



The Co-Creation of a New Patient and Visitor
Hospital Experience Feedback Protocol:
A Pragmatic Action Research Study

by

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Abstract

Increasing demand for patient-centred care has seen developments in the science of capturing hospital experience feedback as a means of assessing quality care. The majority of published findings regarding experiences of hospital care are based on quantitative surveys, with data being collected after patients have been discharged. Despite this, there is growing recognition that the collection of real-time qualitative experience data (during patient admission) provides richer and more useful information to improve care provision. However, virtually no published approaches for capturing and measuring experience feedback data include guidance about how to deliver this feedback in a way which is meaningful to nurses. Moreover, key stakeholders, such as nurses, patients, and family members, are rarely involved in all stages of planning how feedback should be collected and shared. This research aimed to explore how these stakeholders might co-create a new protocol to collect patient and family hospital experience feedback and share this feedback with nurses so that patients' and families' perspectives can be heard.

The study employed a pragmatic action research approach, wherein patients, family members and nurses ($n=16$) formed an action research advisory group (the Advisory Group). With a desire to improve upon current methods of collecting feedback data, the Advisory Group designed a protocol to capture in-patient unit-level, qualitative, real-time experience feedback. Phase one of the study consisted of problem identification and reconnaissance. Phase two (Action Cycles 1 to 9) consisted of the creation and evaluation of a new feedback protocol, referred to as RHEPORT (Real-time Hospital Experience Posters).

Two data sets were collected during the field work: 1. hospital experience feedback data from patients and family members (visitors), and 2. evaluation data on the RHEPORT Protocol and its development. The RHEPORT Protocol was refined through field-testing, which comprised nine Action Cycles across three years. Two hundred and forty-one participants (178 patients, 60 visitors, and three of unknown status) provided hospital experience data. The three dominant themes in the hospital experience feedback data were: 1. Physical comfort, 2. Respect for patients' values, preferences and expressed needs, and 3. Information, communication, and education. Four hundred and seven evaluation responses (227 patient responses, 70 visitor responses and 110 nurse responses) regarding the RHEPORT Protocol were collected, and the data were shared with the 16-member Advisory Group for their reflection and evaluation. Three principle findings that emerged from evaluation data collected about the RHEPORT Protocol and its development were: 1. a pragmatic action

research approach resulted in the successful co-creation of a new experience feedback protocol (RHEPORT), 2. the final version of the RHEPORT Protocol comprised five core components to support the collection and distribution of meaningful patient or visitor feedback, and 3. a willingness to recommend the hospital to friends or family is not necessarily representative of a patient or visitor's hospital experience. This study illustrates the challenges and successes of creating a new hospital experience feedback protocol with key stakeholders. However, perhaps more importantly, this research contributes to the field of patient and family hospital experience by allowing the voices of these stakeholders to be both heard and acknowledged.

Statements and declarations

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Statement of co-authorship

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Paper 1: Located in Appendix A

Edwards, Kelly J. Walker, Kim & Duff, Jed 2015, 'Instruments to measure the inpatient hospital experience: A literature review', Patient Experience Journal: Vol. 2: Iss. 2, Article 11.

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The candidate was the primary author and contributed approximately 70% of the planning, preparation, execution, analysis and writing of the paper. Author's 2 and 3 contributed 15% each to the analysis & interpretation of research data and to critically revising the paper.

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‘The only realm in which humans are an unimpeachable source of truth is that of their own feelings and experiences.’

Marcus Buckingham,
Head of ADP Research Institute – People + Performance

‘... in every interaction, we have a choice to make...
Sometimes we never know the impact a small gesture might have’

Deanna Frings, MS Ed, CPXP
Vice President, Learning and Professional Development
The Beryl Institute

Glossary

Co-creation	A collaborative and creative process, where design (defining the problem and possible solution) and production (implementing and then evaluating the possible solution) are executed by stakeholders and end-users (Fitzsimons et al. 2017; Voorberg, Bekkers & Tummers 2015).
Clinical nurse	In this study, refers to a member of a nursing team (Registered Nurse, enrolled nurse, Assistant in Nursing, and/or student nurse) who provides direct clinical care to patients in a clinical setting (see Terminology section, below).
Co-design	In healthcare, co-design refers to partnering with healthcare consumers, family members, and healthcare providers to improve health services through a design-led process applying creative and participatory principles (Blomkamp 2018; Dawda & Knight 2018)
Domain	Refers to how the Picker Organisation measures and/or categorises a distinct underlying aspect of patient-centred care (Sizmur & Redding 2010).
E. Coli (Escherichia coli)	E. coli are a group of bacteria located in the gut. Some strains cause minor illnesses, such as urinary tract infections. Other strains cause more severe disease such as pneumonia, and haemolytic uraemic syndrome (Healthdirect 2020).
Emoji	Initially developed in Japan, emoji (plural 'emojis') are “digital pictograms” (Stark & Crawford 2015, p. 1) that often appear in digital social communication, such as text messages, email and social media. Emojis were designed to “facilitate a wider range of text-based emotional communication” (Stark & Crawford 2015, p. 4).
Enrolled nurse	A person qualified to provide nursing care under the direct or indirect supervision of a Registered Nurse (Nursing and Midwifery Board of Australia 2019)
Family	In a patient-centred healthcare model, ‘family’ status is determined by the patient. Typically, family can include blood relatives, non-blood relatives, relations formed by marriage, including same-sex partners and de-facto partners, and the patient’s social network of friends (Sze et al. 2019).
Friends and Family Test (FFT)	A customer loyalty metric introduced by the UK National Health Service, designed to identify a willingness to recommend a particular healthcare service.
Healthcare recipients	Consumers of healthcare services (typically patients, clients, carers, family members).
Healthcare providers	Authorised providers of healthcare services.
In-patient unit	Formerly referred to as a ‘ward’; area or specialty service within a hospital.

Net Promoter Score (NPS)	A customer loyalty metric designed to identify a willingness to recommend developed by (and a registered trademark of) Fred Reichheld, Bain & Company, and Satmetrix.
Patient-centred care (PCC)	A model of providing care which respects and responds to the person (patient) as central to the healthcare decision-making process and journey (Delaney 2018). Also referred to as person-centred care, patient-centred care includes the core concepts of respect and dignity, information sharing, shared decision-making and collaboration (Sze et al. 2019).
Patient and family centred care (PFCC)	A model of providing patient-centred care in which the patient and family are partners with the provider and care team (Sze et al. 2019)
Patient experience	The Beryl Institute defines patient experience as “the sum total of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care” (Wolf et al. 2014, p. 8).
Patient and public involvement (PPI)	The inclusion of patients and the public (patients, potential patients, carers, and users of healthcare services) in the design, conduct, and/or dissemination of healthcare research. The focus is on research carried out ‘with’ or ‘by’ patients and members of the public rather than ‘to’ them (INVOLVE 2020).
Participants	In the present study, refers to people taking part in a field-test.
Registered Nurse	In Australia, a person who has completed the prescribed education, demonstrates competence to practice, and is registered under the Health Practitioner Regulation National Law as a Registered Nurse in Australia and is responsible and accountable to the Nursing and Midwifery Board of Australia (Nursing and Midwifery Board of Australia 2019).
Service recovery	The resolution provided by a company to a dissatisfied customer, thereby converting them to a loyal customer.
Visitor	In this study, refers to someone visiting a patient while the patient is in hospital.

Terminology

The terminology used in this thesis, as well as the decisions behind their adoption or variation, should be clarified. For ease of readability, the word ‘patient’ or ‘healthcare recipient’ is used to describe a direct recipient of healthcare (Lemus Alcántara et al. 2018). I acknowledge and understand that terminology such as ‘patient’ may imply a power imbalance and/or a lack of awareness that ‘consumer’, ‘customer’, ‘person’, or ‘client’ are now more commonly preferred terms; no such meaning is implied.

Today ‘person-centred care’ as opposed to ‘patient centred care’ is the more widely adopted and accepted term in both practice and literature (Edgar, Wilson & Moroney 2020). I have chosen however to use the phrase ‘patient-centred care’ as this was the term used at the time by participants and members of the Advisory Group. The word ‘patient’ however may suggest a passive recipient of care, reducing the person to a disease or set of symptoms (Ekman et al. 2011). Such a meaning is, in fact, in direct contrast to the aims of patient or person centred care, where the patient is an active decision-maker in his or her healthcare journey. A recent review of literature on person-centred and patient-centred care suggests person-centred and patient-centred are different constructs, and that ‘person-centred care’ incorporates the “whole life of the patient” (Eklund et al. 2018, p. 3). While I respect and recognise that a holistic view of healthcare is necessary, I make no such distinction between patient-centred and person-centred care in this thesis.

Similarly, recipients of mental healthcare or treatment are today more respectfully referred to as ‘clients’ or ‘survivors’ rather than patients, in both the clinical and community settings. I have chosen again to use the word ‘patient’ when referring to this population in recognition of the express wishes of the young adult mental healthcare recipients in this study. Every participant interviewed in this cohort referred to themselves as a patient, and, when asked, said I should use the word patient and not client or survivor.

In addition, I acknowledge that patient- or person-centred care also often now includes the word family (for example, patient and family-centred care). In the hospital setting, it is the patient who usually designates and defines their ‘family’ (Clay & Parsh 2016), though again, for ease of readability, ‘family’, in this study, refers to a person or people related (biologically, emotionally, or legally) to a patient. As this study progressed, it became clear that, given the timeframe, determining the exact nature of the relationship between a patient and a visiting guest would be difficult (i.e., would the patient describe or consider them a family member). Therefore, a decision was made to refer to a person visiting a patient in a hospital as a

‘visitor’. A visitor is not to be confused with someone who is visiting the hospital with a purpose other than visiting a patient (for example visiting staff, contractors, etc.).

I have chosen to adopt the term ‘clinical nurse’ to refer to a member of the nursing team (Registered Nurse, enrolled nurse, Assistant in Nursing, and student nurse) who provides direct clinical care to patients in a clinical setting. I acknowledge the term ‘clinical nurse’ is often used to refer to a ‘Clinical Nurse Specialist’, a Registered Nurse who has undertaken additional studies in a specialised field, and/or has worked in a specific area for many years. I, however, use the term more broadly to include any person in a nursing role with direct patient contact. Also, I use the term ‘nursing staff’ to include Assistants in Nursing (AINs), Nurse Unit Managers (NUMs), Clinical Nurse Educators (CNEs) and student nurses on professional experience placement working in the hospital who participated in the field-test.

Individuals who were members of the research advisory group are referred to collectively as Advisory Group members, or individually by an allocated pseudonym. Members of the Advisory Group are considered both ‘co-creators’ and ‘co-researchers’, and these terms are used interchangeably throughout. Conversely, ‘participant’ refers to patients, family (visitors), clinical nurses, student nurses, Assistants in Nursing (AINs), Nurse Unit Managers (NUMs) and Clinical Nurse Educators (CNEs) who participated in the field-test.

Abbreviations

AC	Action Cycle
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIN	Assistant in Nursing
ARC	Action Research Cycles
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNE	Clinical Nurse Educator
CST	Critical Social Theory
EBCD	Experience-based co-design
ERIC	Education Information Resources Center
FFT	Friends and Family Test
HaPI	Health and Psychosocial Instruments
HCAPHS	Hospital Consumer Assessment of Healthcare Providers and Systems
HKIEQ	Hong Kong Inpatient Experience Questionnaire
HREC	Human Research Ethics Committees
ICE	Intensive Care Experience ICE questionnaire
INPQCS	Irish National Perception of Quality of Care Survey
IOM	Institute of Medicine (now known as the NAM)
I-PAHC	Patient experiences with inpatient care
IPU	In-patient unit
JBH	Joanna Briggs Institute
MEDLINE	Medical Literature Analysis and Retrieval System
NAM	National Academy of Medicine (formerly the IOM)
NHS NAIS	NHS National Adult Inpatient Survey
NORPEQ	Nordic Patient Experiences Questionnaire
NPS	Net Promoter Score
NSNS	Newcastle Satisfaction with Nursing Scale
NUM	Nurse Unit Manager
PAQS-ACV	Patient's Assessment of Quality Scale – Acute Care Version
PCC	Patient-centred care
PDRC	Practice Development and Research Council
PEECH	Patient Evaluation of Emotional Care during Hospitalisation
PEES-50	Patients' Experience-based Evaluation Scale
PEQ	Patient experience questionnaire
PFCC	Patient and family centred care
PPE-15	Picker Patient Experience Questionnaire

PPI	Patient and public involvement
PPIE	Patient and public involvement and engagement
PPQ	Patient Perceptions of Quality
PREM	Patient reported experience measures
PsychINFO	Psychology and Behavioural Sciences Collection
QPP	Quality from the Patient's Perspective Questionnaire
RN	Registered Nurse
ROE	Return on experience
SIPES	Scottish Inpatient Experience Survey
V	Version
WHO	World Health Organization

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Chapter 1 Introduction

This thesis explores the process of co-creating a new protocol designed to capture and relay patient and visitor hospital experience feedback to clinical nurses. This introductory chapter describes how I came to the research, the research philosophy (Section 1.1), and how this study was designed and conducted to address the research question practically and systematically (Section 1.2). Background information to orient the reader to the context and research setting, along with important themes, trends and pertinent theories will be highlighted in this chapter (Section 1.3). The methodological approach will be introduced (Section 1.4), and an overview of the thesis will be presented (Section 1.5).

1.1 Candidate and research philosophy

How I came to the research

In 2013, I had recently completed my first year of nursing as a 'new graduate' Registered Nurse. A specific encounter with a patient at this time led to my realisation that we, as healthcare professionals, might well be providing care with little insight into what matters most to those receiving it. While I was attending to my daily tasks, I unintentionally ignored a passing comment an elderly male patient made. Looking in the mirror at his reflection, he remarked, "I guess this must be the end of the road for me." He then went on to tell me that he had been married for more than 50 years, and that he had never gone a day in his life without shaving. Not having time to help him shave at that moment, I went about administering his medication and obtaining vital signs and completed all the tasks I thought necessary. It was not until later that night when I looked in the mirror myself that I was reminded of his comment, and it truly resonated with me. I knew his wife was visiting that afternoon, and that as the couple lived several hours away from the hospital, this would have been the first time she had seen him since his operation. If I had truly listened to him at the time, I would have realised that his appearance mattered far more to him at that moment than anything else I was doing. It was from this insight that I took an interest in models of care delivery, and ultimately in interrogating how nurses can better hear the voices of their patients. Eventually, this search led me to the subject of patient experience.

For many years, healthcare providers have recognised that patient perceptions on their care experience are a fundamental component of care delivery (French 2003; Fröjd et al. 2011; Larrabee & Bolden 2001; Marram 1973; Singh & Prasher 2019). However, how events and priorities of care are interpreted or understood, vary considerably between providers and recipients of care (Cooke & Thackray 2012; Lee & Yom 2007; Suhonen et al. 2012). In 2012, despite this knowledge, there existed a gap in the literature assessing patient perceptions of experience from both the healthcare provider and recipient's points of view regarding the same episode of care. In 2013–14, as part of a Bachelor of Nursing Honours degree, I conducted a study that explored one patient's hospital experience from multiple perspectives. The findings of that study suggested that healthcare providers are not always aware of what matters to the patient and their family during their hospital experience (Edwards, Duff & Walker 2014).

Another key finding from my Honours research was the importance of capturing experience data during the episode of care. Perceptions of experience change over time, as do views about what matters. As such, real-time experience data provides meaningful information about how the hospital admission was experienced without being subjected to recall bias (Black & Jenkinson 2009; Edwards, Duff & Walker 2014). Near real-time (close to the event) feedback is also an effective approach for keeping track of and improving “relational aspects of care” (Graham et al. 2018, p. vi). Aspects such as emotional support, dignity and compassion are often not captured in traditional experience surveys, which are typically administered after the event (Graham et al. 2018; Moore et al. 2020). Concerns and challenges regarding the collection of real-time feedback in a hospital setting however have been raised (Graham et al. 2018; Maben et al. 2012; Moore et al. 2020; Russell 2013). Staff may potentially choose participants most likely to provide positive feedback (Graham et al. 2018) whereas patients may be reluctant to provide negative feedback for fear of retribution (Maben et al. 2012; Moore et al. 2020; Russell 2013). However, while real-time data may be compromised by fear and potential sampling bias, collecting feedback at the point of care is considered necessary to inform practice and drive improvements (Francis 2013). One of the recommendations from my honours study for future research therefore, was to identify and evaluate interventions designed to obtain real-time experience feedback data (Edwards, Duff & Walker 2014). That is the impetus for this study.

Frames of reference

Consistent with an interpretivist paradigm, my ontological stance is based on a rejection of the assumption that reality or truth exists beyond our perception. As a nurse working with people who have varying understandings of their own situation, and observing that backgrounds of patients frame their understandings, it is very evident to me that there is no one reality. Therefore, with reference to Merriam and Tisdell (2015), I subscribe to the notion that truth is a subjective construct, and that multiple truths co-exist. As such, this study did not seek to develop an experience feedback protocol which establishes the 'truth' or the 'reality' of a patient's experience, but rather to capture and relay their perception of experience at a given time and in a particular circumstance.

My position and beliefs are relevant to this study because the process of working in collaboration with others, as I have done, requires an appreciation of subjectivity. Today, subjectivity in qualitative health research is considered valuable as a means to understand the complex and nuanced ways in which the world is understood and experienced (Clark & Vealé 2018). The dominant positivistic paradigm in health research, however, has continued to pursue the "one true reality" stance (Castagno 2012, p. 393). A criticism of such positivist views is that unobservable phenomena are not considered (Denzin & Lincoln 2011). In this space, the experiences of patients (i.e., how they experience their hospital stay) would be considered unobservable phenomena, and as such may not be valued nor subjected to inquiry.

While post-positivism acknowledges unseen entities (Creswell 2014), it does not reject the notion of truth. Instead, it seeks an 'estimation' of truth (Kelly, Dowling & Millar 2018). The pursuit of an 'estimation of truth', however, remains incongruent with my ontological stance that there is no one truth. In the 19th Century, philosophers sought to further question concepts of truth, reasoning that classical scientific methods may not be suited to the fields of social and cultural research (Grbich 1999). It is this distinction between the sciences (Social and pure Science), which was a catalyst for the interpretive paradigm (Kelly, Dowling & Millar 2018). In opposition to forms of positivism, the interpretivist paradigm, where I position myself, respects both subjectivity and intersubjectivity, and acknowledges multiple realities. As such, there is no single 'truth' but rather multiple 'truths' (Merriam & Tisdell 2015). Within this paradigm, I, the researcher, also recognise and accept that my own experiences shape both my perception and interpretation of the research results.

The qualitative research presented in this thesis is shaped by my personal frames of reference, and by those of others who participated in the research. These frames of reference include, but are not limited to, life experiences, preferences, values and culture, and beliefs. While we cannot disengage from our values or worldview (Hines 2012), we can be reflexive and seek to recognise and respect the effect our frames of reference have on constructed realities. I also accept and declare, therefore, that as the primary author of this work, in which I have documented the events and experiences that occurred over the research period, I am, as Hines (2012, p. 156) suggests, essentially shaping and thus 'creating' the past. My role in this research, therefore, is also not as a 'searcher' of unbiased truths, nor do I claim distance and objectivity. Rather, I sought to 'understand' the realities of patients, visitors and the Advisory Group members who co-created the new protocol through the creation of shared understandings, rather than to identify any single truth. This ontological position lends itself well to a participatory and collaborative methodology, as it incorporates respect and appreciation for both subjectivity and the knowledge of others.

1.2 Research question

Key concerns that underpinned the inception of this study included how hospital experience feedback is traditionally captured from patients, and how it is then relayed back to healthcare providers. Current methods of capturing patient and family experiences of care are predominantly quantitative, despite evidence suggesting that qualitative data is more useful for understanding the complexities of experiences (Edwards, Walker & Duff 2015). Also, most experience feedback data are collected after the patient has left the hospital. However, research suggests that perceptions of experience change over time, and that data should be collected as close to the event as possible. In addition, experience feedback is often not effectively relayed back to clinical nurses, despite their apparent impact on a patient's hospital experience.

Capturing what matters most to patients and relaying that information effectively is key to improving the patient and family's experiences of care (Coulter, Fitzpatrick & Cornwell 2009). Accordingly, if patients are to be central to their healthcare journey, as current quality care provision approaches dictate, patients and family members must be central to research aimed at improving healthcare delivery. Very few methods, however, have been designed to capture patient and family experiences of hospital care that include patients and families in both design and evaluation (Edwards, Walker & Duff 2015). As a result, this study sought to address these issues by collaboratively working with local stakeholders. Accordingly, patients,

family members and Registered Nurses were involved in the development and field-testing of a new hospital experience feedback protocol.

Based on engagement with these stakeholders, and gaps in the literature regarding available approaches to capture patient and family hospital experience feedback, the research question is as follows:

Research question

How might we co-create a new protocol designed to collect patient and family hospital experience feedback and share this with clinical nurses so that patients' and families' perspectives can be heard?

1.3 Background

This section is designed to orient the reader to concepts and theories that are raised throughout the thesis and to inform the discussion (see Chapter Six). In particular, patient-centred care, patient experience, and associated concepts of transparency, stakeholder involvement, co-creation, and patient loyalty will be considered. While the initial literature review (see Chapter Two) was, in fact, the starting point for this study, additional research, concepts and theories informed the development of the new patient and visitor feedback protocol over the five-year study period. Key concepts are introduced here and expanded upon throughout the thesis.

Patient-centred care, patient experience, and 'nothing about me without me'

An imperative towards placing the patient at the centre of his or her own healthcare has resulted in patient-centred care (PCC) being a personalised model of quality care provision (Delaney 2018). This study is positioned against a backdrop of developments across the healthcare field to do with patient-centred care. Contemporary quality healthcare delivery questions the biomedical and paternalistic models of the past, where the unique human being was neither recognised nor solicited as a key decision-maker in their own healthcare (Delaney 2018). The concept of ideal care being patient-centred has existed for decades, however, though it was not until 2001 that the term 'patient-centred care' entered the public healthcare policy lexicon (Epstein et al. 2010). The landmark report produced by the Institute of Medicine (IOM), titled *Crossing the Quality Chasm* (2001), identified patient experience as

a critical aim of patient-centred care. A patient-centred approach to healthcare is now both endorsed and promoted worldwide (Coyne, Holmström & Söderbäck 2018).

Patient-centred care is founded in a flexible 'working partnership' between healthcare providers (such as clinical nurses) and healthcare recipients (patients and/or family) (Delaney 2018). Patient-centred care also considers the 'patient' as more than just their illness. It takes into account the patient's unique and expert knowledge, their individual needs, values and preferences (Australian Commission on Safety and Quality in Health Care 2019; Royal College of General Practitioners 2014). Therefore, it stands to reason that the patient's experiences of care should be solicited and valued by healthcare providers, with shared decision-making about future healthcare decisions (Clayman, Gulbrandsen & Morris 2017; Coyne, Holmström & Söderbäck 2018; Ekman et al. 2011). In recent years, healthcare decision-makers across the globe have been keen to adopt various strategies to implement and measure patient-centred care (Australian Commission on Safety and Quality in Health Care 2011; Luxford, Safran & Delbanco 2011). These same decision-makers have increasingly broadened their focus to include the experiences of patients and their family members as a means of assessing patient-centred care. Measuring or evaluating a patient's experiences of care is, therefore, central to being able to provide patient-centred care (Smirnova et al. 2017).

Benefits of improving the patient experience include reduced lengths of stay, improved health outcomes, and cost reductions (Cliff 2012; De Silva 2013; Epstein et al. 2010; Wolf, Ekman & Dellenborg 2012). Positive experiences have also been linked to decreased incidences of pressure injuries (Isaac et al. 2010), and to more positive perceptions of patient safety culture among staff (Lyu et al. 2013; Sorra et al. 2014). Patient loyalty and retention are also positively linked to experience, as are reduced malpractice risk, and increased staff satisfaction and nurse retention (Browne et al. 2010). In addition to the benefits of optimising hospital experiences for both healthcare provider and recipient, various processes and systems also inform a need to capture patient experience data. These include accreditation, quality improvement, benchmark facilitation, pay for performance, and public and funding accountability (Kalucy, Katterl & Jackson-Bowers 2009).

