the response category ‘The patient does not need an interpreter’. Removal of this item reflects the needs of the sample; they all spoke English. This does not necessarily reflect the needs of the target population (older people in hospital) [217]. This example highlights the need to include people who do not speak English in research; while noting the practical realities I encountered in trying to do so.

Item 8.5 'Staff arranged access to interpreters to involve family, friends or carers in my care. *When I wanted these family, friends or carers involved in my care' was removed from both the patient and carer versions for the same reason as Item 3.2. The item was not relevant to the sample population but is likely relevant to the target population (older people in hospital).

Item 8.3 'Staff include my family, friends or carers in the bedside discussion at shift handover. *When I wanted these family, friends or carers involved in my care' and Item 8.4 'Staff responded quickly when my family, friends or carers reported my condition had deteriorated' were deleted from the patient version as most (patient) respondents selected the 'Not Applicable' response category. These items are clearly relevant to carers and it makes sense that these items were retained in the final 18-item carer version of the instrument.

Item 3.4 'Staff have provided care consistent with my cultural / religious / spiritual beliefs' and Item 3.5 'Staff have respected my sexual identity' were deleted from the carer version as most (carer) respondents selected the 'Not Applicable' response category. The items were not seen as relevant to the carer sample. However, these items might be relevant to the target population [217].

6.6.2.2. Items removed and retained during Rasch analysis

There is a balance between retaining content validity (established in the early stages of a study) and achieving construct validity (through the requirements of Rasch analysis to remove items that are determinantal to the model). All 39 items remaining in the patient and carer versions of the instrument, at the beginning of the Rasch analysis, were there because they had been developed through the rigorous Delphi panel process (Chapter 4) and subjected to review through the Pilot study (Chapter 5), suggesting they all had content validity.

During the process of Rasch analysis there were numerous iterative steps and decisions that needed to be made about whether to retain or remove an item. Some of these decisions were easy to make, particularly where there were compelling statistical reasons to remove an item. Other decisions were marginal, the statistics might be marginal and/or the supporting research or policy evidence for retaining the item might be modest. For these, 'expert' judgement is required. I will now step through examples of such decision making for items retained and items removed during the Rasch analysis. These examples include items from across the 10 Principles, items across the patient and carer analyses and reasons for removal across each of the steps of the Rasch analysis (fit statistics and response dependency).

Due to response dependency, a decision had to be made to remove either Item 1.1 ‘I have felt safe when staff provide care to me’ or Item 1.3 ‘Staff have been rough in the way they provide care’ in both the patient and carer versions. Preference was given to retaining Item 1.1, because it uses language (‘rough’) directly related to Principle 1, which is about abuse. Patients, carers and health care staff need to be able to talk honestly and openly about the issue of abuse, given the extensive evidence of the abuse of older people in care [4, 5, 14]. Item 1.3 was retained in the final patient and carer versions of the instrument.

Due to response dependency, Item 2.3 ‘Staff have been respectful when they speak with me’, was removed from both the patient and carer versions. The item appeared in multiple high residual item correlations with other items (4 correlations in the patient version with items 1.3, 2.4, 2.5 and 9.2 and 2 correlations in the carer version with items 2.4 and 2.5. Noting Items 1.3, 2.4, 2.5 and 9.2 was retained in the final patient version and Item 2.5 was retained in the final carer version.

Item 3.3 ‘Staff have asked if I have cultural / religious / spiritual beliefs that are important to me’ was retained because it contains valuable content. Upon initial inspection, it would appear this item should be removed due to its misfit (Infit 2.42 MnSq, Outfit 2.55 MnSq), however removal of the item had a detrimental effect on the model (PSI dropped from 2.71 to 2.29 and ISI dropped from 6.76 to 5.73). Upon investigation, the likely cause of the misfit was the item was not responding as the model expected. Where all other items had a ‘ceiling effect’, supporting the highest level of dignity in care, Item 3.3 was an outlier, as most people selected the ‘Never’ response category, which represents the lowest level of dignity in care.

This finding reveals that, in this sample, the conversation about cultural / religious / spiritual beliefs is not routinely being initiated by staff. Asking people about their cultural / religious / spiritual beliefs is important as such beliefs can influence how patients’ understand health concepts, how they take care of their health, and how they make decisions related to their health [22 218 219]. Opening the conversation about cultural, religious and spiritual beliefs is of vital importance if staff are to understand and provide care to a person that reflects their individuality (Principle 3). Item 3.3 performed in the same way in the patient and carer versions; the item was retained in both versions of the instrument.

Item 4.2 ‘I have been involved, as much as I wanted to be, in decisions about my care’ was retained as relevant to patients. This item was removed in the carer version as it was identified in multiple high residual correlations with other items. Noting item 8.2 ‘I have been involved in decisions about the patient’s care. * When the patient was unable to participate and/or when the patient wanted family, friends or carers involved’ was retained in the carer version. It makes sense that items under Principle 4 ‘Independence, Choice and Control’ were identified as more relevant to the patients and items under Principle 8 ‘Engage with family, friends and carers’ were deemed to be more relevant to carers.

Item 4.4 ‘I believe I can choose to refuse treatment’ was retained in the patient version despite a marginally higher Infit (1.57 MnSq and Outfit (2.08 MnSq). To afford patients ‘Independence, choice and control’ (Principle 4) they must be given as much opportunity to say what they *do not* want, as they have to say what they *do* want [220]. Hospitals are designed, and staff are trained, to provide interventions. Refusing treatment can be seen to be going against the natural flow of hospital processes [221]. Of course, no one wants to refuse ‘care’, but there is evidence that older people, particularly those approaching the end of their life, do receive interventions that may not contribute to their quality of life or quality of death [221, 222]. Open discussions about what not to do need to be supported, item 4.4 was retained. While Item 4.4 was retained as relevant to patients. This item was removed in the carer version due to a marginally high misfit (Infit 1.81 MnSq); PSI increased marginally (from 2.76 to 2.80) with removal of the item.

Due to response dependency, Item 5.2 ‘Staff provide care that reflects an understanding of my needs (such as my vision, hearing, memory, mobility and dietary needs)’ was removed from both the patient and carer versions as it was considered to be a complex item to comprehend and score. In preference, Item 5.1 ‘I have been given enough time to explain what I need’ was retained, as it is simple and affirms that it is the patient who knows what they need.

Response dependency was evident across all five items, about privacy, under Principle 6. ‘Expert’ judgement determined that it might be, in the process of supporting a patient to use the toilet, bedpan or having a pad changed, where staff could make a real difference as to how ‘private’, and therefore how ‘dignified’, the experience was for the patient. Item 6.4 ‘I feel my privacy is respected when I am using the toilet, bedpan or changing a pad’ was retained and items 6.1, 6.2, 6.3 and 6.4 were removed.

Item 7.1 ‘Staff have made sure there is an opportunity to talk about any concerns’ was retained as it was the only item relating to Principle 7 (‘Ensure people feel able to complain without fear of retribution’) remaining after the removal of items with non-scalable response categories (where items 7.2, 7.3, 7.4 and 7.5 were removed).

Item 8.1 ‘Staff have asked me which family, friends or carers I want involved in my care’ was retained in the patient version despite a marginally high Infit (1.75 MnSq). When developing content for the questionnaire in the Delphi panel process (Chapter 4), it was clear that there were two major concerns about the involvement of family/friends in care. The first was that there were some family/friends who had a substantial caring role and they did not feel their role was acknowledged by staff [223], this is particularly significant for people with dementia in hospital [10]. The second was that some patients felt family/friends were making decisions about care without respecting their (the patient’s) preferences. Both concerns emphasise the need to ask the patient who they want involved in their care [22, 47]. The involvement of carers is of particularly importance to the many older people in hospital who have dementia [11, 59]. While Item 8.1 was retained as relevant to patients, this item was removed in the carer version due to a marginally high misfit (Infit 1.81 MnSq); PSI increased marginally (from 2.72 to 2.76) with removal of the item.

Item 9.3 ‘The patient was given enough time to do what they were capable of doing themselves’ was retained as relevant to carers. This item was removed in the patient version as it was identified in multiple high residual correlations with other items.

Item 9.4 ‘I have been supported to maintain my personal appearance’ was retained as relevant to patients. This item was removed due to response dependency in the carer version as it appeared in high item correlations with three items (9.1, 9.2 and 9.4).

Item 10.1 ‘Staff include me in the bedside discussion at shift handover’ was retained as relevant to patients, despite a marginally higher Infit (1.66 MnSq), because involving the patient in the bedside discussion at shift handover is an opportunity to engage with the patient and in doing so make some contribution to addressing loneliness and isolation [224] [22]. This item was removed due to response dependency in the carer version. Noting Item 8.3 ‘Staff include family, friends or carers in the bedside discussion at shift handover. * When the patient was unable to participate and/or when the patient wanted family, friends or carers involved', covering the same content as Item 10.1, was retained in the carer version.

Due to response dependency, an 'expert' decision was made to retain Item 10.2 'Staff have supported me to stay physically and mentally active' in both the patient and carer version, oin preference to Item 10.3 'Staff have helped me to find things to do to keep me from being bored', which was removed from both the patient and carer versions.

6.6.3 Items included in the final patient version and carer version of the instrument

6.6.3.1. Items in common across the final patient and carer versions of the instrument

Following the process of determining which items to remove and which items to retain, there were 13 items remaining in common across the final 23-item patient version and the final 18-item carer version of the instrument (Figure 6. 17). Eight of the 10 Principles of Dignity in Care (Principle 1, 2, 3, 4, 5, 6, 7 and 10) were covered by the 13 items in common. There were no items retained in common across the patient and carer versions from Principles 8 or 9. The 13 items retained in common across the patient and carer versions are presented below (Figure 6. 17).

13 items in common (the patient perspective is presented here)

Item 1.3 Staff have been rough in the way they provide care

Item 1.5 Staff have helped to control my pain

Item 2.2 Staff introduce themselves by telling me their name and role

Item 2.5 My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels...)

Item 3.1 Staff have called me by my preferred name

Item 3.3 Staff have asked if I have cultural / religious / spiritual beliefs that are important to me

Item 4.3 Staff have asked my permission before they provide care

Item 5.1 I have been given enough time to explain what I need

Item 5.3 Staff have encouraged me to ask questions

Item 5.5 Staff have encouraged me to be involved in planning my discharge from hospital

Item 6.4 I feel my privacy is respected when I am using the toilet, bedpan or changing a pad

Item 7.1 Staff have made sure there is an opportunity to talk about any concerns

Item 10.2 Staff have supported me to stay physically and mentally active

10 items unique to Patient Version

Item 1.2 Staff come to see me soon after I press the call bell

Item 2.1 Staff wear name badges large enough to read

Item 2.4 Staff have been considerate in how they provide care to me

Item 4.2 I have been involved, as much as I wanted to be, in decisions about my care

Item 4.4 I believe I can choose to refuse treatment

Item 5.4 Staff have spoken with me about my care in ways I understand

Item 8.1 Staff have asked me which family, friends or carers I want involved in my care

Item 9.2 Staff have spoken to me as an equal

Item 9.4 I have been supported to maintain my personal appearance

Item 10.1 Staff include me in the bedside discussion at shift handover

5 items unique to Carer Version

Item 8.2 I have been involved in decisions about the patient's care * When the patient was unable to participate and/or when the patient wanted family, friends or carers involved

Item 8.3 Staff include family, friends or carers in the bedside discussion at shift handover * When the patient was unable to participate and/or when the patient wanted family, friends or carers involved

Item 8.4 Staff responded quickly when I reported the patient's condition had deteriorated

Item 9.3 The patient was given enough time to do what they were capable of doing themselves

Item 9.5 Staff took too long to respond when the patient needed to go to the toilet

Figure 6. 17 Final items across patient and carer versions

6.6.3.2. Items unique to the patient version and unique to the carer version

There were 10 items included in the final 23-item patient version that were unique to the patient version (Figure 6. 17). There were 5 items in the final 18-item carer version that were unique to the carer version (Figure 6. 17).

Item 1.2 ‘Staff come to see me soon after I press the call bell’ was included in the final patient version of the instrument for Principle 1. The self-explanatory ‘call, don’t fall’ message promotes use of the call bell as ‘the most important button in your hospital room and why you need to press it’ and highlights the importance of this item to patients [225]. It may not be possible for the carer to respond to this item if they have not been present with the patient for long period of time, and it is understandable why this item was not retained in the carer version. However, Item 9.5 ‘Staff took too long to respond when the patient needed to go to the toilet’ was retained in the carer version and is similar to Item 1.2.

Item 2.1 ‘Staff wear name badges large enough to read’ and Item 2.4 ‘Staff have been considerate in how they provide care to me’ were the two items retained in patient version of the instrument for Principle 2. The ‘#hello my name is’ [147] campaign was created by a doctor, who in her role as a terminally ill patient, made the observation that many staff looking after her did not introduce themselves before delivering care. The campaign includes a name badge featuring the ‘hello my name is’ logo. Carers who are not present with the patient for long periods of time might not notice whether staff are wearing name badges, this might explain why Item 2.1 was not included in the carer version.

Item 4.2 ‘I have been involved, as much as I wanted to be, in decisions about my care’ was retained in the patient version. A similar item ‘I have been involved, as much as I wanted to be, in decisions about my care and treatment’ was identified in seven different instruments measuring experience of care’ [24, 26, 32, 123, 124, 134, 135]. Being ‘involved’ is core to the experience of dignity in care [226]. Item 4.2 was not retained in the carer version, but the same content was retained in Item 8.2 ‘I have been involved in decisions about the patient’s care *When the patient was unable to participate and/or when the patient wanted family, friends or carers involved’ of the carer version.

Item 4.4 ‘I believe I can choose to refuse treatment’ was retained in the patient version. ‘Consent, capacity and the right to say no’ [227] are topics that are challenging to integrate into standard practice. Over-intervention near end of life [221] suggests change is required and that change requires a health service that can speak openly about choice and the right to refuse treatment. Carers might not understand their role in making such decisions, particularly if they are not acknowledged as the legal 'Person Responsible', which may help explain why the item was not included in the carer version.

Item 5.4 'Staff have spoken with me about my care in ways I understand' was included in the final patient version of the instrument under Principle 5.

Item 8.1 'Staff have asked me which family, friends or carers I want involved in my care' was included in the final patient version of the instrument for Principle 8. Whereas three other items under Principle 8 were included in the carer version (8.2 mentioned above and 8.3 mentioned below). Given Item 8.4 'Staff responded quickly when I reported the patient's condition had deteriorated' has a focus on carer reporting [228], it is not surprising the item was unique to the carer version [228].

Item 9.2 'Staff have spoken to me as an equal' and Item 9.4 'I have been supported to maintain my personal appearance' were the two items retained in patient version of the instrument for Principle 9. The final carer version also included two unique items from Principle 9, including Item 9.3 'The patient was given enough time to do what they were capable of doing themselves' and Item 9.5 'Staff took too long to respond when the patient needed to go to the toilet'.

Item 10.1 'Staff include me in the bedside discussion at shift handover' was included in the final patient version. Sharing similar content, Item 8.3 'Staff include family, friends or carers in the bedside discussion at shift handover *When the patient was unable to participate and/or when the patient wanted family, friends or carers involved' was included in the final carer version.

6.6.4 Bias

'Expert' judgement influencing which items should be retained and removed from an instrument, as it is developed, does introduce the potential for bias. The reality is this research study contains many potential sources of bias.

Undertaking research with older vulnerable people requires human connection. Such connection has the potential to introduce bias. There was potential for bias in every step of the data collection process. Asking nurses to identify which patients (and/or carers) I could approach may have had the potential to introduce bias. Patients who are more well, more satisfied and are more easily able to communicate might be given preference over patients who are more unwell, more distressed, have cognitive impairment or have different communication needs.

Patients (and carers) who told me they had a connection to research, perhaps a family member had completed a PhD, or had a connection to Flinders University, were the most enthusiastic participants. Perhaps there was potential for bias in this connection.

Gratitude bias has been observed in older people in receipt of care [4]. I observed that respondents completing the questionnaire, at times, provided responses that were incongruent with some of the experiences they had volunteered to share with me. If I had not been sitting with them while they completed the questionnaire I would not have known of this discrepancy. Gratitude bias is likely evident in the substantial ceiling effect seen in the data. The cause was a disproportionate number of 'Always' responses, indicating the participant recorded high levels of dignity in care on these items.

Gratitude bias is not a new and unexpected finding in the reporting of patient experience, but it does highlight the limitations of questionnaires in measuring experience of care [27, 229]. Awareness of gratitude bias does highlight the need for health services to consider undertaking work to allow patients and carers to have the confidence to provide honest reporting of their experience (Dignity in Care Principle 7, Figure 1. 1). There is more to understanding experience of care, than use of the questionnaire alone. Human interaction is essential in investigating experience of care, even if it is a potential source of bias.

6.6.5 Limitations

The development of the 50-item questionnaires used in the Stage 3 data collection was driven by content validity. Items and their response categories were developed according to the experts on the Delphi panel and the experts who participated in the pilot study. Items and response categories were not constrained, in the early stages of the study, by the requirements of Rasch analysis. The richness of the content developed through this process was, to some extent, compromised when preparing the data for Rasch analysis. This meant removing items that had all non-scalable response categories. This also meant removing data from items that had just one non-scalable response category. All content removed should be reconsidered in future (post-doctoral) development of the instrument.

Several items, containing content judged by the Delphi panel to be of value to the target population, were deemed as not relevant to the sample population of the study (determined by excessive ‘Not Applicable’ responses). Those items, particularly those relating to the need for interpreters, should also be reconsidered in any future development of the instrument.

The study was designed to have patient and carer versions of the same questionnaire, containing the same items, but worded so as to be appropriate for the respondent. This design feature was not achieved as a result of the Rasch analysis. The final patient and carer versions of the instrument have 13 items in common. The patient version has an additional 10 items, which are only in the patient version. The carer version has an additional five items, which are only in the carer version.

6.6.6 Conclusion

The final instrument had 13 items representing 8 (of the 10) Principles of Dignity in Care. The final patient version of the instrument included an additional 10 unique items, resulting in a 23-item instrument which demonstrated robust fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability. The final carer version of the instrument included an additional 5 unique items, resulting in an 18-item instrument which demonstrated acceptable fit to the Rasch model, supporting unidimensionality, construct validity and internal reliability, but results should be considered exploratory and preliminary as the findings need to be verified with a larger sample. Both versions warrant further development. Measuring experience of care is difficult, many instruments are developed to this point and progress no further, thus perpetuating a gap in the research for sound instruments, to be filled by yet another instrument that does not reach its potential. A robust instrument cannot be developed to its final form in one research study. The case for a patient and carer questionnaire, based on the 10 Principles of Dignity in Care, is sound, and this preliminary assessment of validity and internal reliability indicates the basis of a sound instrument of measure. Further development of items and further analysis of validity and reliability for both the patient and carer versions of the instrument are required.

7. Discussion

Perhaps the most common error committed by clinical researchers is to dismiss existing scales too lightly, and embark on the development of a new instrument with an unjustifiably optimistic and naïve expectation they can do better [2]

7.1 Introduction

In this chapter I will discuss the evidence I found in support of the 10 Principles of Dignity in Care as the conceptual framework for a new Patient Reported Experience Measure. I will explain how the research question was answered by presenting my findings against the original aims of the study. Further to these findings, I will discuss the accumulation of knowledge I gained undertaking research in the clinical setting with older vulnerable people. This includes the requirement to meet the specific needs of older people, in both the content and the method of administration of the Patient Reported Experience Measure. The questionnaire is the dominant tool used to administer Patient Reported Experience Measure. Questionnaires can require motivation and effort to complete and so there is an imperative to use questionnaires that include content of relevance and importance to older people. It is also important to acknowledge that not all older patients will be able to complete a questionnaire (or have a carer who can complete it on their behalf) and it is necessary to adopt and adapt other ways of reporting their experience of care. Other methods of administration of the content of the questionnaire should be considered. The process of developing content for the Dignity in Care Questionnaire has been rigorous and has been has built on the robust framework of the 10 Principles of Dignity in Care. The content (items) of the questionnaire could be used to guide the implementation of quality improvement activities.

7.2 Findings

7.2.1 The Evidence

The Literature Review provided multiple sources of evidence for the relevance and robustness of the 10 Principles of Dignity in Care as the conceptual framework for the Patient Reported Experience Measure (PREM).

First, dignity is recognised internationally in health care rights. In Australia, dignity is recognised in both health care rights and aged care rights. Dignity has a prominent place in health and aged care policy and clinical guidelines. A questionnaire based on the 10 Principles of Dignity in Care could be used to measure and monitor the translation of these rights, policy and the recommendations of guidelines into practice.

Second, the review of concept analyses across care concepts revealed the core ‘attributes’ of dignity in care, patient-centred care and person-centred care align strongly to 3 (of the 10) Principles of Dignity in care, these include Principle 2 (Support people with the same respect you would want for yourself or a member of your family), Principle 3 (Treat each person as an individual by offering a personalised service) and Principle 4 (Enable people to maintain the maximum possible level of independence, choice and control).

There was good coverage of ‘attributes’ across the care concepts ‘dignity’ and ‘patient-centred’ care for Principle 5 (Listen and support people to express their needs and wants). There was some coverage of ‘attributes’ across the care concepts ‘dignity’ and ‘patient-centred’ for Principle 8 (Engage with family members and carers as care partners) and Principle 10 (Act to alleviate people’s loneliness and isolation). There was some coverage of ‘attributes’ across the care concepts ‘dignity’, ‘patient-centred’ and ‘person-centred’ care for Principle 9 (Assist people to maintain confidence and a positive self-esteem).

There was no to scant coverage of ‘attributes’ across the care concepts ‘dignity’, ‘patient-centred’ and ‘person-centred’ for Principle 1 (Zero tolerance of all forms of abuse), Principle 6 (Respect people’s privacy) or Principle 7 (Ensure people feel able to complain without fear of retribution). This was an important finding and will be discussed further in Section 7.4.2.

The review of ‘attributes’ of commonly used care concepts that did not map to the 10 Principles, led to the conclusion that none appeared to present a clearly articulated component of care that could be considered an important addition to fill a gap in coverage across the 10 Principles.

Given there was no alignment of the ‘attributes’ of compassionate care and any of the 10 Principles of Dignity in Care, I reached the same conclusion as Blomberg et al (2016) who found in their systematic review of compassionate care that ‘this is a body of literature that seems to have little useful to say to nurses in practice’ [21] (p.153).

Third, no existing experience of care instrument could be found that included items that covered all 10 Principles, however several items from 16 existing experience of care questionnaires could be mapped to the 10 Principles and were included in the original item pool, prepared for the Delphi panel, for this study.

The comprehensive review of the literature contributed to the development of the content validity of the evolving PREM, ensuring relevant content was included and that content reflected the entirety of the concept being measured [186].

7.2.2 The Aims

The three aims of the study were met and are presented against the main findings of the study.

The fist aim was gain consensus from a panel of experts on the content to be used to measure each of the 10 Principles of Dignity in Care, for the patient and carer versions of the questionnaire that were to progress to the pilot study. This aim was achieved by a Delphi panel of 57 experts, including 19 consumers, were able to reach consensus on 69 items to include in the pilot study of the questionnaire.

The second aim was to assess the: face validity of the items, ease of administration, number of items, time demands on respondents, scoring and interpretation with patients and carers in the hospital setting. This aim was achieved through the completion of a pilot study in which 52 patients and carers participated in a cognitive interview while they completed the questionnaire, and in doing so, helped to refine the items and scoring used in the evolution of the revised 50-item questionnaire.

The third aim was to collect questionnaire data to commence the process of validity and reliability assessment. This aim was achieved through the collection of 200 patient and 77 carer questionnaires, which allowed the preliminary analysis of unidimensionality, validity and internal reliability.

7.2.3 The Research Question

The research question ‘Is it possible to develop, and undertake a preliminary assessment of the unidimensionality, validity and reliability of, a PREM based on the 10 Principles of

Dignity in Care, for use by older people (and their carers) in the hospital setting?' was successfully answered.

I completed a research study to develop a questionnaire, based on the 10 Principles of Dignity in Care, for use by older people (and their carers) in the hospital setting. The preliminary assessment of unidimensionality, validity and internal reliability of the Dignity in Care Questionnaire revealed the patient version is psychometrically robust and ongoing development of the instrument is justified and warranted and the carer version is sound but requires further testing with a larger sample. A PREM cannot be developed to completion by one person in one research study. The proposed future stages of research to continue development of the Dignity in Care Questionnaire (DiCQ) are presented in Chapter 8 Conclusion.

In reaching these findings, many aspects of undertaking research with potentially vulnerable people in the clinical setting and the role of the questionnaire in measuring and monitoring experience of care were encountered. These aspects of my research provide a richness of discovery that should not be lost and form the basis of the following discussion topics.

7.3 The questionnaire as a Patient Reported Experience Measure

The questionnaire is the most common form of PREM and its value is unquestionable. Questionnaires offer a relatively cheap and efficient way to gather large amounts of data that can be summarised and displayed in reports to show comparative performance across sites and over time, for a concept (experience of care) that is challenging to measure. It was my optimistic belief that if it were possible to report experience of care, in the same succinct format used to report other commonly monitored indicators (such as falls, infections, length of stay), then it might be possible to raise the prominence of experience of care amongst those with the highest level of accountability. For the executive and the Board to obtain an accurate report on experience of care, it must be possible to obtain a representative sample of patients in the questionnaire collection process. It was clear from my research that many older vulnerable people were likely to be excluded from reports on experience of care.

7.3.1.1. Who is willing, able and happy to complete a questionnaire?

Within the context of my research study, there were very few people on each of the data collection wards who could be approached to determine if they would consider participating.

While this was limiting for my study, it also made me appreciate the limitations of questionnaires in obtaining a representative response from patients (and their carers) on the ward.

Survey fatigue is real, many people simply do not want to complete a questionnaire. For those who are prepared to complete a questionnaire, they might not feel comfortable in being completely honest in their responses. There are people who do not speak English. Many people have advanced dementia and cannot complete a questionnaire. There are many people who do not have a carer available to spend time with them while they are in hospital and so are not available or able to report, from their perspective, on the experience of care.

Capturing the exact number of people who fall into each category would have been interesting for my study, but it would have been difficult, time consuming and would have diverted me from the major focus of my research.

I begin this part of the discussion considering those who could, and were mostly happy to talk, but reluctant to complete a questionnaire. It is difficult to make a purchase or receive a service without being asked to complete a survey on your experience [230]. Such exposure might diminish the value of surveys and people might be willing to just give a quick and positive response to make the requests go away. The most common question I had from potential participants was ‘How many questions are there?’, despite the fact people many people said they were bored and would be pleased to have someone to speak with. Most people were pleased with the topic ‘Dignity in Care’ but were not keen on the method. It is very difficult to explain that if you want the health service executive and the Board to know what is happening at the bedside, a questionnaire is a necessary and powerful way to communicate the message.