Government mandates and experience-dependent remuneration schemes (such as those in the United States) have further flagged experience as a priority area (Cliff 2012; Epstein et al. 2010; Wolf, Ekman & Dellenborg 2012), which no doubt accounts for the increased volume of experience data collected over the past decades. Australia, Canada, China and Hong Kong, New Zealand, Singapore, the United States, and most European countries regularly collect

patient experience data at a national or local level (Australian Commission on Safety and Quality in Health Care 2011; Burt et al. 2017; Ministry of Health Manatu Hauora 2013; Murray 2008; Robert et al. 2011). Consequently, the growing demand for patient-centred care (Coulter, Fitzpatrick & Cornwell 2009) has seen parallel developments in the science of capturing patient and family experience data in recent years (Browne et al. 2010; Sheard et al. 2019). Of particular importance to this study is the body of research that addresses what tools or instruments are available to measure or evaluate and understand patient experience.

Prior to 1995, experience research consisted of small scale studies using predominantly qualitative methods (Russell 2013). Attempts to measure quality healthcare from the patient's perspective initially took the form of patient satisfaction measures (Russell 2013). However, satisfaction and experience are separate constructs. Satisfaction is a rating of care, whereas experience is a perception of what did or didn't happen during that episode of care (Browne et al. 2010; Russell 2013). Patient satisfaction, while often a component of the experience, is simply an evaluation of care provided relative to expectation (Larson et al. 2019). Satisfaction alone provides limited information regarding experience, particularly as most patients are 'satisfied' with the care they received (Kalucy, Katterl & Jackson-Bowers 2009, p. 1). Patients who are 'satisfied' with their care, however, may report negative experiences (Russell 2013). During the late 1990s, it became clear that relying on patient satisfaction data as a proxy for patient experience data for quality improvement was inherently problematic and potentially misleading. The reason being that satisfaction with care and an optimal care experience are two very different things (Kalucy, Katterl & Jackson-Bowers 2009).

Survey based satisfaction data are beneficial for assessing trends over time, but results are not sensitive to specific experiences (Coulter, Fitzpatrick & Cornwell 2009; Jenkinson, Coulter & Bruster 2002). For example, if ten per cent of respondents rate their satisfaction with service as 'poor', this gives healthcare providers no information on what needs to be addressed. Conversely, knowing precisely the details of what respondents perceived to have happened (hence their experience) opens up possibilities for a change in practice. Herein lies the real value of capturing experience feedback. Changes can be made which demonstrate to the patients and families that their perspective has been valued, and as such that care provision is patient-centred. Ideally, such a change in practice based on experience feedback would happen as soon as possible, so that a 'service recovery' (problem correction) could take place. At the extreme end of service recovery motives lies the phenomenon known as the 'service recovery paradox' (SRP) (Hübner, Wagner & Kurpjuweit 2018; Mount 2012).

There is evidence to support the idea that a negative experience addressed beyond what a customer deemed necessary can result in a more positive experience than had a negative event not occurred (Hübner, Wagner & Kurpjuweit 2018; Mount 2012). This result is, however, dependent upon the collection of real-time or near-time feedback.

Today, to accommodate substantially larger sample sizes methods to capture patient experience feedback are predominantly quantitative (Centers for Medicare & Medicaid Services 2013; Russell 2013). One of the main criticisms of these quantitative approaches is that traditional experience surveys tend not to collect free-flowing comments or patient narratives, which can include aspects of care that may have been overlooked (Detz, López & Sarkar 2013; Grob et al. 2016; López et al. 2012). There are numerous other methods to 'measure', capture or evaluate the patient experience. Today, patients and family most commonly provide experience feedback through surveys, formal complaints or compliments, and via social media. Meaningful measurement of experience, however, remains intrinsically problematic given its multifaceted and subjective nature. As such, no gold standard measurement instrument for hospital experience exists.

The task of capturing experience data is made more difficult by the fact that there is no clear definition of what actually constitutes the 'patient experience' (Balik, Zipperer & Watson 2011; Hobbs 2009). Global leaders from The Beryl Institute, dedicated to improving the patient experience through collaboration and shared knowledge, define patient experience as "the sum total of all interactions, shaped by an organisation's culture, that influence a patient perceptions, across the continuum of care" (Wolf et al. 2014, p. 8). Of particular relevance to this study is the word 'perceptions', as it reflects "what is recognised, understood and remembered by patients and support people", and is "based on individual experiences such as beliefs, values, cultural background" (The Beryl Institute 2019). Experience is therefore always a highly contextualised perception of events. From this perspective, people (patients or their families) may be the subject of, or be subjected to, similar healthcare events, yet they may experience those events very differently, given that perception is highly subjective. This definition of patient experience was highly relevant to this study, as the aim was to capture these perceptions of individual experiences through the development of a new feedback protocol.

It is also important to note that experiences individuals reflect upon or share with others are, in fact, memories of their experience – what they remember. It is the patient's and family's memories of experiences which are being captured and considered when experience data is

being collected. This is relevant because memories of experience can be shaped by numerous factors, including, but not limited to, the treatment outcome (the end result) (Zajchowski, Schwab & Dustin 2017), the emotional content of the past experience (Sheldon & Donahue 2017), and atypical occurrences (the highs and lows of an experience) (Morewedge, Gilbert & Wilson 2005). Experience memories are also recreated by how a person believes they would have felt, behaved or thought at the time, as opposed to how they actually did (Ross & Wing 2018). Capturing the patient's memory of an experience is therefore central to ensuring that patient-centred care is provided in future. As such, this project sought to capture memories of experience.

In order that patient-centred care is practiced and the patient experience optimised, care must be respectful and responsive to the individual needs and wants of the patient (Australian Commission on Safety and Quality in Health Care 2010; Institute of Medicine (IOM) 2001). It is thus implied that a patient-centred care experience requires the one delivering the care to 'know' the patient, and to have a unique understanding of their individual requirements and desires. While it has long been agreed that the patient perception is a fundamental component of care delivery (French 2003; Fröjd et al. 2011; Marram 1973) as mentioned, perceptions of experiences can vary considerably between providers and recipients of care (Black, Varaganum & Hutchings 2014; Cooke & Thackray 2012; Edwards, Duff & Walker 2014; Lee & Yom 2007; Suhonen et al. 2012). Accordingly, patients and relevant stakeholders are increasingly considered experts on patient experience, and integral informants in research design.

Since the 1990s, as the desire to capture experience feedback has increased, several frameworks have been developed to help capture its key dimensions or domains (Coulter, Fitzpatrick & Cornwell 2009; Kumah 2019). The Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) in the United States (Giordano et al. 2010) and the Picker Principles of Patient-Centred Care (Picker Institute 2013) in the United Kingdom, Europe and Australia are perhaps the most widely recognised, but a number of other frameworks (often versions of the HCAHPS or Picker 'core domains' of patient experience) exist (see Appendix B Frameworks of experience). These same frameworks or domains of experience are also often used to categorise or analyse the experience data collected. For example, in Australia, in July 2014, the States and Territories purchased a renewable licence (coordinated by the ACSQHC) to use the Picker Organisation's 58-item survey to assess public hospital experiences. The responses are then primarily analysed and interpreted against the Picker Institute domains of care (Grant, Khan & Taylor 2016). Despite the perceived utility of these frameworks, however,

and their adoption in Australia and internationally, there are intrinsic limitations associated with their use (discussed in further detail in Chapter Two). This study therefore aimed to develop a responsive process which shifted away from a standardised, one-size-fits-all approach for collecting experience feedback.

Transparency in healthcare

Since the 1980s, trends in patient-centred care have focused on openness and professional accountability in the provision of healthcare (Desai et al. 2017). 'Transparency' in reporting healthcare processes and outcomes has become prominent across the healthcare industry (Blomgren & Sahlin 2016). As such transparency is a concept considered in this study. Hospitals are increasingly required to be 'transparent' about their performance in areas such as waiting and treatment times, funding, infection rates, and staffing ratios (Adams 2011; Australian Institute of Health and Welfare 2019; Australian Medical Association (AMA) 2018; Birnsteel 2009). The highly debated release of performance measures in the early 2000s shifted quickly from whether transparency was a good idea to what the measures should be (Galvin et al. 2005; Lee, Meyer & Brennan 2004). In addition to the increasing trend among consumers to share hospital experiences via social media (e.g. Twitter, blogs, Instagram, or Facebook) and publicly accessible rating sites (Findlay 2016; Schlesinger et al. 2015; Sick & Abraham 2011), 'transparency' in healthcare comes from two further sources: interested third parties (including government agencies), and healthcare providers themselves.

Healthcare consumers are sharing their hospital stories by way of both traditional and electronic word of mouth, predominantly on the internet (Browne et al. 2010; Hong et al. 2019). Interested third party organisations, such as the Leapfrog Group in the United States, publish hospital 'safety grades' (from A to F) online, based on deaths due to error, injury, infection and accident. They claim, for example, that the risk of death doubles for patients at 'D'- and 'F'-grade hospitals (The Leapfrog Group 2018). Care Opinion (UK), Care Opinion Ireland, and Patient Opinion Australia (POA) display patient and family healthcare experience feedback comments online, freely accessible to the public (Patient Opinion Australia 2019). Healthcare consumers can and do now access multiple feedback and comparison websites, and studies suggest that consumer decision-making is affected by what they read on these sites (Loria 2019). Hospital administrators have had to respond and react, just as the hotel industry and University administrators have had to address feedback on rating sites such as TripAdvisor, and 'rate my lecturer' sites (Edwards et al. 2007). As a result, the public has had a greater exposure to the inner workings of hospitals. At the same time, we have witnessed

increased seeking of consumer experience feedback in a bid to improve hospital experiences (Levay & Waks 2009).

Governments are also taking notice of this increased consumer demand for transparency, and of the impact patient experience has on outcomes. The National Health Information Standards and Statistics Committee (NHISSC) and the Australian Commission on Safety and Quality in Healthcare have established the Patient Experience Information Development Working Group (PEIDWG) (Australian Commission on Safety and Quality in Health Care 2012). This group examines reporting of national patient experience data and how best to utilise that information. Locally, hospitals are outsourcing experience data collection, or conducting small-scale in-house studies, often for internal communication only (Australian Commission on Safety and Quality in Health Care 2012). While the United States and the United Kingdom governments are required to publish experience data allowing consumers to compare hospitals publicly, many countries do not. In Australia, for example, hospital-specific experience data is not currently readily available. There is, however, the government-run 'Myhospitals' website, which allows the public to search and compare over a thousand public and private hospitals (Australian Institute of Health and Welfare 2018; National Health Performance Authority (NHPA) 2015). In more recent years, major private health insurance companies, such as Medibank Private (2019) and the Hospital Contributions Fund (HCF) (2019), have started to publish their findings based on what their members have told them about their hospital experiences.

The current argument in support of transparency is that a transparent healthcare system enables patients and their family members to make informed decisions about their healthcare providers (Rozenblum & Bates 2013). While patient feedback through avenues such as social media is typically provided for the benefit of other patients, hospitals are now paying more attention to this immediate and unedited commentary (Atherton et al. 2019). This information is then used to improve the care experience hospitals are offering (Adams 2011; Atherton et al. 2019). The experience feedback of patients and family members is, in turn, influencing the healthcare decision-making of other patients regarding which service or services a consumer will use (Farley et al. 2014; Laukka, Rantakokko & Suhonen 2019). Both care recipients and providers are recognising that the patient's experience is an indicator of the value and quality of healthcare delivery.

Nonetheless, there is a mounting unease on the part of healthcare providers about the potential impacts of such open electronic feedback (Hong et al. 2019). Readers of online

patient feedback, for example, can repost or re-tweet that feedback, thus ‘amplifying’ the story – a story over which healthcare providers have very little control (Adams 2011; Patel et al. 2015). This research offers an opportunity to address this concern by creating a mechanism for identifying current issues in real-time, and providing an outlet for patients and their families to express their experiences to the hospital.

Patient and public involvement (PPI) and co-creation

Patient and public involvement in health and social care research are increasing, and evidence suggests that multiple benefits stem from the inclusion of patients, family members and the public in research (Bergerum et al. 2019). These benefits include enhancements to research quality and appropriateness, user-relevant questions and objectives, user-friendly information, more appropriate recruitment strategies, and improved implementation and dissemination of findings (Brett, Staniszewska, Mockford, Herron-Marx, et al. 2014; Jennings et al. 2018). In practice, however it often remains “conceptually and theoretically vague” (Madden & Speed 2017, p. 3) Non-tokenistic stakeholder involvement is necessary for healthcare research, yet complicated. The desire and/or requirement to publish (as applies to most professional academics) (Yadav & Shankar 2018) may explain the increased inclusion of stakeholder input and co-creation in academic literature over the past five years. While some scientific journals, such as the *Journal of American Medical Association* and the *Annals of Internal Medicine*, publish ‘summaries for patients’, the *BMJ* (formerly the *British Medical Journal*) has spearheaded the movement to promote patient participation in clinical research. The journal requires transparency in patient participation for publication, and now includes patients in its peer review processes (Richards et al. 2013). More recently, academics and researchers have begun to include qualitative accounts of patients’ experiences in quantitative research regarding those patients. However, Liabo et al. (2018) suggest that it is a common misconception that including qualitative studies equates to genuine stakeholder involvement. The BMJ Patient and Public Partnership, established in 2014, requires that authors of research papers wishing to publish in any of their portfolio of journals must document if and how patients are involved in all aspects of the research. This includes setting research questions and outcome measures, and moves from design through to implementation and dissemination of the results (BMJ Publishing Group 2019; Wicks et al. 2018).

Healthcare innovation literature that focuses on patient and public involvement often references concepts such as co-design, co-production and co-creation to signify a level of

stakeholder involvement (Fitzsimons et al. 2017). These concepts are frequently used interchangeably, as they share similar philosophical assumptions. The prefix 'co-' refers to 'cooperative' or 'collaborative' (Blomkamp 2018), implying a shared definition of a joint relationship. The terms 'co-production', 'co-design' and 'co-creation', are also often used interchangeably, with co-design and co-production becoming increasingly popular terms in healthcare policy and research (Filipe, Renedo & Marston 2017; Green 2016). 'Co-production' was coined in the 1970s by economist Elinor Ostrom (Ostrom 1996), and further developed by academics such as Edgar Cahn (2004) to include aspects of social justice (fair and just relationships between individuals and society). Cahn (2004, p. 35) suggests that co-production is "the active process of remedying or preventing whatever would violate our sense of social justice." Co-design can loosely be described as any participatory or collaborative activity (Blomkamp 2018). Likewise, co-production emphasises the engagement and integration of multiple stakeholder perspectives which shape both the understanding and processes of knowledge generation (Rycroft-Malone et al. 2016). Osborne, Radnor and Strokosch (2016, p. 643) differentiate co-design and co-production by suggesting that co-design is the result of intentional involvement, whereas co-production can be voluntary or involuntary, citing the example of dementia patients in a residential care setting who 'co-produce their own experience' though not necessarily voluntarily.

'Co-design', particularly, in the context of healthcare, experience-based co-design (EBCD), posits that patients and family are 'experts' in their care, and that the 'co-' in fact refers to a shared leadership between recipients and providers (Bate & Robert 2007; Sanders & Stappers 2008). The concept of 'experience-based co-design' (EBCD) has recently emerged in the healthcare arena, where patients, family members and healthcare providers identify priorities, plan and implement change, and reflect upon successes, with all participants having an equal status (Donetto et al. 2015). Co-creation refers explicitly to the participation of end-users (Von Hippel 1989; Voorberg, Bekkers & Tummers 2015). Reflective of the complexities within the field, there is no consensus on one definition of 'co-creation', and numerous models exist in the fields of business, design and innovation (Alves, Fernandes & Raposo 2016; Ramaswamy & Ozcan 2018). Likewise, various models of co-creation also exist in healthcare (Greenhalgh et al. 2016). The definition adopted in this thesis draws on the 'value co-creation' model (from business management literature) and the 'experience-based co-design' (EBCD) model (from design science) (Bate & Robert 2007; Greenhalgh et al. 2016). Value co-creation refers to the active role consumers assume in creating value together with an organisation (Ranjan & Read 2016). Value co-creation means more than customers merely

adding value to a future design by providing their feedback. While co-creation and co-production are often more similarly defined, Voorberg, Bekkers and Tummers (2015) make a distinction between co-creation and co-production, in that co-creation involves 'citizens' at the initiation and design level. In contrast, co-production involves 'citizens' in co-implementation. The literature seems to further differentiate the terms by placing more of an emphasis on the value aspect of co-creation (Gebauer, Johnson & Enquist 2010; Ranjan & Read 2016; Voorberg, Bekkers & Tummers 2015). Value co-creation is informed by what is known as 'service-dominant logic' (SDL), developed by Vargo and Lusch (2004). The value within this paradigm is created by the interactive process between provider and end-user, with an emphasis on 'with' the consumer rather than 'to' them (Hammervoll 2014; Vargo & Lusch 2014). A key tenet of SDL is that consumer involvement in a production process results in the creation of more value (Hammervoll 2014; Lusch & Vargo 2006). Value creation, however, extends beyond elements of production (or co-production), and includes experiences of consumption and value delivery (Ranjan & Read 2016). Under this paradigm, in a healthcare experience, the 'value' is co-created by the provider and the recipient of care. Technically, co-creation can take place at any stage of a production process, for example, during the design (co-design) or production (co-production) stage. This study, however, adopts a more holistic definition; 'co-creation' refers to the entire process of design (defining the problem and possible solution) and production (implementing the possible solution). This recognition and inclusion of the entire spectrum of events from ideation to end-user adoption and evaluation aligns with the patient-centred care philosophy and collaborative intent of this study.

Experience-based co-design, the second component underpinning the co-creation definition adopted in this study, was developed by Bate and Robert (Bate & Robert 2007; Greenhalgh et al. 2016), and is also a widely used approach in healthcare improvement (Donetto, Tsianakas & Robert 2014). The central tenet of experience-based co-design in healthcare is that services are continually redesigned based on the experiences of healthcare consumers (Bate & Robert 2006, 2007). The popularity of experience-based co-design in health research is due in part to the increasing importance placed on patient-centred care (Bate P & Robert G 2007; Mulvale et al. 2019). Co-creation under either the value-based or experience-based framework is not merely a matter of consumer or stakeholder involvement, but an active process of peer review whereby new value is produced together (Bettencourt, Lusch & Vargo 2014).

A central role must be played by consumers or stakeholders from beginning to end.

Greenhalgh et al. (2016, p. 393) define co-creation as "the collaborative generation of

knowledge by academics working alongside stakeholders”. That is the definition used in this thesis.

Achievement of co-creation is not explicitly defined in the literature. However, knowledge from multiple disciplines and experiences informs it (Tossavainen 2017). Greenhalgh et al. (2016) suggest that co-creation can be achieved by adopting three principles:

1. A systems perspective (which recognises and respects emergent multiple interacting entities, and that outcomes cannot be fully predicted in advance);
2. A creative approach to research (with human experience at its core); and
3. Attention to governance (power relationships) and process.

Co-creation, therefore, acknowledges interrelationships and interacting systems, respects stakeholder experience and seeks collaborative governance, where end-users have an active involvement in various production process stages (Voorberg, Bekkers & Tummers 2015). In this thesis, therefore, co-creation refers to the strategy adopted by bringing multiple local stakeholders together to design, produce and evaluate a mutually valued outcome (a new patient experience feedback protocol). These stakeholders are co-creators, co-producers and co-owners of the knowledge produced (Genat 2009; Khan & Chovanec 2010; Tossavainen 2017). Under this definition, co-creators are also considered to be co-researchers. Both the definition and principles of co-creation are congruent with the aims of patient-centred care, and with the credo adopted in this study: ‘nothing about me without me’. Chapter Three will further demonstrate how co-creation can be operationalised through action research. The complexities of stakeholder involvement and co-creation in this study will be examined throughout the text.

Patient loyalty and willingness to recommend

The issue of patient loyalty and willingness to recommend emerged over the course of this study and relates to one of its key findings. This section provides a broad background to this concept and how it has been used and measured internationally. Patient loyalty is a vital component of a healthcare provider’s business success (Zhou et al. 2017). Loyalty has also been positively linked to patient satisfaction and patient experiences (Fatima, Malik & Shabbir 2018; Kessler & Mylod 2011; Meesala & Paul 2018; Zhou et al. 2017). It is assumed that through positive experiences and satisfaction, loyalty and repeat patronage is built. Loyalty to one healthcare provider over another also creates a patient base willing to recommend that provider to their friends, family, colleagues, and broader community (Wolf 2016a). Tools such

as the Net Promoter Score (NPS) (Reichheld 2003) and the Friends and Family Test (FFT) (Wilberforce et al. 2019) seek to represent loyalty as a 'willingness to recommend' score. Private and public hospitals are adopting either the NPS or FFT in their patient experience surveys across Australia. The NPS, for example, is used by the nation's largest private hospital operator, Ramsay Health Care, across 60 facilities (Ramsay Health Care 2019), and by St Vincent's Health Australia across their 39 (Australian Commission on Safety and Quality in Health Care 2012). The FFT has been included in Victorian public hospitals since 2012 (Victorian Public Sector Commission 2014). Questions regarding willingness to recommend are also routinely asked in patient experience surveys in New South Wales (The Bureau of Health Information 2019), Queensland (Queensland Government 2018), Western Australia (C. Patterson 2019, personal communication, 12 December), and South Australia (Government of South Australia 2018; Pearse 2005). Private health insurance companies also routinely survey their members (such as Medibank Private and its 37,000 participants) across all Australian states, asking them about their likelihood to recommend (Medibank Private Limited 2019).

Developed in 2003 by management consultant Fred Reichheld, the NPS is a customer loyalty metric designed to be used across industries (Reichheld 2003). Asked a single question, 'Would you recommend this business to your friends and family?', participants respond (usually on a ten-point scale) from 'definitely would not' to 'definitely would'. The score essentially provides a ratio of 'promoters' to 'detractors', calculated by subtracting the percentage of detractors (those who wouldn't recommend) from the percentage of promoters (those who would) (Krol et al. 2015; Reichheld 2003). The NPS is considered a 'global item' (an overall rating). It is included in the 32-item HCAHPS nationally standardised survey used in the United States, and internationally for measuring consumers' perceptions of their hospital experiences (Centers for Medicare & Medicaid Services 2017). Patients are asked whether they would recommend the hospital to their friends and family, with response options being 'would definitely', 'would probably', 'would probably not' or 'would definitely not'. Over 2.8 million surveys were completed in the United States by patients discharged from hospital between July 2017 and July 2018, all answering the willingness to recommend question (see Appendix C Hospital Characteristics Comparison chart).

In England, the NPS is implemented as the Friends and Family Test (FFT) (Wilberforce et al. 2019). Launched in 2013 and rolled out in phases over the following year, all National Health Service (NHS) acute hospital trusts in the country collected data based on the FFT. The NHS considered the FFT an essential feedback tool (when combined with follow-up questions), as

it provided a “mechanism to highlight both good and poor patient experience” (National Health Service 2020). In the United Kingdom alone, it is estimated that the willingness to recommend question has been administered over 25 million times (National Health Service 2014), making it “the largest collection of ‘real-time’ patient experience data in the world” (National Health Service 2014; Wilberforce et al. 2019, p. 32). By the end of 2019, approximately 1.3 million pieces of FFT feedback were being gathered each month across the UK (National Health Service 2020). The scores were published at monthly intervals on NHS websites, with nine out of ten people responding that they would recommend the NHS service they used (National Health Services 2014). One of the key benefits identified by the NHS was the ‘swift’ and ‘granular’ data the FFT provides (National Health Service 2014).