7.3.1.2. Do older people feel free to comment?

There were participants who were willing to complete the questionnaire but did not appear to feel comfortable to be completely honest in their responses. The concept of gratitude bias is well documented [27, 229] and I was not surprised to encounter this in my data collection. I was present with many patients (and carers) when they completed the questionnaire. Several participants recorded very positive scores for items, even when those same items had triggered a memory of an experience of indignity in care, which had happened during their current hospital admission. I was hesitant to explore the gap between the experience they had shared with me and the score they had recorded on the questionnaire, as I did not wish to influence the person's score. In general conversation, some patients made it clear they did not want to record, through the questionnaire, that which they had experienced. Some participants would write it off as a one-off experience and did not feel it warranted a less than perfect score on the questionnaire. Despite making explicit the requirement for participant confidentiality in the consent process, some participants acknowledged a fear of retribution.

From my experience, in general, I do not believe older people feel free to provide completely honest comment about their experience of care. It was unforgettable to sit with an older person while they expressed their sincere fear. There is a strong connection here between Principle 1 (Zero tolerance of all forms of abuse) and Principle 7 (Ensure people feel able to complain without fear of retribution). Clearly, people who fear retribution are vulnerable to abuse. There is an ingrained societal norm, possibly more pronounced in older generations, to be grateful for care. The fear of retribution has been exposed by multiple reports on abuse of older people in care [4, 15, 231]. Regardless, the reports continue to be produced [14] and it is not clear that the exposure of the subject through these reports has afforded older people the freedom to comment without fear.

There is an important message that needs to be translated into practice. Older people (and their carers) must be allowed, and encouraged, to comment, with the intent and purpose of feeling safe, being free from harm or abuse and to improve the experience of care. Principle 7 'Ensure people feel able to complain without fear of retribution' heralds this call for change. Gallini (2011) made a similar observation in his evaluation of the Dignity in Care Campaign in an Acute Healthcare Trust in England, with the recommendation that it was necessary to 'Identify mechanisms for patient to raise concerns in a safe and supportive way, without fear of it affecting their care' [39].

7.3.1.3. People unable to complete a questionnaire

The Dignity in Care Campaign in the United Kingdom had a focus on vulnerable older people, including people with dementia. Gallini (2011, p. 148) in his evaluation of the Dignity in Care Campaign made the following observation that 'Further consideration should be given in relation to the nurse's role in identifying and supporting patients who are particularly vulnerable to a loss of dignity, that includes patients with communication difficulties and where English is not a first language, and those patients with confusion or dementia' [39].

In Australia, people with dementia who are in hospital require a high level of care, with almost all hospitalisations (97%) of people with at least one diagnosis of dementia being coded with the highest or second-highest level of clinical complexity. According to the Australian hospital statistics, the majority (71%) were of the highest clinical complexity, compared with 16% of hospitalisations without a diagnosis of dementia [232]. Older people in hospital are at risk of harm [13] and older people with dementia in hospital are at even greater risk of harm [11, 12]. Oakden [14] will serve as a constant reminder of how enormously important it is to understand, measure and monitor the experience of vulnerable people in care. If carers had been able to complete the DiCQ, and that data were routinely reported to the executive and governing body of Oakden, the abuse of Oakden residents would have been identified far earlier and the trauma to those who had to fight long and hard to expose the truth, would have been averted.

7.3.1.4. Those who could on behalf of those who couldn't

Many of the people with dementia in hospital are unable to complete a questionnaire and that is why this research included a 'carer' version of the questionnaire, to allow carers to respond on the patient's behalf. The greatest limitation, however, was identifying carers for those who could not complete a questionnaire. There appear to be many older people in hospital who do not have carers (family/friends) who are able to spend time with them.

Historically, the people I was seeking to recruit into my study, have been excluded from research. More recently, there has been a growing awareness that people with dementia should be given the opportunity to participate in research [233, 234]. Much work has been undertaken to understand capacity to consent and the role of the 'person responsible' [199]. Putting these into practice, in the clinical setting, in the role of researcher, and as an outsider to the organisation, were far more challenging. I found it difficult to access information critical to recruitment. Most hospital wards use a patient handover sheet, much of the information on that sheet was helpful in understanding which patients I should and should not approach. Some wards would allow me to have the sheet. Some Shift Co-ordinators would go through the sheet with me to explain which patients (and carers) I could approach and which I should not and why. Some wards were reluctant to allow me access to the handover sheet.

Some Shift Co-ordinators would just indicate yes or no to which patients I could approach, without explanation. Information about whether the person had capacity to participate in care research was not (understandably) included on the handover sheet. Information about whether the person had a legally active 'person responsible' [199] was not included on the handover sheet. While my ethical and governance approvals enabled access to medical records, I did not feel staff approved my accessing the paper-based medical record, and such information was not necessarily easy to locate.

These were some of the aspects of being a researcher in the clinical environment that were challenging. If more research into how care is provided and experienced was undertaken, and the presence of external researchers were commonplace, I am sure the difficulties I encountered would be resolved. It was my observation that every ward appears to generate local quality improvement activities, but no ward I attended appeared to have had experience in working alongside an external clinical care researcher. I could find little in the literature about undertaking care research in practice [235, 236]. I have worked as a clinical nurse and a university-based researcher. I believe there is great potential for more robust, built-in (i.e., not just 'project' based) collaboration between universities and hospitals. Vast sums are expended on external consultants to improve health services; I suspect more investment in collaborative research and implementation of findings may prove a more efficient investment.

7.3.1.5. People who do not speak English as their first language

The challenges of carer recruitment also influenced my ability to recruit patients (and carers) who did not speak English as their first language. In my experience, any point of complexity would diminish the likelihood of recruitment. One aspect of this was the amount of time and engagement required with the nurse to pursue recruitment of a patient (or carer) who required an interpreter. It was not as simple as the nurse saying, 'that patient speaks Vietnamese', and me replying, 'sure I'll call the interpreter'. It was possible the patient (or carer) was not presented as a potential recruit, because they did not speak English. The patient might have been too unwell, had infectious precautions, might have been about to undergo a procedure or might have been disinterested. It was also difficult for me to understand the person's carer status. Would the family approve if I called an interpreter? Would a family member prefer to act as an interpreter? However, there might be no family present, and I would not know if or when they would be in the hospital. Does the patient have family? It was extremely disappointing that I was not able to expend one dollar of the funds the Hospital Research

Foundation awarded me to fund interpreters for participants who did not speak English as their first language. It was extremely disappointing to return the funds unspent. However, all I experienced and learned from my doctoral research will be put to good use in proposed future (post-doctoral) stages of my study, which will involve focused recruitment of people from diverse communities as detailed in the concluding Chapter 8 (Conclusion).

7.3.1.6. Other reasons patients (and carers) could not participate

In addition to those with dementia, those who did not speak English as their first langue and those without a carer present, the other group of older people who were unable to participate in this research were those requiring Personal Protective Equipment (PPE) to be used by those providing care. Due to the isolation of these people, understanding their experience of care is enormously important. It was logistically impossible to include people requiring PPE in my study. I could not take anything out of the room, and so it would have been impossible to gain a signed consent and have the patient (and/ or carer) complete a paper-based questionnaire. Given I was interacting with multiple older people on every data collection day, it did not seem wise to push the boundaries to explore how these patients could possibly be involved.

In April 2020, as I made the final additions to my thesis, the care of people requiring staff to wear PPE has been raised to worldwide prominence with the Covid-19 pandemic. Older people are at greater risk of morbidity and mortality as a result of Covid-19 and other infectious diseases [237]. Being able to deliver and measure the experience of dignity in care for those with infectious precautions is an urgent priority area for future research.

7.3.1.7. Selection bias

The limitations to participation most certainly contributed to selection bias in my research. The groups of people excluded from this study are more likely to be vulnerable (and so require complex care) and isolated (because they do not speak English as their first language and/or due to the use of PPE). This leaves people who speak English and have less complex care needs to be most able to participate. These patients are more likely to be able to undertake their ‘activities of daily living’ without much support. At this point I have reached the full circle of my argument in this chapter, that there is a risk a Dignity in Care Report presented in summary form, may be not be representative of all older people (and their carers) accessing the health service. The questionnaire has a role, but its limitations must be acknowledged. Alternative methods of reporting patient experience must be accommodated.

7.3.1.8. Can a questionnaire measure all key aspects of Dignity in Care?

The limitations of the questionnaire extend beyond its ability to represent the target population. The questionnaire also presents limitations to the content that can be included in a scalable, measurable form. Content generated and supported by the Delphi panel and scrutinised by the participants in the pilot study had to be removed from the instrument for the purpose of Rasch analysis. Items can only be included if they can be presented with a scalable response format (such as ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’ and ‘Always’). It was not possible to present some content with these response categories. This does not mean the content is not important. It simply exposes a limitation in using questionnaires.

The challenges of using scalable response categories are demonstrated with this item, ‘I have discussed my Advance Care Directives with staff’. In the 69-item Pilot Study version of the questionnaire, this was Item 4.6 and it had the following response categories ‘Never’, ‘Rarely’, ‘Sometimes’, ‘Often’, ‘Always’ and ‘I do not have an Advance Care Directive’. It became clear in the Pilot study that participants struggled to respond to this item because most respondents did not know what an Advance Care Directive was. This led to many interesting discussions where I learned that people mistook Advance Care Directives for an Aged Care Assessment or a hospital discharge letter. It was clear that most people did not understand it was a separate legal document. The item is extremely important. An Advance Care Directive is a way to have your say when you no longer have legal capacity to make decisions [200]. Every older inpatient should talk about their Advance Care Directives with staff to ensure care will be consistent with their wishes should their decision-making capacity change. If the patient does not have capacity, the staff should be discussing the existence and content of an Advance Care Directive with the patient’s ‘Person Responsible’.

To ensure the item could be retained for the Stage 3 data collection, the response categories had to be changed to reflect the answers the pilot study participants wanted to provide. The revised response categories for the item (now item 4.5 in the 50-item version of the questionnaire) were ‘Yes’, ‘No’, ‘I do not know what an Advance Care Directive is’ and ‘I do not have an Advance Care Directive’. The information to be collected from these response categories is vitally important to health services, but if included in a questionnaire, it cannot be included in the calculation of the patient (or carers) summary Dignity in Care score, as it does not have scalable response categories. The item could be asked along with other items without scalable response categories and included in a set of questions (often along with demographic type questions) at the front of the questionnaire.

The point is, not every component of Dignity in Care can be captured in a format with 'Never', 'Rarely', 'Sometimes, 'Often', 'Always' type response categories, required for Rasch analysis. That does not mean the content is not of great importance to the experience of Dignity in Care for older people.

7.4 Other methods of Patient Reported Experience Measures

As identified in Sections 7.3.1.1. to 7.3.1.6, many older vulnerable people cannot complete a questionnaire and many older vulnerable people do not have a carer present, or involved at all, who could report on the experience of care on their behalf. PREMs need to include questionnaires, for those who can use them, and include other methods for those who cannot.

7.4.1 Using the content of the questionnaire employing other PREM methods

An important observation I made in my study, was that the content of the questionnaire formed an excellent foundation for a discussion with patients (and carers) about their experience of dignity in care. This was particularly the case for patients who staff had suggested I could speak with to determine if they were able to participate in my research. Some patients were able to engage in discussion of the content of the items, but they were not able to independently complete the questionnaire. This made me appreciate that the content of the questionnaire has great value and could be used outside of the questionnaire format.

Some health services are introducing roles such as the 'Patient and Family Representative' whose role it is 'to provide a "voice" for the patient, families, carers and consumers who may find it difficult speak up about issues or who may want to comment about their excellent experiences in the ward/unit' [238]. Potentially, (for those unable to independently complete a questionnaire) the items in the questionnaire could be used to guide a discussion with consumers about their experience of care. Use of the content of the questionnaire in this way might greatly enhance the depth of discussion about experience of care.

Using the content of the questionnaire in this way allows the person (in a role like that of the Patient and Family Representative) to be present in the ward environment to both connect with patients (and carers) on a personal level and to observe the experience of care from their own perspective. This is extremely important given there are many older vulnerable people in hospital who do not have a carer who can advocate for them, should there be concerns about care.

The content of the questionnaire could also be used as the basis for quality improvement activities. By way of example, from my data, it was clear that patients (and carers) were mostly not being asked if they had any religious, cultural or spiritual beliefs that were important to them (item 3.3). This is an important finding, given there is evidence that health care providers should have these discussions with patients (and carers) [22, 218, 219]. This item could be used as a quality improvement initiative to raise awareness of this as a topic of discussion, including how to have conversations with patients (and carers) about their cultural, spiritual or religious beliefs.

7.4.2 Content relevant to older people captured by the 10 Principles but missing from other care-concepts.

The terms 'patient-centred' [75, 76, 81, 82] and 'person-centred' [71, 83, 239] are adequately developed to have undergone concept analyses. A significant finding, when exploring the alignment of the 'attributes' identified in these concept analyses against the 10 Principles of Dignity in Care, was the absence of content relevant to Principle 1 (Zero tolerance of all forms of abuse), Principle 6 (Respect people's privacy) and Principles 7 (Ensure people feel able to complain without fear of retribution).

Principles 1, 6 and 7 represent content of importance to older people. Reports detailing the abuse of older people [4, 5, 14], all published within the last decade, justify the need to speak honestly and openly about abuse with older people and health care providers. In addition to the revelations of abuse within health services, there has been a vast expansion of policy on the topic of 'elder abuse' [64, 65, 240] reinforcing the reality that risk of abuse is real. There is a major inconsistency between these reports and policy and the 'attributes' of 'patient-centred' and 'person-centred' care. This is a gap that is filled by Dignity in Care Principle 1 and highlights the need for this message to be made explicitly and openly by all health services, that there must be a 'Zero tolerance of all forms of abuse'.

A breach of privacy should be considered a form of abuse. In the process of assisting someone with washing and toileting, there is an opportunity to afford a person dignity [16, 101, 241]. There are environmental constraints around the provision of dignity, and these should be designed out of health services. But even in the finest built structures, there is the potential for indignity, if the person providing care does not understand the power they hold to afford a person dignity through privacy, or not. Privacy is absent from the 'attributes' assigned to 'patient-centred' and 'person-centred' care, but it is a gap filled by Dignity in Care Principle 6 'Respect People's Privacy'.

Older people might be at greater risk of abuse if they do not feel free to complain. In fact, it is difficult to see how health services can continue to improve if older people do not feel free to complain without fear of retribution. As observed in Section 7.2.1.2, in my experience of data collection, I did not feel older people felt free to complain without fear of retribution. The absence of such content in the 'attributes' of 'patient-centred' and 'person-centred' reinforces my own experience and the findings of other authors, that older people do not feel free to complain [15, 66]. Dignity in Care fills this gap with Principle 7 'Ensure people feel able to complain without fear of retribution'.

Identifying the gaps in content across commonly used care concepts, and acknowledging the important gaps the 10 Principles fill, reinforces the success of this research study in capturing the full extent of content important to older people, which serves as powerful evidence for the content validity of the new PREM I have developed. This is further examined in the next section where I explore the content in common and the content that is unique to the Australian Hospital Patient Experience Question Set (AHPEQS) [32] and the DiCQ.

7.4.3 Items in common and items unique to the Australian Hospital Patient Experience Question Set and the Dignity in Care Questionnaire

For those who can complete a questionnaire or engage in a discussion about the content of a questionnaire or use the content of a questionnaire to guide quality improvement activities, every effort should be made to ensure the content is relevant. This requires the content of a questionnaire to be developed for the target audience. It was my proposition, back in the Introduction (Chapter 1) that the AHPEQS [32] was a generic instrument designed for use by all adult inpatients and, as such, might not meet the specific needs of older people. Now that I have the final version of the items included in the DiCQ, it is time to test that proposition. Appendix L shows the items in common across the AHPEQS and the DicQ.

There were only two items that contained similar content across the AHPEQS and the DiCQ. First, the AHPEQS item number 5 ‘I was involved as much as I wanted in making decisions about my treatment and care’ was almost identical to DiCQ (Patient Version) item 4.2 ‘I have been involved, as much as I wanted to be, in decisions about my care’ and also to DiCQ (Carer Version) item 8.2 ‘I have been involved in decisions about the patient’s care (When the patient was unable to participate and/or when the patient wanted family, friends or carers involved). Second, AHPEQS item number 8 ‘I received pain relief that met my needs’ was similar to DiCQ item 1.5 ‘Staff have helped to control my pain’ (Appendix L).

Where the AHPEQS is more generic in the wording of items (e.g., question number 2. My individual needs were met’) the DiCQ is more specific (e.g., Item 2.5 My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…) and Item 3.3 Staff have asked if I have cultural / religious / spiritual beliefs that are important to me). The specific nature of the items in the DiCQ make implementation clearer (e.g., Item 2.1 ‘Staff wear name badges large enough to read’, ‘Item 2.2 Staff introduce themselves by telling me their name and role’ and Item 3.1 ‘Staff have called me by my preferred name’).

The tone is different. AHPEQS question number 11. ‘My harm or distress was discussed with me by staff’ is different in tone to DiCQ Item 7.1 ‘Staff have made sure there is an opportunity to talk about any concerns’, but possibly have a similar intent.

Issues that might be more relevant to older people, including topics relating to privacy (Principle 6) Item 6.4 ‘I feel my privacy is respected when I am using the toilet, bedpan or changing a pad’ are absent from the AHPEQS. Content relating to the involvement of family is also absent from the AHPEQS, but included in the DiCQ (e.g., Item 8.1 ‘Staff have asked me which family, friends or carers I want involved in my care’).

The AHPEQS has a vital role as the national generic PREM. Over recent years, the demographic of patients in Australian hospitals has changed. Caring for older vulnerable people is now core business for all Australian hospitals. The Dignity in Care PREM has been developed for older people, to measure and monitor the way care is delivered and experienced, under the robust framework of the 10 Principles of Dignity in Care.

7.5 Conclusion

Through my research, I have commenced the process of developing a PREM based on the 10 Principles of Dignity in Care. The DiCQ has been designed to meet the needs of older people (and their carers) in the hospital setting. The questionnaire is the core tool used in PREM, but the limitations of their use with older vulnerable people must be acknowledged. To extend its potential, the content of the DiCQ could be used to administer PREMs using other methods. For example, the content (the items) could be used as the foundation of a discussion with older people, who cannot independently complete a questionnaire, to explore their experience of care. The items of the questionnaire could be used to guide quality improvement initiatives. Used in such a way, the qualitative findings could be presented alongside the quantitative summary of the findings of the questionnaire to contribute to a regular report on experience of care.

In the following Chapter I will conclude my thesis by presenting a plan to continue the development of the Dignity in Care PREM. I will make recommendations as to how the findings of my research can be used to improve the experience of care for older people (and their carers) in hospitals and other settings.

8. Conclusion

Reasoning draws a conclusion, but does not make the conclusion certain,
unless the mind discovers it by the path of experience [242]

8.1 Significance of the research

Older people are at greater risk of harm when in hospital [13], including the harm of indignity [15, 16]. In response, health services need to enable older people to report on their experience of care. To do this, health services require measurement tools specifically designed and developed to meet the needs of older people. These tools also need to accommodate the older person's 'carer' if the patient is unable to report on their own experience of care.

My research has responded to this need. Through a rigorous process of development, involving a broad range of experts and consumers, under the robust framework of the 10 Principles of Dignity in care, I have commenced the process of developing the Dignity in Care Questionnaire. The questionnaire was designed specifically for older people (and their carers) when they are in hospital. The items in the Dignity in Care Questionnaire are clear, specific and implementable. They are written in plain English. The questionnaire includes a common core of 13 items for use by patients and carers, and an additional 10 items unique to patients and 5 items unique to carers.

Framing the Dignity in Care Questionnaire within the 10 Principles of Dignity in Care has resulted in coverage of content that is absent from 'attributes' identified in multiple concept analyses of 'patient-centred', 'person-centred' and 'compassionate' care. The content, captured by the 10 Principles that fills gaps identified in other care concepts, includes items under Principle 1 (Zero tolerance of all forms of abuse), Principle 6 (Respect people's privacy) and Principle 7 (Ensure people feel able to complain without fear of retribution).

The 10 Principles also cover content in common with other care concepts. There is alignment between the 'attributes' of other care concepts and seven (of the 10) Principles of Dignity in Care, including Principle 2 'Support people with the same respect you would want for yourself or a member of your family', Principle 3 'Treat each person as an individual by offering a personalised service', Principle 4 'Enable people to maintain the maximum possible level of independence, choice and control', Principle 5 'Listen and support people to express their needs and wants', Principle 8 'Engage with family members and carers as care partners', Principle 9 'Assist people to maintain confidence and a positive self-esteem' and Principle 10 'Act to alleviate people's loneliness and isolation'. Evidence of this alignment supports the use of the 10 Principles as a proxy message and measure of 'patient-centred' and 'person-centred' care.

Dignity is the word most prominent in rights and a word in common use in the community. To promote health literacy, there should be a shift away from the bureaucratic terminology of the poorly defined terms [75, 81, 83] [42] such 'patient-centred', 'person-centred', 'compassionate care', 'relationship-centred care' and 'individualised' care and a shift toward the consumer empowering message contained in the 10 Principles of Dignity in Care.

The items that constitute the patient (and carer) versions of the Dignity in Care Questionnaire, herald the evolution of a new PREM that can be used to measure aspects of care that are important and relevant to older people (and their carers).

These items hold a message that can be used by health services to improve the experience of care for older people. They can be used, as designed, in the form of a questionnaire and they can be used as the foundation of a discussion about experience of care, with those unable to complete a questionnaire. The messages contained in the items can be used in education and training and to guide the implementation of quality improvement activities.

Dignity is not a fad, it is a human, health and aged care right. While writing this conclusion, I have been reading the Interim Report of the Royal Commission into Aged Care in Australia [62]. The report is titled 'Neglect'. Dignity in Care is an obvious and compelling response. Indeed, the 2018 revision of the Aged Care Standards include as Standard 1 'Consumer dignity and choice' [60]. As I write, there is also a Disability Royal Commission underway. The title is 'Violence, Abuse, Neglect and Exploitation of People with Disability' [63]. Again, 'Dignity' needs to be the headline response.

8.2 Strengths and Limitations

8.2.1 Strengths

The great strength of this study is that the questionnaire is built from a conceptual framework that arose from the feedback of hundreds of members of the public and the message 'Dignity in Care' has remained a powerful force for change in the provision of care in the United Kingdom.

A strength of the 10 Principles is that they are short, simple, easily understood and implementable statements, that can be used as a proxy for the more elusive and poorly defined [42], but much touted, 'person-centred' care.

The contribution of 57 experts though the Delphi panel resulted in a robust process of item development. The contribution of 52 expert patients and carers through the pilot study resulted in a robust interrogation of the draft questionnaire, which greatly improved the face validity and content validity of the questionnaire used for the major data collection. The methods used in the data analysis are contemporary and rigorous and provide confidence in the results.

Of significance, the Dignity in Care Questionnaire (DiCQ) underwent preliminary assessment of unidimensionality, validity and internal reliability using Rasch analysis. This method is not yet in common use in the development of PREMs. Publication of this research may herald a new direction for the methods of data analysis used in the testing of experience of care instruments. Rasch analysis should and could be used in testing the unidimensionality, content validity and internal reliability of PREMs. Authors who do not use these techniques could rightly be challenged.

8.2.2 Limitations

I was unable to recruit to the sample size I has set as a target for the carer version of the questionnaire, for the purpose of Rasch analysis.

There was good representation from culturally and linguistically diverse communities in the content development (Delphi panel) stage of the study, however I was unable to recruit participants who spoke English as a second language in the data collection stage of the study.

There was good representation from Aboriginal people in the content development (Delphi panel) stage of the study, however there were few Aboriginal people recruited in the data collection stage of the study.

8.3 Future Research

I am not alone in thinking the investment in dignity in care research is justified. The second (of 10) priorities for research identified by the Canadian Dementia Priority Setting Partnership in 2018 was 'What can be done to support emotional well-being, including maintaining a sense of dignity, for persons with dementia?' [243].

It is impressive that the United Kingdom has remained committed to Dignity in Care for over a decade, but more recently 'compassionate care' is blurring the message. Compassion is to 'suffering' [196] as dignity is to 'value' [196]. Given 'compassionate care' has no robust definition or measure, it is far more powerful to demonstrate compassion, where that is appropriate, in delivering the 10 Principles of Dignity in Care. Everyone, including older people, and people with dementia, have a right to dignity, to be treated with value, not simply acknowledged for their perceived suffering.

Research needs to focus on the messages that are core to the experience of care. Ongoing development of the message needs to reflect the content of contemporary policy and health care reviews. But reframing and renaming these core messages under a care concept with a new name, with an ambiguous message, is not helpful. Language needs to be consistent with human, health and aged care rights. Research needs to focus far more heavily on the implementation of those rights into practice. The 10 Principles of Dignity in Care algin well to Australian health and human rights. Dignity in Care is a proven message and there is a strong case, supported by rights, policy and standards, for pursuing research to implement Dignity in Care into practice. I have commenced the process of developing the questionnaire to measure the implementation of Dignity in Care into practice, as detailed in Stages 1, 2 and 3 in Table 8. 1. No PREM can be developed into its final form in one research study. I have proposed future Stages 4, 5 and 6 of the study (Table 8. 1) to continue development of the DiCQ.

Proposed future Stage 4 of the research is designed to continue testing the validity and reliability of the DiCQ (Table 8. 1). The assessment of the DiC (Carer Version) undertaken in Stage 3 of the study was able to demonstrate acceptable unidimensionality, validity and internal reliability, but the sample of 77 carers, upon which the analysis was undertaken, means the findings should be considered preliminary and exploratory. Proposed future Stage

4a should include further assessment of the carer version of the DiCQ with a large sample size.

Many challenges were encountered in recruiting people who do not speak English as a first language into Stage 2 and Stage 3 of the study. Proposed future Stage 4b should include targeted recruitment of people from diverse communities, including people who do not speak English as their first language, to allow assessment of cross-cultural validity.

People requiring health care staff to wear PPE were excluded from Stage 2 and Stage 3 of the study. Given the worldwide Covid-19 pandemic and the increased use of PPE, further research is required to ensure older vulnerable people, further isolated by nature of the PPE requirements, are able to report on their experience of care. Proposed future Stage 4c includes the exploration of methods to include patients requiring PPE.

Consideration should be given to undertaking test retest assessment of reliability in Stage 4d of proposed future research. The value and appropriateness of undertaking test retest must be examined given it is possible a person's experience of dignity in care could change over a period of 1 to 2 days.

Once the instrument has undergone further development and testing through proposed Stage 4a-4d, the instrument should be adequately developed to assess, in proposed future Stage 4e, its responsiveness, to test the ability to measure change over time.

Research is required to explore the methods used to measure and monitor patient experience for older people (and their carers), including people with dementia. The message (10 Principles of Dignity in Care) and the instrument (the DiCQ) are vital components of the methods but measuring patient (and carer) experience requires much more than the administration of a questionnaire. This is a field of research that has not kept pace with demographic changes in our hospital populations. Proposed future Stage 5 of the research is includes exploration of how the content of the content of the DiCQ questionnaire can be used in the administration of PREMs using methods such as: patient (and carer) discussions about experience of care, consumer focus groups, the framing the telling of patient stories and in the implementation of quality improvement activities (Table 8. 1).

Proposed future Stage 6 of the research is to assess the validity of the DiCQ with older and/or vulnerable people in aged care and disability settings (Table 8. 1).

Table 8. 1 Current and Future Research

	Current Research Study			**Future Research**		
Stage	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6
Year	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23
	PhD			Post-doctoral		
Purpose	Delphi study for Item Generation	Pilot Study to assess face validity of patient and carer versions of the DiCQ	Preliminary assessment of unidimensionality, validity and reliability of the patient and carer versions of the DiCQ	4a. Further assess carer version with a large sample size 4b. Assess cross cultural validity 4c. Explore methods to include patients requiring PPE 4d. Assess test retest reliability 4e. Assess responsiveness	5. Assess the use of the content of the questionnaire in the administration of PREMs using methods such as: - Patient (and carer) discussions. - Consumer focus groups. Framing the telling of patient stories. - Quality Improvement activities.	6a. Assess validity in residential aged care 6b. Assess validity in residential disability services

8.4 Recommendations

1. Continue the development of the DiCQ, as detailed in proposed future Stages 4, 5 and 6 (Table 8. 1).

2. With ongoing development, the DiCQ should be used to support the implementation of:

    2a. Recommendation One of the Clinical Guidelines for Dementia in Australia, which states ‘Health and aged care professionals should provide person-centred care, by identifying and responding to the individual needs and preferences of the person with dementia, their carer(s) and family. The 10 Principles of Dignity in Care should be used as the standard by which care is delivered and evaluated’ [59].

    2b. Standard One of the Aged Care Quality Standards, which state ‘People are all shaped by personal characteristics, experiences, values and beliefs. Aged care consumers have the same diversity of characteristics and life experiences as the rest of the community. Each consumer has social, cultural, language, religious, spiritual, psychological and medical needs that affect the care, services and supports they need. No two consumers’ lived experiences are the same. What is respectful or dignified for one consumer might not be for another. This means organisations need to take the time to listen to and understand each consumer’s personal experience. They need to work with consumers in an inclusive and respectful way, using a consumer-focused approach. It’s important for an organisation to address diversity, whether or not a consumer has told them about their unique life experiences or characteristics. Using strategies to support the organisation’s commitment to diversity helps consumers to feel confident sharing their identity and helps the workforce to see them as a whole person’ [60].

    2c. Partnering with Consumers Standard of the Australian Commission for Safety and Quality in Health Care, which includes ‘Action 2.3 Review the effectiveness of the Charter of Healthcare Rights. Measure the impact of the charter to see whether promotion efforts are successful and whether this affects patient experience. Strategies may include: Conducting surveys of patients to check whether they have received the charter, and whether the rights in the charter have been respected’ [22].

8.5 A final note

Hospitals need a meaningful message and method to measure and monitor the implementation of care that is consistent with that message. There is a strong case, based on substantial evidence, for adopting the message articulated by the 10 Principles of Dignity in Care. Older people, including people with dementia, are core business for hospitals. Greater effort is required to measure and monitor their experience of care and use that information to acknowledge good practice and improve unacceptable practice. The 10 Principles of Dignity in Care represent the core attributes of patient-centred and person-centred care, plus they cover important content not covered by patient-centred and person-centred care. There is power in the message. The message is important, because ***everybody*** has a (human, health and aged care) ***right*** to dignity!

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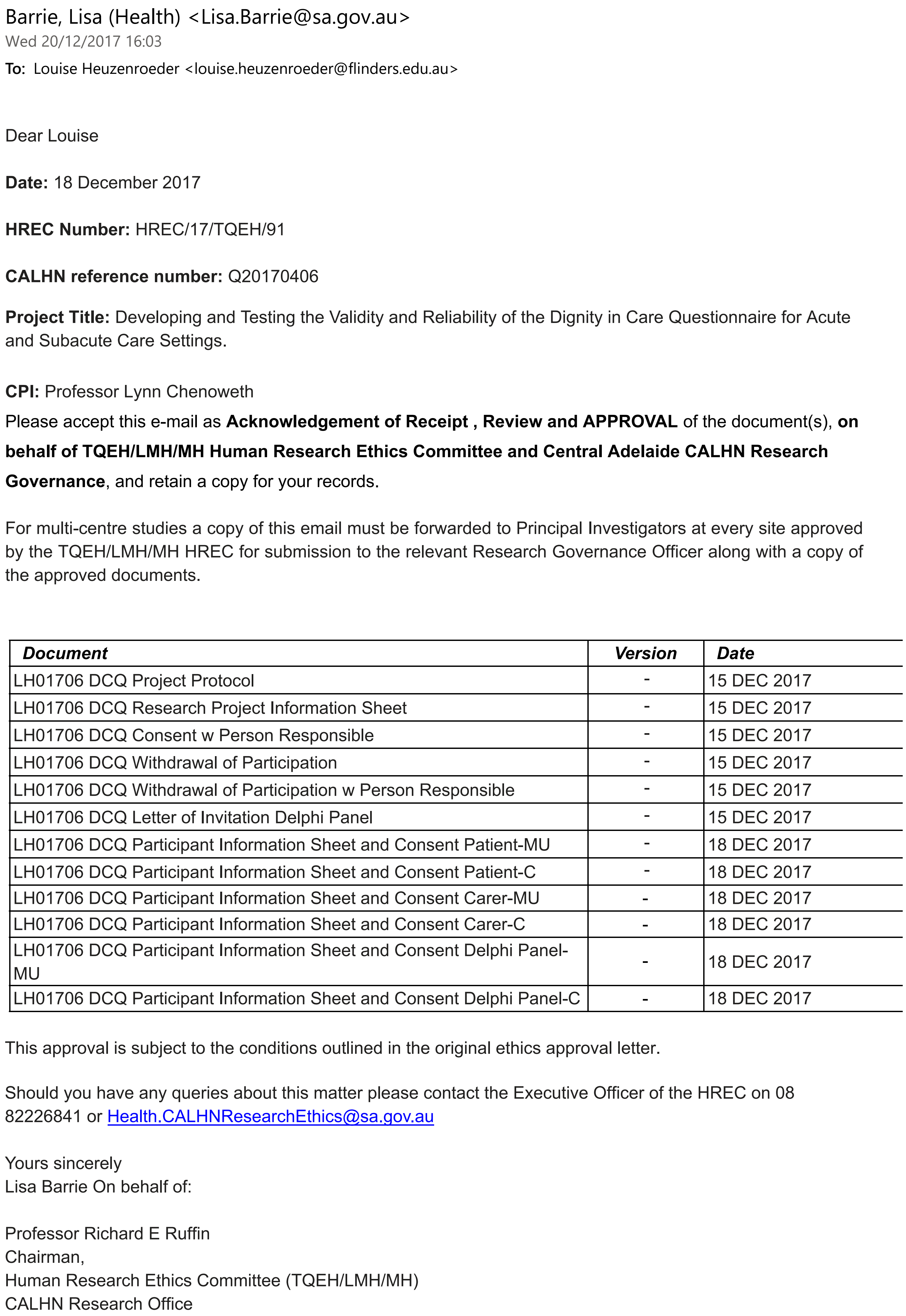
Appendix A1 Ethics Approval



Barrie, Lisa (Health) <Lisa.Barrie@sa.gov.au>
Wed 20/12/2017 16:03
To: Louise Heuzenroeder <louise.heuzenroeder@flinders.edu.au>

Dear Louise

Date: 18 December 2017

HREC Number: HREC/17/TQEH/91

CALHN reference number: Q20170406

Project Title: Developing and Testing the Validity and Reliability of the Dignity in Care Questionnaire for Acute and Subacute Care Settings.

CPI: Professor Lynn Chenoweth

Please accept this e-mail as **Acknowledgement of Receipt , Review and APPROVAL** of the document(s), **on behalf of TQEH/LMH/MH Human Research Ethics Committee and Central Adelaide CALHN Research Governance**, and retain a copy for your records.

For multi-centre studies a copy of this email must be forwarded to Principal Investigators at every site approved by the TQEH/LMH/MH HREC for submission to the relevant Research Governance Officer along with a copy of the approved documents.

Document	***Version***	***Date***
LH01706 DCQ Project Protocol	-	15 DEC 2017
LH01706 DCQ Research Project Information Sheet	-	15 DEC 2017
LH01706 DCQ Consent w Person Responsible	-	15 DEC 2017
LH01706 DCQ Withdrawal of Participation	-	15 DEC 2017
LH01706 DCQ Withdrawal of Participation w Person Responsible	-	15 DEC 2017
LH01706 DCQ Letter of Invitation Delphi Panel	-	15 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Patient-MU	-	18 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Patient-C	-	18 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Carer-MU	-	18 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Carer-C	-	18 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Delphi Panel-MU	-	18 DEC 2017
LH01706 DCQ Participant Information Sheet and Consent Delphi Panel-C	-	18 DEC 2017

This approval is subject to the conditions outlined in the original ethics approval letter.

Should you have any queries about this matter please contact the Executive Officer of the HREC on 08 82226841 or Health.CALHNResearchEthics@sa.gov.au

Yours sincerely
Lisa Barrie On behalf of:

Professor Richard E Ruffin
Chairman,
Human Research Ethics Committee (TQEH/LMH/MH)
CALHN Research Office

Phone: 08 8222 6841 | DX: 465101 | Email: Health.CALHNResearchEthics@sa.gov.au | Web:
http://www.basilhetzelinstitute.com.au/research/information-for-researchers/human-research-ethics-committee/
Ground Floor, Basil Hetzel Institute for Translational Health Research, The Queen Elizabeth Hospital, 28 Woodville Road,
Woodville South SA 5011

Government of South Australia
SA Health
Central Adelaide Local Health Network Inc.

Appendix A2 Governance Approval CALHN

Government of South Australia
SA Health

Central Adelaide Local Health Network
Human Research Ethics Committee
Level 3, Roma Mitchell House
North Terrace, Adelaide SA
Australia 5000

Ground Floor, Basil Hetzel Institute for Translational Research
28 Woodville Road, Woodville SA
Australia 5000

T : 08 7117 2229
T : 08 8222 6841
E : Health.CALHNResearchEthics@sa.gov.au

27 March 2018

Professor Alison Kitson
College of Nursing and Health Sciences
Flinders University

Dear Professor Kitson,

Project title: Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting.

MyIP ref: 10024
CALHN ref: Q20170406
HREC ref: HREC/17/TQEH/91
SSA ref: SSA/18/CALHN/56

RE: Governance authorisation

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to commence at Royal Adelaide Hospital, SA.

Authorisation is valid from **27 March 2018 to 31 August 2019**. Proposed extensions beyond this term must be submitted to the CALHN Research Office.

The following conditions apply to the authorisation of this research project. These are additional to those conditions imposed by the Human Research Ethics Committee (HREC) that granted ethical approval to this project:

1. Authorisation is limited to the site/s identified in this letter only.
2. Project authorisation is granted for the term specified above, or until the project is complete (whichever date is earlier).
3. The study must be conducted in accordance with the conditions of ethical approval provided by the lead HREC, SA Health policies, and in conjunction with the standards outlined in the *National Statement on Ethical Conduct in Human Research* (2007) and the *Australian Code for the Responsible Conduct of Research* (*2007).*
4. Proposed amendments to the research protocol or conduct of the research which may affect both the ongoing ethical acceptability of the project and the site acceptability of the project are to be submitted to the CALHN Research Office after a HREC decision is made.
5. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted via email to the CALHN Research Office;
6. For all clinical trials, the study must be registered in a publicly accessible trials registry prior to enrolment of the first participant.
7. A copy of this letter should also be maintained on file by the Coordinating Principal Investigator as evidence of project authorisation.
8. Notification of completion of the study at this site is to be provided to the CALHN Research Office.

All future correspondence regarding this study must include the MyIP reference number and CALHN reference number in the subject header.
We wish you every success in your research project.

Yours sincerely

Bernadette Swart
Manager, CALHN Research Office
Ph: 8222 3890
Email: bernadette.swart@sa.gov.au
Email: Health.CALHNResearchGovernance@sa.gov.au

Appendix A3 Governance Approval NALHN LMH

Government of South Australia
SA Health

Northern Adelaide Local Health Network

Research Governance Office
Level 2, Clinical Trials Unit
Lyell McEwin Hospital
Haydown Road
ELIZABETH VALE SA 5112
Tel: 08 8182 9346
Email: healthnalhnrgo@sa.gov.au

07 January 2019

Prof Alison Kitson
Exec. Dean, College of Nursing & Health Sciences
Flinders University
Sturt Road
Bedford Park SA 5042

Dear Prof Kitson,

HREC reference number: HREC/17/TQEH/91
SSA reference number: SSA/18/NALHN/151
Project title: *Developing and Testing the Validity and Reliability of the Dignity in Care Questionnaire for Acute and Subacute Care Settings.*

I am pleased to advise that the above project is approved to be conducted at **Lyell McEwin Hospital.**

This approval is subject to compliance with the conditions set out below in addition to the conditions specified by the reviewing HREC.

1. Record keeping is maintained in accordance with GCP, NHMRC, State and National guidelines.
2. Notify the NALHN Research Governance Office of:

- Any HREC approved amendments to the project
- The annual progress of the project (annual report)
- Extensions to the ethical approval of the project
- Serious or unexpected adverse effects for NALHN participants
- Site based protocol deviations
- Any changes to the indemnity, insurance arrangements or CTRA for the project
- Your inability to continue as Principal Investigator or any other change in research personnel involved in this project
- Failure to commence the study within 12 months of site approval / or if a decision is taken to end the study at this site
- Any other unforeseen events
- Any other matters which may impact the conduct of the project in NALHN
- A comprehensive final report at study completion including any published material
- Site audits and final audit report

3. Maintain confidentiality of NALHN participants at all times, as required by law.
4. Dispose of research materials in accordance with the requirements outlined in the NHMRC Australian Code for the Responsible Conduct of Research.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

The NALHN Research Governance Office may conduct an audit of the project at any time.

Please note: templates for the post approval submission of documents to the RGO can be accessed from: http://www.basilhetzelinstitute.com.au/research/information-for-researchers/nalhn/forms-and-templates/

Should you have any queries about the consideration of your Site Specific Assessment form, please contact me on 08 8182 9346 or healthnalhnrgo@sa.gov.au

The SSA reference number should be quoted in any correspondence about this matter.

Yours sincerely

Roy Sneddon
Research Governance Officer
Northern Adelaide Local Health Network (LMH/MH/PHC)

Key Dates:

Document	Due date
Annual Report	09 June - annually until completion

Appendix A4 Governance Approval NALHN MH

Government of South Australia
SA Health

Northern Adelaide Local Health Network

Research Governance Office
Level 2, Clinical Trials Unit
Lyell McEwin Hospital
Haydown Road
ELIZABETH VALE SA 5112
Tel: 08 8182 9346
Email: healthnalhnrgo@sa.gov.au

15 Jan 2018

Prof Alison Kitson
Exec. Dean, College of Nursing & Health Sciences
Flinders University
Sturt Road
Bedford Park SA 5042

Dear Prof Kitson,

HREC reference number: HREC/17/TQEH/91
SSA reference number: SSA/17/NALHN/100
Project title: Developing and Testing the Validity and Reliability of the Dignity in Care Questionnaire for Acute and Subacute Care Settings.

I am pleased to advise that the above project is approved to be conducted at **Modbury Hospital.**

This approval is subject to compliance with the conditions set out below in addition to the conditions specified by the reviewing HREC.

1. Record keeping is maintained in accordance with GCP, NHMRC, State and National guidelines.
2. Notify the NALHN Research Governance Office of:

- Any HREC approved amendments to the project
- The annual progress of the project (annual report)
- Extensions to the ethical approval of the project
- Serious or unexpected adverse effects for NALHN participants
- Site based protocol deviations
- Any changes to the indemnity, insurance arrangements or CTRA for the project
- Your inability to continue as Principal Investigator or any other change in research personnel involved in this project
- Failure to commence the study within 12 months of site approval / or if a decision is taken to end the study at this site
- Any other unforeseen events
- Any other matters which may impact the conduct of the project in NALHN
- A comprehensive final report at study completion including any published material
- Site audits and final audit report

3. Maintain confidentiality of NALHN participants at all times, as required by law.
4. Dispose of research materials in accordance with the requirements outlined in the NHMRC Australian Code for the Responsible Conduct of Research.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

The NALHN Research Governance Office may conduct an audit of the project at any time.

Please note: templates for the post approval submission of documents to the RGO can be accessed from: http://www.basilhetzelinstitute.com.au/research/information-for-researchers/nalhn/forms-and-templates/

Should you have any queries about the consideration of your Site Specific Assessment form, please contact me on 08 8182 9346 or healthnalhnrgo@sa.gov.au

The SSA reference number should be quoted in any correspondence about this matter.

Yours sincerely

Alison Barr
Research Governance Officer
Northern Adelaide Local Health Network (LMH/MH/PHC)

Key Dates:

Document	Due date
Annual Report	09 June - annually until completion

Appendix A5 Governance Approval SALHN

Office for Research

Flinders Medical Centre
Ward 6C, Room 6A219
Flinders Drive, Bedford Park SA 5042
Tel: (08) 8204 6453
E: Health.SALHNOfficeforResearch@sa.gov.au

Government of South Australia
SA Health
Southern Adelaide Local Health Network

Final Authorisation for Governance

23 January 2018

Professor Alison Kitson
College of Nursing and Health Sciences
Flinders University

Dear Professor Kitson,

OFR Number: 13.18
HREC reference number: HREC/17/TQEH/91
SSA reference number: SSA/18/SAC/20
Project title: Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hopsital setting.
Principal Investigator: Professor Alison Kitson

On the basis of the information provided in your Site Specific Assessment submission, I am pleased to inform you the SALHN Chief Executive Officer has granted approval for this study to commence at Flinders Medical Centre, SA.

The below documents have been reviewed and approved:

- Site Specific Assessment form

HREC reviewed documents listed on the approval letter are accepted as part of the site authorisation.

The OFR reference number should be quoted in any correspondence about this matter.

If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.

TERMS AND CONDITIONS OF ETHICS AND GOVERNANCE APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

- If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
- Compliance with the National Statement on Ethical Conduct in Human Research (2007) & the Australian Code for the Responsible Conduct of Research (2007).
- To immediately report to the Office for Research anything that may change the ethics or scientific integrity of the project.
- Report Significant Adverse events (SAEs) as per SAE requirements available on the Office for Research website.
- Submit an annual report on each anniversary of the date of final approval and in the correct template from the Office for Research website.
- Confidentiality of research participants MUST be maintained at all times.
- A copy of the signed consent form must be given to the participant.
- Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
- All requests for access to medical records at any SALHN site must be accompanied by this approval letter.

- Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the SALHN as standard practice without the approval of the SALHN New Medical Products and Standardisation Committee or the SALHN New Health Technology and Clinical Practice Innovation Committee (as applicable). Please refer to the relevant committee link on the SALHN intranet for further information.
- Researchers are reminded that all advertisements/flyers need to be approved by the committee, and that no promotion of a study can commence until final ethics and executive approval has been obtained. In addition, all media contact should be coordinated through the FMC media unit.

Should you have any queries about the consideration of your Site Specific Assessment form, please contact the Office for Research on 8204 6453 via email: Health.SALHNOfficeforResearch@sa.gov.au.

Yours sincerely

S Windsor

Simon Windsor
Research Governance Officer
Office for Research

Appendix A6 Delphi Panel Letter of Invitation

Government of South Australia
SA Health

Date
By email

Dear ____________

Re: Invitation to become a member of a Delphi panel

I am writing to invite you to become a member of the Delphi panel for the research study titled ‘Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting’.

The purpose of this study is to develop a questionnaire to measure the experience of care that is consistent with the 10 Principles of Dignity in Care.

The first stage of the study involves convening a Delphi Panel of experts who will make recommendations on the development of the questionnaire and its scoring.

The Delphi panel process will take place over the period February to June 2018. As a member of the Delphi panel you will be required to participate in three or four “rounds” of panel deliberations, these will all take place by email, there will be no face to face meetings.

Your participation will require you to be able to provide responses and written comments to proposed questionnaire items and scoring in each “round” of Delphi panel deliberations, within a two-week turnaround. We estimate that your response to each Delphi panel “round” would take at most 1 hour of your time.

Further information is provided in the attached Research Study Participant Information Sheet/Consent form.

If you would like more information or are interested in being part of the Delphi Panel please contact Louise Heuzenroeder, PhD Candidate, who is undertaking the research, by email louise.heuzenroeder@flinders.edu.au or by telephone on 0408 544 604.

Yours sincerely,

Alison Kitson
Vice-President & Executive Dean
College of Nursing and Health Sciences
Flinders University

Appendix A7 Delphi Panel Participant Information and Consent Form

Government of South Australia
SA Health

Flinders
UNIVERSITY

Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Protocol Number	LH01706
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Associate Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder
Location	Royal Adelaide Hospital, Flinders Medical Centre, Modbury Hospital

---

1 Introduction

You have been invited to become a member of the Delphi panel for the research study titled ‘Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting’.

This Participant Information Sheet/Consent Form tells you about the research study and the role of the Delphi panel members. Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about.

If you choose to take part in the study as a member of the Delphi panel, you will need to sign the Consent form (attached). Your involvement will only be known to the researcher. The information you provide in the Delphi panel process will be de-identified.

2 Do I have to take part in this research study?

Participation in this research study is voluntary. If you don’t wish to take part, you don’t have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

3 What is the purpose of this research study?

The purpose of this research study is to develop a questionnaire that could be used to measure patients’ and carers’ experience of receiving care that is consistent with the 10 Principles of Dignity in Care.

The 10 Principles of Dignity in Care evolved from the findings of a 2006 online survey conducted by the Department of Health in the United Kingdom. The 10 Principles of Dignity in Care are:

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people’s privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people’s loneliness and isolation.

http://www.dignityincare.org.uk/

This research study will take place over 3 stages.

In **Stage 1** a Delphi panel of experts, including consumers, carers and health care staff, will contribute to the development of the Dignity in Care Questionnaire, which will include a version for use by patients and a version for use by their carer (i.e., their family/friend/advocate).

In **Stage 2** the Delphi panel approved Dignity in Care Questionnaire will be tested with a small sample of consumers (aged 65 years and older, 50 years and older for Aboriginal people) who are inpatients in one South Australian hospital and with their carers. The Dignity in Care Questionnaire may be amended based on the findings of the pilot.

In **Stage 3** the validity and reliability of the Dignity in Care Questionnaire will be tested using the Questionnaire responses obtained from a larger sample of patients (aged 65 years and older, 50 years and older for Aboriginal people) and their carers across three South Australian hospitals.

4 What does participation in this research as a member of the Delphi panel involve?

We are using the Delphi panel process to contribute to the development of the questions to be included, and the scoring to be used, in the Dignity in Care Questionnaire. The Delphi panel will include members with expertise as consumers, carers, health care staff and those with expertise in policy, management and advocacy.

All communication with Delphi panel members will be undertaken by email. There will be no face to face meetings of the Delphi panel. The Delphi panel process will be undertaken over approximately 5 months (February to June 2018). Delphi panel members will need to participate in three to four rounds of questionnaire development.

In preparation for round one of the Delphi panel, the researcher will review relevant literature and existing questionnaires to identify items which are similar to each of the 10 Principles of Dignity in Care. This process may identify several questions which align with each of the 10 Principles.

The researcher will collate the questions under each of the 10 Principles of Dignity in Care and develop a scale for rating each of the questions. The Delphi panel members will then be requested to rate the questions for importance and relevance. Delphi panel members will also be asked to recommend changes to the wording of existing questions and to include additional questions which they consider important in explaining any of the 10 Principles of Dignity in Care.

After each Delphi panel round the researcher will collate the information and provide feedback to the panel members. This iterative process (i.e., Round 2, Round 3, Round 4…) will continue until there is acceptable consensus on the questions to be included, their wording and scoring.

Once acceptable consensus has been reached, the questionnaire will be pilot tested. The Dignity in Care Questionnaire may be amended based on the findings of the pilot.

At the end of Stage 2 of the study, the final version of the Dignity in Care Questionnaire will be emailed to Delphi panel members, this will mark closure of the Delphi panel process. You may choose to receive email progress updates over the remaining Stage 3 and Stage 4 of the study.

5 Do you have a concern or a complaint?

If you would like to speak to someone about a concern or a complaint you have about the research study, the contact details of the Ethics Committee Co-Ordinator are provided in Section 9 of this Information Sheet.

6 What will happen to information about me?

The information the researcher will collect and use will include the answers you provide on the questionnaires during the Delphi panel process. We will also note the expertise of Delphi panel members, but we will not identify participants by name.

7 Who is organising and funding the research?

Louise Heuzenroeder has been awarded a Dementia Australia Research Foundation Consumer Priority PhD Scholarship to undertake this research. The results of this research will be used by the researcher to obtain a Doctor of Philosophy (PhD).

8 Who has reviewed the research project?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the Central Adelaide Local Health Network (TQEH/MH/LMH), HREC Number HREC/17/TQEH/91. This approval has been recognised by the ethics committees of all three hospitals involved in the study and by Flinders University's Ethics Committee. The National Health and Medical Research Council's Health Research Ethics Application Reference Code for the study is LH01706.

9 Do you want to speak to someone about the research study?

If you would like to speak to someone about the research study, contact details are provided below for the Researcher and the HREC Executive Officer.

Researcher

Name	Louise Heuzenroeder
Position	PhD Candidate Flinders University
Telephone	0408 544 604
Email	louise.heuzenroeder@flinders.edu.au

Human Research Ethics Committee

Name	Heather O'Dea
Position	HREC Executive Officer
Telephone	8222 6841
Email	Health.CALHNResearchEthics@sa.gov.au

Government of South Australia
SA Health

Flinders
UNIVERSITY

Consent Form –Delphi Panel

Project Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Protocol Number	LH01706
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Associate Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future relationship with the research team members, their employers or the research funding agency.