FFT scoring is based on the NPS model – promoters minus detractors (National Health Service 2014). A review of the FFT reported that its strengths were the real-time nature of the method, inclusivity and the supplementary qualitative data provided to staff, who felt they could understand what they were doing well and what needed improvement (National Health Service 2014). A criticism, however, was that the scoring method was not easily understood by frontline staff (National Health Service 2014). Interestingly, and of relevance to this study, the qualitative feedback provided (on a voluntary basis) after the FFT question was deemed to be the most useful aspect, identifying specific issues and good practice (National Health Services 2014). As a result of the review, a mandatory follow-up question was introduced about why a patient gave a particular response regarding whether they would or would not recommend the hospital. However, this free text feedback is not collected nationally. The text is analysed locally, but there is no requirement to make these comments public. Moreover, according to the Programme Communications Manager of Insight and Feedback Team NHS England and NHS Improvement (G Radcliffe 2019, personal communication, 11 June) there has been no test of correlation between FFT scores and the free text comments to assess whether positive experiences align with a willingness to recommend and vice versa. There is, however, an awareness that ratings do not always match the experience comments.

1.4 Methodological approach

The conceptual framework initially guiding this research was based on the tenets of patient-centred care and the credo ‘Nothing about me without me’. Therefore, this project focused on co-creating a protocol with key stakeholders for capturing and relaying experiences of care in a manner that was respectful and reflective of a patient-centred approach. A participatory and collaborative methodology, such as action research, was well suited to this aim.

Action research, as the name suggests, is premised upon taking informed action to bring about change. Through action, and then reflection upon action, change is observed and evaluated, with conclusions drawn (Hearn, Swan & Geels 2019). Action research is a reflective inquiry process which requires both collaborative participation and analysis by and for those affected by the action. As Street's (2003) diagrammatic representation of the action research process indicates (see Figure 1), participants in action research identify problems, then plan, implement and evaluate actions aimed at improving the current situation. Evaluation, in turn, leads to new plans to be actioned and evaluated, often resulting in a replanning of the original aims based on these findings.

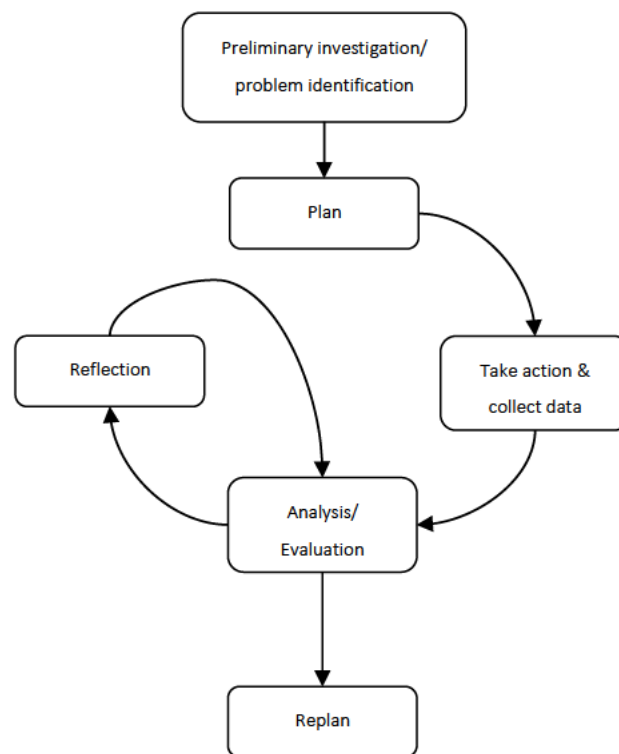


Figure 1 The action research process (Street 2003, p. 223)

Action research in healthcare is widely used to investigate both experiences of care and professional practices (Koshy, Koshy & Waterman 2010). Action research counters the often-critiqued separation between theory and practice, particularly in the field of nursing (Koshy, Koshy & Waterman 2010; Street 2003). Action research will be further discussed in Chapter Three.

1.5 Structure

This thesis chronicles the journey from conception to field-testing and evaluation of a co-created new patient and visitor hospital experience feedback protocol. This is a non-

traditional thesis in that there is no separate 'results' or 'findings' section. This material is instead included throughout Chapter Five, which chronicles the nine Action Cycles of this study.

This introduction, **Chapter One**, has provided an account of how I came to the research, my philosophical position, the research question, and contextual background, as well as a brief introduction to action research.

Chapter Two presents a literature review and discussion regarding what instruments were available to capture and measure or evaluate the patient experience in a hospital setting before 2013 (at the inception of this study). An abridged and modified version of this review was published in the *Patient Experience Journal (PXJ)* in 2015 (see Appendix A). Approval to include this published review in this thesis is provided in Appendix D. The findings from this initial review informed the research question, research objectives, choice of methodology, and research design. Additional instruments identified from 2013–2020 are also included in this chapter.

Chapter Three presents the action research methodology adopted to guide this study. An overview of the theoretical foundations of action research, the different types of action research, and action-oriented approaches in healthcare are examined. A background to action research, the types of action research, and the adoption of pragmatic action research approach for this study will be provided in Chapter Three. The facilitation of an action research study, the importance of action cycles and monitoring change will also be discussed.

Chapter Four outlines the research design. The development of the research question and objectives will also be discussed here. Participant recruitment (including recruitment of members of an Action Research Advisory Group (Advisory Group) and field-test participants), data collection, data analysis, and validity in action research will also be examined. Ethical considerations, including ethics approvals and consent, will be highlighted in this chapter, as will ethical considerations for specific field-test participants.

Chapter Five reports on the nine Action Cycles undertaken throughout this study. These are presented sequentially; however, as the timeline (see Table 8) reflects, the research process itself was not linear. Each Action Cycle section will report on the individual cycles' aim, plan, implementation (and findings), and reflection (including evaluation of the findings). Action Cycles 1-4 and 7-9, will conclude with a summary of both lessons learnt from the cycle and questions raised. This chapter will end with a summary of key findings.

Chapter Six is the discussion and conclusion chapter. This chapter discusses the key findings from the nine Action Cycles presented in Chapter Five, and how they address the research question and objectives. This chapter will address the adoption of an action research approach, and the challenges and successes of collaborative engagement, participation, and co-creation. A brief discussion on the experience feedback produced as a result of field-testing the new protocol will be discussed in relation to the hospital experience literature. Core components of the new feedback protocol will be examined and considered, as will willingness to recommend as an indication of the patient's experience. This chapter also contains a reflection upon my role as a novice action researcher and PhD candidate, and will identify contributions and implications of the research. Limitations of the study will be considered, and current and future directions summarised, before closing remarks.

Chapter 2 Literature Review

An initial literature review was conducted early in my candidature to identify what tools or instruments were being used to capture experience feedback, and to help refine the research question. This review considered literature from the period 2000 to 2013, and was subsequently published (Edwards, Walker & Duff 2015) (see Appendix A). This chapter is based on that review, with some individual sections modified, expanded, or updated. Between 2013 and 2020, there were additional instruments published, and this more recent research is discussed towards the end of the chapter.

In recent years, there have been developments in the science of measuring patient experience, and thus a range of approaches are now being used to capture and evaluate experience (Browne et al. 2010). Broadly speaking, patient experience information can be collected by survey, patient feedback processes, or narrative methods (interviews and patient stories) (De Silva 2013; Kalucy, Katterl & Jackson-Bowers 2009). Approaches can further be divided according to generalisability (the extent to which the findings can be reasonably applied to a broader population), and the depth of the information supplied (De Silva 2013). The Health Foundation (De Silva 2013) contends that strategies for measuring patient experience lie on a two-axis continuum (see Figure 2).

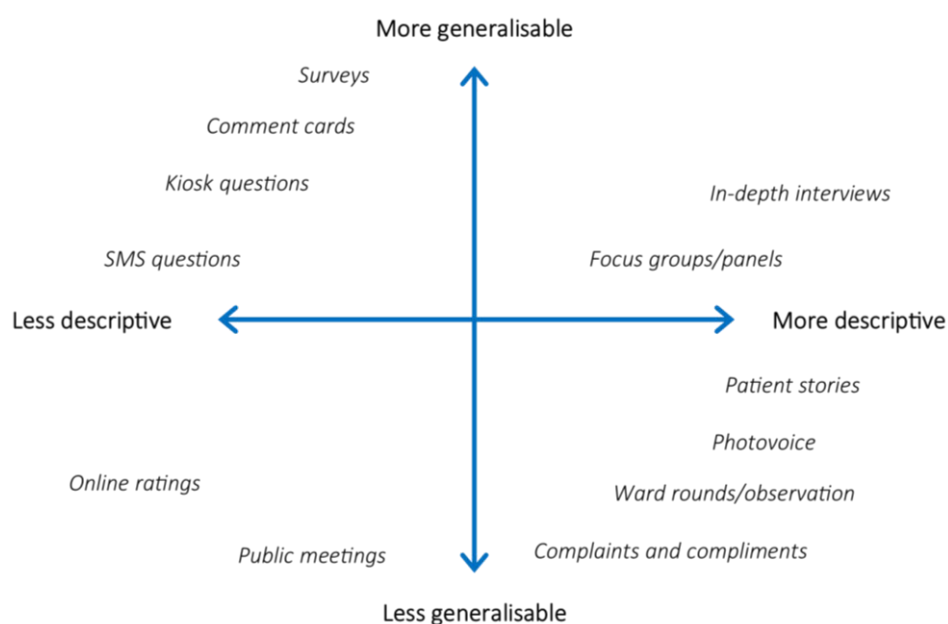


Figure 2. The Health Foundation (De Silva 2013) examples of methods used to measure patient experience of health services

Systematic reviews show that numerous instruments are being used to measure or evaluate patient experience (Robert et al. 2011; Russell 2013). The number and heterogeneity of these tools make it difficult to compare findings, which also explains why so few studies are eligible for systematic reviews of issues to do with patient experience (Hudon et al. 2011; Russell 2013). Hudon and colleagues' (2011) systematic review, for example, identified more than 3,000 articles dealing with patient perceptions of patient-centred care. Of these, only 26 (fewer than one per cent) met the inclusion criteria.

Efforts to define, capture, and analyse patient experience are gathering momentum. It therefore stands to reason that there is value in trying to elicit experience data from those receiving the care, and to effectively relay those findings to providers of care. While numerous studies have examined aspects of patient-reported experience using various instruments, little attention has been paid to identifying and critiquing such tools (De Silva 2013; Russell 2013). Therefore, this chapter intends to review the literature for patient experience instruments, and to critique these tools in terms of richness of experience data, generalisability, and strengths and weaknesses.

2.1 Search strategy

A three-stage search strategy was used. Stage one focused on pre-identified tools, as per the Health Foundation's (The Health Foundation 2014) 'Helping Measuring Patient-Centred Care' database of measurement instruments which contains some of the most commonly used validated tools for measuring patient-centred care (De Silva 2014). This database is derived from screening of more than 200,000 studies on patient-centred care published between 2000 and 2013. Using the 'category filter', tools used to specifically explore 'experience' were identified. The following databases were then searched for additional instruments:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Education Information Resources Center (ERIC)
- EBSCO
- Health and Psychosocial Instruments (HaPI)
- Medical Literature Analysis and Retrieval System (MEDLINE), and
- Psychology and Behavioural Sciences Collection (PsychINFO).

With the following search strategy:

((T1 experience AND ((patient or person or family) AND (centred))) or ((MH 'patient satisfaction') OR (MH 'Patient attitudes') or 'patient experience*')) AND

(Patient satisfaction OR patient experience*) AND (reliabil* OR validat* OR development) OR (questionnair* OR survey* OR tool* OR instrument*)

OR

Tl((reliabil* OR validate* OR development)) AND ti((experience* OR satisfaction)) AND (questionnaire* OR survey* OR tool* OR instrument*)

References from websites of leading patient-centred care organisations (see Table 1) were examined for additional instruments that may have been excluded from the results of the original search strategy. Experts in the field of patient experience and patient experience measurement or evaluation were also contacted for additional relevant studies.

Table 1 Patient-centred care organisations

Australian Institute for Patient and Family Centred Care	aipfcc.org.au
Institute for Healthcare Improvement	ihi.org
Institute for Patient and Family Centred Care	ipfcc.org
The King's Fund	kingsfund.org.uk
Planetree	planetree.org
Studer Group	studergroup.com
The Schwartz Centre	theschwartzcenter.org/
World Health Organization – Patients for Patient Safety	who.int/patientsafety/en/

Source: Australian Commission on Safety and Quality in Health Care (ACSQHC) 2011, *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*, Sydney









Presentations, conference proceedings, government agencies, abstracts, and other forms of published and unpublished resources from additional fields were also considered.

'Snowballing' (evaluating new links identified through included relevant links) was then undertaken. Finally, once instruments were identified, associated articles describing the development and/or validation of the tools were sought using the same databases.

2.2 Selection criteria

Titles and abstracts were initially considered using a modified version of Beattie and colleagues' (2014) 'Inclusion Selection Questions' for instruments to measure patient experience of healthcare quality in hospitals (see Table 2).

Table 2 Inclusion selection questions

Does the study report the development and/or validation of a patient-reported experience measure instrument?	Yes  Go to question 2	No  Reject
Is the context a hospital setting or intended for use in a hospital setting?	Yes  Go to question 3	No  Reject
Is the population 'adult inpatient', or 'adult inpatient family member'?	Yes  Go to question 4	No  Reject
Is the study measuring the patient, family member perspective of the patient's experience of care?	Yes  Go to question 5	No  Reject

Because of translation costs, only studies in English were included. Only studies that reviewed the experience within a hospital setting (medical or surgical) were included. Studies primarily concerned with specific events or issues (such as patient discharge or safety) were not included. Studies examining measurements for specific specialist areas within the hospital setting were included as long as there was an overnight stay within a hospital. For example, intensive care, obstetrics, and/or orthopaedics were included, because the aim was to identify measurement instruments regardless of the patient's reason for admission. Studies which only considered specific populations within specialist areas were not considered.

Studies concerning adult patients (over 18) who had spent at least one night in the hospital (when known) were included. Studies concerning family members or providers of care to patients (who had spent at least one night in hospital) were included. Studies which tested measures to identify hospital experience specific to participants with intellectual disabilities or psychiatric disorders were excluded based on the assumption that the instruments had likely been developed for those particular needs.

Only primary studies, which directly reported on either development, validation, or development *and* validation of patient-reported experience instruments, published in a print or online journal or report were included. Studies which used an included tool, but which did not directly report on development or validation were not included. All studies pertaining to the experience instruments were included, regardless of date. For instruments with two or more published studies on development or validation, the original, most recent, or most

informative articles were used. Quantitative, qualitative, and multi-method studies were all considered. The sample size was not a criterion for inclusion or exclusion. There were no geographical restrictions. Generalised research regarding experience and what matters to patients and their family members was not included, as the focus was on instruments for measurement and evaluation rather than findings using a particular approach.

2.3 Identified experience instruments and their characteristics

Thirteen relevant patient experience feedback instruments were identified (See Table 3 and Appendix E Results flowchart) and seventeen associated studies (regarding development and or validation) were identified (see Table 4 and Appendix F for Literature Review Evidence Table). Two instruments were developed in the United States (HCAHPS, PAQS-ACV), one in Hong Kong (HKIEQ), one in Ireland (INPQCS), five in the United Kingdom (NSNS, NHS NAIS, PPE-15, howRwe, ICE) one in Australia (PEECH), one in Norway (PEQ), one in Sweden (QPP) and one joint development in Norway, Sweden, Iceland and Denmark (NORPEQ).

Table 3 Experience instruments

Hong Kong Inpatient Experience Questionnaire (HKIEQ)
Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)
howRwe
Intensive Care Experience ICE questionnaire (ICE)
Irish National Perception of Quality of Care Survey (INPQCS)
Newcastle Satisfaction with Nursing Scale (NSNS)
NHS National Adult Inpatient Survey (NHS NAIS)
Nordic Patient Experiences questionnaire (NORPEQ)
Patient Evaluation of Emotional Care during Hospitalisation (PEECH)
Patient Experience Questionnaire (PEQ)
Patient's Assessment of Quality Scale (PAQS-ACV)
Picker Patient Experience Questionnaire (PPE-15)
Quality from the Patient's Perspective (QPP)

Table 4 Selected Literature Characteristics

INSTRUMENT NAME	STUDY AUTHORS	INSTRUMENT COUNTRY DEVELOPMENT	STUDY TITLE
HONG KONG INPATIENT EXPERIENCE QUESTIONNAIRE (HKIEQ)	(Wong, Coulter, Cheung, Yam, Yeoh, et al. 2013)	Hong Kong	Validation of inpatient experience questionnaire
	(Wong, Coulter, Cheung, Yam, Eng-Kiong, et al. 2013)		Item generation in the development of an inpatient experience questionnaire: A qualitative study
HOSPITAL CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS (HCAHPS)	(Giordano et al. 2010)	United States	Development, implementation, and public reporting of the HCAHPS Survey
	(Goldstein et al. 2005)		Measuring hospital care from the patients' perspective: An overview of the CAHPS Hospital Survey development process
HOWRWE	(Benson & Potts 2014)	United Kingdom	A short generic patient experience questionnaire: howRwe development and validation
INTENSIVE CARE EXPERIENCE ICE QUESTIONNAIRE (ICE)	(Rattray, Johnston & Wildsmith 2004)	United Kingdom	The intensive care experience: Development of the ICE questionnaire
IRISH NATIONAL PERCEPTION OF QUALITY OF CARE SURVEY (INPQCS)	(Sweeney, Brooks & Leahy 2003)	Ireland	Development of the Irish national patient perception of the quality of care survey
NEWCASTLE SATISFACTION WITH NURSING SCALE (NSNS)	(Thomas et al. 1995)	United Kingdom	Obtaining patients' views of nursing care to inform the development of a patient satisfaction scale
	(Thomas et al. 1996)		Newcastle satisfaction with nursing scales: An instrument for quality assessments of nursing care
NHS NATIONAL ADULT INPATIENT SURVEY (NHS NAIS)	(Reeves et al. 2002)	United Kingdom	Development and pilot testing of questionnaires for use in the Acute National Health Service (NHS) Trust Inpatient Survey Programme
NORDIC PATIENT EXPERIENCES QUESTIONNAIRE (NORPEQ)	(Oltedal et al. 2007)	Norway, Sweden, Iceland, Denmark.	The NORPEQ patient experiences questionnaire: Data quality, internal consistency and validity following a Norwegian inpatient survey

PATIENT EVALUATION OF EMOTIONAL CARE DURING HOSPITALISATION (PEECH)	(Murrells et al. 2013) (Williams & Kristjanson 2009)	Australia	Measuring relational aspects of hospital care in England with the 'Patient evaluation of emotional care during hospitalisation' (PEECH) survey questionnaire Emotional care experienced by hospitalised patients: Development and testing of a measurement instrument
PATIENT EXPERIENCE QUESTIONNAIRE (PEQ)	(Kjell et al. 2004)	Norway	The patient experiences questionnaire: Development, validity and reliability
PATIENT'S ASSESSMENT OF QUALITY SCALE - ACUTE CARE VERSION (PAQS-ACV)	(Lynn, McMillen & Sidani 2007)	United States	Understanding and measuring patients' assessment of the quality of nursing care
PICKER PATIENT EXPERIENCE QUESTIONNAIRE (PPE-15)	(Jenkinson, Coulter & Bruster 2002)	United Kingdom (using data from the United Kingdom, Germany, Sweden, Switzerland, USA)	The Picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries
QUALITY FROM THE PATIENT'S PERSPECTIVE QUESTIONNAIRE (QPP)	(Larsson & Larsson 2002)	Sweden	Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire

The number of participants in each study ranged from 25 (HIEQ) to 19,720 (HCAHPS). Instrument development consisted primarily of literature reviews and focus groups, followed by item generation, pilot testing, and appraisal. The theoretical or guiding principles were only identified for eight of the 13 instruments. The Institute of Medicine for HCAHPS, Picker domains for HKIEQ and NHS NAIS, grounded theory for PEECH, PAQS-ACV, QPP, patient-centred care for PPE-15, and the concept that all patients want high-quality service from staff and the organisation as a whole for howRwe. All studies included only patients as participants and intended users of the instruments. All studies aimed to develop, test and/or report on a patient experience instrument. Patients and/or family members were involved in the development of at least eleven instruments (HCAHPS, HKIEQ, INPQCS, NSNS, NHS NAIS, PEECH, PEQ, PAQS-ACV, PPE-15, QPP, howRwe). The articles for the ICE (Rattray, Johnston &

Wildsmith 2004) and NORPEQ instruments (Oltedal et al. 2007) did not report whether patients were involved.

All but three instruments (PEECH, ICE, and NORPEQ) were developed and tested using mixed-methods approaches. Qualitative methods (interviews and focus groups) were predominantly used for item generation, with quantitative and qualitative methods used to test and analyse the instruments. All instruments identified were survey-based, providing mainly quantitative data, with items ranging from four questions (howRwe) to 95 (INPQCS). Two instruments included comment sections (HKIEQ and NHS NAIS), and two included comment sections for each item (PEECH and howRwe).

Eight instruments used a paper-only survey mode (NSNS, NHS NAIS, PEECH, PEQ, PAQS-ACV, PPE-15, QPP, and NORPEQ). Two instruments used a telephone-only mode (HKIEQ and INPQCS). The HCAHPS instrument uses four modes (mail-only, telephone-only, mail with telephone follow-up, and interactive voice response (IVR)). howRwe is designed for use with multiple modes – paper, touchscreen device (such as kiosks, smartphones, and tablets), web browsers, and telephone. Touchscreens were used for testing. It is not clear from the literature what mode the ICE instrument was tested under. None of the articles identified a corresponding feedback mechanism (that is, how the information provided by the instrument is to be fed back to patients or clinicians).

Five instruments (NSNS, PEECH, PAQS-ACV, QPP and howRwe) were designed to collect data during the hospital stay, and the remainder post-discharge (ranging from immediately post-discharge to up to twelve months post-discharge). Eight instruments provide the recipient with quantitative data (HCAHPS, INPQCS, NSNS, PEQ, PAQS-ACV, PPE-15, QPP, and ICE), four provide quantitative and limited qualitative data (HKIEQ, NHS NAIS, PEECH, howRwe); none providing qualitative data only. It is unclear what type of data are provided with the NORPEQ Instrument. As demonstrated in Figure 3, p29, all instruments fell into the more generalisable, less descriptive part of the spectrum.

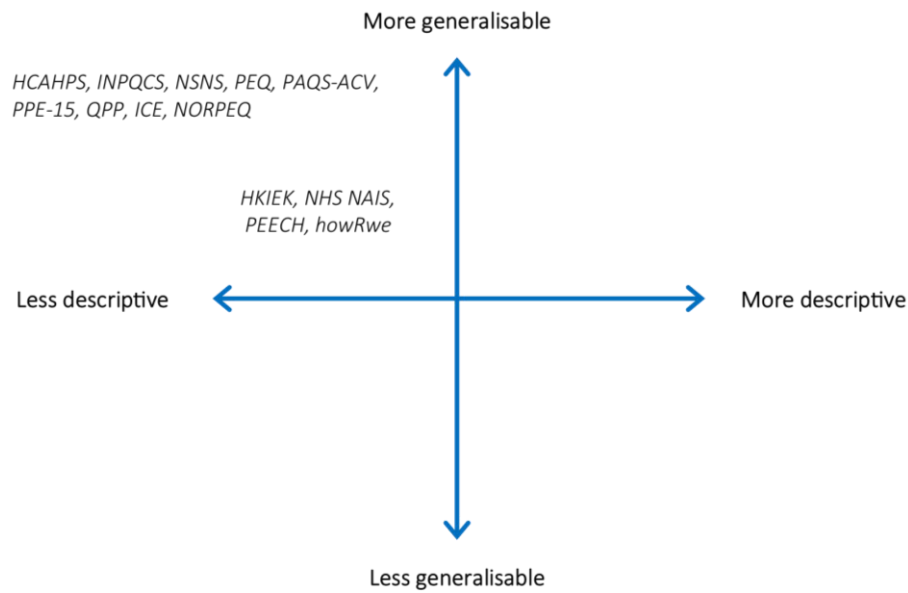


Figure 3 Experience instruments identified to measure patient experience in hospital

2.4 Evaluation and critique of published instruments

Many hospital administrators outsource larger scale studies to companies, such as Press Ganey, Gallup, Dr Forster, and the Picker Institute, while others use in-house resources (Pearse 2005). While thousands of studies are published regarding patient experience, often the information provided regarding the method of collection or instrument used is limited (Garratt, Solheim & Danielsen 2008). Despite this real-world practice of capturing experience data, there are very few (13, see Table 4) validated and published instruments or approaches explicitly designed to examine the hospital experience, and even fewer (five, the NSNS, PEECH, PAQS-ACV, QPP and howRwe) designed to obtain experience feedback during the episode of care.