I understand that I will be given a signed copy of this document to keep.

Name of Participant ______________________________

Signature ____________________ Date ____________________

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† ______________________________

Signature ____________________ Date ____________________

Note: All parties signing the consent section must date their own signature.

Appendix A8 Research Project Information Sheet

Project Title

Developing and testing the reliability and validity of a questionnaire to measure **Dignity in Care** for older people (and their 'carer') in the hospital setting.

Developing the questionnaire

I am asking patients if they would be happy to complete the draft Dignity in Care questionnaire to help me work out which questions to include and which questions to exclude.

If you are happy to be involved, you just need to complete the questionnaire, which will take about 15 minutes, but you can take as much time as you need.

Your family or friend can undertake the family / friend version of the questionnaire.

Your responses on the questionnaire will be known only to the researcher. Your responses will not be available to any hospital staff.

Hello, my name is Louise

I am undertaking research for my PhD to develop a Dignity in Care Questionnaire.

A large proportion of patients in Australian hospitals are older people, many of these people have complex health problems and may be vulnerable when in hospital.

There is strong support for developing better methods for measuring, and monitoring, these peoples' experience of care.

The purpose of my research is to develop a questionnaire that could be used to measure patients' and their family's experience of receiving care that is consistent with the 10 Principles of Dignity in Care (listed over the page).

Ethics Approval HREC/17/TQEH/91

http://flinders.edu.au/people/louise.heuzenroeder

The 10 Principles of Dignity in Care

1. Zero tolerance of all forms of abuse.

2. Show people respect.

3. Treat each person as an individual by offering a personalised service.

4. Enable people to maintain the maximum possible level of independence, choice and control.

5. Listen and support people to express their needs and wants.

6. Respect people’s privacy.

7. Ensure people feel able to complain without fear of retribution.

8. Engage with family members, friends and carers as care partners.

9. Assist people to maintain confidence and a positive self-esteem.

10. Act to alleviate people’s loneliness and isolation.

http://www.dignityincare.org.uk/

Appendix A9 Participant Information and Consent Form (Patient)

Government of South Australia
SA Health

Flinders UNIVERSITY

Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Ethics Reference	HREC/17/TQEH/91
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder
Location	Complete for each site

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research study, titled ‘Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting’.

This Participant Information Sheet/Consent Form tells you about the research study. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

If you decide you want to take part in the research study, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research study
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 Do I have to take part in this research study?

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to.

If you decide to take part and later change your mind, you are free to withdraw from the study at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your current or future care, your relationship with the hospital staff or your relationship with the hospital where you are a patient.

3 What is the purpose of this research study?

We believe health services need better methods of measuring patients' and carers' experience of care. The purpose of this research study is to develop a questionnaire that could be used to measure patients' and carers' experience of receiving care that is consistent with the 10 Principles of Dignity in Care.

The 10 Principles of Dignity in Care evolved from the findings of a 2006 online survey conducted by the Department of Health in the United Kingdom. The purpose of the survey was to allow the Minister for Care Services to hear directly from the public about their own experiences of being treated with dignity, in care services. The 10 Principles of Dignity in Care are:

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

http://www.dignityincare.org.uk/

The research study will take place over 3 stages.

Stage 1 is the work of a Delphi panel to support the development of two versions of the Dignity in Care Questionnaire; a version for use by people who are admitted to hospital and a version for use by their carer (i.e., their family/friend/advocate).

Stage 2 is pilot testing the questionnaire on a smaller sample of consumers and carers. The pilot test will be part of finalising the development of the questionnaire in preparation for the following stages.

Stage 3 will involve testing the questionnaire on a much larger sample of patients who are aged 65 and older (Aboriginal people aged 50 and over) and their carers. The purpose of this stage of the research is to test the validity and reliability of the questionnaire. Validity and reliability are measured using statistical tests on the information we collect from the questionnaires. If a questionnaire has acceptable validity it means it is measuring what it is meant to measure, that is the 10 Principles of Dignity in Care. If a questionnaire has acceptable reliability it means it can produce reproducible information. If we find the Dignity in Care Questionnaire demonstrates acceptable validity and reliability, we can recommend its use in Australian hospitals.

4 What does participation in this research involve?

Two separate Participant Information Sheets will be developed; a version that includes the paragraph under Pilot Study (below) and a version that includes the paragraph under Data Collection (below). Text highlighted in yellow will be deleted in the final versions printed for use.

Pilot Study

Pilot Testing Taking part in the research study will require you to complete the Dignity in Care Questionnaire, which should take about 20 minutes. You will also be asked to participate in an interview with the researcher.

The purpose of the interview is to obtain your thoughts on the number of questions, the wording of the questions, what you think the questions mean and whether you think there are questions that should be removed and others that should be added. The interview will take about 30 minutes and, with your consent, will be tape recorded. There will be no further involvement required.

Data Collection

Taking part in the research study will require you to complete the Dignity in Care Questionnaire, which should take about 15 minutes.

You will be asked to complete the questionnaire once. There will be no further involvement required.

If you choose to take part in the study, you will need to sign the Consent form (attached). By signing the Consent form, you agree to give permission to the research team to collect and use information about you, but only that which is relevant for the research.

Your information will only be used to test the validity and reliability of the questionnaire under development.

The information you provide in the questionnaire will not be provided to any staff in the hospital where you are a patient.

The Clinical Director of each of the wards included in the study has provided written support for the research. The researcher will work closely with the Clinical Directors and with Chief Investigator of the study and the associate investigators to ensure the research is appropriately monitored.

5 Who is being asked to participate in this research study?

You are being invited to participate because you are a patient currently admitted to ____________________.

We want to focus this research study on older people, and we want to include the diversity of people who access hospital services.

The research *will include* people:

- Who are aged 65 years or older (50 years and older for Aboriginal and Torres Strait Islander people); and
- Who are patients in the ________________ ward of the _______________ hospital
- During the period __________________________ to ____________________________

The researchers *want to include*:

- Aboriginal and Torres Strait Islander people
- People from culturally and linguistically diverse backgrounds
- People who have dementia (including Alzheimer's Disease)

Informed consent will be required for all participants. This will require the development of a survey that is meaningful to Aboriginal and Torres Strait Islander people, access to interpreters for people who do not speak English and the support of a carer who can provide legal consent on behalf of a person who is unable to give consent.

The research will exclude people:

- Who are unable to give consent and who do not have a carer who can legally give consent on their behalf
- Who are in the last days of life

6 What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research.

If, through our research, we can demonstrate the questionnaire is a valid and reliable measure of Dignity in Care, the questionnaire could be implemented across Australian hospitals to provide a method by which future patients can report their experience of receiving Dignity in Care. Hospitals could use this information to guide education and training and improve their performance in the provision of Dignity in Care.

7 What are the possible risks and disadvantages of taking part?

Participating in the study may have the potential to cause some people to reflect on an experience of care that was unpleasant or traumatic. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, please talk to the doctors and nurses looking after you, to ensure your concerns are addressed promptly.

If you are not satisfied with how your concerns were managed by the doctors and / or nurses and you would like to speak to someone else about your care or concerns, you can contact the Consumer Advisory Service, whose contact details are provided in Section 13 of this form.

8 Do you have a concern or a complaint?

If you would like to speak to someone about a concern or a complaint you have about the research study, the contact details of the Ethics Committee Co-ordinator are provided in Section 13 of this Information Sheet.

It is mandatory for all of SA Health’s hospitals to comply with the Consumer Feedback Management Policy Directive (2011). This policy is publicly available. To obtain a copy, please ask the Researcher or the Ethics Committee Co-ordinator (contact details provided in Section 13).

9 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw, you will be asked to complete and sign a ‘Withdrawal of Consent’ form; which will be provided to you by the researcher.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the Consent form, you agree to give permission to the researcher to collect and use information about you, but only that which is relevant for the research. Only the researcher will have access to the information you provide that identifies you. The researcher will replace your name with a reference code. This means you cannot be identified in the information we will analyse and report on for this research study. The researcher will be the only person who has the list that links the names of participants to the reference code list.

The information the research team collects and use will include the answers you provide on the questionnaire, your medical conditions, your age, the language you speak at home and your usual living arrangements (i.e., whether you live independently at home, in a retirement village or an aged care facility).

All study documents and data, including scanned consent forms and recordings of qualitative interviews, will be stored according to this project's Flinders University Research Data Management Plan. Recordings of qualitative interviews will be deleted immediately after they have been transcribed. Consistent with the Australian Code for the Responsible Conduct of Research (Section 2.1.1) data collected for the study will be stored for a period of 5 years after the publication of the results of the study.

Research data will be stored on the Flinders University OneDrive server in accordance with Flinders Records Management Policy. Storage of research data is treated as "restricted" according to Flinders Information Classification.

11 Who is organising and funding the research?

The results of this research will be used by the researcher Louise Heuzenroeder to obtain a Doctor of Philosophy (PhD). Louise has been awarded a Dementia Australia Research Foundation Consumer Priority PhD Scholarship to undertake this research.

Louise is undertaking her research through Flinders University. She is being supervised by the Chief Investigator of this study, Professor Alison Kitson, and Professor Richard Woodman, both of whom are from Flinders University and Dr Faizal Ibrahim who is a Geriatrician at The Queen Elizabeth Hospital in South Australia.

This study is being undertaken over 3 years from September 2017 to September 2020. The study will be written up and will be publicly available as Louise Heuzenroeder's PhD thesis. The researchers will seek to publish the findings in academic journals. If you would like to receive a summary of the findings, please let the researcher know. Please feel free to contact the researcher by telephone on 0408 544 604, or you may wish to follow progress and milestones of the research study via Twitter @louheuzenroeder where links to publications and conference presentations will be made available.

12 Who has reviewed the research project?

The research project has been reviewed by the Dementia Australia Research Foundation's Scientific Panel, in awarding the researcher the Consumer Priority PhD Scholarship.

The research project has been reviewed by the Flinders University Graduate Research School in awarding Louise Heuzenroeder admission to the University's PhD program.

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee. This research project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the Central Adelaide Local Health Network (TQEH/MH/LMH). This approval has been recognised by the ethics committees of all three hospitals involved in the study and by the Flinders University Ethics Committee. The National Health and Medical Research Council's Health Research Ethics Application Reference Code for the study is HREC/17/TQEH/91.

13 Do you want to speak to someone about the research study?

If you would like to speak to someone about the research study, contact details are provided below for the Researcher and the HREC Executive Officer.

Researcher

Name	Louise Heuzenroeder
Position	PhD Candidate Flinders University
Telephone	0408 544 604
Email	louise.heuzenroeder@flinders.edu.au

Human Research Ethics Committee

Position	HREC Executive Officer
Telephone	8222 6841
Email	Health.CALHNResearchEthics@sa.gov.au

If you would like to speak to someone about your care concerns, please contact the Consumer Advisor

Consumer Advisory Service – complete for each site

Position	Consumer Advisor
Telephone	
Email	

Government of South Australia
SA Health

Flinders UNIVERSITY

Consent Form – Adult providing own consent

Project Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Ethics Reference Number	HREC/17/TQEH/91
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Associate Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder
Location	Flinders Medical Centre

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant ______________________

Signature of Participant ______________________

Date ______________________

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher ______________________

Signature of Researcher ______________________

Date ______________________

Appendix A10 Participant Information and Consent Form (Carer)

Government of South Australia
SA Health

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Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Ethics Reference	HREC/17/TQEH/91
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Associate Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder
Location	Complete for each site

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research study, titled 'Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting'.

This Participant Information Sheet/Consent Form tells you about the research study. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

If you decide you want to take part in the research study, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research study
- Consent to be involved in the research described
- Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 Do I have to take part in this research study?

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide to take part and later change your mind, you are free to withdraw from the study at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the current or future care of your family/friend, your relationship with the hospital staff or your relationship with the hospital where your family member/friend is a patient.

3 What is the purpose of this research study?

We believe health services need better methods of measuring patients' and carers' experience of care. The purpose of this research study is to develop a questionnaire that could be used to measure patients' and carers' experience of receiving care that is consistent with the 10 Principles of Dignity in Care.

The 10 Principles of Dignity in Care evolved from the findings of a 2006 online survey conducted by the Department of Health in the United Kingdom. The purpose of the survey was to allow the Minister for Care Services to hear directly from the public about their own experiences of being treated with dignity, in care services. The 10 Principles of Dignity in Care are:

1. Zero tolerance of all forms of abuse.
2. Support people with the same respect you would want for yourself or a member of your family.
3. Treat each person as an individual by offering a personalised service.
4. Enable people to maintain the maximum possible level of independence, choice and control.
5. Listen and support people to express their needs and wants.
6. Respect people's privacy.
7. Ensure people feel able to complain without fear of retribution.
8. Engage with family members and carers as care partners.
9. Assist people to maintain confidence and a positive self-esteem.
10. Act to alleviate people's loneliness and isolation.

http://www.dignityincare.org.uk/

The research study will take place over 3 stages.

Stage 1 is the work of a Delphi panel to support the development of two versions of the Dignity in Care Questionnaire; a version for use by people who are admitted to hospital and a version for use by their carer (i.e., their family/friend/advocate).

Stage 2 is pilot testing the questionnaire on a smaller sample of consumers and carers. The pilot test will be part of finalising the development of the questionnaire in preparation for the following stages.

Stage 3 will involve testing the questionnaire on much larger samples of patients aged 65 and older (Aboriginal people aged 50 and over) and their carers. The purpose of this stage of the research is to test the validity and reliability of the questionnaire. Validity and reliability are measured using statistical tests on the information we collect from the questionnaires. If a questionnaire has acceptable validity it means it is measuring what it is meant to measure, that is the 10 Principles of Dignity in Care. If a questionnaire has acceptable reliability it means it can produce reproducible information. If we find the Dignity in Care Questionnaire demonstrates acceptable validity and reliability, we can recommend its use in Australian hospitals.

4 What does participation in this research involve?

Two separate Participant Information Sheets will be developed; a version that includes the paragraph under Pilot Study (below) and a version that includes the paragraph under Data Collection (below). Text highlighted in yellow will be deleted in the final versions printed for use.

Pilot Study

Pilot Testing Taking part in the research study will require you to complete the Dignity in Care Questionnaire, which should take about 20 minutes. If you would like to use the iPad the researcher can show you how it works. You will also be asked to participate in an interview with the researcher.

The purpose of the interview is to obtain your thoughts on the number of questions, the wording of the questions, what you think the questions mean and whether you think there are questions that should be removed and others that should be added. The interview will take about 30 minutes and, with your consent, will be tape recorded. There will be no further involvement required.

Data Collection

Taking part in the research study will require you to complete the Carer version of the Dignity in Care Questionnaire, which should take about 15 Minutes.

You will be asked to complete the questionnaire once. There will be no further involvement required.

If you choose to take part in the study, you will need to sign the Consent form (attached). By signing the Consent form, you agree to give permission to the research team to collect and use information about you, but only that which is relevant for the research.

Your information will only be used to test the validity and reliability of the Carer version of the questionnaire under development.

The information you provide in the questionnaire will not be provided to any staff in the hospital where your family member/friend is a patient.

The Clinical Director of each of the wards included in the study has provided written support for the research. The researcher will work closely with the Clinical Directors and with Chief Investigator of the study and the associate investigators to ensure the research is appropriately monitored.

5 Who is being asked to participate in this research study?

You are being invited to participate because you have been identified as a carer (i.e., a family member/friend) of a person who is currently admitted to __________________.

We want to focus this research study on older people, and we want to include the diversity of people who access hospital services.

The research *will include* people:

- Who are aged 65 years or older (50 years and older for Aboriginal and Torres Strait Islander people); and
- Who are patients in the _______________ ward of the ______________ hospital
- During the period ________________________ to __________________________

The researchers *want to include*:

- Aboriginal and Torres Strait Islander people
- People from culturally and linguistically diverse backgrounds
- People who have dementia (including Alzheimer's Disease)

Informed consent will be required for all participants. This will require the development of a survey that is meaningful to Aboriginal and Torres Strait Islander people, access to interpreters for people who do not speak English and the support of a carer who can provide legal consent on behalf of a person who is unable to give consent.

The research will exclude people:

- Who are unable to give consent and who do not have a carer who can legally give consent on their behalf
- Who are in the last days of life

6 What are the possible benefits of taking part?

There will be no clear benefit to you from your participation in this research.

If, through our research, we can demonstrate the Dignity in Care Questionnaire is a valid and reliable measure of Dignity in Care, the questionnaire could be implemented across Australian hospitals to provide a method by which future patients and carers can report their experience of receiving Dignity in Care. Hospitals could use this information to guide education and training and improve their performance in the provision of Dignity in Care.

7 What are the possible risks and disadvantages of taking part?

Participating in the study may have the potential to cause some people to reflect on an experience of care that was unpleasant or traumatic. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, please talk to the doctors and nurses looking after you, to ensure your concerns are addressed promptly.

If you are not satisfied with how your concerns were managed by the doctors and / or nurses and you would like to speak to someone else about your care or concerns, you can contact the Consumer Advisory Service, whose contact details are provided in Section 13 of this form.

8 Do you have a concern or a complaint?

If you would like to speak to someone about a concern or a complaint you have about the research study, the contact details of the Ethics Committee Co-ordinator are provided in Section 13 of this Information Sheet.

It is mandatory for all of SA Health's hospitals to comply with the Consumer Feedback Management Policy Directive (2011). This policy is publicly available. To obtain a copy, please ask the Researcher or the Ethics Committee Co-ordinator (contact details provided in Section 13).

9 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; which will be provided to you by the researcher.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the Consent form, you agree to give permission to the research team to collect and use information about you, but only that which is relevant for the research. Only the researcher will have access to the information you provide that identifies you. The researcher will replace your name with a reference code. This means you cannot be identified in the information we will analyse and report on for this research study. The researcher will be the only person who has the list that links the names of participants to the reference code list.

The information the research team collects and use will include the answers you provide on the questionnaire and your relationship to the patient.

All study documents and data, including scanned consent forms and recordings of qualitative interviews, will be stored according to this project's Flinders University Research Data Management Plan. Recordings of qualitative interviews will be deleted immediately after they have been transcribed. Consistent with the Australian Code for the Responsible Conduct of Research (Section 2.1.1) data collected for the study will be stored for a period of 5 years after the publication of the results of the study.

Research data will be stored on the Flinders University OneDrive server in accordance with Flinders Records Management Policy. Storage of research data is treated as "restricted" according to Flinders Information Classification.

11 Who is organising and funding the research?

The results of this research will be used by the researcher Louise Heuzenroeder to obtain a Doctor of Philosophy (PhD). Louise has been awarded an Dementia Australia Research Foundation Consumer Priority PhD Scholarship to undertake this research.

Louise is undertaking her research through Flinders University. She is being supervised by the Chief Investigator of this study, Professor Alison Kitson, and Professor Richard Woodman, both of whom are from Flinders University and Dr Faizal Ibrahim who is a Geriatrician at The Queen Elizabeth Hospital in South Australia.

This study is being undertaken over 3 years from September 2017 to September 2020. The study will be written up and will be publicly available as Louise Heuzenroeder's PhD thesis. The researchers will seek to publish the findings in academic journals. If you would like to receive a summary of the findings, please let the researcher know. Please feel free to follow progress and milestones of the research via Twitter @louheuzenroeder where links to publications and conference presentations will be made available.

12 Who has reviewed the research project?

The research project has been reviewed by the Dementia Australia Research Foundation's Scientific Panel, in awarding the researcher the Consumer Priority PhD Scholarship.

The research project has been reviewed by the Flinders University Graduate Research School in awarding Louise Heuzenroeder admission to the University's PhD program.

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee. This research project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee (HREC) of the Central Adelaide Local Health Network

(TQEH/MH/LMH). This approval has been recognised by the ethics committees of all three hospitals involved in the study and by the Flinders University Ethics Committee. The National Health and Medical Research Council's Health Research Ethics Application Reference Code for the study is HREC/17/TQEH/91.

13 Do you want to speak to someone about the research study?

If you would like to speak to someone about the research study, contact details are provided below for the Researcher and the HREC Executive Officer.

Researcher

Name	Louise Heuzenroeder
Position	PhD Candidate Flinders University
Telephone	0408 544 604
Email	louise.heuzenroeder@flinders.edu.au

Human Research Ethics Committee

Position	HREC Executive Officer
Telephone	8222 6841
Email	Health.CALHNResearchEthics@sa.gov.au

If you would like to speak to someone about your care concerns, please contact the Consumer Advisor

Consumer Advisory Service – complete for each site

Position	Consumer Advisor
Telephone	
Email	

Government of South Australia
SA Health

Flinders
UNIVERSITY

Consent Form – Carer

Project Title	Developing and testing the reliability and validity of a questionnaire to measure Dignity in Care for older people (and their carer) in the hospital setting
Ethics Reference Number	HREC/17/TQEH/91
Project Sponsor	Flinders University
Principal Investigator	Professor Alison Kitson
Associate Investigators	Professor Richard Woodman Dr Faizal Ibrahim Ms Louise Heuzenroeder
Location	Flinders Medical Centre

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting the patient's care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant ______________________

Signature of Participant ______________________

Date ______________________

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher ______________________

Signature of Researcher ______________________

Date ______________________

Appendix B Delphi Panel Round One Summary

Principle 1. Zero tolerance of all forms of abuse	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
I felt safe	1.1	35	11	3	0	**94%**	I have felt safe when staff provide care to me	1.1			1	
I felt I was a burden to care for	1.2	30	6	13	1	72%	Removed		1			
I did not feel I was looked after properly	1.3	30	6	13	1	72%	Removed		1			
I was made to feel worthless	1.4	30	6	12	0	75%	Removed		1			
I was given care when I needed it	1.5	33	8	6	3	**82%**	I have been given care when I need it	1.5			1	
I felt disrespected	1.6	32	4	9	3	75%	Removed		1			
The staff made me feel safe	1.7	34	7	5	3	**84%**	Staff have been gentle in how they provide care to me	1.2			1	
I have felt fearful	1.8	31	4	7	4	76%	Removed		1			
I have been emotionally abused	1.9	30	8	5	4	**81%**	Staff have been cruel in the way they speak to me	1.11			1	
I have been physically abused	1.10	33	6	5	3	**83%**	Staff have been rough in the way they provide care	1.9			1	
I have been physically restrained against my will	1.11	34	5	5	2	**85%**	I have had my arms and legs tied down to restrain me	1.10			1	
I have been given medication to restrain me	1.12	25	13	7	2	**81%**	I have been given medication to keep me quiet	1.8			1	
I was free to interact with other people	1.13	31	6	7	2	**80%**	Principle 10	10.1		1		
The staff have made sure I was aware of my healthcare rights	1.14	40	3	3	2	**90%**	Principle 4	4.1		1		
Staff come to see me soon after I press the call bell							Additional item	1.3				1
Staff come to see me soon after I call out for help							Additional item	1.4				1
Staff have made sure I am free of pain							Additional item	1.6				1
I have been given enough to eat and drink							Additional item	1.7				1
I have been afraid of some staff							Additional item	1.12				1
I have been left in pain							Additional item	1.13				1

Principle 2. Support people with the same respect you would want for yourself or a member of your family	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
The staff introduced themselves by telling me their name	2.1	30	14	8	1	**83%**	Staff introduce themselves by telling me their name and role	2.2			1	
The staff introduced themselves before treating or caring for me	2.2	39	10	0	0	**100%**	Staff introduce themselves before providing care	2.3			1	
I have been cared for in a courteous and considerate manner	2.3	42	3	2	0	**96%**	Staff have been respectful when they speak with me	2.4			1	
The staff have taken time to get to know me	2.4	29	3	13	2	68%	Removed		1			
The staff have taken the time to learn about me as a person	2.5	27	4	14	2	66%	Removed		1			
The staff made me feel at ease by being friendly and warm in conversation	2.6	32	5	7	3	**79%**	Combined with (reworded) 2.3				1	
I have been treated with respect	2.7	44	2	2	0	**96%**	Staff respect my dignity when supporting me to use the bedpan or toilet	2.6			1	
I have been treated with dignity	2.8	44	2	2	0	**96%**	Staff respect my dignity when supporting me to eat and drink	2.7			1	
Staff wear name badges large enough for me to read							Additional item	2.1				1
Staff have made sure I have my hearing aid and glasses on when I am awake							Additional item	2.5				1

Staff have spoken to me like I am a child							Additional item	2.8				1
Staff have spoken over me							Additional item	2.9				1
Staff have spoken to my family instead of speaking to me							Additional item	2.10				1
Staff talk about me, in front of me, without including me							Additional item	2.11				1
Principle 3. Treat each person as an individual by offering a personalised service	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
The staff asked me how I prefer to be addressed?	3.1	42	7	0	0	**100%**	Staff have asked me what I prefer to be called	3.1			1	
The staff greeted me in a way that made me feel comfortable	3.2	39	4	3	1	**91%**	Staff have called me by my preferred name	3.2			1	
The staff took time to find out more about me as a person	3.3	34	1	10	0	78%	Removed		1			
My cultural beliefs have been considered and respected	3.4	41	3	3	0	**94%**	Staff have asked me if I have cultural beliefs that are important to my care Staff have provided care consistent with my cultural beliefs	3.4 3.5			1	
My religious beliefs been considered and respected	3.5	38	5	5	0	**90%**	Staff have asked me if I have religious beliefs that are important to my care Staff have provided care consistent with my religious beliefs	3.6 3.7			1	
My spiritual beliefs been considered and respected	3.6	40	2	5	0	**89%**	Staff have asked me if I have spiritual beliefs that are important to my care Staff have provided care consistent with my spiritual beliefs	3.8 3.9			1	
My sexuality was understood, considered and respected	3.7	37	4	4	1	**89%**	Staff have respected my sexual identity	3.10			1	
I have been in an environment that enabled me to heal	3.8	24	6	14	3	64%	Removed		1			
I have had access to an Interpreter when I needed one	3.9	39	6	1	0	**98%**	Staff have asked about my language and asked if I need an interpreter	3.3			1	
Principle 4. Enable people to maintain the maximum possible level of independence, choice and control	R1 ITEM	INCLUDE	INCLUDEw CHANGE	EXCLUDE	NORESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
I have been able to maintain the maximum possible level of independence	4.1	33	5	8	2	79%	Removed		1			
I have been able to maintain the maximum possible level of choice	4.2	32	5	8	2	79%	Removed		1			
I have been able to maintain the maximum possible level of control	4.3	30	2	12	2	70%	Removed		1			
The staff have taken enough time to explain things to me	4.4	38	2	7	2	**82%**	Now covered in Principle 5			1		
The staff have explained what is happening to me in ways I understand	4.5	40	4	3	1	**92%**	Staff have explained what is happening to me in ways I understand	4.7			1	
I have been involved, as much as I wanted to be, in discussions about my care and treatment	4.6	42	6	1	0	**98%**	I have been involved, as much as I wanted to be, in discussions about my care	4.4			1	
I have been involved, as much as I wanted to be, in decisions about my care and treatment	4.7	41	5	2	1	**94%**	I have been involved, as much as I wanted to be, in decisions about my care	4.5			1	
I have felt in control of what was happening to me	4.8	34	2	6	4	78%	Removed		1			
The staff assumed I could not make decisions?	4.9	29	8	9	1	79%	Removed		1			
The staff encouraged me to ask questions	4.10	41	0	6	1	**85%**	Moved to Principle 5	5.1		1		
My views have been listened to and acted upon by staff	4.11	43	5	0	1	**98%**	Moved to Principle 5	5.2		1		
The staff have been open and forthcoming with information	4.12	34	4	8	2	79%	Removed		1			
Staff have given me a brochure on my Health Care Rights (from Principle 1)							Additional item	4.1				1

Staff have asked me if I have an Advance Care Directive							Additional item	4.2				1
My Advance Care Directive has been used to plan my care							Additional item	4.3				1
Staff ask my permission before they provide care							Additional item	4.6				1
I have been able to refuse treatment							Additional item	4.8				1
I have been able to discuss my end of life wishes with staff							Additional item	4.9				1
Principle 5. Listen and support people to express their needs and wants	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
I was given enough time to explain what I needed	5.1	44	2	2	1	**94%**	I have been given enough time to explain what I need	5.2			1	
I was given enough time to explain what I wanted	5.2	35	3	10	1	78%	Removed		1			
The staff understood my main health concerns	5.3	31	6	9	1	79%	Removed		1			
I felt the staff assumed they knew what I needed	5.4	33	2	12	1	73%	Removed		1			
I felt the staff assumed they knew what I wanted	5.5	30	2	13	1	70%	Removed		1			
The staff showed interest in my ideas about my health	5.6	28	5	13	1	70%	Removed		1			
The staff paid attention to me (looked at me, listened carefully)	5.7	40	2	6	0	**88%**	Covered in additional item				1	
The staff let me talk without interruption	5.8	33	1	13	1	71%	Removed		1			
The staff have been available to help me when I needed them	5.9	33	3	10	1	77%	Removed		1			
The staff made sure there was 'time to talk', and a chance to voice any concerns or simply have a chat	5.10	30	9	9	2	**78%**	Moved (and reworded) to Principle 7	7.1		1		
I have been provided with clear information so I could make informed choices about my care	5.11	39	8	2	1	**94%**	Covered in additional item				1	
The staff have been open to my opinions and allowed me to participate in planning my care	5.12	37	9	2	1	**94%**	Staff have involved me in planning my care	5.3			1	
The staff have given me an opportunity to discuss my wishes for care at the end of my life	5.13	39	5	1	3	**92%**	Moved to Principle 4	4.9		1		
I have been given a paper copy of the plan for my care for the time I am in hospital							Additional item	5.4				1
Staff have encouraged me to be involved in planning my discharge from hospital							Additional item	5.5				1
My views have been listened to and acted upon by staff (from Principle 4)							Additional item	5.6				1
I have had difficulty understanding some staff							Additional item	5.7				1
Staff assume they know what I need, without asking me							Additional item	5.8				1
Staff encouraged me to ask questions							Additional item	5.1				1
Principle 6. Respect people's privacy	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
My privacy has been respected	6.1	35	3	10	0	79%	Removed		1			
I have been given privacy when discussing my condition or treatment	6.2	45	2	2	0	**96%**	I have been given privacy when talking about condition or treatment	6.1			1	
I have been given privacy when being examined or treated	6.3	45	2	2	0	**96%**	I feel my privacy is respected when I am being examined or treated	6.2			1	
Information about me has been treated confidentially	6.4	42	2	5	0	**90%**	Staff appear to treat my information confidentially	6.5			1	
I have been given privacy when using the toilet	6.5	39	4	6	0	**88%**	I feel my privacy is respected when I am using a bedpan or the toilet	6.4			1	
I have been given privacy when having a wash or shower	6.6	39	3	7	0	**86%**	I feel my privacy is respected when I am having a wash	6.3			1	
I have been given care in a way that ensured I have not felt embarrassed	6.7	36	2	10	0	79%	Removed		1			

I have access to my health record when requested							Additional item	6.6				1
Principle 7. Ensure people feel able to complain without fear of retribution	R1 ITEM	INCLUDE	INCLUDEw CHANGE	EXCLUDE	NORESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
The staff have explained the process of making a complaint, or a compliment, about my experience of care	7.1	36	5	6	0	**87%**	Covered in additional item				1	
I have been supported to raise any concerns or complaints with the appropriate person	7.2	39	5	4	0	**92%**	Covered in additional item				1	
I have had my concerns and complaints treated with respect and dealt with in a timely manner	7.3	37	9	1	0	**98%**	Covered in additional item				1	
I believe I would receive fair treatment if I made a complaint	7.4	33	4	8	0	**82%**	Covered in additional item				1	
I felt I could make a complaint without it affecting my care	7.5	37	6	2	0	**96%**	I believe I could make a complaint without it affecting my care	7.3			1	
Staff made sure there was an opportunity to talk about any concerns							Additional item	7.1				1
I have felt like I could make a complaint if I needed to							Additional item	7.2				1
I understand how to make a complaint							Additional item	7.4				1
I made a complaint and it was taken seriously							Additional item	7.5				1
I made a complaint and it was dealt with in a satisfactory timeframe							Additional item	7.6				1
I made a complaint and I was satisfied with the outcome							Additional item	7.7				1
My care improved after I made a complaint							Additional item	7.8				1
Staff treated me badly after I made a complaint							Additional item	7.9				1
Principle 8. Engage with family members and carers as care partners	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
The staff have taken enough time to explain things to my family/friends	8.1	29	9	9	1	79%	Removed		1			
The staff explained what is happening in ways my family/friends could understand	8.2	33	5	10	1	78%	Removed		1			
My family/friends been involved as much as I wanted them to be, in decisions about my care and treatment	8.3	41	5	2	0	**96%**	My family or carers been involved as much as I wanted them to be, in decisions about my care	8.2			1	
The expertise of my family/friends been recognised and valued by staff when working out how to provide my care	8.4	37	2	7	0	**85%**	Covered in additional item				1	
My family/friends have been included in planning my care and treatment with me, and the staff looking after me	8.5	27	8	11	1	74%	Removed		1			
My opinions, about the involvement of my family or friends in my care, were respected	8.6	34	3	8	2	79%	Removed		1			
I had opportunities for my family and carers to be involved in my treatment and care, if I wanted	8.7	31	3	10	2	74%	Removed		1			
Staff have asked me which family members or carers I want involved in my care							Additional item	8.1				1
Staff talked to my family or carers about my care when I was unable to communicate							Additional item	8.3				1
Staff supported my family or carers to be with me, when I wanted my family or carers with me							Additional item	8.4				1
Staff listened and acted quickly when my family or carers told them my condition had deteriorated							Additional item	8.5				1
Staff arranged intepreters for my family or carers when I wanted them to be involved in my care							Additional item	8.6				1
Principle 9. Assist people to maintain confidence and a positive self-esteem	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
The staff made me feel welcome	9.1	40	4	2	2	**92%**	Staff have made me feel welcome	9.1			1	
Staff spoke about me, in front of me, as if I wasn't there	9.2	37	2	8	1	**81%**	Reworded in Principle 2	2.11		1		
I have been given assistance with my meals in a way that helped me maintain my confidence and self-esteem	9.3	36	8	4	2	**88%**	Reworded in Principle 2	2.7		1		

I have been given assistance to use the toilet in a way that made me feel respected	9.4	36	7	4	3	**86%**	Reworded in Principle 2	2.6		1		
I have been given assistance to maintain my personal appearance in a way that made me feel respected	9.5	39	6	5	1	**88%**	I have been given assistance to maintain my personal appearance in a way that made me feel respected	9.6			1	
I was treated with less respect because of my age	9.6	28	7	10	2	74%	Removed		1			
I was given enough opportunity to do what I am capable of doing myself	9.7	40	3	1	3	**91%**	I have been given enough opportunity to do what I am capable of doing myself	9.4			1	
Staff have spoken to me as an equal							Additional item	9.2				1
When talking about my care, the doctors and nurses include me in the discussion							Additional item	9.3				1
Staff have supported me to stay physically and mentally active							Additional item	9.5				1
Staff took too long to get to me and I soiled myself							Additional item	9.7				1
Staff have taken my meals away before I could eat it							Additional item	9.8				1
Staff have spoken to me in a language that I couldn't understand							Additional item	9.9				1
Principle 10. Act to alleviate people's loneliness and isolation	R1 ITEM	INCLUDE	INCLUDE w CHANGE	EXCLUDE	NO RESPONSE	CONSENSUS	OUTCOME	R2 ITEM	REMOVE	RELOCATE	REWORD	ADD
A volunteer has spent time with me	10.1	31	7	9	1	79%	Removed		1			
I have been lonely	10.2	35	2	9	1	79%	Removed		1			
I had no one to talk to	10.3	33	3	11	1	75%	Removed		1			
The staff spent the right amount of time with me	10.4	28	5	9	4	72%	Removed		1			
I felt invisible	10.5	27	1	17	2	60%	Removed		1			
I felt as if no one cared about me	10.6	38	3	5	2	**85%**	I felt as if no one cared about me	10.6				
I felt like giving up	10.7	27	2	17	2	60%	Removed		1			
Staff made an effort to involve me	10.8	36	2	6	3	**81%**	Covered in additional items				1	
Staff made an effort to keep me active	10.9	37	6	4	1	**90%**	Covered in additional items				1	
I was able to interact socially with other people	10.10	38	8	2	0	**96%**	I have been free to interact with other people	10.1			1	
I felt socially isolated	10.11	28	2	14	2	65%	Removed		1			
Staff have supported me to find things to do to keep me from being bored							Additional item	10.2				1
I have been able to afford to pay to watch the tv							Additional item	10.3				1
I have been able to listen to a radio							Additional item	10.4				1
I have access to the internet to use my telephone or tablet to stay in touch with people							Additional item	10.5				1
								TOTAL	**37**	**10**	**45**	**48**

Appendix C Delphi Panel Round Two Summary

				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 1. Zero tolerance of all forms of abuse**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
1.1	I have felt safe when staff provide care to me	**2.24**	**37**	21	6	2	2	2	2	2	1.1		1				
1.2	Staff have been gentle in how they provide care to me	**3.24**	17	4	2	3	4	3	0	1	1.2	Reword to "Staff have been considerate in how they provide care to me"				1	
1.3	Staff come to see me soon after I press the call bell	**3.81**	**27**	2	7	8	0	2	3	5	1.3		1				
1.5	I have been given care when I need it	**3.25**	**36**	9	7	7	2	5	2	4	1.4		1				
1.6	Staff have helped to control my pain	**3.85**	**33**	5	5	2	9	5	4	3	1.7		1				
1.9	Staff have been rough in the way they provide care	**3.81**	**26**	2	6	3	6	3	5	1	1.5		1				
1.10	I have had my arms and legs tied down to restrain me	**3.8**	20	6	1	2	1	3	6	1	1.6		1				
Remove these items…..																	
1.4	Staff come to see me soon after I call out for help	4.73	11	0	3	0	2	1	2	3				1			
1.7	I have been given enough to eat and drink	4.91	**32**	0	1	5	6	7	10	3				1			
1.8	I have been given medication to keep me quiet	4.4	15	0	2	5	1	2	2	3				1			
1.11	Staff have been cruel in the way they speak to me	4.42	19	1	3	2	4	3	2	4				1			
1.12	I have been afraid of some staff	4.5	**34**	5	2	4	6	3	5	9				1			
1.13	I have been left in pain	4.81	16	2	1	0	2	5	2	4				1			
				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2Item	**Principle 2. Support people with the same respect you would want for yourself or a member of your family**	MEAN	TOTAL	1	2	3	4	5	6	7	R3Item	Outcome					
2.1	Staff wear name badges large enough for me to read	**4.2**	20	4	2	4	0	3	0	7	2.1		1				
2.2	Staff introduce themselves by telling me their name and role	**3.24**	**29**	8	7	3	2	2	4	3	2.2		1				
2.3	Staff introduce themselves before providing care	**3.18**	**33**	8	10	3	2	4	2	4	2.3		1				
2.4	Staff have been respectful when they speak with me	**2.73**	**41**	15	8	8	1	4	2	3	2.4		1				
2.9	Staff have spoken over me	**4.55**	11	0	2	1	2	2	3	1	2.5		1				
2.11	Staff talk about me, in front of me, without including me	**3.66**	**35**	8	4	6	2	8	3	4	2.6		1				
	Staff rush me when providing care										2.7	Additional item					1
Remove these items…																	
2.5	Staff have made sure I have my hearing aid in, glasses on and teeth in on when I am awake	4.77	**35**	2	2	5	8	3	6	9				1			
2.7	Staff respect my dignity when supporting me to eat and drink	4.77	**35**	1	1	4	10	6	9	4				1			
2.8	Staff have spoken to me like I am a child	4.95	19	1	1	2	4	3	2	6				1			
2.10	Staff have spoken to my family instead of speaking to me	4.65	**23**	1	3	1	4	5	7	2				1			
Moved																	
2.6	Staff respect my dignity when supporting me to use the bedpan or bathroom	**3.63**	**43**	6	5	9	10	6	6	1	6.4	Relocated to Principle 6			1		
				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 3. Treat each person as an individual by offering a personalised service**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
3.1	Staff have asked me what I prefer to be called	**1.74**	**35**	26	5	0	1	0	0	3			1				
3.2	Staff have called me by my preferred name	**2.17**	**41**	12	20	4	3	0	1	1	3.1		1				
3.3	I have had access to an interpreter	**3.77**	**43**	8	8	8	3	1	8	7	3.3		1				
	Staff have asked the Top 5 most important things they need to know about me										3.2	Additional item					1
3.4	Staff have asked me if I have cultural beliefs that are important to my care	**3.76**	25	2	4	8	4	2	1	4				1			

3.5	Staff have provided care consistent with my cultural beliefs	**3.64**	**36**	0	6	11	12	4	3	0	3.4		1				
3.6	Staff have asked me if I have any religious beliefs that are important to my care	**4.08**	13	1	1	2	3	4	2	0				1			
Remove these items…																	
3.7	Staff provided care consistent with my religious beliefs	**4.43**	**28**	1	0	3	11	9	3	1	3.5		1				
3.8	Staff have asked me if I have any spiritual beliefs that are important to my care	4.65	17	1	0	3	1	8	3	1				1			
3.9	Staff provided care consistent with my spiritual beliefs	5.28	**29**	0	0	3	2	12	8	4	3.6		1				
3.10	Staff respected my sexual identity	5.43	**44**	1	2	4	5	4	14	14	3.7		1				
			FREQUENCY Priority 1 to 7										RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 4. Enable people to maintain the maximum possible level of independence, choice and control**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
4.2	Staff have asked me if I have an Advance Care Directive	**3.92**	25	7	1	1	3	5	7	1	4.1		1				
4.3	I have discussed my Advance Care Directive with staff	**4.68**	**34**	3	4	3	3	6	8	7	4.2		1				
4.4	I have been involved, as much as I wanted to be, in discussions about my care	**2.37**	**41**	14	11	8	5	1	2	0	4.4		1				
4.5	I have been involved, as much as I wanted to be, in decisions about my care	**2.71**	**42**	8	14	9	7	2	1	1	4.5		1				
4.6	Staff ask my permission before they provide care	**3.19**	**36**	8	5	9	6	4	2	2	4.6		1				
4.7	Staff have explained what is happening to me in ways I understand	**3.28**	**43**	6	9	8	12	3	5	0	4.7		1				
4.8	I have been able to refuse treatment	**5.24**	**38**	1	2	3	6	7	7	12	4.3		1				
Remove these items….																	
4.10	Staff have given me a brochure on my healthcare rights	5.54	28	2	1	1	2	4	6	12				1			
4.9	I have been able to discuss my end of life wishes with staff	5.31	**32**	1	0	4	1	11	7	8				1			
			FREQUENCY Priority 1 to 7										RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 5. Listen and support people to express their needs and wants**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
5.1	Staff have encouraged me to ask questions	**3.2**	**41**	6	9	13	4	2	7	0	5.3		1				
5.2	I have been given enough time to explain what I need	**2.73**	**44**	15	10	3	10	0	6	0	5.1		1				
5.3	Staff have involved me in planning my care	**2.62**	**42**	12	13	7	5	1	2	2	5.2		1				
5.4	I have been given a paper copy of the plan for my care for the time I am in hospital	**4.35**	**31**	2	4	4	4	9	4	4	5.4		1				
5.5	Staff have encouraged me to be involved in planning my discharge from hospital	**4.63**	**46**	2	4	7	6	10	11	6	5.5		1				
5.6	My views have been listened to and acted upon by staff	**3.21**	**43**	9	6	8	10	8	1	1	5.6	Reword to "My preferences have been listened to and acted upon by staff"				1	
5.8	Staff assume they know what I need, without asking me	**5.57**	**37**	2	1	3	2	5	8	16	5.7		1				
Remove this item….																	
5.7	I have difficulty understanding some staff	5.66	29	0	2	0	3	8	4	12				1			
			FREQUENCY Priority 1 to 7										RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 6. Respect people's privacy**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
6.1	I have been given privacy when talking about my condition and treatment	**2.04**	**46**	20	12	8	4	2	0	0	6.1		1				
6.2	I feel my privacy is respected when I am being examined or treated	**2.17**	**46**	14	17	11	2	1	1	0	6.2		1				
6.3	I feel my privacy is respected when I am having a wash	**3.62**	**45**	1	6	13	16	7	2	0	6.3		1				
6.4	I feel my privacy is respected when I am using a bedpan or toilet	**3.35**	**46**	8	6	6	15	10	1	0	6.4	Reworded and relocated from 2.6				1	
6.5	Staff treat my information confidentially	**4.28**	**46**	5	2	4	6	22	7	0	6.5						

6.6	I have access to my health record when requested	**5.23**	**42**	2	2	3	2	3	30	0	6.6	Retain unchanged	1				
	My personal space is respected										6.7	Additional item					1

				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 7. Ensure people feel able to complain without fear of retribution**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
7.1	Staff made sure there was an opportunity to talk about any concerns	**2.27**	**45**	24	6	5	4	2	3	1	7.1		1				
7.2	I have felt I could make a complaint if I needed to	**3.27**	**33**	9	7	2	5	3	5	2	7.2		1				
7.3	I believe I could make a complaint without it affecting my care	**3.16**	**42**	6	13	10	6	2	2	3	7.3		1				
7.4	I understand how to make a complaint	**3.13**	**40**	4	12	11	6	3	3	1	7.4	Reword to "I know who to contact if I have a complaint"				1	
7.5	I made a complaint and it was taken seriously	**4.03**	**35**	2	2	9	8	10	2	2	7.5		1				
7.7	I made a complaint and I was satisfied with the outcome	**5.06**	**35**	1	1	4	7	8	4	10	7.6		1				
7.9	Staff treated me badly after I made a complaint	**4.96**	24	3	1	2	2	4	4	8	7.7		1				
Remove these items…..																	
7.6	I made a complaint and it was dealt with in a satisfactory timeframe	5.31	**26**	0	1	2	3	7	8	5				1			
7.8	My care improved after I made a complaint	5.07	27	2	3	0	4	2	9	7				1			

				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2Item	**Principle 8. Engage with family members and carers as care partners**	MEAN	TOTAL	1	2	3	4	5	6	7	R3Item	Outcome					
8.1	Staff have asked me which family members or carers I want involved in my care	**2.09**	**46**	27	6	2	7	1	3	0	8.1		1				
8.2	My family or carers have been involved, as much as I wanted them to be, in decisions about my care	**2.57**	**46**	9	22	4	3	7	1	0	8.2		1				
8.3	Staff talked to my family or carers about my care when I was unable to communicate	**4.14**	**44**	3	4	8	8	11	10	0	8.3		1				
8.4	When I wanted my family or carers with me, staff supported them to be with me	**3.3**	**46**	3	6	21	10	2	4	0	8.4		1				
8.5	Staff responded quickly when my family reported my condition had deteriorated	**3.6**	**45**	7	5	4	14	13	2	0	8.5		1				
8.6	Staff arranged access to interpreters for my family or carers when I wanted them involved in my care	**4.84**	**43**	1	3	6	3	9	21	0	8.6		1				

				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 9. Assist people to maintain confidence and a positive self-esteem**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
9.1	Staff have made me feel welcome	**2.92**	**36**	13	8	3	1	5	4	2	9.1		1				
9.2	Staff have spoken to me as an equal	**3.21**	**29**	7	8	3	3	2	3	3	9.2		1				
9.3	When talking about my care, the doctors and nurses include me in the discussion	**2.41**	**44**	16	13	6	5	0	2	2	9.3	Reword to "When talking about my care, the staff include me in the discussion"				1	
9.4	I have been given enough opportunity to do what I am capable of doing myself	**3.56**	**43**	8	7	8	8	4	1	7	9.4		1				
9.5	Staff supported me to stay physically and mentally active	**4.3**	**40**	0	4	11	8	5	10	2	9.5		1				
9.6	I have been supported to maintain my personal appearance	**4.14**	**43**	2	6	7	7	13	6	2	9.6		1				
9.7	Staff took too long to get to me and I soiled myself	**4.72**	**29**	1	1	6	5	6	4	6	9.7	Reword to "Staff took too long to get to me when I needed the bathroom"				1	
Remove these items…..																	
9.8	Staff have taken my meals away before I could eat it	5.45	22	0	0	1	6	2	8	5				1			

9.9	Staff have spoken in a language that I couldn’t understand	5.56	27	1	1	1	2	7	4	11				1		
				FREQUENCY Priority 1 to 7									RETAIN	REMOVE	RELOCATE	REWORD	ADD
R2 Item	**Principle 10. Act to alleviate people’s loneliness and isolation**	MEAN	TOTAL	1	2	3	4	5	6	7	R3 Item	Outcome					
10.1	I have been free to interact with other people	**2.22**	**46**	17	14	10	0	3	2	0	10.1		1				
10.2	Staff have supported me to find things to do to keep me from being bored	**2.33**	**46**	15	17	7	2	2	2	1	10.2	Reword to "Staff helped me to find things to do to keep me from being bored"				1	
10.3	I have been able to afford to pay to watch the tv	**4.3**	**44**	2	0	6	19	9	8	0	10.4	Reword to "I was able to access a television by my bedside"				1	
10.4	I have been able to listen to a radio	**4.11**	**45**	0	4	11	11	14	5	0	10.5		1				
10.5	I have had access to the internet so I could use my telephone or tablet to stay in touch with people	**4.31**	**45**	1	3	8	10	15	8	0	10.6		1				
10.6	I felt as if no one cared about me	**3.48**	**44**	11	9	5	2	1	16	0	10.7	Reword to "I feel as if staff do not care about me"				1	
	I had access to a Volunteer, if I wanted one										10.3	Additional item					1
												TOTAL	**56**	**20**	**1**	**9**	**4**

Appendix D1 Delphi Panel Round Three Summary (Patient Version)

R3	**Round 3 Version sent to Delphi panel**	Suggested change	Outcome	**Post R3**	Post Round 3 Version with changes
Principle 1. Zero tolerance of all forms of abuse					
1.1	I have felt safe when staff provide care to me				
1.2	Staff have been considerate in how they provide care to me				
1.3	Staff come to see me soon after I press the call bell	Add "not applicable" to the scale, not everyone uses the call bell	Changed. Option added "I have not used the call bell"		Scale changed for this item
1.4	I have been given care when I need it				
1.5	Staff have been rough in the way they provide care				
1.6	I have had my arms and legs tied down to restrain me				
1.7	Staff have helped to control my pain				
Principle 2. Show people respect					
2.1	Staff wear name badges large enough to read	Name badge should include name and role	Role is covered in item 2.2 The focus of item 2.1 is on "readable"		
2.2	Staff introduce themselves by telling me their name and role	Change 'telling' to 'giving'	No change. Keep language simple		
2.3	Staff introduce themselves before providing care				
2.4	Staff have been respectful when they speak with me				
2.5	Staff have spoken over me				
2.6	Staff talk about me, in front of me, without including me				
2.7	Staff rush me when providing care				
Principle 3. Treat each person as an individual by offering a personalised service					
3.1	Staff have called me by my preferred name				
3.2	Staff have asked what the Top 5 most important things they need to know about me			3.2	Staff have asked what are the most important things they need to know about me
3.3	I have had access to an interpreter				
3.4	Staff have provided care consistent with my cultural beliefs	Remove 'not applicable' - everyone has cultural beliefs	Changed to "I'd prefer not to answer"		Scale changed for this item
3.5	Staff provided care consistent with my religious beliefs				
3.6	Staff provided care consistent with my spiritual beliefs				
3.7	Staff respected my sexual identity	Remove 'not applicable' - everyone has a sexual identity	Changed to "I'd prefer not to answer"		Scale changed for this item
Principle 4. Enable people to maintain the maximum possible level of independence, choice and control					
4.1	Staff have asked me if I have an Advance Care Directive		Now item 4.5	4.1	I have been involved, as much as I wanted to be, in discussions about my care
4.2	I have discussed my Advance Care Directive with staff		Now item 4.6	4.2	I have been involved, as much as I wanted to be, in decisions about my care
4.3	I have been able to refuse treatment		Now item 4.7	4.3	Staff have asked my permission before they provide care
4.4	I have been involved, as much as I wanted to be, in discussions about my care		Now item 4.1	4.4	Staff have explained what is happening to me in ways I understand
4.5	I have been involved, as much as I wanted to be, in decisions about my care		Now item 4.2	4.5	Staff have asked me if I have an Advance Care Directive
4.6	Staff ask my permission before they provide care	Change to "have asked"	Change made. Now item 4.3	4.6	I have discussed my Advance Care Directive with staff
4.7	Staff have explained what is happening to me in ways I understand	Change to "Staff have made sure I understand what is happening to me"	No change. Now item 4.4	4.7	I have been able to refuse treatment