Direct patient feedback is the core method for measuring patient experience (Coulter, Fitzpatrick & Cornwell 2009). Approaches for capturing this experience data divide broadly into quantitative and qualitative methods, and there are several different methods in each category for examining patient experience (Russell 2013), see Figure 2, p21). The literature confirms that quantitative structured questionnaires or surveys are the most common approach published (Coulter, Fitzpatrick & Cornwell 2009; Crow et al. 2002; Pearse 2005; Russell 2013; Wong, Coulter, Cheung, Yam, Yeoh, et al. 2013). Such quantitative research, however, is not capable of providing rich and nuanced information regarding individual experience, and for this reason, patient interviews are becoming increasingly popular as a means of obtaining qualitative experience data (Blickem & Priyadharshini 2007; Boyd 2007; Lees 2011; Sørli et al. 2006). Cleary and colleagues (2014) suggest qualitative research is the

optimal scholarly means of understanding patient experience, while Russell (2013, p. 1) holds that information gleaned from surveys is virtually “useless for improving patient’s experience”. This literature review identified no published work based on qualitative instruments.

Experiences cannot be reliably evaluated by using standard questions (Coulter, Fitzpatrick & Cornwell 2009), nor by focusing solely on individual aspects of the overall experience (Edwards, Duff & Walker 2014). Accordingly, collection of experience data requires multiple approaches to enhance validity (Russell 2013). Many hospitals and larger institutions use more than one method to collect experience data. New South Wales Health, for example, began surveying experience in 2007 using a two-pronged approach: Picker surveys and a patient journey methodology, covering sequential steps from admission to discharge and beyond (Kalucy, Katterl & Jackson-Bowers 2009). Mixed methods are increasingly being used in practice to collect experience data in other parts of the world (Russell 2013). It is difficult to understand why there are no published qualitative instruments, given the adoption of qualitative approaches, and expert opinion stating that qualitative research is ideally suited to capturing experience data. This view is also echoed by De Silva (2013) and Russell (2013), who identified research regarding the testing and validation of survey tools, but very little on qualitative techniques.

While four instruments (HKIEQ, NHN NAIS, PEECH, HowRwe) found in this review do contain comment sections, providing limited qualitative data, all instruments identified were considered to be ‘less descriptive, more generalisable’. Despite the call for increased qualitative data collection, it must be acknowledged that there are significant benefits to the use of quantitative approaches, including economies of scale, applicability to a broader population, anonymity, ease of implementation, ease of analysis (particularly in the case of closed-ended questions), lower costs (less human resources), less time (De Silva 2013), exclusion of interviewer bias, and high response rates (Coulter, Fitzpatrick & Cornwell 2009). Their limitations, however, are significant.

Surveys are not suitable for those with low literacy or for people who do not speak the language of the survey. As such, they have the potential for self-selection bias (Coulter, Fitzpatrick & Cornwell 2009). Surveys also tend to reflect concerns of administrators, and often represent manager or clinician agendas (Coulter, Fitzpatrick & Cornwell 2009). Six instruments (HKIEQ, INPQCS, NSNS, NHS NAIS, PPE-14, PEQ) found in this review were developed using patient focus groups. However, the resulting surveys represent the issues

identified by the focus groups, rather than of those who completed the questionnaire. Because of this, De Silva (2013) argues that survey approaches cannot provide in-depth data, nor are they well suited to gathering data on sensitive issues. Despite these limitations, most hospitals continue to use standardised surveys because they allow comparison and benchmarking against other institutions – a concern for administrators (Benson & Potts 2014). This approach is of limited value to the individual patient, their family members, or the people providing direct care for them.

The solution to obtaining richer data does not lie with more detailed surveys. While surveys tend to have good response rates, their length can be a deterrent to completion, reducing their value (Castle et al. 2005). The NHS NAIS survey, for example, has seen response rates decline from 64 per cent in 2001 (Department of Health 2003) to 49 per cent in 2013 (Department of Health 2014). Shorter survey instruments do reduce participant burden, which was an objective behind the establishment of the howRwe (Benson & Potts 2014) and QPP instruments (Larsson & Larsson 2002). Not surprisingly, however, a comparison between the PPE-15 and PEECH Instruments found that the longer PEECH Instrument provided more data on interpersonal aspects of quality of care than the shorter Picker Institute Instrument (Murrells et al. 2013).

Nation, state and even hospital-wide surveys usually produce non-attributable experience data (Price et al. 2014). That is, they don't necessarily reflect the care delivered by the provider or providers who were directly responsible for the experience (Price et al. 2014). The recent focus on improving experience (Giordano et al. 2010) suggests that data collected at the episode of care, from patients, at an inpatient unit level may have the most significant effect on services (Russell 2013). Slow feedback to staff is an ongoing criticism of patient experience surveys (Robert & Cornwell 2013). By the time frontline clinicians receive information, they may well argue that such practices have now improved (Barron et al. 2014). Experience responses should be focused on specific episodes of care and specific providers so that the data has the best possible applicability and sensitivity to context (Price et al. 2014).

Real-time feedback

Collecting real-time (when the patient is in the hospital) or near-time experience data (immediately post-discharge) is the most effective way to ensure it is meaningful (Russell 2013). However, only five instruments in the review (NSNS, PEECH, PAQS-ACV, QPP, howRwe) were validated based on collection in real-time, and one was near-time (immediately post-discharge; ICE). The healthcare industry has been slow to adopt real-time practices, even

though other sectors, such as the leisure industry, have been using real-time measures to elicit feedback for decades (Brown, Davidson & Ellins 2009). Timing of data collection is crucial, as it provides the recipient with what has been referred to as ‘fresher’ information (Brown, Davidson & Ellins 2009, p. 4). Staff, in particular, perceive such timely information as having greater validity (Brown, Davidson & Ellins 2009). Two studies which used the PEECH instrument – one administered while the patient was in the hospital (Williams & Kristjanson 2009) and one post-discharge (Murrells et al. 2013) – found that differences in findings could be influenced by recall bias. Recall bias is often a problem with data collected post-discharge (Castle et al. 2005). As a result, the UK Department of Health now requires all hospitals to collect ‘real-time’ or ‘rapid’ feedback (during or immediately after) from hospital patients (Australian Commission on Safety and Quality in Health Care 2011). Obtaining such contemporaneous experience data may highlight gaps and provide more meaningful information to healthcare providers on how to improve patient experiences of care.

Ethical and validity concerns regarding the real-time collection of experience data have been identified. For example, there may be a tendency for patients to offer positive feedback for fear of jeopardising treatment or being seen as difficult (Delnoij 2009; Kalucy, Katterl & Jackson-Bowers 2009; Maben et al. 2012; Russell 2013). Experience research, however, is different in that it does not ask patients to rate the quality of care; instead, it seeks to identify what they perceive to have happened (or not happened) (Agency for Healthcare Research and Quality 2017). NSNS tool results suggested that responses did not differ when collected at hospital or at home, suggesting that patients can be asked about their experiences before they leave the hospital without introducing bias (Reeves et al. 2002; Thomas et al. 1996). Hesitancy to express negative opinions is another factor, but this may be demographic or culturally specific. Wong and colleagues (2013) suggest that Hong Kong patients who are asked about their experience interpret this as a request for suggested improvements or for complaints, and thus describe a less positive hospital experience (Wong, Coulter, Cheung, Yam, Yeoh, et al. 2013).

According to Brown, Davidson and Ellins (2009), the perception on the part of respondents that their experiences could improve those of other patients is a powerful incentive to offer truthful real-time feedback. Indeed, the existence of online communities such as PatientsLikeMe, HealthTalkOnline and Yelp.com suggest that large numbers of patients are, in fact, keen to share their experiences online (Basch 2014; Ranard et al. 2016). Benefits of such online platforms are that reviews are often real-time and provide actionable feedback (Ranard et al. 2016). While ethical concerns cannot be overlooked, with more and more

hospitals seeking real-time data, the value of real-time data to hospital administrators also appears to outweigh any ethical concerns. In the UK, the Patient Experience Tracker (PET), a handheld device which allows patients to answer five multiple-choice questions while they are in hospital, is currently being used at more than 42 hospital trusts (Brown, Davidson & Ellins 2009). The Picker Institute's Frequent Feedback system also makes use of handheld devices to gather data in real-time (Brown, Davidson & Ellins 2009). Customer Research Technology (CRT) provides a range of products to hospitals, including handheld devices and touchscreen kiosks for real-time data-gathering purposes (Brown, Davidson & Ellins 2009). Other approaches include patient stories or interviews, paper-based methods, stand-alone kiosks, and telephone and online systems (Brown, Davidson & Ellins 2009). While most instruments identified in the review were paper-based, only five could be considered real-time. This lack of validated approaches raises concerns. Patients and their family members are actively voicing their hospital experiences in real-time, whether in passing comments to one another or to staff, or through social media and websites. While hospitals are beginning to collect real-time data, very few methods specifically designed for this purpose have been described in the literature. This is the gap which this study seeks to address.

Feeding back feedback

It would appear from this literature review that most instruments were developed without considering how feedback could be given to clinical nurses. Similarly, none of the development papers discuss how easy (or not) it is for nursing staff to interpret findings from the published instruments. Given the increased focus on patient-centred care models and attention to patient experience, giving timely and effective feedback to care providers is imperative. Indeed, McCance, McCormack and Dewing (2011, p. 1) argue that "we [healthcare clinicians] might think we are delivering care that looks like one thing, but in reality, it is quite another". While most of the literature in this review did not discuss the importance of reporting or feedback mechanisms, the Picker Institute Europe (2014) states that reporting the findings to patients and staff is crucial. The Institute (2014) suggests a 'collect, communicate, act' strategy, whereby results are readily available to staff. Interestingly, only one study (INPQCS) discussed the distribution of feedback to clinicians. The staff were informed of the interviews to be carried out in the INPQCS, and were advised that they staff would have access to the information once collated, although the paper does not discuss methods of doing so (Sweeney, Brooks & Leahy 2003).

There is little evidence available on how best to use and disseminate patient experience feedback (Coulter, Fitzpatrick & Cornwell 2009). According to research, clinical nurses tend not to feel ownership of results from surveys, often claiming that the feedback does not apply to them or their practice (Davies et al. 2011; Draper, Cohen & Buchan 2001; Reeves & Seccombe 2008). Despite this gap, none of the studies in this review identified a preferred mechanism for relaying feedback to clinicians. Clinical nurses are disproportionately responsible for day-to-day decision-making affecting the patient's experience, but evidence suggests that survey results tend to be communicated first to senior hospital administrators, from whom they slowly trickle down through the hierarchical channels (Davies et al. 2011; Reeves, West & Barron 2013). There is also a need to improve the timing of sharing feedback with clinical nurses. Commitment from every employee is required to optimise a patient's experience (Burger, Hoogerhuis & Standish 2014), but commitment alone may not be sufficient, as clinical nurses often report difficulty interpreting quantitative results (Edwards et al. 2011). Because of this, patient and family experience feedback ought to be shared in a way that is meaningful to frontline clinicians. Brown, Davidson and Ellins (2009) found that using the patient's own voice not only reflects a patient-centred care philosophy, but also enhances staff perception of the feedback's importance. The Francis Inquiry into the Mid Staffordshire NHS Foundation Trust reported that "results and analysis of patient feedback including qualitative information needs to be made available to all stakeholders in as near-real-time as possible" (Picker Institute Europe 2014). According to Reeves, West and Barron (2013), experience feedback needs to be unit-specific (i.e. department, ward or speciality) and rapid, and staff need the opportunity to discuss the findings. The findings of this literature review raise concerns about the utility of instruments for their intended or proposed purpose, given that none of the instruments were reported as having been designed with unit specificity, speed, or clinical staff in mind.

Measuring what matters

Ensuring we measure or identify what matters most to patients is essential to improving their experience (Coulter 2017). Instruments or approaches, therefore, must be designed with appropriate guiding principles and methodologies, and must be reflective of the population they serve. Guiding theory or principals were identified in the associated literature for only eight studies. HKIEQ and NHS-NAIS were based on Picker Domains (see Appendix B). The Institute of Medicine (IOM) domains (see Appendix B) were the guiding principles for the creation of the HCAHPS instrument. Patient-centred care and the assumption that all patients

want high quality service from staff and/organisations as a whole were the basis upon which the PPE-15 and howRwe instruments were developed, respectively. One of the significant criticisms of patient satisfaction surveys and surveys which assess perceptions of quality care from a validity point of view is their lack of theoretical foundation (Larsson & Larsson 2002). Only three instruments (PEECH, PAQS-ACV, QPP) were found to be based on a theoretical model, all of which used grounded theory.

It is generally accepted that instruments need to be developed which are sensitive to local healthcare systems, cultural needs and patient expectations (Wong, Coulter, Cheung, Yam, Eng-Kiong, et al. 2013). Gaining popularity within qualitative social research are participatory methodologies, in which the emphasis is on participation by all relevant stakeholders, including collaboration between researchers and participants (Polit & Beck 2010). The NHS recommends bringing staff and patients together to design service improvements (Coulter, Fitzpatrick & Cornwell 2009), while Brown, Davidson and Ellins (2009) state that patients must be involved in the design of experience measure instruments. While all studies in this review involved participants in knowledge development at some stage, it is unclear whether patients were involved at every stage. Cleary et al. (2014, p. 903) argued that “authentic and genuine consultation with stakeholders” is key to developing experience instruments. Thus, participatory methodologies are well suited to developing such an instrument. It is interesting to note that, while most instruments were developed with some stakeholder input, none were identified which were based upon a participatory methodology. It would appear this is an ideal methodology to underpin research aimed at improving patient experience.

2.5 Additional instruments and tools since 2015

In 2015, a systematic review was published (Beattie et al. 2015) identifying instruments (questionnaires) to measure patient experience of healthcare quality in hospitals. These authors identified eleven instruments, seven of which were also included in my literature review. Three would not have been included in my review based on the selection criteria: the short version Quality from the Patient’s Perspective, the Patient Experiences with Inpatient Care (I-PAHC) and the Patient’s Perceptions of Quality (PPQ) instruments. Beattie et al. (2015) included both long and short versions of the QPP, and mine only the long. The I-PAHC (Webster et al. 2011) was excluded from my review because it was designed to assess healthcare experiences only in low-income settings. The PPQ (Rao, Peters & Bandeen-Roche 2006) was excluded because the primary focus of the scale is to measure care quality and the instrument was based on satisfaction rather than experience. One additional instrument was

identified from Beattie et al.'s (2015) review: the Scottish Inpatient Experience Survey (SIPES), (see Table 5).

Since 2015, new instruments for examining patient experience have been developed. PREMs (Patient Reported Experience Measures), as they are now more commonly referred to, are in widespread use, and are often targeted to specific patient populations or conditions (Male et al. 2017). A recent systematic review of the reliability and validity of available PREMs (Bull et al. 2019) found 25 designed explicitly for inpatient hospital use. Six of these (HCAHPS, HKIEQ, NHS NAIS or AIPS, NORPEQ, PEQ, and PPE-15) have been accounted for in my literature review. Of the remaining 19 instruments, 14 were developed for specific illnesses, patient populations, and particular types of procedure (such as day surgery, which does not usually result in an overnight stay in hospital). These specific instruments would have been excluded from my review, given the focus on tools for the wider inpatient population. Bull et al. (2019) also included both short and long versions of instruments (HKIEQ), whereas I only included one version. Four new tools were identified from Bulle et al.'s (2019) review: the Flemish Patient Survey, the French In-patient Experience Questionnaire, the Inpatient Satisfaction Questionnaire and the Patients' Experience-based Evaluation Scale (see Table 5).

Table 5 Additional instruments – selected characteristics

INSTRUMENT NAME	STUDY AUTHORS	INSTRUMENT COUNTRY OF DEVELOPMENT	STUDY TITLE
FLEMISH PATIENT SURVEY	(Bruyneel et al. 2017)	Netherlands	New instrument to measure hospital experiences in Flanders
FRENCH IN-PATIENT EXPERIENCE QUESTIONNAIRE	(Labarere et al. 2001)	France	Development of a French inpatient questionnaire
INPATIENT SATISFACTION QUESTIONNAIRE	(González et al. 2005)	Spain	Development and validation on an inpatient satisfaction questionnaire
PATIENTS' EXPERIENCE-BASED EVALUATION SCALE (PEES-50)	(Tian, Tian & Zhang 2014)	China	An evaluation scale of medical services quality based on 'patients' experience.'
SCOTTISH INPATIENT EXPERIENCE SURVEY (SIPES)	(Scottish Government 2012; Scottish	Scotland	Scottish Inpatient Patient Experience Survey 2010: Volume 2: Technical report; Scottish Inpatient Experience

	Government 2010)		Survey 2012 Volume 2: Technical report
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All instruments followed similar developmental paths to those examined in my 2015 review: literature reviews, followed by focus groups or in-depth interviews with patients, establishment of expert panels or steering committees, item development, pilot testing, and appraisal. None of these new instruments appears to include family or friend representatives in the expert or focus groups, though the SIPES instrument had a Research Advisory Group which included “representation from the general public” (Scottish Government 2010, p. 120). Four instruments (the French In-patient Experience questionnaire, the Inpatient Satisfaction questionnaire, PEES-50 and SIPES) were designed to be primarily administered by post. However, the Flemish Patient Survey can be delivered face to face. The Flemish survey is conducted at or post-discharge. All other instruments are designed to be completed post-discharge. Only one instrument (The Flemish Patient Survey) could be considered near-real-time, as it can be administered at the time of discharge.

All instruments provide quantitative feedback, and two also provide limited qualitative data. The SIPES includes a section for comments, with headings such as ‘the hospital ward’ and ‘care and treatment’ (Scottish Government 2010, p. 65). The Flemish Inpatient Experience Questionnaire includes one open-ended item requesting general feedback. All five instruments were designed for patient responses only. In terms of theoretical underpinnings, the French In-patient Experience Questionnaire was developed with consideration of both ‘patient perception’ and the ‘patient voice’, while the PEES-50 was constructed according to a ‘patient-centred’ theoretical framework. The development of SIPES was based on a thematic framework developed during a literature review. While feedback from the instruments is available to healthcare administrators and, in the case of The Flemish Patient Survey, results are made publicly available via a central website (Bruyneel et al. 2017), none of the tools has an easily identifiable inbuilt feedback mechanism to clinical nurses.

2.6 Limitations

This review was not exhaustive and did not assess every available study regarding patient experience measurement. There are “tens of thousands of studies” (De Silva 2013, p. 6) purporting to measure patient experience, and assessing everyone is beyond the scope of this review. The purpose here was to identify published instruments used to capture, measure, or evaluate the patient and/or family experience in a hospital setting in which the instrument

itself was the main focus of the study. For the purpose of this review ‘measurement of experience’ referred to reported expectations, satisfaction with, feelings of, or statements about the “processes or events that occur or do not occur, in the course of a specific episode of care” (Ministry of Health Manatu Hauora 2013, p. 9). A different definition may have produced different results.

2.7 Conclusion

Current perspectives in healthcare suggest that a fundamental tenet of patient-centred care is patient experience. The impetus towards patient-centred care suggests that capturing patient experience data will take on even more importance. Progress has been made in the past decades in the science of measuring patient experience (Browne et al. 2010). This review demonstrates that, while there are a number of approaches available to measure experience in the hospital setting, these are not without limitations.

The first key concern influencing this study is the **lack of co-creation** in the development of available hospital experience feedback tools. Despite the widespread acceptance of patient-centred care and the importance of patient experience, patients and family members are rarely involved in all stages of development of instruments for capturing hospital experiences (Edwards, Walker & Duff 2015). There continues to be a **lack of real-time data collection**, despite increasing awareness of its importance. Real-time data collection limits recall bias and provides an opportunity to address issues as they arise (Boev 2012). Collecting hospital experience data post-discharge remains common practice (Edwards, Walker & Duff 2015). Current literature also suggests a **lack of qualitative methods** specifically designed to capture patient experiences of hospital care. Most tools about which studies have been published designed to elicit patient experience data provide quantitative findings (Edwards, Walker & Duff 2015) despite qualitative findings being reported to offer richer and more useful data (Cleary et al. 2014; Lees 2011; Russell 2013). This is not to say that qualitative methods are not being used in healthcare, nor that there are not a substantial number of studies using qualitative methods to capture experience data. It merely highlights a gap in the literature regarding validated qualitative instruments specifically designed to capture patient experiences. Finally, none of the identified instruments designed to capture patient experience feedback includes a preferred method for relaying patient and family feedback to nurses. This **lack of feedback mechanism** is significant, given that nurses are ideally placed to affect patient experiences. The evidence suggests, however, that they often struggle with the complexity, value, validity and timeliness of patient experience feedback (Sheard et al. 2019).

Ideally, a patient and family feedback instrument or approach would be designed using a participatory methodology. Browne and colleagues (2010) confirm that studies exploring the validity and reliability of new data collection methods should be supported. Therefore, in recognition of the current gaps in the literature, this study developed and evaluated a new feedback process which is:

1. Co-designed and co-evaluated (co-created),
2. Captures in-patient unit level, real-time patient experience feedback,
3. Provides qualitative data, and
4. Includes a specific mechanism for the sharing of feedback with clinical nurses.

Chapter 3 Methodology

This chapter deals with the theoretical foundations of the action research methodology employed in this study. A general introduction to action research is provided to situate the chapter. Action research in healthcare, and the historical developments in the approach, including the different types of action research, are then discussed. The importance of collaboration, co-creation, and patient voice in respect to action research will be highlighted, along with the practicalities of conducting it, and its tensions. Finally, processes to monitor and evaluate change are addressed.

3.1 Questions and objectives

To answer the research question (see Section 1.2), this study aimed to develop and evaluate a new hospital experience feedback process so that patient and family perspectives on their hospital experiences could be heard. As highlighted in the literature review, this process needed to be co-created by stakeholders, obtain qualitative real-time feedback, and have a mechanism for sharing feedback with the clinical nursing staff. The research objective, therefore, was to co-create a new protocol that could be used to capture unit-level, qualitative, real-time, patient and family hospital experience feedback, and share it with clinical nurses. Accordingly, an action research methodology was chosen.