Principle 5. Listen and support people to express their needs and wants					
5.1	I have been given enough time to explain what I need				
5.2	Staff have involved me in planning my care				
5.3	Staff have encouraged me to ask questions				
5.4	I have been given a paper copy of the plan for my care for the time I am in hospital	Change "for the time" to "while"	No change. May be understood to be a plan for post discharge (but given to patient/carer while they are in the hospital)	5.4	Staff have given me a written plan of care for the time I am in hospital
5.5	Staff have encouraged me to be involved in planning my discharge from hospital				
5.6	My preferences have been listened to and acted upon by staff				
5.7	Staff assume they know what I need, without asking me				
Principle 6. Respect people's privacy					
6.1	I have been given privacy when talking about my condition and treatment				
6.2	I feel my privacy is respected when I am being examined or treated				
6.3	I feel my privacy is respected when I am having a wash				
6.4	I feel my privacy is respected when I am using a bedpan or toilet	Suggest including "or having my toileting pad changed" Suggest matching the wording for this same item for the Carers.	Change made	6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad
6.5	My personal space is respected				
6.6	Staff treat my information confidentially	Change to "My information is treated confidentially"	No change		
6.7	I have access to my health record when requested	Change to "I could access my health records when I wanted to"	Changed to "Hospital medical record". The item may have been taken to mean "My Health Record"	6.7	I have had access to my hospital medical record when requested
Principle 7. Ensure people feel able to complain without fear of retribution					
7.1	Staff made sure there was an opportunity to talk about any concerns				
7.2	I have felt I could make a complaint if I needed to	Change to "I know I could make a complaint if I needed to"	No change. There is a difference between knowing and feeling		
7.3	I believe I could make a complaint without it affecting my care				
7.4	I know who to contact if I have a complaint	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item		Scale changed for this item
7.5	I made a complaint and it was taken seriously	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item		Scale changed for this item
7.6	I made a complaint and I was satisfied with the outcome	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item		Scale changed for this item
7.7	Staff treated me badly after I made a complaint				
Principle 8. Engage with family members and carers as care partners					
8.1	Staff have asked me which family members or carers I want involved in my care				
8.2	My family or carers have been involved, as much as I wanted them to be, in decisions about my care	Change to "My family or carers have been involved in decision about my care *"	Change made	8.2	My family or carers have been involved in decision about my care *
8.3	Staff talked to my family or carers about my care when I was unable to communicate				
8.4	When I wanted my family or carers with me, staff supported them to be with me				
8.5	Staff responded quickly when my family reported my condition had deteriorated				
8.6	Staff arranged access to interpreters for my family or carers when I wanted them involved in my care	Change to "Staff arranged access to interpreters for my family or carers when it was needed"	Change made	8.6	Staff arranged access to interpreters to involve family or carers in my care *
					* When I wanted my family or carer involved

Principle 9. Assist people to maintain confidence and a positive self-esteem					
9.1	Staff have made me feel welcome				
9.2	Staff have spoken to me as an equal				
9.3	When talking about my care, the staff include me in the discussion				
9.4	I have been given enough opportunity to do what I am capable of doing myself				
9.5	Staff supported me to stay physically and mentally active				
9.6	I have been supported to maintain my personal appearance				
9.7	Staff took too long to get to me when I needed the bathroom	Change to "Staff took too long to respond when I needed to go to the toilet"	Change made	9.7	Staff took too long to respond when I needed to go to the toilet
Principle 10. Act to alleviate people's loneliness and isolation					
10.1	I have been free to interact with other people				
10.2	Staff have supported me to find things to do to keep me from being bored	Change from "have supported" to "helped"	Change made	10.2	Staff have helped me to find things to do to keep me from being bored
10.3	I had access to a Volunteer if I wanted one	Change to "I have had access to a Volunteer"	Change made	10.3	I have had access to a Volunteer
10.4	I was able to access a television by my bedside				
10.5	I have been able to listen to a radio				
10.6	I have had access to the internet so I could use my telephone or tablet to stay in touch with people				
10.7	I feel as if the staff do not care about me	Remove not applicable - everyone should rate how they experience staff feelings about them	The item was removed to make way for additional item about Aboriginal Liaison Officer	10.7	I am an Aboriginal person and I have had access to an Aboriginal Liaison Officer, if I wanted one

Appendix D2 Delphi Panel Round Three Summary (Carer Version)

R3	Round 3 Version sent to Delphi panel	Suggested change	Post R3	Post R3	Post Round 3 Version with changes
Principle 1. Zero tolerance of all forms of abuse					
1.1	The patient is safe when staff are providing care	Change from "The patient is safe when staff are providing care" to "feels safe"- one infers physical safety and the other infers emotional sense of safety.	Change made	1.1	I have felt the patient is safe when staff are providing care
1.2	Staff have been considerate in the way they provide care to the patient				
1.3	Staff come to see the patient soon after we call the bell	Add "not applicable", not everyone uses the call bell	Change made. Option added "The patient has not used the call bell"	1.3	Staff come to see the patient soon after we press the call bell
		Should "we call the bell" read "we press the call bell" which matches the patient's version of the question	Change made		
1.4	The patient has been given care when they needed it				
1.5	Staff have been rough in the way they provide care to the patient				
1.6	The patient has had their arms and legs tied down to restrain them				
1.7	Staff have helped to control the patient's pain	Providing pain relief is not abuse – wouldn't this be better as "Staff have not tried to control my pain" ?	People can score "never" or "rarely" to achieve this outcome		
Principle 2. Show people respect					
2.1	Staff wear name badges large enough to read				
2.2	Staff introduce themselves by telling me their name and role				
2.3	Staff introduce themselves to the patient before they provide care	Change to "Staff introduce themselves to both of us before they provide care to the patient"	Changed to "Staff introduce themselves before they provide care"	2.3	Staff introduce themselves before they provide care
2.4	Staff have been respectful when they speak to the patient	Change to "Staff have been respectful when they speak to us (the patient and myself)"or… "and to me"	Feedback is mixed about whether a number of items under Principle 2 should cover both patient and carer in the way the items are worded. Noting the Principle is about "show people respect" (ie not just the patient).However, if items include both patient and carer, interpretation and scoring is difficult.Conclusion, clearer if this item is about the patient.Noting involvement of family/carer covered in Principle 8.		
2.5	Staff speak over the patient	Change to "Staff speak over us (the patient and myself)"	No change. It is possible the staff speak over the patient to the carer.		
2.6	Staff talk about the patient, in front of us, without including us	Change to "Staff talk about the patient in front of the patient without including them"	Change made	2.6	Staff talk about the patient, in front of the patient, without including them
2.7	Staff rush the patient when providing care				
Principle 3. Treat each person as an individual by offering a personalised service					
3.1	Staff have called the patient by their preferred name				
3.2	Staff have asked the Top 5 things they need to know about the patient	Delete the words "Top 5"	Change made	3.2	Staff have asked what are the most important things they need to know about the patient

3.3	Staff supported the patient to have access to an interpreter	Change to "Staff have helped the patient access an interpreter"	Change made	3.3	Staff have arranged access to an interpreter (with a scale option "Intepreter not required")
		Perhaps a star as in 5.4 to indicate if they wanted one/needed one as it may not be applicable to the patient.	Change made		
3.4	Staff have provided care consistent with the patient's cultural beliefs	Remove 'not applicable' - everyone has cultural beliefs	Changed to "I'd prefer not to answer"	3.4	Scale option added "I'd prefer not to asnwer"
3.5	Staff have provided care consistent with the patient's religious beliefs			3.5	Scale option added "I'd prefer not to asnwer"
3.6	Staff have provided care consistent with the patient's spiritual beliefs	This one would be very difficult to assess and would be highly dependent on perception.	Change made to scoring	3.6	Scale option added "I'd prefer not to asnwer"
3.7	Staff respected the patient's sexual identity	Remove 'not applicable' - everyone has a sexual identity	Changed to "I'd prefer not to answer"	3.7	Scale option added "I'd prefer not to asnwer"
Principle 4. Enable people to maintain the maximum possible level of independence, choice and control					
4.1	Staff have asked if the patient has an Advance Care Directive		Now item 4.5	4.1	I have been involved, as much as the patient wanted me to be, in discussions about the patient's care
4.2	Staff have discussed the patient's Advance Care Directive with us	If the patient still has capacity they should only discuss things with the carer if the patient wants them too; if the patient has lost capacity, they should discuss everything with the carer.	Change made Now item 4.6	4.2	I have been involved, as much as the patient wanted me to be, in decisions about the patient's care
		Suggest changing "Staff have discussed ..." to "We have discussed the patient's Advance Care Directive with staff."	Emphasis is on staff being aware and actively making it a part of discussion.		
4.3	I have been able to refer staff to the patient's Advance Care Directive to support the patient to refuse treatment	The Advance Care Directive only comes into effect if the patient has lost capacity, so the carer would not be referring the staff to the patient's ACD "to support the patient to refuse treatment" but instead "to refuse treatment in line with the patient's wishes, as expressed in the ACD".	Change madeCovered in Item 4.6 and 4.7	4.3	Staff have asked the patient's permission before they provide care
		Add "unwanted" before the word "treatment"	If refused, it is assumed to be unwanted		
4.4	I have been involved, as much as the patient wanted me to be, in discussions about the patient's care		Now item 4.1	4.4	Staff explain what is happening to the patient in ways they understand
4.5	I have been involved, as much as the patient wanted to be, in decisions about the patient's care	Change to "I have been involved as much as the patient wanted (insert 'me') to be"	Change made. Now item 4.2	4.5	Staff have asked if the patient has an Advance Care Directive
4.6	Staff ask the permission of the patient before they provide care	Change to "Staff ask the patient's permission before they provided care"	Change made	4.6	Staff have discussed the patient's Advance Care Directive with me *
		Change to "have asked"	Change made. Now item 4.3		
4.7	Staff explain what is happening to the patient in ways we understand		Now item 4.4	4.7	Staff have provided care consistent with the patient's Advance Care Directive *
					* When the patient did not have 'capacity' to make decisions
Principle 5. Listen and support people to express their needs and wants					
5.1	I have been given enough time to explain what the patient needs *				
5.2	Staff have involved me in planning the patient's care **	This fits both the one-star and two-star category	Changed to "* When the patient was unable to participate and/or when the patient wanted me to be involved"		
5.3	Staff have encouraged me to ask questions				

5.4	I have been given a paper copy of the plan for the care of the patient for the time they are in hospital **	Change to "Staff have provided me with a written plan of care for the time the patient will be in hospital *"			Staff have provided me with a written plan of care for the time the patient will be in hospital *
		Change "for the time" to "while"	No change. May be understood to be a plan for post discharge (but given to patient/carer while they are in the hospital)		
5.5	Staff have encouraged me to be involved in planning the patient’s discharge from hospital **				
5.6	The patient’s preferences have been listened to and acted upon by staff				
5.7	Staff assume what the patient needs without asking us	Change to "Staff assume what the patient needs without asking"	Change made	**5.7**	Staff assume what the patient needs without asking
		Change to “without asking the patient” unless the patient has lost capacity, in which case it should be “without asking me”. If the patient has capacity, the staff do not need to ask the carer. (This is also a problem in other statements).	Change made. “us” had been removed		
	* When the patient was unable to				* When the patient was unable to participate and/or when the patient wanted me to be involved
	** When the patient wanted me to be involved				
Principle 6. Respect people’s privacy					
6.1	The patient has been given privacy when talking about their condition and treatment				
6.2	The patient's privacy is respected when they are being examined or treated				
6.3	The patient's privacy is respected when they are having a wash				
6.4	The patient’s privacy is respected when they are using a bedpan or the toilet	Suggest including “or having my toileting pad changed” Suggest matching the wording for this same item for the Carers.	Change made	6.4	The patient's privacy is respected when they are using the toilet, bedpan or having a pad changed
6.5	The patient personal space is respected	“patient” should be “patient’s"	Change made		
6.6	The patient's information is treated confidentially				
6.7	The patient has had access to their health record when requested	Change to "The patient could access their health record when they wanted to"	No change. Hospitals may have policies for access to records, so "when requested" retained	6.7	The patient has had access to their hospital medical record when requested
Principle 7. Ensure people feel able to complain without fear of retribution					
7.1	Staff made sure there was an opportunity to talk about any concerns				
7.2	I have felt I could make a complaint if I needed to				
7.3	I believe I could make a complaint without it affecting the patient’s care				
7.4	I know who to contact if I have a complaint	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item	7.4	Change made to scale "Yes", "No", "Unsure"
7.5	I made a complaint and it was taken seriously	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item	7.5	Change made to scale "Yes", "No", "I did not make a complaint"
7.6	I made a complaint and I was satisfied with the outcome	The 5 point terms used (Never through to Always) do not make sense for this item	Scale changed for this item	7.6	Change made to scale "Yes", "No", "I did not make a complaint"
7.7	Staff treated the patient badly after we made a complaint	More often applies to “after I made a complaint” (rather than “we”)	Change made	7.7	Change made to scale "Yes", "No", "I did not make a complaint" Staff treated the patient badly after I made a complaint
		Suggested addition “Staff treated the patient and/or me badly after we made a complaint”	Mixed feedback about a number of items include patient and/or me (ie carer). Including patient and carer makes scoring difficult.These items really need to be presented separately.Focus is on patient.		

Principle 8. Engage with family members and carers as care partners					
8.1	Staff have asked which family members should be involved in the patient's care	If the patient has capacity, it should say: Staff have asked "the patient" which family members etc. Some family members think they have "a right" to be involved in the patient's care, which they do not. If the patient has lost capacity, the carer could say who should be involved.	Change made to 8.1 and 8.2	8.1	Staff have asked which family members should be involved in the patient's care *
8.2	I have been involved, as much as the patient wanted me to be, in decisions about the patient's care			8.2	I have been involved in decisions about the patient's care *
8.3	Staff talked with me when the patient was unable to communicate			8.3	Staff talked with me when the patient was unable to communicate *
8.4	Staff supported me to be with the patient when the patient wanted me to be with them	I note that you have tried to avoid s/he by using "them, they, their" – but sometimes that becomes clumsy because those words refer to more than one person, i.e., plural. That is the case here. Perhaps you could reword it to say "when that is what the patient wanted."	Change made	8.4	Staff supported me to be with the patient when that is what the patient wanted
		Change "supported" to "facilitated"	No change. Need to keep language simple.		
8.5	Staff responded quickly when I reported the patient's condition had deteriorated				
8.6	Staff arranged access to interpreters for me and my family	I don't think it needs "and my family"	Change made	8.6	Staff arranged access to interpreters to involve family or carer in the patient's care *
		Why have an interpreter for my family? – they may not have a caring role.	Change made		
					* When the patient was unable to participate and/or when the patinet wanted family or carers involved
Principle 9. Assist people to maintain confidence and a positive self-esteem					
9.1	Staff have made me feel welcome				
9.2	Staff have spoken to me as an equal	I don't think "as an equal" is right here. I am not sure how to replace it other than perhaps going to negate the negatives ie Staff did not put me down when speaking to me or did not make me feel inadequate or something along those lines.	No change Equal in "personhood" Not equal as in a colleague or peer. If not equal, then implies patient's/carers are less than equal. Test with patients and carers in pilot.		
9.3	When talking about the patient's care, the staff included us in the discussion	Change to "When talking about the patient's care, the staff included me in the discussion whenever the patient wanted me to be included"	Change made (to match format in Principle 5)	9.3	When talking about the patient's care, the staff include me in the discussion *
9.4	The patient was given enough time to do what they were capable of doing themselves				
9.5	Staff supported the patient to stay physically and mentally active				
9.6	The patient was supported to maintain their personal appearance				
9.7	Staff took too long to get to the patient when they needed the bathroom	This sentence reads as if the staff needed to go to the bathroom. It's another case of a problem caused by using a plural pronoun. Could you say "Staff took too long to respond when the patient needed to go to the bathroom"?	Change made	9.7	Staff took too long to respond when the patient needed to go to the toilet
					* When the patient wanted me to be involved

Principle 10. Act to alleviate people's loneliness and isolation					
10.1	The patient has been free to interact with other people				
10.2	Staff supported the patient to find things to do to keep them from being bored			10.2	Staff have helped the patient to find things to do to keep them from being bored
10.3	The patient has had access to a Volunteer, if they wanted one				
10.4	The patient has had access to a television at their bedside				
10.5	The patient was able to listen to the radio				
10.6	The patient has had access to the internet so they could use their telephone or tablet to stay in touch with people				
10.7	I feel as if the staff do not care about the patient	Remove not applicable - everyone should rate how they experience staff feelings about them	The item was removed to make way for additional item about Aboriginal Liaison Officer	10.7	The patient is an Aboriginal person and has had access to the Aboriginal Liaison Officer, if they wanted one

	General comment	Notes	Outcome
	In the Carer survey, I wonder whether it better to use a different term instead of patient. If all carers are family members, then perhaps you could say 'relative' instead. For a DIC survey the word 'patient' seems a little outdated.	'Carer' and 'Patient' are not ideal words.Ideal words do not exist in English language.Much debated topic.No consensus.Using 'patient' and 'carer' consistently across the two documents at least makes it easier to understand.Changing these words requires a much broader debate starting with health consumer advocacy organisations.It is beyond the scope of my study to address this substantial and long-standing problem.	Explore terminology in pilot test
	We are concerned that, the term 'carer' is used to include the following, therefore would like the standard to show that staff know and understand the difference and respect it. a. Visitors who are not welcome at all, eg. perpetrators of dfv, elder abuse b. Social visitors c. Those whom the 'patient' has consented to being privy to private medical information d. Family/friends in are not in category (b) e. Those whom the 'patient' has nominated as alternate decision makers in the advanced care directive	Changes made to definition of a "carer" on the front page of the carer version.	
	The carers section is not quite comparable to the patients. I don't know if that matters, however, at times it is asking the carer about the patient's experience, whereas other times it is asking about the carer's experience. If these are to correlate they may be asking about different things.	Purpose of questionnaire is not to analyse patient versus carer perspective. But to understand patient perspective and carer perspective.	No change

Notes:
1. Where more than one panellist has suggested the same change, the suggested change has been noted and not repeated in the table.

Appendix E1 69-item Dignity in Care Questionnaire (Patient Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.1	I have felt safe when staff provide care to me	Never	Rarely	Sometimes	Frequently	Always	
1.2	Staff have been considerate in how they provide care to me	Never	Rarely	Sometimes	Frequently	Always	
1.3	Staff come to see me soon after I press the call bell	Never	Rarely	Sometimes	Frequently	Always	I have not used the call bell
1.4	I have been given care when I need it	Never	Rarely	Sometimes	Frequently	Always	
1.5	Staff have been rough in the way they provide care	Never	Rarely	Sometimes	Frequently	Always	
1.6	I have had my arms and legs tied down to restrain me	Never	Rarely	Sometimes	Frequently	Always	
1.7	Staff have helped to control my pain	Never	Rarely	Sometimes	Frequently	Always	I had no pain

Principle 2. Show people respect

2.1	Staff wear name badges large enough to read	Never	Rarely	Sometimes	Frequently	Always	
2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Frequently	Always	
2.3	Staff introduce themselves before providing care	Never	Rarely	Sometimes	Frequently	Always	
2.4	Staff have been respectful when they speak with me	Never	Rarely	Sometimes	Frequently	Always	
2.5	Staff have spoken over me	Never	Rarely	Sometimes	Frequently	Always	
2.6	Staff talk about me, in front of me, without including me	Never	Rarely	Sometimes	Frequently	Always	
2.7	Staff rush me when providing care	Never	Rarely	Sometimes	Frequently	Always	

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called me by my preferred name	Never	Rarely	Sometimes	Frequently	Always	
3.2	Staff have asked ***the most important things*** they need to know about me	Never	Rarely	Sometimes	Frequently	Always	
3.3	I have had access to an interpreter	Never	Rarely	Sometimes	Frequently	Always	I do not need an interpreter
3.4	Staff have provided care consistent with my cultural beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.5	Staff have provided care consistent with my religious beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.6	Staff have provided care consistent with my spiritual beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.7	Staff have respected my sexual identity	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.1	I have been involved, as much as I wanted to be, in ***discussions*** about my care	Never	Rarely	Sometimes	Frequently	Always	
4.2	I have been involved, as much as I wanted to be, in ***decisions*** about my care	Never	Rarely	Sometimes	Frequently	Always	
4.3	Staff have asked my permission before they provide care	Never	Rarely	Sometimes	Frequently	Always	
4.4	Staff have explained what is happening to me in ways I understand	Never	Rarely	Sometimes	Frequently	Always	
4.5	Staff have asked me if I have an Advance Care Directive	Never	Rarely	Sometimes	Frequently	Always	
4.6	I have discussed my Advance Care Directive with staff	Never	Rarely	Sometimes	Frequently	Always	I do not have an Advance Care Directive
4.7	I have been able to refuse treatment	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what I need	Never	Rarely	Sometimes	Frequently	Always	
5.2	Staff have involved me in planning my care	Never	Rarely	Sometimes	Frequently	Always	
5.3	Staff have encouraged me to ask questions	Never	Rarely	Sometimes	Frequently	Always	
5.4	Staff have given me a written plan of care for the time I am in hospital	Never	Rarely	Sometimes	Frequently	Always	
5.5	Staff have encouraged me to be involved in planning my discharge from hospital	Never	Rarely	Sometimes	Frequently	Always	
5.6	My preferences have been listened to and acted upon by staff	Never	Rarely	Sometimes	Frequently	Always	
5.7	Staff assume they know what I need, without asking me	Never	Rarely	Sometimes	Frequently	Always	

Principle 6. Respect people’s privacy

6.1	I have been given privacy when talking about my condition and treatment	Never	Rarely	Sometimes	Frequently	Always	
6.2	I feel my privacy is respected when I am being examined or treated	Never	Rarely	Sometimes	Frequently	Always	
6.3	I feel my privacy is respected when I am having a wash	Never	Rarely	Sometimes	Frequently	Always	
6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Never	Rarely	Sometimes	Frequently	Always	
6.5	My personal space is respected	Never	Rarely	Sometimes	Frequently	Always	
6.6	Staff treat my information confidentially	Never	Rarely	Sometimes	Frequently	Always	
6.7	I have had access to my hospital medical record, when requested	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

Principle 7. Ensure people feel able to complain without fear of retribution

7.1	Staff have made sure there is an opportunity to talk about any concerns	Never	Rarely	Sometimes	Frequently	Always	
7.2	I have felt I could make a complaint if I needed to	Never	Rarely	Sometimes	Frequently	Always	
7.3	I believe I could make a complaint without it affecting my care	Never	Rarely	Sometimes	Frequently	Always	
7.4	I know who to contact if I have a complaint	Yes	No				
7.5	I made a complaint and it was taken seriously	Yes	No	I did not make a complaint			
7.6	I made a complaint and I was satisfied with the outcome	Yes	No	I did not make a complaint			
7.7	Staff treated me badly after I made a complaint	Yes	No	I did not make a complaint			

Principle 8. Engage with family members and carers as care partners

8.1	Staff have asked me which family members or carers I want involved in my care	Never	Rarely	Sometimes	Frequently	Always	
8.2	My family or carers have been involved in decisions about my care	Never	Rarely	Sometimes	Frequently	Always	
8.3	Staff talked to my family or carers about my care when I was unable to communicate	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.4	When I wanted my family or carers with me, staff supported them to be with me	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.5	Staff responded quickly when my family reported my condition had deteriorated	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.6	Staff arranged access to interpreters to involve family or carers in my care *	Never	Rarely	Sometimes	Frequently	Always	Interpreter not required

* When I wanted family or carers involved

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.1	Staff have made me feel welcome	Never	Rarely	Sometimes	Frequently	Always	
9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Frequently	Always	
9.3	When talking about my care, the staff include me in the discussion	Never	Rarely	Sometimes	Frequently	Always	
9.4	I have been given enough opportunity to do what I am capable of doing myself	Never	Rarely	Sometimes	Frequently	Always	
9.5	Staff have supported me to stay physically and mentally active	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
9.6	I have been supported to maintain my personal appearance	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
9.7	Staff took too long to respond when I needed to go to the toilet	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

* When the patient wanted me to be involved

Principle 10. Act to alleviate people's loneliness and isolation

10.1	I have been free to interact with other people	Never	Rarely	Sometimes	Frequently	Always	
10.2	Staff have helped me to find things to do to keep me from being bored	Never	Rarely	Sometimes	Frequently	Always	
10.3	I was able to access a tv by my bedside	Never	Rarely	Sometimes	Frequently	Always	
10.4	I have been able to listen to a radio	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
10.5	I have had access to the internet, so I could use my telephone or tablet to stay in touch with people	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
10.6	I have had access to a Volunteer	Yes			No		I did not want a volunteer
10.7	I am an Aboriginal person and I have had access to an Aboriginal Liaison Officer, if I wanted one	Yes			No		I am not an Aboriginal person

Appendix E2 69-item Dignity in Care Questionnaire (Carer Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.1	I have felt the patient is safe when staff are providing care	Never	Rarely	Sometimes	Frequently	Always	
1.2	Staff have been considerate in the way they provide care to the patient	Never	Rarely	Sometimes	Frequently	Always	
1.3	Staff come to see the patient soon after we press the call bell	Never	Rarely	Sometimes	Frequently	Always	The patient has not used the call bell
1.4	The patient has been given care when they need it	Never	Rarely	Sometimes	Frequently	Always	
1.5	Staff have been rough in the way they provide care to the patient	Never	Rarely	Sometimes	Frequently	Always	
1.6	The patient has had their arms and legs tied down to restrain them	Never	Rarely	Sometimes	Frequently	Always	
1.7	Staff have helped to control the patient's pain	Never	Rarely	Sometimes	Frequently	Always	The patient had no pain

Principle 2. Show people respect

2.1	Staff wear name badges large enough to read	Never	Rarely	Sometimes	Frequently	Always	
2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Frequently	Always	
2.3	Staff introduce themselves before providing care	Never	Rarely	Sometimes	Frequently	Always	
2.4	Staff have been respectful when they speak to the patient	Never	Rarely	Sometimes	Frequently	Always	
2.5	Staff have spoken over the patient	Never	Rarely	Sometimes	Frequently	Always	
2.6	Staff talk about the patient, in front of the patient, without including them	Never	Rarely	Sometimes	Frequently	Always	
2.7	Staff rush the patient when providing care	Never	Rarely	Sometimes	Frequently	Always	

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called the patient by their preferred name	Never	Rarely	Sometimes	Frequently	Always	
3.2	Staff have asked ***the most important things*** they need to know about the patient	Never	Rarely	Sometimes	Frequently	Always	
3.3	Staff have arranged access to an interpreter	Never	Rarely	Sometimes	Frequently	Always	The patient does not need an interpreter
3.4	Staff have provided care consistent with the patient's cultural beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.5	Staff have provided care consistent with the patient's religious beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.6	Staff have provided care consistent with the patient's spiritual beliefs	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer
3.7	Staff have respected the patient's sexual identity	Never	Rarely	Sometimes	Frequently	Always	I'd prefer not to answer