3.2 Action research

The term ‘action research’ covers a broad range of research approaches with diverse origins (Reason & Bradbury 2005). Originating from branches of adult education, sociology, feminist studies, community and critical psychology, many versions of action research methodologies have emerged over the past half-century (James, Slater & Bucknam 2011). These include community-based participatory research (CBPR), appreciative inquiry (AI), living theory (LT), participatory research (PR), participatory action research (PAR), participatory action learning and action research (PALAR), and participatory rural appraisal (PRA) (James, Slater & Bucknam 2011; Tierney et al. 2016). Since the 1970s, action research has proved popular in fields such as education, economics, social sciences, public administration, and, more recently, in healthcare (Donetto et al. 2015; James, Slater & Bucknam 2011; Ozanne & Saatcioglu 2008). It was not until the 1990s, with the World Congress on Action Research,

held at Griffith University in Brisbane, Australia, that the move towards a sharing of approaches across disciplines commenced (Action Learning Action Research Association Inc (ALARA) 2018). Tripp (2005) argues that the initial lack of awareness of other kinds of action inquiry among scholars from different disciplines is perhaps the very reason that so many versions of action research exist. The result of such diverse origins and varied applications of action research is that there is no one, all-encompassing definition. According to Efron and Ravid (2013), the characteristics of action research are that it is:

1. **Constructivist.** Action researchers are the generators, rather than receivers of knowledge.
2. **Situational.** The research is context- and situation-specific.
3. **Practical.** The research is based on questions of concern or interest to the action researchers, and its results are relevant to practice improvement.
4. **Systematic.** Research is purposeful, systematically planned, and methodical.
5. **Cyclical.** Action research commences with a question, and results in the application of knowledge acquired, which leads to new questions and new sequences of research.

Cordeiro and Soares (2018, p. 1002) give four common principles is characteristic of all action research:

1. Participation and collaboration.
2. A cycle of planning, action, observation, and reflection.
3. Knowledge building that considers participants' realities.
4. Social change and problem solving.

The emergence of action research was a response to concerns that methods of inquiry within the positivist paradigm failed to fully account for the social context and the unique knowledge that people within a given context possessed (Bradbury & Lifvergren 2016). Hence, action research embraces departure from the 'expert knows best' approach, to one that values the engagement of people who are at the centre of change processes (Bradbury & Lifvergren 2016). The knowledge and understandings of local people are considered 'expert' (Kemmis, McTaggart & Nixon 2014e). Action research, therefore, is well suited to this study, given that the aim is to understand not only peoples' experiences, but also the context in which these experiences occur to improve how experience feedback is collected and shared.

In action research, 'change' via 'action' is brought about by a cyclical process known as Action Cycles (AC), which combine action and reflection, theory and practice (Reason & Bradbury 2005). In its purest form, action research, as a collaborative endeavour, is designed to create change through a series of Action Cycles, comprising enquiry, intervention, and evaluation

(Grbich 1999). Seen as more than mere problem solving, action research attempts to “understand and improve the world by changing it” (Grbich 1999, p. 207). Action Research is, therefore, concerned with the development of practical knowledge through collaboration with local people. In this sense, participants in an action research study can be understood as co-researchers or co-creators (Genat 2009; Khan & Chovanec 2010; Tossavainen 2017). Through a collaborative imperative, action research does not seek to establish a generalisable truth, but rather pragmatic outcomes based in local knowledge, and a reflective sense of what matters (Bradbury & Reason 2008). Knowledge is, accordingly, generated about the interrelationship between social and cultural situations and human behaviour (Bradbury & Reason 2008). As a result, context-specific and locally responsive action can be developed to improve practice.

Action research in healthcare

Action research has grown in popularity since its adoption in the mid-1980s to improve practices in a range of healthcare settings (Reed 2005). Healthcare systems today are facing ever-greater challenges (Bradbury & Lifvergren 2016). Ageing populations and increasing numbers of patients with co-morbidities, coupled with the growing demand for patient-centred care (PCC) have resulted in healthcare organisations having to “deliver more with less” (Mohrman & Shani 2012, p. 2). Today, such delivery necessitates the involvement of patients in health research, which in turn is central to the primary goals of patient-centred healthcare – that is, to place the patient at the centre of care (Cleary et al. 2014). Because it respects the knowledge of the stakeholder, action research as a methodology is well suited to healthcare research (Baum, MacDougall & Smith 2006; Lowes & Hulatt 2013) and, in particular, to nursing research (Reed 2005). One reason for this is that action research is seen as a way to bridge the gap between theory, research and practice (Holter & Schwartz-Barcott 1993; Koshy, Koshy & Waterman 2010; Lingard, Albert & Levinson 2008; Waterman et al. 2001).

Action research is primarily concerned with collaborative learning, reflection, action, and positive change (Bradbury & Lifvergren 2016; Hudon et al. 2016; Nicolaidis & Raymaker 2015). As highlighted above, action research demands stakeholder participation, and respects the stakeholder as having ‘expert’ knowledge which they then share through the research process. As Bradbury and Lifvergren (2016, p. 270) put it, the goal of conventional healthcare research is to “understand about”, whereas action research in healthcare is meant “to understand and improve with”. The focus of action research in healthcare moves beyond

simple outcome measurement towards exploring and co-generating solutions to practical problems (Donnelly & Morton 2019; Koshy, Koshy & Waterman 2010). The action researcher in the healthcare context – such as in this study – therefore takes on the role of co-creator, along with other local stakeholders, such as patients, family members, and nurses. The best course of action is determined through discussion and negotiation between co-creators.

Action research is a mechanism for healthcare staff to improve their practice, in turn enhancing the environment for healthcare recipients (patients and their families) (Koshy, Koshy & Waterman 2010). The findings of recent studies suggest that the implementation of action research in healthcare settings facilitates organisational change and clinician empowerment, both of which result in improved quality of care (Montgomery, Doulougeri & Panagopoulou 2015). Action research can also lend itself to a more macro and holistic view of health in general, which considers the environmental, social and economic factors, beliefs and attitudes that shape the healthcare environment (Hughes 2008; Montgomery, Doulougeri & Panagopoulou 2015). Similarly, applying a holistic and patient-centred care lens, where the patient and family are valued as experts is congruent with the participative nature of action research (Hughes 2008). The trend towards adopting action research in healthcare, in essence, mirrors the shift from traditional biomedical models of care delivery to the more holistic approach of patient-centred care, and hence is highly appropriate for this study.

History of action research

An ‘actionist’ approach to research can be traced back to the work of J. L. Moreno (1889–1974), a Romanian-American psychiatrist, in the early 20th Century (McTaggart 1994). However, it was Kurt Lewin (1890–1947), who met with Moreno several times in 1935 (Moreno 1953), who is most widely credited with first constructing a theory of action research in the early 1940s (James, Slater & Bucknam 2011). A social psychologist, Lewin conducted research at the Tavistock Institute, which was famed for producing innovative, knowledge-based solutions for contemporary problems aimed at social change (Reason & Bradbury 2005; The Tavistock Institute 2019). Atypical of social research at the time, Lewin did not see the researcher role as that of an ‘outsider’, but rather as an active participant in both the research and change processes (Maksimović 2010). Lewin also saw value in including ‘everyday people’, and conducting research in real-life settings. He believed that it was impossible to try and understand a system if one does not try to change it (Maksimović 2010).

Collier (1884-1968) an American social worker and anthropologist, and close friend of Lewin, actually used the terminology of action research one year prior to Lewin, in 1945 (Hockley, Froggatt & Heimerl 2013; Neilsen 2006), however, he remains overlooked as a co-founder (Maksimović 2010). According to Hockley (2013), Collier's view regarding action research in education was that the findings of such research ought to be actioned by both administrators and laypersons. As such, Collier argued that local people must participate in the research (Hockley 2013). Action research developed through the years, advancing from Lewin's original view of it as a short-term intervention towards a longer-term and cyclical process referred to across the educational literature (Reason & Bradbury 2005). In the 1950s, Stephen Corey (1904–84) and other American researchers adopted action research for studying educational problems (Koshy, Koshy & Waterman 2010). Corey was also adamant that teachers, supervisors and administrators must research their own practice to improve it (Corey 1953). From this perspective of local stakeholder engagement and collaboration, action research lends itself to the current study, where both recipients and providers of healthcare have an interest in the research questions and their outcomes.

In the UK, Lawrence Stenhouse's seminal work *An Introduction to Curriculum Research and Development* (1975) further propelled action research as an ideal approach to improving educational practice (Koshy, Koshy & Waterman 2010); ideal because the research is undertaken by 'Practitioners' (the subjects of practice) – in his *Introduction's* case, educators – so that they may improve their practices. In the 1980s, Australian Educationalists Stephen Kemmis and Wilfred Carr established a new direction for action research by drawing on the work of German Philosopher Jürgen Habermas (1929–), specifically his *Theory of Knowledge Constitutive Interest* (1972). From this work, Carr and Kemmis (Carr & Kemmis 1986; Kemmis, McTaggart & Nixon 2014a) distinguished three types of action research – technical, practical, and critical (or emancipatory). This new development was well received by those in the field of education, and was also adopted by action researchers in healthcare settings (Koshy, Koshy & Waterman 2010).

Types of action research

Habermas' (1972) work provided a theoretical background and epistemological blueprint for Carr and Kemmis (Carr & Kemmis 1986; Kemmis, McTaggart & Nixon 2014a) to develop their typology of technical, practical and critical action research. Most action research approaches can be mapped to one of these categories. The following sections will briefly address each type in order to position the approach adopted for this project.

Technical action research

Technical action research is based in Habermas' (1972) 'technical interests'. Technical interests are focused on the production of knowledge that is objective and replicable. They are oriented towards testing a particular (pre-determined) intervention. The primary purpose of technical action research is to improve a known outcome of practice; for example, an improvement in student test scores or patient health outcomes (Kemmis, McTaggart & Nixon 2014c). This approach is ideally suited to specific areas of healthcare research. For example, Fenton (2008) successfully developed a post-fall assessment algorithm, using a technical approach, which could be used by clinical staff. The knowledge produced in this type of action research is 'technical' in that it is predictive and provides a causal explanation (Duesbery & Twyman 2019). The role of the researcher is that of 'outsider', clearly distinguished from that of the participant or subject (Coghlan & Brydon-Miller 2014). The goal of technical action research is to improve practice to achieve the desired outcome. Success is based on matching outcome with aspiration (Kemmis 2008). While others can be involved in the study, the researcher determines the action and makes sense of the observations and other data (Kemmis 2008; Kemmis, McTaggart & Nixon 2014c). Such research is 'on' or 'for' people as opposed to 'with' them (Coghlan & Brydon-Miller 2014). Seen as a 'technical approach to reasoning', in technical action research, the researcher identifies the problem and intervention with the intention of promoting more efficient and effective practice (Kemmis, McTaggart & Nixon 2014c). The engagement of participants is a means to an end, rather than the end itself.

'Others', such as participants, may be involved in a technical approach. However, they are typically seen as 'objects' of the action, rather than stakeholders equally situated within the context (Kemmis, McTaggart & Nixon 2014c, p. 70). Therefore, in technical action research, the relationship between the researcher and the participants affected by the research is not reciprocal (Kemmis, McTaggart & Nixon 2014c). One criticism of this approach is that it fails to question the original goals of the research (Kemmis 2008). Also, a lack of participant ownership and insufficient participant 'buy-in' can potentially result in changes that are unsustainable. Further, a lack of consideration of broader political, social and historical contexts is another frequently critiqued aspect of the technical approach (Coghlan & Brydon-Miller 2014). The approach's success, however, can result in improved outcomes of practice, be they more effective or more efficient (Kemmis, McTaggart & Nixon 2014c).

Practical action research

Practical action research is similar to technical action research in that it has the technical aspirations for change and is often researcher-directed. Practical action research differs in that 'others' involved in the setting have a 'voice' (Kemmis 2008; Kemmis, McTaggart & Nixon 2014c). Knowledge based in what Habermas (1972) refers to as 'practical interests' is located within the interpretive paradigm. This knowledge values peoples' lived experiences, focusing on interpretations and shared understandings of reality (Gunbayi 2020). Practical action research seeks an understanding between participants and the researcher about their subjective realities, as opposed to the positivist paradigm under which researchers see themselves as outsiders 'looking in' on research.

In this type of research, again the researcher usually designs or chooses the changes that are to be made to current practice. Aimed at improving people's subjective understandings of their practices, practical action, unlike technical, recognises that all outcomes cannot be pre-known (Kemmis 2008; Kemmis, McTaggart & Nixon 2014c). This is important because the goal of the researcher or researchers is a change of understandings and in the outcome of practice (Kemmis 2008). Such an understanding requires an acceptance and appreciation for others' knowledge and lived experiences. By adhering to this principle, the researcher ensures a focus on the fact that people in the local setting will live with the consequences of the action. In this sense, the participants are considered 'experts' in their field. While the academic or external researcher may still guide the research, he or she respects and takes on the views and responses of the participants the research affects (Kemmis, McTaggart & Nixon 2014c).

Criticisms of this practical approach are that it distorts conclusions, because broader social, economic and political systems which shape how we view and act within the world are not considered (McNiff 2013). The capacity to bring about change that addresses broader interests is therefore limited, and, as a result, change may be difficult to action, or may have a limited effect. Benefits, however, from a practical perspective, are that projects involve others but remain somewhat researcher-directed (Kemmis, McTaggart & Nixon 2014c).

Critical (or emancipatory) action research

According to Carr and Kemmis (1986), critical, or emancipatory, action research is based on what Habermas refers to as 'emancipatory interests'. Emancipatory interests are concerned with exposing the operation of the dominant power relations, injustices, values and beliefs

that constrain us (Field 2019). Such interests emerged from a broader school of thought known as critical social theory (CST). Critical social theory was concerned with the dominance of positivist science, and rejected the interests of empirical and analytical sciences (Bachmann & Moisis 2019; Habermas 1987). CST is concerned with the emancipatory interest in autonomy, and with the notion that individual autonomy requires the autonomy of other individuals in society (Blaikie & Priest 2019; Browne 2017).

The crucial function of CST is to expose and disrupt dominant forces that can result in marginalisation and oppression (Harney 2015), thereby bringing improvement in the human condition (Hockley 2013). Concepts such as 'taken-for-granted' (or unexamined) assumptions, ideology (a system of organising beliefs) and hegemony (the dominance exerted by one group over another, and the mechanisms that sustain and maintain these oppressive circumstances) are central components of CST. Habermas, who belonged to the 'second generation' of the Frankfurt School of critical theorists, stressed that for society to change, critical self-reflection and acting responsibly upon that reflection were vital (Anderson 2014). Thus, critical or emancipatory action research abandons the traditional hierarchy of 'researcher' and 'subject' (or stakeholder). Stakeholders work together with the researcher to identify problems, set the research agenda, and develop a critical and self-critical understanding of the situation towards an emancipatory goal (Given 2008; Kemmis 2008). This is done with a view to critiquing and disrupting beliefs and practices that support the domination of one group's interests over another, with the aim of developing more just and equitable circumstances (Kemmis, McTaggart & Nixon 2014a). Unlike technical and practical action research, critical action research seeks to improve practice and self-understanding, but also to critique social and/or work settings (Kemmis 2008).

Other distinctions

In addition to the typology of technical, practical and critical action research (Carr & Kemmis 1986), other action researchers have adopted different terminology, but they have been essentially based on the same knowledge-related interests, as discussed above. Grbich (1999), for example, identifies three forms of action research: 'directed', 'participatory' and 'post-modern'. Grbich (1999) suggests that, in healthcare research, there is a spectrum of action research. The spectrum begins at the experimental end of the continuum, where the emphasis is on scientific experimentation. At this end, the researcher is in the driver's seat. At the opposite end lies empowerment and emancipation. Towards the emancipatory end of the spectrum sits what is known as participatory action research (PAR), whereby a group or team

of people (usually stakeholders) come together to identify problems, and develop and evaluate solutions (James, Slater & Bucknam 2011). Here, patients, family members and clinicians would be equal co-researchers. Postmodern action research sits at the very end of this part of the spectrum, and is focused on genuine equality with the intent of transforming and restructuring relationships and settings. McKernan (1991) classifies three action research approaches according to the three classical research paradigms: positivist, being the 'scientific-technical' approach as adopted by Lewin, whereby an objective reality can be gained from observable data (Hockley 2013); a 'practical' approach, based on interpretive understandings gained from working on practical problems; and finally, a 'critical emancipatory' approach for education-specific action research (Hockley, Froggatt & Heimerl 2013).

Pragmatic action research

It was important to have an understanding of the different types of action research in order to choose an approach which best suited the question and context of the study. It became apparent early on that no one approach was ideal. As such, a pragmatic action research approach was adopted. A 'pragmatic action approach' is a fit-for-purpose approach in which multiple approaches are deemed relevant if they support action (Greenwood 2007). A pragmatic action research approach can be used when circumstances are such that no single typology of action research is ideal, nor one single point of view is sufficient to answer the research question. While there is ongoing inquiry and redesign in all approaches, the complexity of the problem is the reason for diverse stakeholder participation in pragmatic action research rather than any moral or political agenda (Greenwood 2007; Kuitenbrouwer 2018). Situational usefulness should dictate the approach taken at each stage (Greenwood 2007). From a pragmatic perspective, no one theory, technique or method is deemed ideal or discounted as long as its contribution upholds the fundamental principles of action research (Greenwood 2007). This study, which aimed to create a new feedback protocol, was not funnelled into a distinct technical, practical, or critical action approach. Given the complexities of the healthcare setting, the fact that the study was conducted in the broader context of a PhD program, it required a more flexible path.

A pragmatic approach enabled a level of fluidity in the research. Under this model, predominantly technical and practical strategies informed the research at various points. For example, I entered the field technically, with a problem that I wanted to address and a broadly defined outcome (a new feedback protocol). Moreover, as a PhD candidate, at the

commencement of the study, I occupied the status of ‘outsider’ researcher, in keeping with a technical position, and I directed the initial course of the study. This included setting up the study, gaining ethics approvals, and organising the Advisory Group. As the project progressed through a number of action cycles, this involved the collaboration of stakeholders (Advisory Group members) to develop mutual understandings and new knowledge. This generative process meant that the project shifted to a more practical approach. Now, the Advisory Group and I shared a mutual understanding about the anticipated general outcome of the study (a new protocol), but the specifics of the outcome were not pre-conceived. To that end, a practical approach underpinned by mutual and ongoing collaboration was most suitable for the progress of the action cycles. The practical action research approach also facilitated the flexibility required to achieve research and academic milestones. Advisory Group members, for example, were aware of my academic deadlines and provided feedback accordingly.

3.4 Collaboration, co-creation, and pragmatic action research

Central to any collaborative endeavour is collaboration; put simply, to “co-labour to achieve common goals” (Poocharoen & Ting 2015, p. 588). Collaboration in healthcare usually refers to the mutual communication and work of healthcare professionals (Emich 2018). In nursing, collaboration denotes intra-professional (between nurses) or inter-professional (between others outside the nursing profession) interactions (Emich 2018). With regard to patient-centred care, however, collaboration is concerned with giving a voice to patients and their families, bringing people together to share ideas, and putting healthcare recipients at the centre of their healthcare journey. Co-creation and collaboration in healthcare moves away from conventional distinctions between provider and recipient, and from mere patient and family engagement and involvement, to a shared creation of healthcare, services and research (Filipe, Renedo & Marston 2017). In this study, collaboration provided opportunities for Advisory Group members (patients, family members and nurses) to participate in discussions as experts in their own fields of knowledge and experience.

Healthcare researchers are increasingly recognising the value of collaboration and are therefore including patients as co-creators (DelNero & McGregor 2017; Fagan et al. 2016; Fleurence et al. 2014; Richards, Snow & Schroter 2016; Shklarov et al. 2017). Ideally, co-creation (see Section 1.3 Background) is operationalised through collaboration and participation, which was a vital characteristic of the pragmatic action research approach adopted to guide this study. If we are to consider the patient and family experience as an “all-encompassing reality”, it stands to reason that the idea of including all voices is crucial (Wolf

2016b, p. 184). In addition to healthcare researchers recognising the benefit of hearing the 'patient's voice', patients themselves are increasingly demanding to be heard (Mohta, Volpp & Heisler 2017). Patients' involvement and collaboration are also both consistent with international policies and ethical practices of patient and public involvement (PPI) in healthcare research (Brett, Staniszewska, Mockford, Herron-Marx, et al. 2014; O'Reilly-de Brún et al. 2018). The patient's voice has shifted from a passive to an active role, becoming a co-contributor and co-owner of healthcare research (Wolf 2016b). "By having the patient voice at the research table, we are able to think about results as being meaningful to patients not just data for academic journals" (Johnson et al. 2016, p. 5). A desire to practice and provide patient-centred care has dictated a shift towards adopting a more democratic model in both healthcare provision and research. This study sought to reflect that shift.

Despite an apparent consensus regarding the necessity of co-creation, and the equality of relationships the term suggests, there is no universal blueprint for what co-creative collaboration entails, nor what it should look like in practice (Filipe, Renedo & Marston 2017). Similarly, there is no easily identifiable guide to ensure collaboration is achieved in an action research study, pragmatic or otherwise. Clauset, Lick and Murphy (2008, p. 51) suggest, however, that "collaborative action research" requires a "synergistic co-mentoring team". The focus of the team should be a common issue or goal, and on creating "momentum toward more insight into the problem" (Mertler 2017, p. 61). MacFarlane et al. (2012, p. 4) suggest that a "participatory learning" and "action methodology" is an adaptive, collaborative, and pragmatic research approach which encourages:

1. Co-design of the research agenda with stakeholders
2. Co-generation of knowledge by key stakeholders
3. Co-analysis of research evidence by key stakeholders
4. Reflection on research findings, and
5. Evaluation leading to identification of next iterative step required.

Selecting action research as a methodological approach created the potential to meaningfully involve stakeholders beyond what has in the past been described as 'tokenistic inclusion' (Domecq et al. 2014). Sacristan et al. (2016), however, suggest that their inclusion has not matched the rate of uptake of patient-centred care, and that often inclusion in research endeavours is merely symbolic (Domecq et al. 2014). This study seeks to address that. By bringing people (nurses, patients, and family members) together to develop a new feedback protocol, pragmatic action research offered a flexible approach to working with both care providers and care recipients as experts. It is through collaboration, inherent within the

action research process, that the experiential knowledge of healthcare providers (clinical nurses) and healthcare recipients (patients and their families) can be shared and their collective voices heard.

3.5 Facilitation of an action research study

Just as a patient-centred culture in healthcare requires practice-based facilitated learning activities (Hardiman & Dewing 2019), successful action research, too, relies on skilled facilitation (Thomas 2008). Establishing a clear sense of purpose from the outset is essential to the facilitation of an action research project, as is a willingness to embrace multiple ways of accumulating knowledge (Pajalic 2015). A sense of purpose ensures the direction is based upon a shared understanding of the problem or issues at hand (Mertler 2017). As discussed in Section 3.3, this study was informed by technical and practical interests. These interests or perspectives provided a guide for the process of facilitation.

Wadsworth (2008) conceptualises two kinds of facilitation. The first, where the researcher “carries out things for ourselves”, and the second where the researcher “keeps watch”, ensuring actions are taken individually or collectively (Wadsworth 2008, p.322). My role in facilitating this study reflected both of these aspects of facilitation; I actively participated in activities and discussion with key stakeholders while at the same time overseeing the research as a whole, as it unfolded.

Cranley et al. (2017, p. 10) have identified nine facilitator roles from a scoping review on the characteristics and facilitation roles associated with healthcare professionals and research use. A ‘research facilitator’ provides support in order to help develop knowledge, research skills and participation in the research (Cranley et al. 2017, p. 4). They suggest that the goal of the facilitator is to ‘drive and motivate’ change and to act as a resource for participants. I was aware that I possessed novice research skills and the clinical background required to support participants in the research endeavour, however conducting action research as part of a doctoral study requires certain compromises. For example, from the outset, I was aware that the majority of writing, dissemination of findings, and decisions regarding publication would rest with me (and my academic supervisors). The time constraints of my candidature and ethical requirements associated with research dictated that several study activities, such as ethics approval applications and patient and family hospital experience interviews, were driven by me alone. My involvement primarily reflected a technical approach to these aspects of the study. While this could create tensions with the principles of democratic and collaborative decision-making that underpin action research, pragmatic choices had to be

made to move the project forward within an academic program. The study was driven by me as the researcher, but other key stakeholders (Advisory Group members, patients, family members, and nurses) worked in partnership with me throughout. As such, I remained very much sensitised to the need to engage these people. I valued their contributions to both the generation of knowledge and action. In this sense, I attempted to 'carry things out' and 'keep watch' at the same time.

Challenges to facilitation, my position as a researcher and role as facilitator

In an ideal scenario, a group of stakeholders would have independently recognised the value of action research and then engaged someone as their 'action scholar' to support their project (Maestrini et al. 2016, p. 293). However, because this project was conceived as a PhD study, this was not possible. Instead, I was the instigator, and approached the future members of the Advisory Group. Working with people who had not previously engaged with action research (in this case, the Advisory Group members) meant that my role as a facilitator included assisting the stakeholders to develop a level of research capacity and proficiency. This role included introducing the stakeholders to the action research process in order to support the group to achieve our research goals. Narrowly defined, the purpose of facilitation is to achieve goals (Tiberg et al. 2017). However, a broader definition – one which I adopted – refers to the development of teams and individuals with a focus on processes and relationships to achieve their goals (Harvey et al. 2002; Tiberg et al. 2017). Power differentials however must be considered and acknowledged in any form of participatory research undertaken (Cook et al. 2019). While my role in assisting the stakeholders to develop action research skills may seem at odds with acknowledging stakeholders as experts in their own right, conducting action research under 'real-world' conditions required me to navigate this tension.

I accepted therefore that there would be an inherent 'power' imbalance in that I would be essentially 'driving' the study. Paradoxically my role as a research facilitator with research skills and knowledge had the potential to 'dis-empower' participants whereby their 'voice' may not have been heard. I needed therefore to carefully consider how to support and work with stakeholders to assist them as co-researchers, and this necessitated a consideration of my position as a researcher in a collaborative project. The early Lewinian view of action research held the 'facilitator' or non-participant researcher to be an outsider (Kemmis, McTaggart & Nixon 2014c). Kemmis and colleagues (Kemmis, McTaggart & Nixon 2014c, p.

52) are critical of this position of “disinterest”. They posit that outsiders must become engaged participants. While I could be considered an ‘outsider’ in one respect – that I adopted the role of researcher based at a university – I was certainly not disinterested. Moreover, while I had been a clinical nurse in the casual pool prior to the field study, clinical nursing staff did not necessarily think of me one of their own. From this perspective, I can be considered an outsider as well. Further, to family and patients, I was a nurse interviewing them. In that capacity, too, I occupied an outsider position as far as their experiences were concerned.

Conversely, as a Registered Nurse who had worked at the hospital, I was also somewhat an ‘insider’, having been a clinical nurse and facilitator, and thus understanding the workings and politics of the hospital. Because of this, I brought a range of assumptions to the study. Most forms of action research expect a participatory worldview that requires participants to be “embedded and reflexive” (Casey, O’Leary & Coghlan 2018, p. 1053). As an insider, I needed to be critical of how these assumptions affected the research and my relationships with the Advisory Group. While I did not set out to investigate the power imbalances between healthcare providers and healthcare recipients, ideally my role would be to facilitate more democratic approaches to the construction of knowledge. Cognisant of the danger of self-deception, and aware of my own bias, I was alert to my potential inability to recognise the extent to which my self-interest and that of other participants overlapped. Would I, for example, feel more aligned to the nurse members in the Advisory Group than to the patients or family members? Adopting a participatory worldview, underpinned by the belief that one’s ‘reality’ is co-created with others and that truth is negotiated and changeable, allowed me to understand and critique my position as a facilitator and co-researcher. Such an epistemological stance meant that my role was not to capture or define an objective ‘truth’ about a patient’s hospital experience. Rather, through my insider/outsider status, I was able to support the sharing of ideas and co-creation of knowledge in and through action.

Hughes (2008) suggests that when employing action research the researcher must believe that the methodology is well suited, and that, ideally, they should have the time required to share ideas with the stakeholders fully and honestly. As a researcher, I wholeheartedly embraced action research as a methodology, although as a PhD candidate, there were time constraints. The shared positionality I adopted (insider and outsider) brought a tension to facilitation, and one that needed to be negotiated. Despite the tensions and barriers, highlighted throughout this thesis, a pragmatic action research methodology to guide the

study was the methodology of best fit to co-create a new hospital experience feedback protocol which would allow patients' and family members' voices to be heard.

Conduct of the action research study

Collaboration and participation occur throughout the entire research process, from problem identification and design, to data collection, analysis, and the application of findings (Ozanne & Saatcioglu 2008). The conduct of action research typically employs recurring action cycles (AC). Usually, an action research study commences with reconnaissance and problem recognition, followed by a series of self-reflective spirals of planning, acting and evaluating, followed by re-planning, and so on (see Figure 4) (Coghlan & Shani 2017; Kemmis, McTaggart & Nixon 2014b, 2014c; Lewin 1946). Each component of the cycle, however, is not a separate and distinct entity. Similarly, cycles can and do overlap or become obsolete (Koshy, Koshy & Waterman 2010). The iterative nature of action cycles allows for the emergence of knowledge through action and reflection on that knowledge. These are the hallmarks of action research (Koshy, Koshy & Waterman 2010). Through this iterative process, the new knowledge developed informs ongoing change.

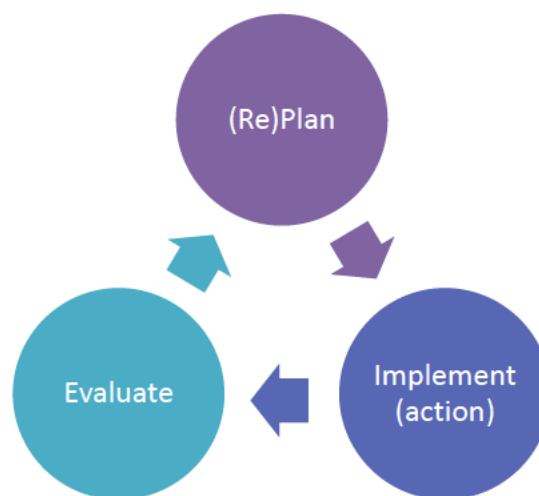


Figure 4 Action sequence (Tripp 2005)

Engaging in action research, particularly in a 'greenfield' site, meant that there needed to be fluidity in its conduct. The cyclical process of planning, implementing, and evaluating, traditionally taken in all action research, facilitated the level of flexibility required. Furthermore, utilising such cycles can facilitate the translation of knowledge into practice through the reflection and implementation of change (McCormack 2015). It is important to note, however, that action research studies rarely use just one mode of research (as

discussed), nor do they encapsulate every characteristic of that mode. They do, however, all utilise a cyclical approach (Tripp 2005). Each activity within the ‘plan, act (or implement), evaluate’ cycle, can also be performed differently, as such, there is no single prescribed method for each step, nor just one way an action research project should be conducted (Kemmis, McTaggart & Nixon 2014b; Tripp 2005).

Action cycle activities

Reconnaissance – preliminary investigation

Action research typically commences with a ‘reconnaissance’ or preliminary investigation during which key stakeholders come together to identify shared concerns about their current practices (Kemmis, McTaggart & Nixon 2014b). Key questions regarding current practice and the ramifications of such practice are discovered and explored. I initially came to the research with a problem, based on my honours thesis on patient experience (Edwards, Duff & Walker 2014) and subsequent work which identified a lack of published qualitative real-time feedback methods (Edwards, Walker & Duff 2015). The ‘reconnaissance stage’ – which formed part of the first Action Cycle – consisted of bringing together a group of patients, family members and Registered Nurses (including me) to form an Action Research Advisory Group (see Action Cycle 1). Early discussion among the group’s members provided an opportunity to collaboratively examine how feedback is collected and consider whether the lack of published qualitative real-time patient experience feedback methods was in fact an area of concern.

Plan

In the planning phase, stakeholders tentatively decide what action will be taken to improve the current practice (or issue under investigation). Importantly, what the results will look like is considered, along with how the change will be monitored. Planning occurs across two interrelated strands (see Figure 4, p54): firstly, planning a change to practice, and secondly, planning how the changes in practice will be evaluated. Kemmis et al. (2014b, p. 335) suggest that planning a change to practice (‘planning the practice’) involves discussions moving from asking “What is to be done?” to questions with more detail, such as “What is to be done about what, by whom, where, when and how?” (Kemmis, McTaggart & Nixon 2014b, p. 335).

Similarly, planning to evaluate the change to practice (‘planning the inquiry’) consists of asking the same questions: what, who, when, where, and how will we evaluate the change? (Kemmis, McTaggart & Nixon 2014b). By considering such issues, detailed plans for change

can be developed based on a collective rationale developed by the stakeholders, thereby providing a systematic way forward. This pathway is represented in Figure 5, below.

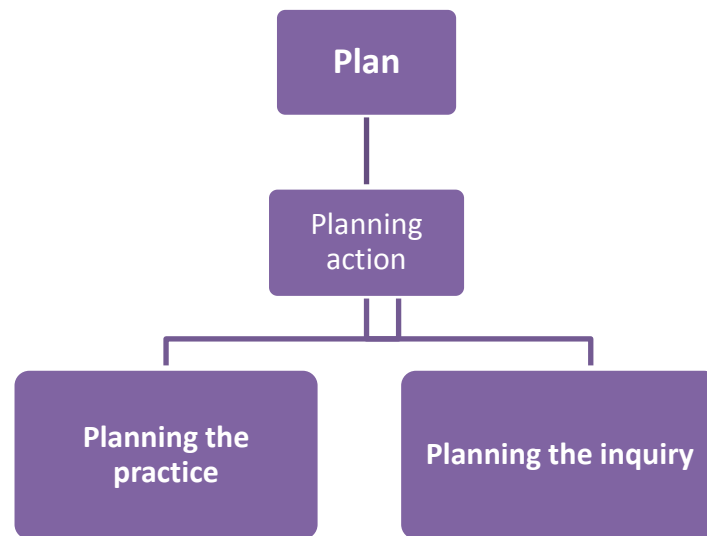


Figure 5 Planning the action – pathway

Act (implement)

During the 'act' stage, participants implement the planned action. In this study, the term 'implement' has been used instead of 'act' or 'action', because Tripp (2005) argues that in each component of the action cycle (whether it be planning, action, or evaluation) there is inherently an action process. Tripp (2005) thus contends that it is more appropriate to use the term 'implement' than 'action'. As with planning, implementation occurs in two interrelated strands (see Figure 6, p57). Firstly, implementation of change to practice and secondly implementation of inquiry. The implementation of inquiry, whereby data are collected throughout the implementation stage, enables monitoring of the action as it occurs and provides information for evaluation and reflection before re-planning. This monitoring is essential, because during the implementation phase, unforeseen circumstances may arise, and if they do, a process of re-planning of the action and the inquiry may be required. While there are no set techniques for data collection in action research, evidence should be gathered regarding both the action taken and the consequences of that action (Kemmis, McTaggart & Nixon 2014b). The pathway to implementation is represented in Figure 6, p57.

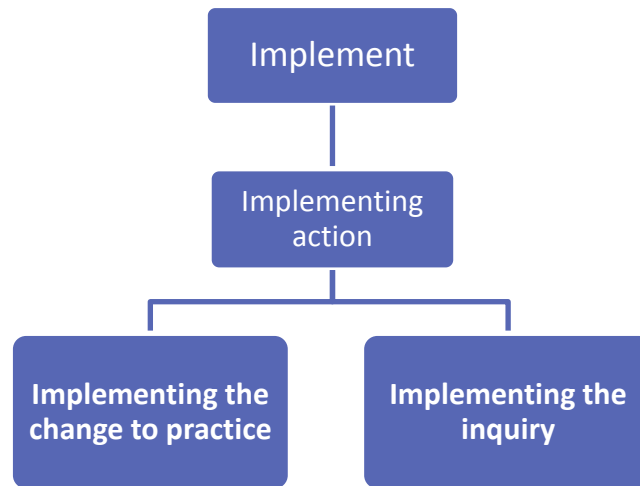


Figure 6 Implementing the action – pathway

Evaluation and reflection

In the 'evaluation' stage, the implemented action is reflected upon, reviewed, and analysed, as is the action inquiry process (see Figure 7). Thus, evaluating the change in practice often involves stakeholders reflecting on the data collected. Achievements, limitations, and consequences are then considered through these reflective stages within each action cycle. Ideally, mutual understandings of issues and perspectives are then reached by the stakeholders. These understanding inform the next action cycle. The pathway for this evaluation is represented in Figure 7, below.

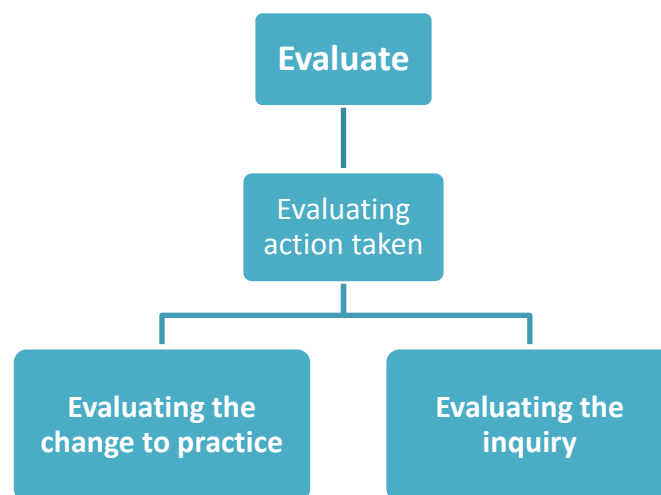


Figure 7 Evaluating the action – pathway

In addition to evaluating the implemented action (change to practice), the inquiry process is also evaluated. Adherence to the aims of the project are considered here. In this study,

evaluating the inquiry meant assessing whether a patient-centred care approach was being upheld. In addition, evaluating the inquiry also considers the extent of collaborative engagement among the stakeholders (here, the Advisory Group). The research process, including the roles and the participation of stakeholders and participants, may also be evaluated at this stage. Future planning is based on these evaluations and reflections, which may also include a return to the literature to make sense of findings and support decision-making about future courses of action.

Monitoring and evaluating change

Action research cycles depend on evaluation and re-evaluation to ensure that knowledge captured is factored into future planning. Such knowledge depends on monitoring and evaluating change (McNiff 2013). Change is therefore examined so that the impact of the action taken can be assessed and reflected upon. Reflection and evaluation of change are key to ensuring the overarching goals of action research are being upheld. There is a range of ways to monitor individual and collective actions and how reflection and evaluation have informed them (McNiff 2013). Data from researcher journals, emails, letters, texts, video, and audio recordings, for example, can be used to monitor both thinking and action. The monitoring of these factors is, therefore operationalised by gathering evaluation data on the inquiry process. McNiff (2013) suggests that change in action research can be specifically monitored across several domains:

- a) Our thinking and practice
- b) Other people's thinking and practice
- c) How we are influencing one another, and
- d) How we are developing new insights and practices through interactions.

While McNiff's domains have been used in this study, it is interesting to note that they are similar to earlier work by Kemmis (1988), who argues that change monitoring occurs across registers of language, activities and social relationships. Kemmis (1988) suggests that changes to people's understandings are expressed through language, changes to practice evident in activities undertaken by participants, and changes to social relationships, as revealed by the way that people interact with each other and with the change process. However, change must also be considered in terms of how individuals and groups who are not directly involved regard it (Kemmis, McTaggart & Nixon 2014d, p. 150). As McNiff (2013, p. 105) advocates, the researcher must monitor "what you [the researcher] are doing" and "what other people are doing". Changes in thinking and practice are seen as reflecting a shared understanding of the

issues at hand, and a willingness to accept action research as a methodology among stakeholders. Such changes also highlight acceptance of the proposed change by study participants. In this study, a change in practice also highlights the extent to which key stakeholders are actively engaged with the research process. A change in activity by study participants demonstrates the extent to which the new action meets the study's aims. Changes in how we influence each other and develop new insights and practices through interactions reflect an acceptance or opposition to the action.

Sense-making

This study was set up to embrace the values associated with patient-centred care, collaboration, co-creation and patient voice, with an appreciation for the technical and practical interests underpinning action research. As an action research study, there is a theory–practice integration under which thought guides action and action guides thought. This approach results in ‘informed action’; the action is always guided by the desired positive outcome, which stems from ‘knowledge’ or ‘understanding’ (Dick, Stringer & Huxham 2009). In action research, when results differ from the desired outcome, sense-making naturally occurs. Dick, Stringer and Huxham (2009) posit that theory in action research refers to these activities of knowledge, understanding and sense-making. Future action is influenced by these activities, and a pragmatic action approach allows for the strategic adoption of multiple techniques or methods which are best suited to the situation or group. These methods can be both eclectic and innovative. The result of this study is a pragmatic action research study adopting a combination of predictive knowledge (technical) and co-generative knowledge (practical), with subjectivity highly valued.

Chapter 4 Research Design

This chapter provides an overview of the research context and study site. The overall structure of the study will be outlined, as well as participant recruitment, data collection, and analysis techniques. The chapter concludes with sections on matters of validity and ethics relevant to action research.

4.1 The research context

This project was conducted in Sydney, Australia, at a tertiary teaching private hospital. At the time of the study (2015–17), the hospital had 270 acute care beds, and provided a wide range of general and specialised medical and surgical services to more than 24,000 patients per annum. The population consisted of adults (aged 16 and over) (St Vincent's Health Australia 2019; St Vincent's Private Hospital Sydney 2015). English was the predominant language spoken at home by in-patients (St Vincent's Private Hospital Sydney 2015). Field-testing of the new feedback protocol took place across six medical and surgical in-patient units (IPUs, formerly referred to as 'wards') and one young adult (age 16 to 25) mental health in-patient facility.

Current experience climate within the hospital

In 2016, the study hospital had a Net Promoter Score (NPS) (willingness by patients and family to recommend the hospital to others) of 82.7 (St Vincent's Health Australia 2019). Any score above zero is considered to be 'good', and above 50 is 'excellent'. This hospital's score was higher than both the national and international benchmarks (St Vincent's Private Hospital Sydney 2015). Gallup polls conducted at the time also indicated a "high level of staff engagement" (the degree to which nurses were fully involved and satisfied with their work), with a low staff turnover rate of four per cent (St Vincent's Health Australia 2019). Low turnover and high staff satisfaction among nurses tends to be associated with better patient experiences (Kutney-Lee et al. 2009; MacLeod 2012; Stephenson 2015). These results suggested that we would encounter predominantly positive hospital experience feedback when testing the RHEPORT Protocol.

4.2 Setting up the study

As a PhD candidate, I was required to attend to several academic and institutional requirements. At the beginning of the study, I broadly defined the research question, obtained access to the research setting, secured ethics approvals to form an Action Research Advisory Group, and subsequently sought additional ethics approvals to field-test the RHEPORT Protocol.

Defining the initial research question

As discussed in Chapter 1, I began my PhD with a desire to improve the patient experience. This goal was based on my previous Honours work researching patient-centred care and the varying perceptions of patient experience (Edwards, Duff & Walker 2014). Recognising that to improve patient-centred care we must capture what matters to patients and their family, and that ‘experience’ is increasingly recognised and solicited as a means of assessing patient-centredness (Smirnova et al. 2017), I crafted the broad research question: *How can we capture the patient’s hospital experience?* Conducting a literature review (see Chapter 2) allowed me to frame the area of study in light of current knowledge.

Based on the matters highlighted in the literature review – lack of stakeholder engagement in tool development, lack of real-time data collection, of published qualitative collection methods and of feedback mechanisms for nursing staff, I initially posed the following question to the Advisory Group:

How can we improve the current methods of capturing and disseminating hospital experience feedback knowing what we know?

Entering the research setting and forming an action research Advisory Group

As discussed in Chapter 2, the involvement of hospital healthcare recipients (patients and family) and providers (clinical nurses) was central to the collaborative nature of this study, and to establishing the Advisory Group. Its members needed to be invested and interested in the area of patient experience, as they would be responsible for driving and championing the project. To recruit these stakeholders, I negotiated access to the hospital site in consultation with the hospital’s Director of Nursing and Professor of Healthcare. After this negotiation, and before recruitment, I applied for and was granted ethics approvals (see Appendix G) to form an Action Research Advisory Group.

Establishment of an Advisory Group

Recruitment and inclusion criteria

Advisory Group members were recruited and then selected based on inclusion criteria (see Table 6). Specific groups were recruited in different ways.

Patient and Family Advisory Group Participants

Patient and family member recruitment flyers (see Appendix H) were placed in the public elevators on the hospital campus, in-patient unit waiting rooms, and in the hospital admission waiting room. These participants were also recruited by word of mouth, and via email.

Interested participants were then sent an information sheet (see Appendix I) outlining the purpose of the study. After discussing the expectations of participation and associated ethical implications, by phone or in-person, participants completed a consent form (see Appendix I) if they were happy to proceed. I collected consent forms before or on the day the Advisory Group first met, which was for a workshop.

Nurses

Nursing recruitment flyers (see Appendix H) were placed in the hospital's staff elevators and break rooms. Clinical Nurse Educators (CNEs) on all medical-surgical units were contacted via email and informed of the study. They were asked to approach nurses they thought might be interested in participating and to provide them with the information flyer directly. The flyer invited nurses to contact me if they wished to know more about the study, and were then sent an Information Sheet (Appendix I). After discussing the expectations with me, nurses agreeing to participate were then advised to seek approval from their respective Nurse Unit Managers (NUMs). After approval, nurses consented by signing a consent form (Appendix I). These were collected before or on the day of the Advisory Group workshop.

Table 6 Advisory Group Member inclusion criteria

TARGET GROUP	INCLUSION CRITERIA
FAMILY MEMBERS	<ul style="list-style-type: none">– Has visited a hospital-admitted in-patient family member in any hospital within the past year.– English-speaking adult, willing and able to participate.
PATIENTS	<ul style="list-style-type: none">– A hospital-admitted in-patient at any hospital within the past year.– English-speaking adult, willing and able to participate.
REGISTERED NURSES	<ul style="list-style-type: none">– Currently a Registered Nurse working in a direct patient clinical care role within the hospital.– English-speaking adult, willing and able to participate.

Action Research Group (Advisory Group) participant details

Eighteen people meeting the inclusion criteria expressed interest in joining the group and all were invited to participate. Fifteen accepted and attended the Advisory Group workshop (see Table 7). In total there were 16 members (including me) in the Advisory Group. All members (excluding me) were allocated pseudonyms to protect their identity in meeting minutes and associated study reports. For those members who identified as ‘patients’, and who had also visited family members in a hospital within the past year, they were invited to choose which role(s) they would like to adopt (patient, family member, or both). Several ‘patient’ Advisory Group members were currently attending out-patient clinics at other hospitals, but none was a current patient of the field study hospital. This decision was made because the research team (me and my research supervisors) felt that current in-patients might not feel comfortable openly discussing issues in front of nurses who may be treating them, and vice versa.

Table 7 Advisory Group member details

NAME	ROLE
Alexia	Registered Nurse
Amelia	Registered Nurse
Andrea	Patient
Becca	Family Member
Eeshani	Patient and Family Member
Irena	Patient
Josh	Registered Nurse
Kelly (PhD candidate)	Registered Nurse
Mette	Patient and Family Member
Miranda	Family Member
Olivia	Registered Nurse
Sarah	Registered Nurse
Selena	Patient
Simon	Registered Nurse
Vanessa	Registered Nurse
Wallace	Registered Nurse

4.3 Structure of the study

The study had two stages: **Stage 1 – Identification and Reconnaissance** and **Stage 2 – Creation and Evaluation** of the feedback protocol. Across these two stages, nine Action Cycles took place. For ease of readability, these nine cycles will be presented in order in Chapter 5. This is not to suggest, however, that one cycle commenced upon completion of the one before; some cycles overlapped (see Table 8). Herr and Anderson (2014) acknowledge that an action research dissertation requires an innovative approach to every aspect of the dissertation

process so that the reader can understand its cyclical nature. More recently, the editors of the journal *Action Research* argued that researchers must challenge the standard traditional academic format of writing up action research projects (Friedman, Gray & Ortiz 2018). In appreciation of these considerations and the work conducted in this project, a somewhat non-traditional approach was adopted in structuring the dissertation (see Chapter 1, 1.5 Structure). For example, there is no distinct 'results' or 'findings' chapter, because this information is provided in the context of each action cycle as they are reported.