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.1	I have been involved, as much as the patient wanted me to be, in ***discussions*** about the patient's care	Never	Rarely	Sometimes	Frequently	Always	
4.2	I have been involved, as much as the patient wanted me to be, in ***decisions*** about the patient's care	Never	Rarely	Sometimes	Frequently	Always	
4.3	Staff have asked the patient's permission before they provide care	Never	Rarely	Sometimes	Frequently	Always	
4.4	Staff have explained what is happening to the patient in ways they understand	Never	Rarely	Sometimes	Frequently	Always	
4.5	Staff have asked if the patient has an Advance Care Directive	Never	Rarely	Sometimes	Frequently	Always	
4.6	Staff have discussed the patient's Advance Care Directive with me *	Never	Rarely	Sometimes	Frequently	Always	The patient does not have an Advance Care Directive
4.7	Staff have provided care consistent with the patient's Advance Care Directive *	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

* When the patient did not have the 'capacity' to make decision

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what the patient needs *	Never	Rarely	Sometimes	Frequently	Always	
5.2	Staff have involved me in planning the patient's care *	Never	Rarely	Sometimes	Frequently	Always	
5.3	Staff have encouraged me to ask questions *	Never	Rarely	Sometimes	Frequently	Always	
5.4	Staff have given me a written plan of care for the time the patient will be in hospital *	Never	Rarely	Sometimes	Frequently	Always	
5.5	Staff have encouraged me to be involved in planning the patient's discharge from hospital *	Never	Rarely	Sometimes	Frequently	Always	
5.6	The patient's preferences have been listened to and acted upon by staff	Never	Rarely	Sometimes	Frequently	Always	
5.7	Staff assume what the patient needs, without asking	Never	Rarely	Sometimes	Frequently	Always	

* When the patient was unable to participate and/or when the patient wanted me to be involved

Principle 6. Respect people's privacy

6.1	The patient has been given privacy when talking about their condition and treatment	Never	Rarely	Sometimes	Frequently	Always	
6.2	The patient's privacy is respected when they are being examined or treated	Never	Rarely	Sometimes	Frequently	Always	
6.3	The patient's privacy is respected when they are having a wash	Never	Rarely	Sometimes	Frequently	Always	
6.4	The patient's privacy is respected when they are using the toilet, bedpan or having a pad changed	Never	Rarely	Sometimes	Frequently	Always	
6.5	The patient's personal space is respected	Never	Rarely	Sometimes	Frequently	Always	
6.6	The patient's information is treated confidentially	Never	Rarely	Sometimes	Frequently	Always	
6.7	The patient has had access to their hospital medical record, when requested	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

Principle 7. Ensure people feel able to complain without fear of retribution

7.1	Staff made sure there was an opportunity to talk about any concerns	Never	Rarely	Sometimes	Frequently	Always	
7.2	I have felt I could make a complaint if I needed to	Never	Rarely	Sometimes	Frequently	Always	
7.3	I believe I could make a complaint without it affecting the patient's care	Never	Rarely	Sometimes	Frequently	Always	
7.4	I know who to contact if I have a complaint	Yes	No				
7.5	I made a complaint and it was taken seriously	Yes	No	I did not make a complaint			
7.6	I made a complaint and I was satisfied with the outcome	Yes	No	I did not make a complaint			
7.7	Staff treated the patient badly after I made a complaint	Yes	No	I did not make a complaint			

Principle 8. Engage with family members and carers as care partners

8.1	Staff have asked which family members should be involved in the patient's care *	Never	Rarely	Sometimes	Frequently	Always	
8.2	I have been involved in decisions about the patient's care *	Never	Rarely	Sometimes	Frequently	Always	
8.3	Staff talked with me when the patient was unable to communicate *	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.4	Staff supported me to be with the patient, when that is what the patient wanted	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.5	Staff responded quickly when I reported the patient's condition had deteriorated	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
8.6	Staff arranged access to interpreters to involve family or carers in the patient's care *	Never	Rarely	Sometimes	Frequently	Always	Interpreter not required

* When the patient was unable to participate and/or when the patient wanted family or carers involved

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.1	Staff have made me feel welcome	Never	Rarely	Sometimes	Frequently	Always	
9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Frequently	Always	
9.3	When talking about the patient's care, the staff included me in the discussion *	Never	Rarely	Sometimes	Frequently	Always	
9.4	The patient was given enough time to do what they were capable of doing themselves	Never	Rarely	Sometimes	Frequently	Always	
9.5	Staff supported the patient to stay physically and mentally active	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
9.6	The patient was supported to maintain their personal appearance	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
9.7	Staff took too long to respond when the patient needed to go to the toilet	Never	Rarely	Sometimes	Frequently	Always	Not Applicable

* When the patient wanted me to be involved

Principle 10. Act to alleviate people's loneliness and isolation

10.1	The patient has been free to interact with other people	Never	Rarely	Sometimes	Frequently	Always	
10.2	Staff have helped the patient to find things to do to keep them from being bored	Never	Rarely	Sometimes	Frequently	Always	
10.3	The patient has had access to a tv at their bedside	Never	Rarely	Sometimes	Frequently	Always	
10.4	The patient was able to listen to the radio	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
10.5	The patient has had access to the internet, so they could use their telephone or tablet to stay in touch with people	Never	Rarely	Sometimes	Frequently	Always	Not Applicable
10.6	The patient has had access to a Volunteer	Yes			No		The patient did not want a volunteer
10.7	The patient is an Aboriginal person and has had access to the Aboriginal Liaison Officer, if they wanted one	Yes			No		The patient is not an Aboriginal person

Appendix F1 Pilot Study Summary Data (Patient Version)

Item	Valid (n)	Missing (n)	Never	Rarely	Sometimes	Frequently	Always	Add. Response
1.1	32				1	4	27	
1.2	32			1	2	2	27	
1.3	32			3	4	9	15	1
1.4	32			1	1	6	24	
1.5	62	1	25	3	2	1	31	
1.6	32		31	1				
1.7	32		1	1	3	22	5	
2.1	30	2	5	1	8	7	9	
2.2	32			1	4	5	22	
2.3	32				5	4	23	
2.4	31	1			1	7	23	
2.5	30	2	12	6	9	1	2	
2.6	30	2	11	9	6	3	1	
2.7	32		11	8	8	2	3	
3.1	31	1				3	28	
3.2	31	1		1	3	6	21	
3.3	32		3					29
3.4	24	8	2				13	9
3.5	23	9	3			1	11	8
3.6	21	11	3				8	10
3.7	29	3	1				18	10
4.1	32		2	2	7	4	17	
4.2	30	2	2	4	2	5	17	
4.3	31	1		1	5	8	17	
4.4	32		1	1	3	9	18	
4.5	31	1	21	1	1		8	
4.6	31	1	11	2		4	14	
4.7	31	1	2	2			6	21
5.1	30	2	1	2	2	4	21	
5.2	32		5	3	3	8	13	
5.3	32		5	1	6	6	14	
5.4	32		28	1	3			
5.5	29	3	14	3	4	1	7	
5.6	29	3	5	2	8	5	9	
5.7	31	1	9	4	8	4	6	
6.1	31	1			3	5	23	
6.2	32				2	3	27	
6.3	29	3	1	1		4	23	
6.4	31	1	1	1	1	4	24	
6.5	32			3	2	4	23	
6.6	22	10	1	2		1	18	
6.7	31	1	3		1		4	23
7.1	30	2	2	4	5	5	14	
7.2	32		2	2	6		22	
7.3	29	3	4		2	2	21	
7.4	31	1	22 (No)				9 (Yes)	
7.5	31	1					5 (Yes)	26
7.6	31	1	2 (No)				3 (Yes)	26
7.7	31	1	7 (No)				1 (Yes)	23
8.1	32		14	2	1	3	12	
8.2	25	7	6	2	3	3	11	
8.3	31	1	3	1	1	1	4	21
8.4	31	1	2	2	2		10	15
8.5	30	2	2		1		1	26
8.6	27	5	1					26
9.1	32		1		1	3	27	
9.2	32			1	2	5	24	
9.3	31	1	1		9	7	14	
9.4	30	2			2	5	23	
9.5	31	1	1	2	1		22	5
9.6	32		4		2	3	17	6
9.7	32		9	3	7	4	4	5
10.1	25	7	3		1	3	18	
10.2	23	9	8	3	4	5	3	
10.3	26	6	2		2	2	20	
10.4	29	3	8	1			9	11
10.5	30	2	6	2			6	16
10.6	31	1	14 (No)				1 (Yes)	16
10.7	32		3 (No)					29

Appendix F2 Pilot Study Summary Data (Carer Version)

Item	Valid (n)	Missing (n)	Never	Rarely	Sometimes	Frequently	Always	Add.Response
1.1	20					8	12	
1.2	20					7	13	
1.3	20		1		5	6	6	2
1.4	19	1			1	3	15	
1.5	18	2	14	3	1			
1.6	20		20					
1.7	20		1			5	9	5
2.1	19	1		2	3	2	12	
2.2	20				4	7	9	
2.3	20				4	7	9	
2.4	20					5	15	
2.5	18	2	8	5	4	1		
2.6	18	2	9	4	4	1		
2.7	19	1	12	2	4	1		
3.1	19	1			1	2	16	
3.2	19	1		1	3	6	9	
3.3	20					2		18
3.4	17	3				3	10	4
3.5	15	5				2	9	4
3.6	15	5				1	9	5
3.7	16	4				1	12	3
4.1	20					4	16	
4.2	20				1	3	16	
4.3	20				2	2	16	
4.4	19	1			2	6	11	
4.5	16	4	5		1	2	8	
4.6	19	1	7		1	1	7	3
4.7	18	2	2			1	5	10
5.1	16	4			3	5	8	
5.2	19	1	2	1	3	5	8	
5.3	19	1	2	1	4	4	8	
5.4	18	2	16			1	1	
5.5	18	2	6	1	1	3	7	
5.6	18	2		1	3	8	6	
5.7	18	2	3	7	7		1	
6.1	20			1	1	6	12	
6.2	20			1	1	1	17	
6.3	18	2		1		1	16	
6.4	17	3		1		2	14	
6.5	18	2		1		3	14	
6.6	16	4		1	1	2	12	
6.7	4	1	2		1		1	
7.1	20		1	1	3	5	10	
7.2	18	2		1	1	3	13	
7.3	17	3			2	1	14	
7.4	17	3	8 (No)				9 (Yes)	
7.5	20						4 (Yes)	16
7.6	19	1					3 (Yes)	16
7.7	19	1	3 (No)					16
8.1	16	4	4	1	1		10	
8.2	17	3	3	1	1	4	8	
8.3	20				2	1	8	9
8.4	19	1			1	2	11	5
8.5	20					4	4	12
8.6	19	1					2	17
9.1	20				1	3	16	
9.2	20				4	4	12	
9.3	20		2		2	5	11	
9.4	17	3		1	3	3	10	
9.5	20			2	1	3	10	4
9.6	19	1		2	4	2	10	1
9.7	19	1	5		6	2	6	
10.1	16	4	2	2	3		9	
10.2	15	5	4	2	4		5	
10.3	17	3			1	2	14	
10.4	18	2	1			1	3	13
10.5	17	3	1				1	15
10.6	15	5	7 (No)				3 (Yes)	5
10.7	19		1 (No)					19

Appendix G1 50-item Dignity in Care Questionnaire (Patient Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.1	I have felt safe when staff provide care to me	Never	Rarely	Sometimes	Often	Always	
1.2	Staff come to see me soon after I press the call bell	Never	Rarely	Sometimes	Often	Always	I have not used the call bell
1.3	Staff have been rough in the way they provide care	Never	Rarely	Sometimes	Often	Always	
1.4	I have had my arms and legs tied down to restrain me	Never	Rarely	Sometimes	Often	Always	
1.5	Staff have helped to control my pain	Never	Rarely	Sometimes	Often	Always	I had no pain

Principle 2. Show people respect

2.1	Staff wear name badges large enough to read	Never	Rarely	Sometimes	Often	Always
2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Often	Always
2.3	Staff have been respectful when they speak with me	Never	Rarely	Sometimes	Often	Always
2.4	Staff have been considerate in how they provide care to me	Never	Rarely	Sometimes	Often	Always
2.5	My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)	Never	Rarely	Sometimes	Often	Always

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called me by my preferred name	Never	Rarely	Sometimes	Often	Always	
3.2	I have had access to an interpreter	Never	Rarely	Sometimes	Often	Always	I do not need an interpreter
3.3	Staff have **asked** if I have cultural / religious / spiritual beliefs that are important to me	Never	Rarely	Sometimes	Often	Always	
3.4	Staff have **provided care** consistent with my cultural / religious / spiritual beliefs	Never	Rarely	Sometimes	Often	Always	Not Applicable
3.5	Staff have respected my sexual identity	Never	Rarely	Sometimes	Often	Always	Not Applicable

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.1	I have been involved, as much as I wanted to be, in ***discussions*** about my care	Never	Rarely	Sometimes	Often	Always	
4.2	I have been involved, as much as I wanted to be, in ***decisions*** about my care	Never	Rarely	Sometimes	Often	Always	
4.3	Staff have asked my permission before they provide care	Never	Rarely	Sometimes	Often	Always	
4.4	I believe I can choose to refuse treatment	Never	Rarely	Sometimes	Often	Always	Unsure
4.5	I have discussed my Advance Care Directive with staff	Yes		No		I do not know what an Advance Care Directive is	I do not have an Advance Care Directive

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what I need	Never	Rarely	Sometimes	Often	Always	
5.2	Staff provide care that reflects an understanding of my needs (such as my vision, hearing, memory, mobility and dietary needs)	Never	Rarely	Sometimes	Often	Always	
5.3	Staff have encouraged me to ask questions	Never	Rarely	Sometimes	Often	Always	
5.4	Staff have spoken with me about my care in ways I understand	Never	Rarely	Sometimes	Often	Always	
5.5	Staff have encouraged me to be involved in planning my discharge from hospital	Never	Rarely	Sometimes	Often	Always	Discharge has not been discussed

Principle 6. Respect people's privacy

6.1	I have been given privacy when talking about my condition and treatment	Never	Rarely	Sometimes	Often	Always
6.2	I feel my privacy is respected when I am being examined or treated	Never	Rarely	Sometimes	Often	Always
6.3	I feel my privacy is respected when I am having a wash	Never	Rarely	Sometimes	Often	Always
6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Never	Rarely	Sometimes	Often	Always
6.5	My personal space is respected	Never	Rarely	Sometimes	Often	Always

Principle 7. Ensure people feel able to complain without fear of retribution

7.1	Staff have made sure there is an opportunity to talk about any concerns	Never	Rarely	Sometimes	Often	Always
7.2	I have felt I could make a complaint if I needed to	No		I'd be reluctant		Yes
7.3	I believe I could make a complaint without it affecting my care	No		I'd be reluctant		Yes
7.4	I know who to contact if I have a complaint	No		Unsure		Yes
7.5	I made a complaint and I was satisfied with the response	Not satisfied with the response		I did not make a complaint		Yes, satisfied with the response

Principle 8. Engage with family, friends and carers as care partners

8.1	Staff have asked me which family, friends or carers I want involved in my care	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.2	My family, friends or carers have been involved in decisions about my care *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.3	Staff include my family, friends or carers in the bedside discussion at shift handover *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.4	Staff responded quickly when my family, friends or carers reported my condition had deteriorated	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.5	Staff arranged access to interpreters to involve family, friends or carers in my care *	Never	Rarely	Sometimes	Often	Always	Interpreter not required

* When I wanted these family, friends or carers involved in my care

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.1	Staff have made me feel welcome	Never	Rarely	Sometimes	Often	Always
9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Often	Always
9.3	I have been given enough opportunity to do what I am capable of doing myself	Never	Rarely	Sometimes	Often	Always
9.4	I have been supported to maintain my personal appearance	Never	Rarely	Sometimes	Often	Always
9.5	Staff took too long to respond when I needed to go to the toilet	Never	Rarely	Sometimes	Often	Always

Principle 10. Act to alleviate people's loneliness and isolation

10.1	Staff include me in the bedside discussion at shift handover	Never	Rarely	Sometimes	Often	Always
10.2	Staff have supported me to stay physically and mentally active	Never	Rarely	Sometimes	Often	Always
10.3	Staff have helped me to find things to do to keep me from being bored	Never	Rarely	Sometimes	Often	Always
10.4	I have been visited by a hospital volunteer	No		Unsure		Yes
10.5	I have had access to an Aboriginal Liaison Officer	No		I am not an Aboriginal person		Yes

Appendix G2 50-item Dignity in Care Questionnaire (Carer Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.1	I have felt the patient is safe when staff are providing care	Never	Rarely	Sometimes	Often	Always	
1.2	Staff come to see the patient soon after we press the call bell	Never	Rarely	Sometimes	Often	Always	The patient has not used the call bell
1.3	Staff have been rough in the way they provide care to the patient	Never	Rarely	Sometimes	Often	Always	
1.4	The patient has had their arms and legs tied down to restrain them	Never	Rarely	Sometimes	Often	Always	
1.5	Staff have helped to control the patient's pain	Never	Rarely	Sometimes	Often	Always	The patient has no pain or appears to have no pain

Principle 2. Show people respect

2.1	Staff wear name badges large enough to read	Never	Rarely	Sometimes	Often	Always
2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Often	Always
2.3	Staff have been respectful when they speak to the patient	Never	Rarely	Sometimes	Often	Always
2.4	Staff have been considerate in the way they provide care to the patient	Never	Rarely	Sometimes	Often	Always
2.5	The patient's basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)	Never	Rarely	Sometimes	Often	Always

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called the patient by their preferred name	Never	Rarely	Sometimes	Often	Always	
3.2	Staff have arranged access to an interpreter for the patient	Never	Rarely	Sometimes	Often	Always	The patient does not need an interpreter
3.3	Staff have **asked** if the patient has cultural / religious / spiritual beliefs that are important to them	Never	Rarely	Sometimes	Often	Always	Unsure
3.4	Staff have **provided care** consistent with the patient's cultural / religious / spiritual beliefs	Never	Rarely	Sometimes	Often	Always	Not Applicable
3.5	Staff have respected the patient's sexual identity	Never	Rarely	Sometimes	Often	Always	Not Applicable

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.1	I have been involved, as much as the patient wanted me to be, in **discussions** about the patient's care	Never	Rarely	Sometimes	Often	Always	
4.2	I have been involved, as much as the patient wanted me to be, in **decisions** about the patient's care	Never	Rarely	Sometimes	Often	Always	
4.3	Staff have asked the patient's permission before they provide care	Never	Rarely	Sometimes	Often	Always	
4.4	I believe the patient could choose to refuse treatment	Never	Rarely	Sometimes	Often	Always	Unsure
4.5	Staff have discussed the patient's Advance Care Directive with me *	Yes		No		I do not know what an Advance Care Directive is	The patient does not have an Advance Care Directive

* When the patient did not have 'capacity' to make decisions

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what the patient needs *	Never	Rarely	Sometimes	Often	Always	
5.2	Staff provide care that reflects an understanding of the patient's needs (such as vision, hearing, memory, mobility and dietary needs)	Never	Rarely	Sometimes	Often	Always	
5.3	Staff have encouraged me to ask questions *	Never	Rarely	Sometimes	Often	Always	
5.4	Staff have spoken with the patient and me, about the patient's care, in ways we understand *	Never	Rarely	Sometimes	Often	Always	
5.5	Staff have encouraged me to be involved in planning the patient's discharge from hospital *	Never	Rarely	Sometimes	Often	Always	Discharge has not been discussed

* When the patient was unable to participate and/or when the patient wanted me to be involved

Principle 6. Respect people's privacy

6.1	The patient has been given privacy when talking about their condition and treatment	Never	Rarely	Sometimes	Often	Always
6.2	The patient's privacy is respected when they are being examined or treated	Never	Rarely	Sometimes	Often	Always
6.3	The patient's privacy is respected when they are having a wash	Never	Rarely	Sometimes	Often	Always
6.4	The patient's privacy is respected when they are using the toilet, bedpan or having a pad changed	Never	Rarely	Sometimes	Often	Always
6.5	The patient's personal space is respected	Never	Rarely	Sometimes	Often	Always

Principle 7. Ensure people feel able to complain without fear of retribution

<table>
<tr><td>7.1</td><td>Staff have made sure there is an opportunity to talk about any concerns</td><td>Never</td><td>Rarely</td><td>Sometimes</td><td>Often</td><td>Always</td></tr>
<tr><td>7.2</td><td>I have felt I could make a complaint if I needed to</td><td colspan="2">No</td><td>I'd be reluctant</td><td colspan="2">Yes</td></tr>
<tr><td>7.3</td><td>I believe I could make a complaint without it affecting the patient's care</td><td colspan="2">No</td><td>I'd be reluctant</td><td colspan="2">Yes</td></tr>
<tr><td>7.4</td><td>I know who to contact if I have a complaint</td><td colspan="2">No</td><td>Unsure</td><td colspan="2">Yes</td></tr>
<tr><td>7.5</td><td>I made a complaint and I was satisfied with the response</td><td colspan="2">Not satisfied with the response</td><td>I did not make a complaint</td><td colspan="2">Yes, satisfied with the response</td></tr>
</table>

Principle 8. Engage with family, friends and carers as care partners

8.1	Staff have asked which family, friends or carers should be involved in the patient's care *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.2	I have been involved in decisions about the patient's care *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.3	Staff include family, friends or carers in the bedside discussion at shift handover *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.4	Staff responded quickly when I reported the patient's condition had deteriorated	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.5	Staff arranged access to interpreters to involve family, friends or carers in the patient's care *	Never	Rarely	Sometimes	Often	Always	Interpreter not required

* When the patient was unable to participate and/or when the patient wanted family, friends or carers involved

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.1	Staff have made me feel welcome	Never	Rarely	Sometimes	Often	Always	
9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Often	Always	
9.3	The patient was given enough time to do what they were capable of doing themselves	Never	Rarely	Sometimes	Often	Always	Not Applicable
9.4	The patient was supported to maintain their personal appearance	Never	Rarely	Sometimes	Often	Always	
9.5	Staff took too long to respond when the patient needed to go to the toilet	Never	Rarely	Sometimes	Often	Always	Not Applicable

Principle 10. Act to alleviate people's loneliness and isolation

<table>
<tr><td>10.1</td><td>Staff include the patient in the bedside discussion at shift handover</td><td>Never</td><td>Rarely</td><td>Sometimes</td><td>Often</td><td>Always</td><td></td></tr>
<tr><td>10.2</td><td>Staff have supported the patient to stay physically and mentally active</td><td>Never</td><td>Rarely</td><td>Sometimes</td><td>Often</td><td>Always</td><td></td></tr>
<tr><td>10.3</td><td>Staff have helped the patient to find things to do to keep them from being bored</td><td>Never</td><td>Rarely</td><td>Sometimes</td><td>Often</td><td>Always</td><td>The patient has not been bored</td></tr>
<tr><td>10.4</td><td>The patient has been visited by a hospital volunteer</td><td colspan="2">No</td><td colspan="3">Unsure</td><td>Yes</td></tr>
<tr><td>10.5</td><td>The patient has had access to an Aboriginal Liaison Officer</td><td colspan="2">No</td><td colspan="3">The patient is not an Aboriginal person</td><td>Yes</td></tr>
</table>

Appendix H Winsteps Control Files

Patient Control File Pre Collapse

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; Excel file created or last modified: 27/02/2020 12:05:30 PM
; PATIENT
;     Excel Cases processed = 200
; Excel Variables processed = 50
ITEM1 = 1 ; Starting column of item responses
NI = 43 ; Number of items
NAME1 = 45 ; Starting column for person label in data record
NAMLEN = 19 ; Length of person label
XWIDE = 1 ; Matches the widest data value observed
CODES = 12345 ; matches the data
TOTALSCORE = Yes ; Include extreme responses in reported scores
; Person Label variables: columns in label: columns in line
@ID = 1E4 ; $C45W4
@GENDER = 6E6 ; $C50W1
@LOSB4Q = 8E9 ; $C52W2
@LOSCAT = 11E11 ; $C55W1
@AGE = 13E14 ; $C57W2
@AGECAT = 16E16 ; $C60W1
@HOSPITAL = 18E18 ; $C62W1

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33; Item 8.3
34; Item 8.4
35; Item 8.5
*

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Item1.1 ; Item 1 : 1-1
Item1.2 ; Item 2 : 2-2
Item1.3 ; Item 3 : 3-3
Item1.4 ; Item 4 : 4-4
Item1.5 ; Item 5 : 5-5
Item2.1 ; Item 6 : 6-6
Item2.2 ; Item 7 : 7-7
Item2.3 ; Item 8 : 8-8
Item2.4 ; Item 9 : 9-9
Item2.5 ; Item 10 : 10-10
Item3.1 ; Item 11 : 11-11
Item3.2 ; Item 12 : 12-12
Item3.3 ; Item 13 : 13-13
Item3.4 ; Item 14 : 14-14
Item3.5 ; Item 15 : 15-15
Item4.1 ; Item 16 : 16-16
Item4.2 ; Item 17 : 17-17
Item4.3 ; Item 18 : 18-18
Item4.4 ; Item 19 : 19-19
Item5.1 ; Item 20 : 20-20
Item5.2 ; Item 21 : 21-21
Item5.3 ; Item 22 : 22-22
Item5.4 ; Item 23 : 23-23
Item5.5 ; Item 24 : 24-24
Item6.1 ; Item 25 : 25-25
Item6.2 ; Item 26 : 26-26
Item6.3 ; Item 27 : 27-27
Item6.4 ; Item 28 : 28-28
Item6.5 ; Item 29 : 29-29
Item7.1 ; Item 30 : 30-30
Item8.1 ; Item 31 : 31-31
Item8.2 ; Item 32 : 32-32
Item8.3 ; Item 33 : 33-33
Item8.4 ; Item 34 : 34-34
Item8.5 ; Item 35 : 35-35
Item9.1 ; Item 36 : 36-36
Item9.2 ; Item 37 : 37-37
Item9.3 ; Item 38 : 38-38
Item9.4 ; Item 39 : 39-39
Item9.5 ; Item 40 : 40-40
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Item10.3 ; Item 43 : 43-43
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IREFER=    AAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAA
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IVALUE A=11234
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; Person Label variables: columns in label: columns in line
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@LOSB4Q = 8E9 ; $C52W2
@LOSCAT = 11E11 ; $C55W1
@AGE = 13E14 ; $C57W2
@AGECAT = 16E16 ; $C60W1
@HOSPITAL = 18E18 ; $C62W1

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12; Item 3.2
33; Item 8.3
34; Item 8.4
35; Item 8.5
*