Table 8 Action Cycle timeline

	2015								2016								2017									
	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
AC 1																										
AC 2																										
AC 3																										
AC 4																										
AC 5																										
AC 6																										
AC 7																										
AC 8																										
AC 9																										

Action Cycles

In addition to the individual action research cycle components (plan, implement, evaluate; see Table 9, below), the aim of each action cycle, along with a summary of lessons learned and questions raised, will be documented under action cycles 1-4, and 6-7 (see Chapter 5). The action cycles reported in the thesis are summarised in Table 9, below.

Table 9 Action Cycles

ACTION CYCLE 1	Advisory Group workshop A. Plan (workshop) B. Implement (conduct workshop) C. Evaluate (group evaluations and personal reflections)
ACTION CYCLE 2	Field-testing new feedback protocol version 1 a. Plan (to field-test V1) b. Implement (field-test V1) c. Evaluate (V1)
ACTION CYCLES 3 TO 4	Field-testing new feedback protocol V2 and V3 a. Plan (to field-test V2, V3) b. Implement (field-test V2, V3) c. Evaluate (V2, V3)
ACTION CYCLE 5	Developed a method to synthesise feedback a. Plan (how to code and theme experience findings) b. Implement (coding and theming experience findings) c. Evaluate (method to code and theme experience findings)
ACTION CYCLES 6 TO 9	Field-testing new feedback protocol V4, V5, V6, V+* a. Plan (to field-test V4, V5, V6, V+) b. Implement (field-test V4, V5, V6, V+) c. Evaluate (V4, V5, V6, V+)

*V+ refers to a modified version of V6 adapted to and field-tested in a young adult mental health in-patient unit.

Stage 1 – Problem identification and reconnaissance

The reconnaissance stage consisted of initial discussions with members of the Advisory Group to explore the problem area further. These discussions took place during a day-long workshop (see Appendix J, Advisory Group Workshop Agenda) to acquaint the group with the problem area, expectations, and the action research process. The Advisory Group considered how we would collectively refer to the new method designed to capture patient and family hospital experience feedback, and what the method would initially look like. Subsequent work continued via email, telephone, and in individual face to face discussions after the workshop. From these exchanges, the Advisory Group named the new feedback process RHEPORT (Realtime Hospital Experience Posters) and determined that the process designed to capture, and relay feedback would be called the RHEPORT Protocol.

Protocols

The Advisory Group agreed upon a protocol-based approach during the Advisory Group workshop in Action Cycle One. Protocols are commonly used by clinical nurses in healthcare, and nurses, patients and other stakeholders are well placed to create them (Price 2010). Protocols are plans, codes of conduct or guidelines outlining a clear and logical method to be adopted to achieve the desired outcome. Clinical protocols are used widely in healthcare

provision for assessment and management. Likewise, care protocols that encompass an agreed-upon framework describing why, who, what and where care is given are routinely used by healthcare providers. In clinical research, the research itself is conducted following a protocol or plan of action (Al-Jundi & SAKKA 2016). To co-create a protocol, we initially looked to the work of (Fixsen et al. 2013) and their evidence-based intervention and implementation research. They posit that intended outcomes are achieved only when programs (or protocols) are implemented well. Similarly, protocols are only as useful as the extent to which they produce benefits for those involved, in keeping with the aims of action research.

Stage 2 – Creation and evaluation of the RHEPORT Protocol

The creation and field-testing of the RHEPORT Protocol comprised nine Action Cycles (Chapter Five, Action Cycles 1-9). Field study participants (patients, family members and clinical nurses) across six medical-surgical units, and one young adult mental health unit were recruited to participate.

Throughout the nine Action Cycles in Stage 2, the Advisory Group worked towards identifying components of the protocol that worked and that did not work as anticipated. We used the Joanna Briggs Institute (JBI) model of evidence-based healthcare (EBHC) to guide this evaluation (Jordan et al. 2019). We specifically considered the model's inner circle, recently re-named the 'pebble of knowledge', which refers to feasibility, appropriateness, meaningfulness, and effectiveness (Jordan et al. 2018). This knowledge, gained throughout the action cycles, allowed the Advisory Group to eventually identify and develop 'core components' which were necessary to ensuring the protocol would be feasible, appropriate, meaningful, and effective.

Feasibility was evaluated by considering the extent to which the protocol was practical or viable (Jordan et al. 2019). When considering **appropriateness**, we examined the degree to which the protocol was relevant for the field study participants (Pearson et al. 2005). To determine **meaningfulness**, we considered whether the perception of the protocol was both positive and useful, based on personal experiences, values, opinions and thoughts (Pearson et al. 2005), again of the field study participants. **Effectiveness** was determined by comparing new protocol findings (i.e. the experience feedback provided) to the current experience literature.

4.4 Recruitment

RHEPORT field study participant recruitment and inclusion criteria

Patients and their families experience hospital processes firsthand, making their perspectives unique, relevant and necessary (National Health Service 2013). Clinical nurses play a role in both impacting and improving the patient and family's hospital experience (Kieft et al. 2014; Niederhauser & Wolf 2018). As such, the opinions, reflections, and evaluations of all of these stakeholders were sought. Field study participants were recruited then selected based on inclusion criteria (see Table 10). Specific groups were recruited differently.

Clinical nurse participants

Clinical nurses were advised of the RHEPORT field study by their respective Clinical Nurse Educators (CNE), and by way of the hospital flyers placed around their in-patient unit. Clinical nurses participated in the field study by providing feedback on the RHEPORT Protocol. Specific recruitment and consent strategies were designed by the Advisory Group, and are discussed under the section Ethical Conduct, Informed Consent, below, and further in the section on Action Cycle 2.

Patient and family member participants

Patients and family members were advised of the RHEPORT field study by way of flyers distributed on the hospital campus and placed in prominent positions in each in-patient unit. Patient and family participants took part in the study by giving experience feedback and/or evaluation data on the RHEPORT Protocol. Specific recruitment and consent strategies were designed by the Advisory Group, and are discussed in the sections on Ethical Conduct (see Chapter Four, Informed Consent) and on Action Cycle 2.

Table 10 Field-test participant inclusion criteria

TARGET GROUP	INCLUSION CRITERIA
CLINICAL NURSES	<ul style="list-style-type: none">– Currently a member of the nursing team working in a direct patient clinical care role within the hospital– English-speaking adult, willing and able to participate
FAMILY	<ul style="list-style-type: none">– Currently visiting admitted hospital in-patients– English-speaking adult, willing and able to participate
PATIENTS	<ul style="list-style-type: none">– Currently admitted hospital in-patients– English-speaking adult, willing and able to participate

4.5 Data collection

Data types and strategies

During this study, two distinct data types were collected: **experience feedback data** and **evaluation data** (see Figure 8). **Experience feedback data** were provided by field study patients and family members about their hospital experiences. **Evaluation data** were provided by all field study participants (patients, family, and clinical nurses) on the RHEPORT Protocol. Several strategies were used to collect experience feedback and evaluation data. Both sets of data were used by the Advisory Group members to iteratively inform the subsequent action cycles, while also serving as records of progress.

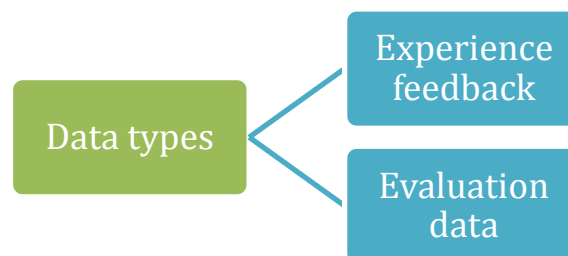


Figure 8 Data types

Experience feedback

Semi-structured face-to-face interviews with patients and family members were used to collect hospital experience feedback data. I conducted these interviews during the field-test period. In my role as the interviewer, I facilitated discussions about the participant's experience by listening and exploring issues they raised. After initially stating 'I'm here to talk about your experience', I then asked participants to 'Tell me something memorable about your experience'. This stimulus question was developed by the Advisory Group during the workshop, and is discussed further in Action Cycle 1 (see Chapter Five). The interviews were conducted individually with a patient or family member and, when requested by the patient, a patient and family member were interviewed as a pair. I took notes based on their first-person accounts in response to the stimulus question. These notes were then read back to the participants. The participant and I refined the notes into 'key comments' at the time of the interview. The participant approved a final key comment which would then appear anonymously on a feedback poster publicly displayed in the unit. This experience data in the form of key comments and notes was made available to Advisory Group members throughout

the study. The findings of this data type appear below in the Experience findings section for each action cycle.

Evaluation data

A formative and summative evaluation process (see Figure 9) was adopted to evaluate both:

1. The change to practice (the RHEPORT Protocol), and
2. The action inquiry process (the development of the RHEPORT Protocol).

Implementation 'data' in health-care action research include stakeholder experiences, with their interpersonal reflections and dialogue (Bradbury & Lifvergren 2016). Evaluation data were thus solicited not only from the patients, family members and clinical nurses participating in the field-test, but also from members of the Advisory Group.

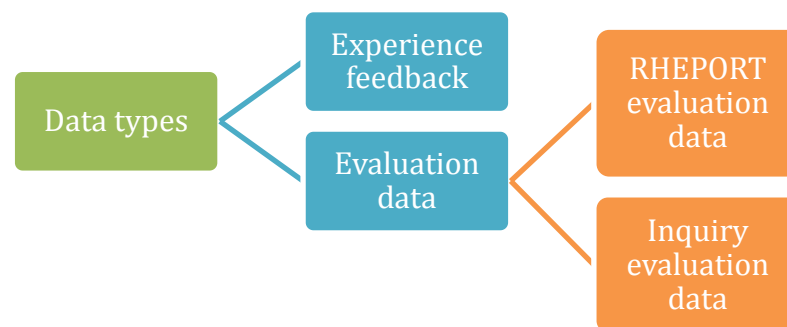


Figure 9 Data types and evaluation

RHEPORT evaluation data were collected to assess whether the protocol (i.e. the change to practice) was considered to be feasible, acceptable, meaningful, and effective. The evaluation data essentially consider how and/or why it did or did not work (Health Foundation 2016). Evaluation data on RHEPORT included survey data, feedback during face-to-face interviews, and feedback provided during guided reflection sessions with the clinical nurses who participated. Three specific groups provided RHEPORT evaluation data:

1. **Patients and family members**, in the form of verbal responses to the question 'What do you think about this [RHEPORT] as a protocol [or process]?' and subsequent discussions during semi-structured interviews,
2. **Clinical nurses**, in the form of written survey and verbal responses to the question 'What do you think about this [RHEPORT] as a protocol [or process]?' Notes taken from discussions during pre-field study testing, and notes taken in discussions during the post-feedback reflection sessions (see Action Cycle 4), and

3. **Advisory Group members:** in the form of notes and written data from group activities during the Group workshop. Group and individual discussions, emails, personal reflections, field notes, and personal journal entries.

I developed and subsequently amended a survey based on Advisory Group feedback (see Appendix K) to collect evaluation feedback from the clinical nurses during the field-tests. The **Nurse Evaluation Survey** elicited the information that the Advisory Group deemed necessary to guide future versions of RHEPORT, namely: whether the nurses read the key comments on the posters, whether the comments made any impression on them, and whether the clinical nurses changed or planned to change any aspect of their practice as a result of reading the comments. The survey also asked the clinical nurses what changes to RHEPORT, if any, they would recommend. This survey formed part of the ethics approval documents for field-testing RHEPORT (see Appendix G).

Inquiry evaluation data were collected to assess whether they generally adhered to the global aims of the study (following the principals of patient-centred care, and respecting the credo ‘nothing about me without me’), and collaborative engagement with the research by the Advisory Group members (see Appendix L). The Advisory Group also used this data to examine any changes in thinking and practice, how we as a group were influencing one another, and how we were developing new insights through our collaborations. The data were collected through numerous strategies, such as via email, notes from Advisory Group discussions and individual meetings, as well as researcher field notes and journal entries. Emails were used as a way of supporting collaborative discussions, and as such were the predominant method of group communication and Advisory Group data collection in this study. As the field study progressed, it became clear that field study participants (patients, family members, and nurses) were also part of the inquiry process; data about their participation in evaluating the protocol were documented in field notes. All evaluation findings in this thesis appear in the Participant evaluation, group evaluation and personal reflections for each action cycle.

4.6 Data analysis

Experience feedback

I conducted a preliminary first-level analysis of the experience data at the end of each data collection day. This process involved reading and rereading the key comments collected from patients and family members, and then identifying themes. The initial purpose of this analysis

was to determine whether RHEPORT was providing hospital experience specific data and thus whether it was addressing the research question. Based on the findings from Action Cycles 1 to 4, it became apparent that additional analysis of experience feedback was necessary in order to effectively relay the findings to the clinical nurses. Advisory Group members subsequently became involved in the analysis of the experience feedback and of the method chosen to do so. This process of data analysis was developed and refined by the Advisory Group and is described in Action Cycle 5.

RHEPORT Protocol evaluation data analysis – evaluating the change to practice

The analysis of the RHEPORT evaluation data focused on what worked, for whom, when, and why. Comments from patients, family members and clinical nurses about RHEPORT were transcribed and subjected to a first-level thematic analysis (Grbich 1999). The first level of analysis involved data being segmented, grouped, and then labelled into key themes with narrative examples. These data were then made available in summary form to members of the Advisory Group along with my field notes and personal reflections. While Advisory Group members were able to view all evaluation data, providing a summation of the data at the end of each field-test supported the members' reflection and collaborative engagement. Based on the Advisory Group's reflections and discussions, changes were made to the RHEPORT Protocol, and the revised version was field tested in the subsequent action cycle. Throughout the nine Action Cycles, the Advisory Group reflected on the evaluation data to identify what worked and what didn't in order to uncover the essential or 'core components' of the RHEPORT Protocol. Fixsen et al. (2009, p. 533) identify "core implementation components" as "implementation drivers" of any protocol. These core components are aspects which are deemed essential and necessary to produce intended outcomes.

Inquiry evaluation data analysis – evaluating the inquiry process

Evaluation of the inquiry process also took place during the reflection and evaluation stages within each action cycle. Adherence to the global aims (following the principals of patient-centred care, and respecting the credo ‘nothing about me without me’), and collaborative engagement (between members of the Advisory Group) was monitored and reflected upon based on McNiff’s (2013) domains of change discussed earlier (see Evaluating, Monitoring Change and the Inquiry Process). These domains (McNiff 2013) served as a guide to examine how our thinking and practices influenced one another, and how we developed new insights throughout the action cycles based on the evaluative data. My summaries and narrative accounts of what happened during the field study were relayed to the Advisory Group and evaluated. The subsequent discussions, our sharing of ideas, and emerging reflections allowed us to explore the adherence to the global aims of the project. Collaborative engagement amongst the Advisory Group members was analysed through transcripts from the Advisory Group workshop, meetings with individual Advisory Group members, emails, and telephone discussions. During the evaluation and reflection stages of the action cycles, the academic literature was also consulted as an additional source of data to inform the Advisory Group discussions and planning.

4.7 Validity in action research

Action research produces knowledge which is specific to both the practice and social situation of practitioners (Herr & Anderson 2014). Validity in action research, therefore, looks to whether the research question was answered, and acknowledges the intrinsic link to a subjective understanding of the social and contextual practical factors that shape findings. The integrity of action research stems from an ability to solve problems by analysing and questioning experiences in field encounters (Levin 2012). The challenge for action researchers is to demonstrate that this was done in a rigorous and relevant manner. To address the quality and validity of action research, I adhered to Herr and Anderson’s (2005) framework, which links the goals to specific quality and validity criteria (see Table 12), and Levin’s (2012) essential factors for academic integrity in action research.

Table 11 Anderson and Herr's goals and validity criteria of action research

ACTION RESEARCH GOALS	QUALITY/VALIDITY CRITERIA
Generation of new knowledge	Dialogic and Process Validity
Achievement of action-orientated outcomes	Outcome Validity
Education of researchers and participants	Catalytic Validity
Achievement of results relevant to the local setting	Democratic Validity
Use of a sound and appropriate methodology	PROCESS VALIDITY

Validity criteria

Dialogic and process validity

While attempting to generate new knowledge, Herr and Anderson (2014) suggest, research data, methods and interpretations should be subjected to peer review (to achieve dialogic validity). This study included peer review by members of the Advisory Group, field study participants, and research supervisors. Process validity relates to the extent to which ongoing learning occurred during the research stages, and is demonstrated through the cyclical problematisations, appropriateness, and transparency of methods and relationships developed (Herr & Anderson 2014; Merriam & Tisdell 2015). This validity is demonstrated in Chapter Five. Additionally, Reed (2005) argues that transparency regarding the processes, the thoughts and feelings of the participants and researchers, along with an identification of problems along the way also contribute to validity in action research. This type of validity can be derived from 'common sense', experience, and 'empathetic involvement in processes' (Fals Borda 2001, p. 33). In this study, transparency regarding the process is provided in the form of procedural steps, direct quotes, field notes, and reflections.

Outcome validity

Outcome validity questions the extent to which the action led to a successful resolution of the problem. This project sought to co-create a new feedback protocol and its successful outcome, the development of the RHEPORT Protocol, as evaluated by members of the Advisory Group and field study participants, is indicative of achieving outcome validity (Herr & Anderson 2014).

Catalytic validity

Catalytic validity questions whether the researchers have ‘changed their views in the process’ and moved towards a better understanding of the research setting, and how these understandings have the potential to transform the reality of the research setting (Herr & Anderson 2014; Merriam & Tisdell 2015, p. 297). In what educational theorist Paulo Friere (2007, p. 138) refers to as “conscientization”, he suggests that the researcher must “know” reality to effectively “transform it”. A demonstration of mutual learning (stakeholders learning from each other), and the degree to which the process focuses, re-orientes and energises participants is critical to demonstrating whether the research aimed at social change accomplishes its objectives. In this study, one of the main objectives was to give patients and their families a voice. The extent to which this was achieved is documented throughout the Action Cycles (Chapter Five) and examined in the discussion (Chapter Six). In this study, catalytic validity is demonstrated by the reflections and evaluations of both RHEPORT and the inquiry process.

Democratic validity

Democratic validity examines the extent to which research is done in collaboration with all stakeholders in a research situation, and whether the research is relevant to the local context (Merriam & Tisdell 2015). This research was conducted by taking multiple perspectives and interests into account, including the views of those participating in the field study.

Democratic validity in this study is demonstrated by changes made to the RHEPORT Protocol based on local knowledge, feedback, and Advisory Group consensus. Group consensus was achieved by verbal acknowledgement of an agreed course of action or when there was differing options or positions, then group members agreed on a compromise.

Academic integrity

To ensure academic integrity in action research, Levin’s (2012) essential factors in the practice of action research were also applied:

1. Research partners
2. Awareness of the researcher’s own bias
3. Standardised methods
4. Alternative explanations
5. Trustworthiness

Research partners

As action research is intended to inform both the practical problems of the situation and to contribute to the wider body of knowledge, the action researcher is often faced with making decisions at the same time as they are collecting data. Because of this, working with a colleague allows the researcher to discuss, interpret and reflect upon field experiences before decisions are made (Levin 2012). Levin (2012, p. 144) argues that this differs for the “on-stage” researcher versus the “off-stage observer” (such as academic supervisors). However, collegial discussions between them allow for different perceptions and interpretations to be brought to centre stage. In this study, Advisory Group members acted as each other’s ‘research partners’, with my supervisors and fellow PhD candidates providing additional opportunities for ‘collegial discussions’ (Levin 2012). By examining our own taken-for-granted assumptions, beliefs and imaginings, the Advisory Group developed our search for objectivity in partnership with others who were doing the same (Heron & Reason 2008).

Awareness of bias

Identifying potential sources of bias enables a more thorough evaluation of our findings and conclusions (Smith & Noble 2014). Transparency in this regard is enhanced when researchers’ experiences, prejudices and personal philosophies are accounted for. Also, demonstrating an appropriate rationale and research design to address issues reduces the “pitfalls” associated with researcher bias (Smith & Noble 2014, p. 100). My philosophy and frames of reference were outlined in Chapter One. Specific reflection and evaluation stages within each action cycle enabled members of the Advisory Group and me to try to identify and address preconceived ideas and potential bias. Experiences, newly identified biases and prejudices, as discovered throughout the research period, along with the plan and rationale to address these issues are highlighted in Chapter Five.

Data collection bias was addressed from the outset by asking open rather than leading questions, relating to both participants’ hospital experiences and evaluation of the RHEPORT Protocol. One of the main challenges in documenting the experience narratives of others and negotiating the final key comments was how to do this without bias. By enabling field study participants to re-read their key comments and edit or re-word them, the potential for data collection bias on my part as the researcher was reduced. Evaluation feedback was also sought from the field study participants during each action cycle, potentially addressing researcher bias.

Standardised methods

Action research data collection and analysis must adhere to accepted procedures (Levin 2012), but this is not to say that methods must be fixed (Chevalier & Buckles 2019). In action research, the results of one method (e.g., survey questions) may lead to the development of another inquiry adopting yet another approach (such as focus groups). Also, methods of collection and analysis can be novel and creative yet accepted procedures. As

Chevalier and Buckles (2019, p. 307) suggest, action research allows for a degree of creative “tinkering” with standard methods. They argue that “ingenious contraptions” often come into being as a result of “tinkering”; un-assembling, learning from the inside out, reassembling and combining parts from other machines to create new uses. Such tinkering occurred throughout the action cycles, and, as a result, versions of the RHEPORT Protocol were adapted based on what worked and what did not in previous cycles.

In this study, Advisory Group members and field study participants evaluated, and thus validated, the RHEPORT Protocol throughout each action cycle. Advisory Group members identified the areas of concern, constructed action plans, and took part in the data analysis, thereby enhancing ‘face validity’. Face validity refers to whether the protocol was appropriate, relevant and sensible to those who would use it (Gravetter & Forzano 2018). Moreover, providing field-test participants with the opportunity to read notes taken and then decide upon the exact wording used for key comments also supported face validity. Also, the decision to manually transcribe the notes and key comments into Excel spreadsheets was, in some ways, an effort on my part to remain as close to the data as possible. Inter-rater reliability, or the degree of agreement between coders is controversial in qualitative research, with opponents arguing it is neither necessary nor appropriate given the analytical goals of qualitative research (O’Connor & Joffe 2020). As a test of internal validity however regarding the coding frame adopted and the experience data analysis, a random ten per cent of key comments were also by two members of the Advisory Group, with little variation found.

Alternative explanations

All findings in this study were fed back to participants and/or Advisory Group members for validation. To negate the possibility of rigid thinking and data blindness the Advisory Group routinely attempted to find alternative explanations for why and what the data may be suggesting. This approach thereby created a ‘critical distance’ which allowed us to consider new ideas, further strengthening the validity of the study (Levin 2012, p. 145). By searching

for alternative explanations, we attempted to mitigate individual and potential group bias and or strong predispositions to specific ideas. Given the iterative nature of the study, we were often able to field-test modified processes based on these alternative explanations and newly generated ideas.

Trustworthiness

‘Trustworthiness’ is often substituted for validity in qualitative research due to the contentious nature of validity and its historical alignment with more positivist research (Herr & Anderson 2014). Levin’s (2012) first four factors (research partners, awareness of own bias, standardised methods, alternative explanations) shaped the integrity of the study, enhancing rigour, while reliability and validity were essentially addressed by trustworthiness. Eikeland (2014) suggests that to demonstrate trustworthiness in action research, researchers must document what has been done as opposed to what they wish they should have done. The researcher must not deliberately omit to appear more politically correct or innovative. If there is one rule of quality and trustworthiness of action research, it is that choices are transparent (Bradbury-Huang 2010). Transparency is also how action research can contribute significantly to scientific knowledge (Levin 2012).