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Item1.1 ; Item 1 : 1-1
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Item2.1 ; Item 6 : 6-6
Item2.2 ; Item 7 : 7-7
Item2.3 ; Item 8 : 8-8
Item2.4 ; Item 9 : 9-9
Item2.5 ; Item 10 : 10-10
Item3.1 ; Item 11 : 11-11
Item3.2 ; Item 12 : 12-12
Item3.3 ; Item 13 : 13-13
Item3.4 ; Item 14 : 14-14
Item3.5 ; Item 15 : 15-15
Item4.1 ; Item 16 : 16-16
Item4.2 ; Item 17 : 17-17
Item4.3 ; Item 18 : 18-18
Item4.4 ; Item 19 : 19-19
Item5.1 ; Item 20 : 20-20
Item5.2 ; Item 21 : 21-21
Item5.3 ; Item 22 : 22-22
Item5.4 ; Item 23 : 23-23
Item5.5 ; Item 24 : 24-24
Item6.1 ; Item 25 : 25-25
Item6.2 ; Item 26 : 26-26
Item6.3 ; Item 27 : 27-27
Item6.4 ; Item 28 : 28-28
Item6.5 ; Item 29 : 29-29
Item7.1 ; Item 30 : 30-30
Item8.1 ; Item 31 : 31-31
Item8.2 ; Item 32 : 32-32
Item8.3 ; Item 33 : 33-33
Item8.4 ; Item 34 : 34-34
Item8.5 ; Item 35 : 35-35
Item9.1 ; Item 36 : 36-36
Item9.2 ; Item 37 : 37-37
Item9.3 ; Item 38 : 38-38
Item9.4 ; Item 39 : 39-39
Item9.5 ; Item 40 : 40-40
Item10.1 ; Item 41 : 41-41
Item10.2 ; Item 42 : 42-42
Item10.3 ; Item 43 : 43-43
END NAMES
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Carer Control File Pre Collapse

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CODES = 12345 ; matches the data
TOTALSCORE = Yes ; Include extreme responses in reported scores
; Person Label variables: columns in label: columns in line
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@GENDER = 5E5 ; $C49W1
@CARER = 7E7 ; $C51W1
@WHYCARER = 9E9 ; $C53W1
@LOSB4Q = 11E12 ; $C55W2
@LOSCAT = 14E14 ; $C58W1
@AGE = 16E18 ; $C60W3
@AGECAT = 20E20 ; $C64W1
@HOSPITAL = 22E22 ; $C66W1

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14; Item 3.4
15; Item 3.5
35; Item 8.5
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1.2 ; Item 2 : 2-2
1.3 ; Item 3 : 3-3
1.4 ; Item 4 : 4-4
1.5 ; Item 5 : 5-5
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2.2 ; Item 7 : 7-7
2.3 ; Item 8 : 8-8
2.4 ; Item 9 : 9-9
2.5 ; Item 10 : 10-10
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3.2 ; Item 12 : 12-12
3.3 ; Item 13 : 13-13
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3.5 ; Item 15 : 15-15
4.1 ; Item 16 : 16-16
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4.3 ; Item 18 : 18-18
4.4 ; Item 19 : 19-19
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5.3 ; Item 22 : 22-22
5.4 ; Item 23 : 23-23
5.5 ; Item 24 : 24-24
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6.5 ; Item 29 : 29-29
7.1 ; Item 30 : 30-30
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8.2 ; Item 32 : 32-32
8.3 ; Item 33 : 33-33
8.4 ; Item 34 : 34-34
8.5 ; Item 35 : 35-35
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9.2 ; Item 37 : 37-37
9.3 ; Item 38 : 38-38
9.4 ; Item 39 : 39-39
9.5 ; Item 40 : 40-40
10.1 ; Item 41 : 41-41
10.2 ; Item 42 : 42-42
10.3 ; Item 43 : 43-43
END NAMES
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Carer Control File Post Collapse

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; Excel file created or last modified: 24/02/2020 1:44:24 PM
; CARER
;     Excel Cases processed = 77
; Excel Variables processed = 52
ITEM1 = 1 ; Starting column of item responses
NI = 43 ; Number of items
NAME1 = 45 ; Starting column for person label in data record
NAMLEN = 23 ; Length of person label
XWIDE = 1 ; Matches the widest data value observed
ISGROUPS = 1111111111111111111111111111111111111111111 ; Partial Credit model: in case items have different rating scales
IREFER=    AAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAAA
CODES = 12345 ; matches the data
IVALUE A=11234
TOTALSCORE = Yes ; Include extreme responses in reported scores
; Person Label variables: columns in label: columns in line
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@GENDER = 5E5 ; $C49W1
@CARER = 7E7 ; $C51W1
@WHYCARER = 9E9 ; $C53W1
@LOSB4Q = 11E12 ; $C55W2
@LOSCAT = 14E14 ; $C58W1
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@HOSPITAL = 22E22 ; $C66W1

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3.5 ; Item 15 : 15-15
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5.4 ; Item 23 : 23-23
5.5 ; Item 24 : 24-24
6.1 ; Item 25 : 25-25
6.2 ; Item 26 : 26-26
6.3 ; Item 27 : 27-27
6.4 ; Item 28 : 28-28
6.5 ; Item 29 : 29-29
7.1 ; Item 30 : 30-30
8.1 ; Item 31 : 31-31
8.2 ; Item 32 : 32-32
8.3 ; Item 33 : 33-33
8.4 ; Item 34 : 34-34
8.5 ; Item 35 : 35-35
9.1 ; Item 36 : 36-36
9.2 ; Item 37 : 37-37
9.3 ; Item 38 : 38-38
9.4 ; Item 39 : 39-39
9.5 ; Item 40 : 40-40
10.1 ; Item 41 : 41-41
10.2 ; Item 42 : 42-42
10.3 ; Item 43 : 43-43
END NAMES
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Appendix I1 Data Collection Summary Data (Patient Version)

Item	**Valid (n)**	**Missing (n)**	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**	**Add. Response**
1.1	200	0	2	2	15	48	133	
1.2	199	1	3	5	44	60	72	15
1.3RC	199	1	1	6	26	37	129	
1.4RC	200	0	1	0	0	0	199	
1.5	200	0	2	3	7	34	109	45
2.1	195	5	11	17	46	49	72	
2.2	200	0	4	4	24	54	114	
2.3	200	0	1	0	10	42	147	
2.4	199	1	1	0	7	56	135	
2.5	200	0	0	2	16	40	142	
3.1	199	1	2	2	9	40	146	
3.2	199	1	11	0	1	1	1	185
3.3	196	4	136	21	15	3	21	
3.4	197	3	26	7	8	4	41	111
3.5	196	4	7	1	3	9	75	101
4.1	197	3	3	9	41	53	91	
4.2	198	2	7	9	38	44	100	
4.3	196	4	5	6	30	46	109	
4.4	195	5	10	7	26	13	112	27
5.1	199	1	7	4	32	60	96	
5.2	199	1	5	9	23	53	109	
5.3	200	0	17	18	44	46	75	
5.4	200	0	4	14	24	59	99	
5.5	200	0	7	12	16	35	55	75
6.1	197	3	5	12	22	37	121	
6.2	200	0	4	3	9	30	154	
6.3	199	1	1	3	12	26	157	
6.4	199	1	2	3	7	25	162	
6.5	198	2	1	2	10	36	149	
7.1	199	1	10	13	37	60	79	
8.1	198	2	49	5	19	21	64	40
8.2	200	0	19	4	14	31	87	45
8.3	199	1	14	9	11	7	23	135
8.4	198	2	1	2	7	12	24	152
8.5	198	2	3	0	1	0	5	189
9.1	199	1	0	0	20	44	135	
9.2	199	1	3	1	18	43	134	
9.3	199	1	1	2	19	42	135	
9.4	198	2	6	9	21	54	108	
9.5RC	197	3	10	19	58	30	80	
10.1	199	1	75	32	32	23	37	
10.2	198	2	17	12	35	49	85	
10.3	200	0	32	22	39	20	21	66

Appendix I2 Data Collection Summary Data (Carer Version)

Item	Valid (n)	Missing (n)	Never	Rarely	Sometimes	Often	Always	Add. Response
1.1	76	1	0	0	8	26	42	
1.2	76	1	0	4	14	25	16	0
1.3RC	76	1	0	1	5	17	53	
1.4RC	76	1	0	0	0	2	74	
1.5	76	1	0	2	2	22	40	10
2.1	77	0	5	6	15	9	42	
2.2	77	0	2	1	16	18	40	
2.3	77	0	1	0	4	19	53	
2.4	77	0	0	0	4	27	46	
2.5	77	0	0	0	9	23	45	
3.1	76	1	1	0	0	17	58	
3.2	77	0	1	0	0	2	0	74
3.3	66	11	30	5	2	6	7	16
3.4	75	2	3	1	0	5	6	60
3.5	76	1	0	0	0	2	29	45
4.1	77	0	1	1	7	14	54	
4.2	76	1	0	2	8	13	53	
4.3	76	1	1	1	8	24	42	
4.4	71	6	2	2	18	8	30	11
5.1	77	0	0	2	11	22	42	
5.2	77	0	1	1	9	28	38	
5.3	76	1	5	8	15	27	21	
5.4	75	2	1	1	11	21	41	
5.5	77	0	2	3	8	7	20	37
6.1	75	2	7	7	13	22	26	
6.2	74	3	1	2	4	18	49	
6.3	72	5	0	0	1	14	57	
6.4	75	2	0	0	2	20	53	
6.5	75	2	0	0	4	22	49	
7.1	75	2	1	2	18	23	31	
8.1	76	1	10	4	5	12	36	9
8.2	76	1	3	5	8	18	35	7
8.3	77	0	14	9	11	7	19	17
8.4	77	0	0	1	8	12	20	36
8.5	77	0	0	0	0	1	1	75
9.1	76	1	1	1	6	17	51	
9.2	76	1	0	1	5	16	54	
9.3	71	6	0	0	10	21	40	
9.4	74	3	2	3	9	25	35	
9.5RC	70	7	3	8	25	17	12	5
10.1	70	7	19	10	13	9	13	6
10.2	74	3	3	4	18	26	23	
10.3	73	4	15	12	11	5	7	23

Appendix J1 39-item Skewness, Kurtosis and Fit Statistics (Patient Version)

Item	Skewness	Kurtosis	MnSq Infit (ZSTD)	MnSq Outfit (ZSTD)	What happened to this item?
1.1	-1.96	**4.49**	0.89 (-0.80)	1.21 (1.03)	**Removed**
1.2	-0.45	0.07	0.75 **(2.85)**	0.81 (1.35)	**Retained**
1.3RC	-1.46	1.36	1.20 (1.62)	1.42 **(2.05)**	**Retained**
1.4RC	**-14.14**	**200.00**	**2.96 (2.33)**	**2.46** (1.64)	**Removed**
1.5	-1.39	**3.47**	0.90 (-0.59)	1.40 (1.51)	**Retained**
2.1	-0.71	-0.39	1.34 **(3.52)**	1.76 **(4.96)**	**Retained**
2.2	-1.56	**2.40**	0.90 (-0.90)	0.81 (1.09)	**Retained**
2.3	**-2.21**	**6.46**	0.65 **(2.53)**	0.55 **(2.21)**	**Removed**
2.4	-1.96	**6.04**	0.64 **(2.74)**	0.73 (1.26)	**Retained**
2.5	-1.67	**2.07**	0.74 (1.91)	0.70 (1.43)	**Retained**
3.1	**-2.50**	**7.60**	1.06 (0.47)	1.10 (0.50)	**Retained**
3.3	1.66	1.39	**2.42 (7.06)**	**2.57 (5.51)**	**Retained**
3.4	-1.36	0.28	**2.02 (5.80)**	**2.21 (5.11)**	**Removed**
3.5	**-2.48**	**7.05**	1.74 **(3.10)**	1.93 **(2.41)**	**Removed**
4.1	-0.91	0.14	0.73 **(3.07)**	0.77 (1.63)	**Removed**
4.2	-1.11	0.51	0.85 (1.64)	0.90 (-0.63)	**Retained**
4.3	-1.37	1.41	0.83 (1.64)	0.69 **(2.01)**	**Retained**
4.4	-1.29	1.01	1.49 **(3.72)**	1.98 **(4.30)**	**Retained**
5.1	-1.32	1.54	0.64 **(4.17)**	0.77 (1.54)	**Retained**
5.2	-1.44	1.59	0.69 **(3.30)**	0.82 (1.11)	**Removed**
5.3	-0.70	-0.57	0.90 (1.20)	0.85 (1.26)	**Retained**
5.4	-1.21	0.77	0.77 **(2.46)**	0.73 (1.26)	**Retained**
5.5	-1.04	0.32	1.09 (0.81)	1.07 (0.45)	**Retained**
6.1	-1.48	1.33	1.01 (0.11)	0.98 (-0.07)	**Removed**
6.2	**-2.74**	**8.00**	0.92 (-0.52)	0.99 (0.02)	**Removed**
6.3	**-2.51**	**6.56**	0.91 (-0.50)	0.76 (-0.96)	**Removed**
6.4	**-3.08**	**10.51**	1.08 (0.53)	0.71 (1.15)	**Retained**
6.5	**-2.38**	**6.60**	0.80 (1.29)	0.68 (1.42)	**Removed**
7.1	-0.96	0.19	0.69 **(3.80)**	0.61 **(3.32)**	**Retained**
8.1	-0.51	-1.28	1.70 **(5.90)**	1.81 **(5.25)**	**Retained**
8.2	-1.25	0.77	1.62 **(4.69)**	1.80 **(3.96)**	**Removed**
9.1	-1.31	0.42	0.61 **(3.30)**	0.53 **(2.60)**	**Removed**
9.2	**-2.01**	**4.64**	0.66 **(2.94)**	0.54 **(2.67)**	**Retained**
9.3	-1.73	**2.90**	0.63 **(3.13)**	0.55 **(2.52)**	**Removed**
9.4	-1.49	1.72	0.91 (-0.86)	0.83 (1.08)	**Retained**
9.5RC	-0.54	-0.75	1.52 **(5.06)**	1.94 **(5.99)**	**Removed**
10.1	0.42	-1.32	1.62 **(5.12)**	1.72 **(4.54)**	**Retained**
10.2	-0.96	-0.10	0.92 (-0.84)	0.84 (1.25)	**Retained**
10.3	-0.20	-1.42	0.88 **(1.03)**	0.89 (-0.72)	**Removed**

Appendix J2 39 Item Skewness, Kurtosis and Fit Statistics (Carer Version)

Item	Skewness	Kurtosis	Infit MnSq (ZSTD)	Outfit MnSq (ZSTD)	What happened to this item?
1.1	-0.85	-0.43	0.77 (1.26)	0.96 (-0.08)	**Removed**
1.2	-0.10	-0.87	0.76 (1.45)	0.96 (-0.13)	**Removed**
1.3RC	-1.73	**2.64**	1.20 (0.92)	1.75 **(2.12)**	**Retained**
1.4RC	**-6.04**	**35.39**	**2.01** (1.66)	**2.10** (1.28)	**Removed**
1.5	-0.85	1.71	1.07 (0.41)	1.18 (0.67)	**Retained**
2.1	-0.99	-0.23	1.61 (3.31)	1.98 **(4.06)**	**Removed**
2.2	-1.18	1.09	1.16 (0.96)	1.20 (0.94)	**Retained**
2.3	**-2.38**	**7.82**	0.80 (-0.89)	0.75 (-0.81)	**Removed**
2.4	-0.94	-0.08	0.53 **(2.76)**	0.52 (2.00)	**Removed**
2.5	-0.95	-0.36	0.65 **(2.02)**	0.67 (1.35)	**Retained**
3.1	**-3.57**	**18.54**	1.19 (0.78)	1.39 (1.07)	**Retained**
3.3	0.33	-1.70	**2.32 (4.03)**	**2.29 (3.48)**	**Retained**
4.1	**-2.06**	**4.55**	0.99 (0.02)	0.96 (-0.05)	**Removed**
4.2	-1.63	1.74	1.20 (0.99)	1.55 (1.78)	**Removed**
4.3	-1.54	**2.86**	1.07 (0.43)	1.25 (1.03)	**Retained**
4.4	-0.63	-0.26	1.75 **(3.53)**	1.97 **(3.50)**	**Removed**
5.1	-1.03	0.14	0.67 **(2.05)**	0.67 (1.53)	**Retained**
5.2	-1.35	**2.37**	0.55 **(2.98)**	0.50 **(2.65)**	**Removed**
5.3	-0.72	-0.27	0.98 (-0.08)	0.91 (-0.47)	**Retained**
5.4	-1.34	1.78	0.64 **(2.21)**	0.57 **(2.10)**	**Removed**
5.5	-1.30	0.90	1.18 (0.84)	0.95 (-0.06)	**Retained**
6.1	-0.78	-0.44	1.20 (1.28)	1.24 (1.32)	**Removed**
6.2	-2.10	**4.87**	1.08 (0.47)	0.94 (-0.14)	**Removed**
6.3	-1.83	**2.52**	0.54 (1.87)	0.40 (1.82)	**Removed**
6.4	-1.35	0.91	0.52 **(2.35)**	0.48 (1.77)	**Retained**
6.5	-1.20	0.47	0.46 **(3.03)**	0.48 **(2.04)**	**Removed**
7.1	-0.76	0.13	0.58 **(3.02)**	0.56 **(2.61)**	**Retained**
8.1	-1.01	-0.17	1.80 **(3.92)**	**2.05 (3.98)**	**Removed**
8.2	-1.03	0.66	1.28 (1.54)	1.23 (1.06)	**Retained**
8.3	-0.27	-1.39	1.25 (1.40)	1.07 (0.40)	**Retained**
8.4	-0.90	-0.23	0.54 **(2.35)**	0.47 **(2.03)**	**Retained**
9.1	**-2.04**	**4.74**	0.94 (-0.22)	1.27 (0.98)	**Removed**
9.2	-1.80	**2.86**	0.64 (1.80)	0.63 (1.27)	**Removed**
9.3	-0.86	-0.61	0.53 **(2.85)**	0.50 **(2.29)**	**Retained**
9.4	-1.35	1.68	0.96 (-0.18)	0.99 (0.03)	**Removed**
9.5RC	0.10	-0.36	1.32 (1.83)	1.40 (1.99)	**Retained**
10.1	0.21	-1.28	1.41 (2.14)	1.33 (0.51)	**Removed**
10.2	-0.80	0.30	0.73 (1.93)	0.71 (1.76)	**Retained**
10.3	-0.01	-1.61	1.13 (0.63)	1.13 (0.54)	**Removed**

Appendix K1 23-item Dignity in Care Questionnaire (Patient Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.2	Staff come to see me soon after I press the call bell	Never	Rarely	Sometimes	Often	Always	I have not used the call bell
1.3	Staff have been rough in the way they provide care	Never	Rarely	Sometimes	Often	Always	
1.5	Staff have helped to control my pain	Never	Rarely	Sometimes	Often	Always	I had no pain

Principle 2. Show people respect

2.1	Staff wear name badges large enough to read	Never	Rarely	Sometimes	Often	Always
2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Often	Always
2.4	Staff have been considerate in how they provide care to me	Never	Rarely	Sometimes	Often	Always
2.5	My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)	Never	Rarely	Sometimes	Often	Always

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called me by my preferred name	Never	Rarely	Sometimes	Often	Always
3.3	Staff have **asked** if I have cultural / religious / spiritual beliefs that are important to me	Never	Rarely	Sometimes	Often	Always

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.2	I have been involved, as much as I wanted to be, in ***decisions*** about my care	Never	Rarely	Sometimes	Often	Always	
4.3	Staff have asked my permission before they provide care	Never	Rarely	Sometimes	Often	Always	
4.4	I believe I can choose to refuse treatment	Never	Rarely	Sometimes	Often	Always	Unsure

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what I need	Never	Rarely	Sometimes	Often	Always	
5.3	Staff have encouraged me to ask questions	Never	Rarely	Sometimes	Often	Always	
5.4	Staff have spoken with me about my care in ways I understand	Never	Rarely	Sometimes	Often	Always	
5.5	Staff have encouraged me to be involved in planning my discharge from hospital	Never	Rarely	Sometimes	Often	Always	Discharge has not been discussed

Principle 6. Respect people’s privacy

6.4	I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Never	Rarely	Sometimes	Often	Always

Principle 7. Ensure people feel able to complain without fear of retribution

7.1	Staff have made sure there is an opportunity to talk about any concerns	Never	Rarely	Sometimes	Often	Always

Principle 8. Engage with family, friends and carers as care partners

8.1	Staff have asked me which family, friends or carers I want involved in my care	Never	Rarely	Sometimes	Often	Always	Not Applicable

* When I wanted these family, friends or carers involved in my care

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.2	Staff have spoken to me as an equal	Never	Rarely	Sometimes	Often	Always
9.4	I have been supported to maintain my personal appearance	Never	Rarely	Sometimes	Often	Always

Principle 10. Act to alleviate people’s loneliness and isolation

10.1	Staff include me in the bedside discussion at shift handover	Never	Rarely	Sometimes	Often	Always
10.2	Staff have supported me to stay physically and mentally active	Never	Rarely	Sometimes	Often	Always

Appendix K2 18-item Dignity in Care Questionnaire (Carer Version)

Stem: During this hospital admission…

Principle 1. Zero tolerance of all forms of abuse

1.3	Staff have been rough in the way they provide care to the patient	Never	Rarely	Sometimes	Often	Always	
1.5	Staff have helped to control the patient's pain	Never	Rarely	Sometimes	Often	Always	The patient has no pain or appears to have no pain

Principle 2. Show people respect

2.2	Staff introduce themselves by telling me their name and role	Never	Rarely	Sometimes	Often	Always
2.5	The patient's basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)	Never	Rarely	Sometimes	Often	Always

Principle 3. Treat each person as an individual by offering a personalised service

3.1	Staff have called the patient by their preferred name	Never	Rarely	Sometimes	Often	Always	
3.3	Staff have **asked** if the patient has cultural / religious / spiritual beliefs that are important to them	Never	Rarely	Sometimes	Often	Always	Unsure

Principle 4. Enable people to maintain the maximum possible level of independence, choice and control

4.3	Staff have asked the patient's permission before they provide care	Never	Rarely	Sometimes	Often	Always

Principle 5. Listen and support people to express their needs and wants

5.1	I have been given enough time to explain what the patient needs *	Never	Rarely	Sometimes	Often	Always	
5.3	Staff have encouraged me to ask questions *	Never	Rarely	Sometimes	Often	Always	
5.5	Staff have encouraged me to be involved in planning the patient's discharge from hospital *	Never	Rarely	Sometimes	Often	Always	Discharge has not been discussed

* When the patient was unable to participate and/or when the patient wanted me to be involved

Principle 6. Respect people's privacy

6.4	The patient's privacy is respected when they are using the toilet, bedpan or having a pad changed	Never	Rarely	Sometimes	Often	Always

Principle 7. Ensure people feel able to complain without fear of retribution

7.1	Staff have made sure there is an opportunity to talk about any concerns	Never	Rarely	Sometimes	Often	Always

Principle 8. Engage with family, friends and carers as care partners

8.2	I have been involved in decisions about the patient's care *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.3	Staff include family, friends or carers in the bedside discussion at shift handover *	Never	Rarely	Sometimes	Often	Always	Not Applicable
8.4	Staff responded quickly when I reported the patient's condition had deteriorated	Never	Rarely	Sometimes	Often	Always	Not Applicable

* When the patient was unable to participate and/or when the patient wanted family, friends or carers involved

Principle 9. Assist people to maintain confidence and a positive self-esteem

9.3	The patient was given enough time to do what they were capable of doing themselves	Never	Rarely	Sometimes	Often	Always	Not Applicable
9.5	Staff took too long to respond when the patient needed to go to the toilet	Never	Rarely	Sometimes	Often	Always	Not Applicable

Principle 10. Act to alleviate people's loneliness and isolation

10.2	Staff have supported the patient to stay physically and mentally active	Never	Rarely	Sometimes	Often	Always

Appendix L Items in common across the Australian Hospital Patient Experience Question Set and the Dignity in Care Questionnaire

Australian Hospital Patient Experience Question Set	**Dignity in Care Questionnaire** **13 items in common between patient and carer version**	**Dignity in Care Questionnaire** **10 items unique to patient version**	**Dignity in Care Questionnaire** **5 items unique to carer version**
1. My views and concerns were listened to			
2. My individual needs were met			
3. When a need could not be met, staff explained why (applies only if Question 2 was answered negatively)			
4. I felt cared for			
5. I was involved as much as I wanted in making decisions about my treatment and care		Item 4.2 I have been involved, as much as I wanted to be, in decisions about my care	Item 8.2 ‘I have been involved in decisions about the patient’s care *
6. I was kept informed as much as I wanted about my treatment and care			
7. It was clear to me that staff had communicated with each other about my treatment and care			
8. I received pain relief that met my needs	Item 1.5 Staff have helped to control my pain		
9. When I was in hospital I felt confident in the safety of my treatment and care			
10. I experienced unexpected harm or distress as a result of my treatment and care			
11. My harm or distress was discussed with me by staff (applies only if Question 10 was answered in the affirmative)			
12. Overall, the quality of treatment and care I received was (very good, good …)			
	Item 1.3 Staff have been rough in the way they provide care	Item 1.2 Staff come to see me soon after I press the call bell	Item 8.3 Staff include family, friends or carers in the bedside discussion at shift handover *
	Item 2.2 Staff introduce themselves by telling me their name and role	Item 2.1 Staff wear name badges large enough to read	Item 8.4 Staff responded quickly when I reported the patient’s condition had deteriorated
	Item 2.5 My basic care needs have been met (such as being able to eat, drink, sleep, wash and use bladder and bowels…)	Item 2.4 Staff have been considerate in how they provide care to me	Item 9.3 The patient was given enough time to do what they were capable of doing themselves
	Item 3.1 Staff have called me by my preferred name		Item 9.5 Staff took too long to respond when the patient needed to go to the toilet
	Item 3.3 Staff have asked if I have cultural / religious / spiritual beliefs that are important to me	Item 4.4 I believe I can choose to refuse treatment	* When the patient was unable to participate and/or when the patient wanted family, friends or carers involved
	Item 4.3 Staff have asked my permission before they provide care	Item 5.4 Staff have spoken with me about my care in ways I understand	
	Item 5.1 I have been given enough time to explain what I need	Item 8.1 Staff have asked me which family, friends or carers I want involved in my care	
	Item 5.3 Staff have encouraged me to ask questions	Item 9.2 Staff have spoken to me as an equal	
	Item 5.5 Staff have encouraged me to be involved in planning my discharge from hospital	Item 9.4 I have been supported to maintain my personal appearance	
	Item 6.4 I feel my privacy is respected when I am using the toilet, bedpan or changing a pad	Item 10.1 Staff include me in the bedside discussion at shift handover	
	Item 7.1 Staff have made sure there is an opportunity to talk about any concerns		
	Item 10.2 Staff have supported me to stay physically and mentally active		