Trustworthiness and transparency inherently originate from the participative nature of the study. The action research process dictated the consideration of multiple perspectives, along with drawing interpretations and conclusions directly from the data while demonstrating a clear rationale. Audit trails, in this case in the form of a researcher diary, field notes, notes from the Advisory Group, individual discussions with members of the Advisory Group, and reflections with a critical intent, demonstrate transparency and trustworthiness of the findings and conclusions (Herr & Anderson 2014). Assumptions held are also clearly signposted, as are the decisions made during each action cycle.

4.8 Ethical considerations

Qualitative research, in general, involves ‘complex ethical responsibilities’ (Iphofen & Tolich 2018, p. 1). Responding to ethical dilemmas as they arise requires a reflexive approach by the researchers (Reid et al. 2018). Accordingly, ‘ethical reflexivity’ is a core feature of ethical practice in action research, as new ethical situations often arise during the action cycles (Roth & Unger 2018). Complicating ethical reflexivity is that ethics approval is required before commencing a research project. Yet action research dictates that the researcher cannot pre-specify what actions will be taken, nor can they predict the ethical issues which may arise.

Technically, even the subject matter should not be pre-specified in action research, as this should ideally emerge from the participants. Practically, however, this cannot be the case when ethics approvals are needed. However, particular steps taken to ensure ethical conduct throughout this study were based on an abridged version of Tripp's (2005) ethical considerations for an action research project. Tripp (2005) suggests that ethical action research should:

1. Address topics of mutual concern
2. Be based on a shared commitment to performing research
3. Enable those involved to actively participate as they wish, and
4. Share control over research processes as evenly as possible.

A template outlining how Tripp's (2005) questions could be considered was developed and approved by the Advisory Group (see Appendix M).

Ethics approvals

As required, minimal risk ethics approvals were obtained from the Social Sciences Human Research Ethics Committee of Tasmania (HREC) (Ethics Reference H0015021) (see Appendix G), and from St Vincent's Private Hospital Sydney Practice Development and Research Council (PDRC) (Ethics reference: Project R 45) (see Appendix G) to establish an action research Advisory Group. Subsequent ethics approvals were also granted from the HREC (Ethics Reference H0015566), and PDRC (Ethics reference: Project R 45) to field-test the RHEPORT Protocol (see Appendix G).

Following these approvals, the study was conducted in line with the National Statement on Ethical Conduct in Human Research (2007, updated 2015) (National Health and Medical Research Council 2007b) and the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council 2007a), along with the parameters as agreed upon in the ethics applications. Progress and final reports were submitted to the respective ethics committees, stating that no incidents or ethical issues arose during the research.

Informed consent

Ethically and legally, all participants in research must receive all the information needed to make an informed choice before consenting to participate (Sacristán et al. 2016). Before joining the Advisory Group, patients and family member participants were given a 'Consumer Information Sheet' (see Appendix I), and clinical nurses were given a 'Registered Nurse Information Sheet' (see Appendix I). All potential members then discussed their

understandings of involvement with me, at which time any questions were answered. Field test participants then consented by signing 'Consumer Consent Form' (see Appendix I) or 'Registered Nurse Consent Form' (see Appendix I), as appropriate.

Given the large number of potential participants in the field-test, and the fact that I was to be the sole interviewer, a novel way of obtaining consent was developed by the Advisory Group and approved by the ethics committees. One of the members of the Advisory Group (who identified as a patient), suggested that rather than seeking written consent from every participant, participants could consent using 'consent cards' (see Appendix N). The process was as follows: I would approach patients and family members and explain the purpose and workings of the study, the overall aims of the project, and the potential risks (that people may recognise parts of their story). Benefits (none, except the possibility of helping to improve the experience of others in the future) and the option to withdraw (only before poster display) were also relayed. Participants were shown mock-up examples of the experience posters as visual guides so that they could see how their experience comments would be displayed (see Appendix O). They were also shown examples of key comments. Participants were then encouraged to ask questions about their involvement and the study, and to verbally state whether they wished to participate. At the end of the interview, participants were given a 'consent card' which advised them of the study's ethics approvals and who to contact should they require further information (see Appendix N). I then created draft posters and consent cards and emailed them to the Advisory Group members for their input. Once these resources were approved by the Advisory Group, they were included in an ethics application and were subsequently approved by the ethics committees.

All participants (clinical nurses, patients, and family members) who provided verbal evaluation feedback also consented verbally by way of the 'consent card' method described above. In the case of the anonymous nurse evaluation surveys, completion was viewed as implied consent. The fact that I was currently employed by the field test hospital as a Registered Nurse and was a PhD Candidate gave rise to a potential conflict of interest. I disclosed this conflict to all participants. Ramifications of this dual role will be considered in the discussion (see Chapter Six).

Anonymity and confidentiality

Protecting the Advisory Group members' and field study participants' identity and ensuring confidentiality was paramount. The Registered Nurse Advisory Group members were

encouraged to discuss their experiences of providing patient-centred care, and patient and visitor members were invited to share their relevant hospital experiences with me and/or the Advisory Group. Therefore, it was important that all Advisory Group members felt safe in the knowledge that these discussions were confidential, and were only documented or utilised to develop RHEPORT and in related research publications (e.g., this thesis and peer-reviewed articles). All Advisory Group members were assigned a pseudonym, used in all publications of research materials.

According to Speed, Davison and Gunnell (2016), patients often feel that negative feedback may jeopardise their care. As such, every effort was made to maximise anonymity of the field study participants and nurses in the participating units. No identifying data were collected or attributed to patients and family members who provided experience or evaluation data during the field study, other than the designation of 'patient' or 'visitor' (family member). Also, when a patient or family member referred to a specific member of staff, this name was subsequently deleted. Names were not included on any posters, nor were any identifiable data brought back to the Advisory Group (which included current nursing staff).

Given the personal nature of the patient and family experience feedback, it was explained to patients and family members during the consent process that the content of their comments could be recognisable to nursing staff and the wider community. Every comment was reviewed by me, and often the Nurse Unit Manager or Clinical Nurse Educator, with this in mind prior to its public display. Identifying remarks were highlighted, and these were either edited or removed. The comments appearing on posters were randomly allocated and not arranged in the order of their collection – which often corresponded to room number. The rationale for this was that participants' anonymity could be compromised by displaying comments from their direct neighbours' rooms. Experience data and key comments were manually entered into Excel spreadsheets in the order interviewed (which was often sequential, i.e. room one, then two, then three, etc.). This was in order to ensure comment placement on posters was not in the same sequential order.

Access to experience and evaluation data and field notes was restricted to Advisory Group members and my supervisors. Unit specific experience data and coded experience findings were also made available to the Nurse Unit Manager and Clinical Nurse Educator of each unit where field-testing took place. Data were stored in a password-protected storage facility (MY SITE-approved data storage, as per the University of Tasmania requirements), and in locked filing cabinets in the UTAS Research Centre, Darlinghurst campus.

Adolescent mental health participants

Specific ethical considerations were required for the inclusion of young (16- to 25-year-old) mental health patients in this study. One of the criticisms of experience research is that it rarely includes those suffering from a mental illness or disorder (Larkin, Boden & Newton 2015; O'Halloran et al. 2019). Given the vulnerability of this population, both the Clinical Nurse Educator and Nursing Unit Manager of the mental health in-patient unit, were consulted for their input at the conception stage, before any initial ethics application submissions. Recruitment and consent proved challenging. Specific details are provided in the section on Action Cycle 9.

Chapter 5 Action Cycles

5.1 Introduction

This study aimed to co-create a new way of obtaining real-time hospital experience feedback from patients and family, in a way that was easily deliverable and accessible to clinical nurses. The following chapter documents the nine Action Cycles which led to the development and evaluation of the new feedback protocol, RHEPORT. As discussed above, each Action Cycle was comprised of Tripp's (2005) three-stage action sequence (planning, implementing and evaluating). This chapter details each cycle as follows: the aim will be identified, followed by an account of the Advisory Group's planning. The Implementation sections in each cycle pertain to how the action was then implemented. Associated findings from that action cycle appear under the Implementation heading. The Evaluation sections for each action cycle report participant and Advisory Group evaluations, and my personal reflections. Finally, a snapshot of 'lessons learnt' and 'questions raised' will conclude Action Cycles 1 to 4 and 6 to 9. Table 12 (below) provides a quick reference for which version of RHEPORT was field-tested on which in-patient unit and during which action cycle.

Table 12 Action Cycle and corresponding unit or action

ACTION CYCLE (AC)	ACTION	IN-PATIENT UNIT
AC 1	Advisory Group Workshop	N/A
AC 2	Field-test RHEPORT V1	A
AC 3	Field-test RHEPORT V2	B
AC 4	Field-test RHEPORT V3	C
AC 5	Thematic coding development and application	N/A
AC 6	Field-test RHEPORT V4	D
AC 7	Field-test RHEPORT V5	E
AC 8	Field-test RHEPORT V6	F
AC 9	Field-test RHEPORT V+	G

5.2 Stage 1 – Identification and reconnaissance

Action Cycle 1: Advisory Group workshop

(May – November 2015)

Aim

The aim of Action Cycle 1 was to recruit and bring together Advisory Group members to identify if there were shared concerns about current experience feedback methods and how this compared to the literature. Further aims were to consider the pros and cons of current hospital experience feedback methods, and to explore possibilities for the creation of a new feedback process. Recognising that patient and public involvement (PPI) must include a level of training (Blackburn et al. 2018), another aim of the workshop was to familiarise the Advisory Group members with the field of study, and with common research and patient experience terminology.

Plan

Planning the workshop and gathering management support

The planning stage of Action Cycle 1 was undertaken by me. In addition to ethics and hospital management approvals, discussed in Chapter Four, a short presentation of the proposed study and its aims was made to senior nursing staff to garner their support for the project and the Advisory Group workshop. Nurse Unit Managers (NUMs) were also contacted individually for their approval to release clinical nurse members of the Advisory Group from their work so they could attend the workshop. The workshop was planned with the explicit intention of bringing stakeholders together in a forum for open discussion where members could explore possibilities for new ways of collecting and disseminating hospital experience feedback. In May 2015, I developed an interactive workshop format. An 'interactive' format was chosen for the workshop because, as Koloski (2012) explains, it encourages creativity, captures multiple responses, and allows for flexibility. I designed the workshop to support the Advisory Group members to share their concerns about how hospital feedback was sought, and to reach a consensus on how best to improve the process of collection.

The content of the Advisory Group workshop was developed by adapting Green and Thorogood's (2013) techniques for planning of group interviews. Firstly, an agenda was developed which identified the research aim, workshop goals, and ground rules (see Appendix J). Other preparation activities I conducted included choosing a setting, recruiting

Advisory Group members, and identifying suitable activities. A physical space for the workshop was found which provided comfort and ease of access – essential factors when wanting to foster the development of collaborative partnerships (National Health Service England 2016). Familiarity, privacy, and cost were also considerations, which led to the decision to secure a suitably sized room on the hospital campus.

Planning the workshop evaluation

A key component of the planning phase of this Action Cycle was to develop a method to evaluate the proposed workshop outcomes, these being:

1. The newly created feedback protocol, and
2. Collaborative engagement.

While Action Cycle 1 aimed to develop a new feedback protocol, it was challenging to plan for its evaluation before the exact nature of the protocol was known. Thus, an evaluation checklist was developed which explored whether the new feedback protocol could be feasible, acceptable, and meaningful to participants, and also effective. In addition, the evaluation checklist also considered whether the protocol and development would adhere to the global aim of patient-centred care and to the credo ‘nothing about me without me’. This checklist was then used to evaluate the content of the proposed feedback protocol (see Appendix L Evaluation Checklist). Advisory Group members’ consensus about the proposed change in practice using the checklist would serve as confirmation that the workshop outcomes had been met.

McNiff’s (2013) ‘Domains of Change’, as discussed in Chapter Three, served as a guide to both monitor and evaluate collaborative engagement during the workshop and throughout the ongoing action cycles. In addition, Tripp’s (2005) ethical considerations for action research served as a guide to ensure ethical conduct (see Appendix M) . Voluntary participation, shared commitment, and shared control amongst participants were the critical components for consideration, as were monitoring our thinking and practices, how we were influencing each other, and whether we were developing new insights and practices.

Implement

Conduct workshop

The Advisory Group workshop was held on 16 September 2015, from 9 am to 4 pm. As the facilitator, I conducted the workshop and acted as a scribe to capture comments and ideas. The session commenced with informal introductions as people arrived and then proceeded

according to the agenda (see Appendix J). Artefacts collected during the workshop consisted of handwritten notes, completed worksheets, whiteboard notes, and researcher recollections from both formal and informal discussions throughout the day.

A variety of individual and group activities took place that were designed to engage the Advisory Group in discussions and identify current methods, processes, and protocols for giving and receiving any type of feedback. These activities resulted in ten recognised 'current methods of delivering feedback in general' used by the public (see Appendix O for findings from specific activities). These methods were:

1. Blogging
2. Email
3. Face-to-face
4. Facebook
5. Evaluation forms
6. Instagram
7. Phone calls
8. Storytelling
9. Text messages
10. TripAdvisor

Four methods were identified as specific ways in which clinical nurses currently receive hospital experience feedback:

1. Cards from patients or family
2. External reports
3. Face-to-face
4. Letters to the hospital

Three additional methods were identified as potential new ways of delivering feedback to clinical nurses:

1. Audio recordings
2. Posters
3. Telephone calls

To develop the first version of the new protocol, the following questions were considered by the Advisory Group:

1. Who will capture the feedback?
2. Who will provide feedback?
3. What questions will be asked?
4. How will the feedback be displayed?
5. What will the new process be, and how will we, as an Advisory Group, evaluate it?

The Advisory Group discussed the pros and cons of each of the three new feedback methods (audio recordings, posters, telephone calls), and reached a consensus that posters would

most likely be an efficient and cost-effective way to display feedback to clinical nurses. By the conclusion of the workshop, the Advisory Group had developed a draft version of a new protocol to capture and disseminate patient and visitor feedback using posters, which would be known as RHEPORT, short for 'Real-time Hospital Experience Posters'. This draft addressed a number of questions, set out in the sections below.

Who will capture the feedback?

Initially, Advisory Group members suggested that hospital volunteers could interview patients and family members. However, subsequent correspondence with senior hospital staff stipulated that I be the sole interviewer of patients and family regarding their hospital experience. Reasons for this included that the interviewer needed to be able to recognise the potential risk to the participant, the hospital or to staff based on what the participants shared. Being a current employee of the hospital, I was aware of reporting channels and adverse events protocols in place. This rationale was presented to the Advisory Group, who agreed that my interviewing the field-test participants was the appropriate strategy.

Who will provide feedback?

Initially, patients and family members were identified as feedback providers. However, Advisory Group member Amelia (a Registered Nurse) highlighted the potential difficulty in establishing whether a visitor's relationship to the patient was familial. Accordingly, the Advisory Group decided that all available patients and any patient visitors (regardless of their relationship to the patient) could participate. Anyone who visited the hospital for reasons other than specifically visiting a patient was excluded from the study. The Advisory Group recognised the importance of anonymity for participants, and as such only their patient or visitor designation, their approximate age, and their gender would be collected.

What questions will be asked?

The Advisory Group agreed that a patient experience feedback mechanism should allow the person giving the feedback to discuss what they want to say rather than, as one of the Advisory Group members, Simon (a Registered Nurse), suggested "*what others may want to ask*". While various prompts were suggested, such as "*Have you ranted and raved to anyone?*", "*Can you tell me about...?*", "*What was the reality of your experience?*", these were ultimately rejected. Selena, a patient member, suggested: "*maybe instead of asking about their [participants'] experience, we should ask them to tell us about something memorable?*" It was unanimously agreed that this was the ideal phrasing for eliciting patient and family feedback. The Advisory Group reasoned that asking for "something memorable" about their

hospital experience would avoid overt prompting, or requesting of either positive or negative feedback. This was important, as it would hopefully allow the patient or visitor to share any experience (positive or negative) that mattered to them.

Concerns were raised by several members regarding whether patients would feel able to give negative feedback while in a hospital setting. Although the promise of anonymity would hopefully address this, the Advisory Group decided that one way to mitigate this might be to ask participants who expressed difficulty in answering the first question regarding a memorable experience, *“What will you tell your friends and family about your hospital experience?”* The Advisory Group speculated that this word-of-mouth feedback would perhaps be a more transparent account.

How will the feedback be displayed?

During workshop discussions, the Advisory Group recognised the value of stories as shared by the patients themselves; Olivia (a Registered Nurse) referred to this data as *“real stories in the patient’s own words”*. There was agreement that, by using patients’ and visitors’ own words, in their own handwriting, the feedback would have the most impact on those reading it. It was decided that I would capture the narratives in note form. Key comments that captured the essence of the experience feedback, or what the participant felt mattered most, would then be negotiated between the patient or visitor and me. These comments would be publicly (and anonymously) displayed on posters throughout the inpatient unit. Poster comments would simply be attributed to a ‘patient’ or a ‘visitor’. The use of emojis (see glossary) was suggested by Alexia (a Registered Nurse) as an innovative way to quickly communicate a message or key piece of feedback in addition to the text. The Advisory Group agreed that this was a novel strategy, and that asking participants to choose an emoji to accompany their key comments was worth field-testing.

What will the process be, and how will the Advisory Group evaluate it?

Members of the Advisory Group agreed with the literature review’s findings: that the feedback protocol should provide qualitative real-time feedback to nurses, and that the feedback should be meaningful for nursing staff, yet easy for patients and family to engage with. To those ends, it was decided that the field study participants (patients, visitors, and nurses) should be consulted regarding their thoughts on the new protocol. The Advisory Group agreed this could be achieved by simply asking the patients and visitors who provided experience feedback how they felt about the RHEPORT Protocol. In addition, the Advisory

Group decided that we should also ask people (patients, family, and clinical nurses) reading the posters how they felt about receiving others' feedback in this way.

With regard to the intended recipients of the feedback (the clinical nurses), the Advisory Group agreed that a short, anonymous, written survey would suffice to capture clinical nurse feedback on the protocol. The findings from these comments and surveys, along with my field notes, comprised the data that the Advisory Group used to evaluate and reflect upon the first version of the RHEPORT Protocol. Below, in Figure 10, is a diagram of the proposed RHEPORT V1 Protocol and its evaluation strategies.

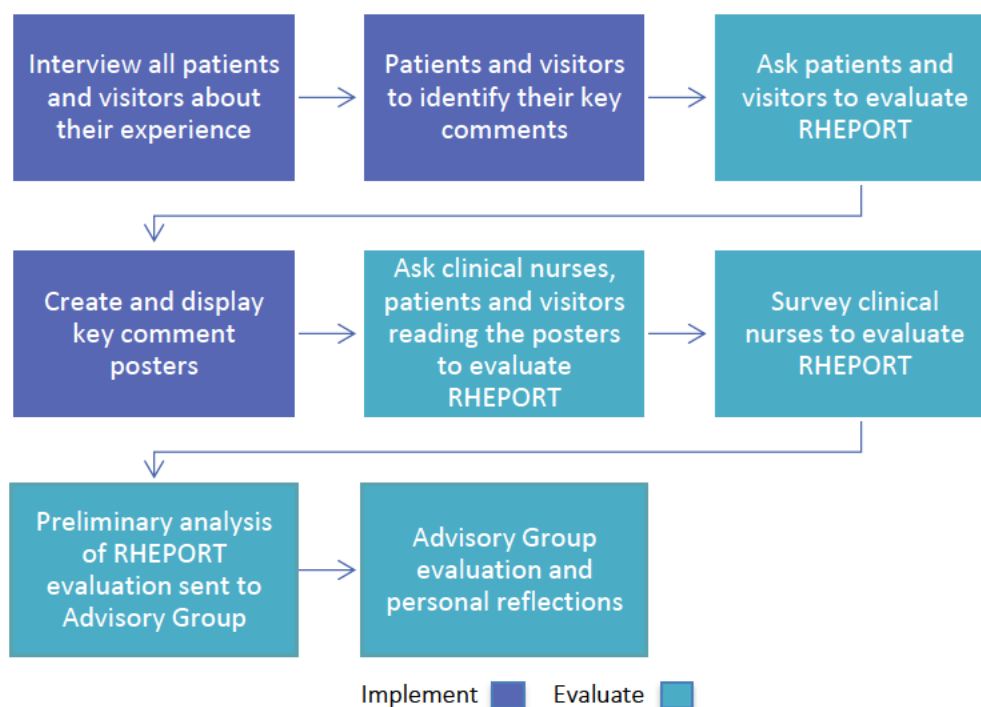


Figure 10 RHEPORT V1 Protocol and evaluation

Evaluate

Group evaluation and personal reflections

All Advisory Group members agreed at the conclusion of the workshop that the first version of RHEPORT was a positive step towards collecting and disseminating real-time hospital experience feedback to clinical nurses. Reflecting on the protocol, several Advisory Group members expressed doubt that participants would give negative feedback. For example, Andrea (a patient) stated that she *"would not feel comfortable complaining, unless it was something really bad"*. Josh (a Registered Nurse) replied that *"many patients complain all the time"*. It was agreed, despite the possibility that participants may not say anything negative, that RHEPORT V1 should be field-tested. Development of the new protocol and consensus by

the Advisory Group to field-test RHEPORT V1 served as confirmation that the aims of Action Cycle 1 had been met. Reflecting on the workshop, the Advisory Group were confident that RHEPORT V1 aligned with the discussed goals of a patient-centred care approach to the research and protocol. They reasoned that it would be the patient's voice being captured, and that the patients and visitors would be sharing what they wanted me to know. Also, as Miranda (a family member) pointed out, *“we are going to ask everyone, not just the people we think are happy”*, aligning with the ‘nothing about me without me’ credo.

By the end of the workshop, Advisory Group members began to use similar phrases – such as ‘real-time feedback’, ‘patient-centred care’, and ‘experience feedback’, indicating the emergence of shared language and possibly a developing sense of ownership. There was significant engagement with the subject matter and with each other during the workshop to develop the protocol, demonstrating that the topic was of mutual concern, and that collaborative intent towards a common goal had been achieved. The workshop allowed members of the Advisory Group (myself included) to learn from ourselves and one another. Given the facilitator-led nature of the workshop, it is debatable whether all participants felt their views were equally considered; however, there was evidence that we were learning from each other’s experiences. I contacted all members individually to seek their feedback on whether they felt heard during the workshop and posed this question again in subsequent group correspondence. All of the group members stated that they felt they had had the opportunity to share their thoughts and contribute to the discussions. On reflection, it was apparent to me that the workshop had been successful in facilitating the collaborative engagement of the Advisory Group members.

Action Cycle 1 summary

Based on the findings from the Advisory Group workshop and subsequent discussions, the lessons learnt and questions raised from Action Cycle 1 are summarised in Table 13, p.90.

Table 13 Action Cycle 1 – lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
PROBLEM AREA	Capturing and disseminating patient and visitor hospital feedback is a topic of mutual concern amongst patients, visitors, and nurses.	
COLLABORATIVE ENGAGEMENT	Nurses, patients, and family members can come together to develop a protocol that may address the identified problem area.	
NEW PROTOCOL		Patients and visitors may be reticent to offer negative feedback while in the hospital setting.

5.3 Stage 2 - Creation and evaluation of the RHEPORT Protocol

Action Cycle 2 - Field-testing RHEPORT V1

(December 2015 – April 2016)

Aim

The aim of Action Cycle 2 was to field-test and evaluate RHEPORT V1.

Plan

Planning for the field test began in December 2015. Inpatient unit A (IPU A, a respiratory and cardiology medical and surgical ward) was chosen as the first study location, given the keen interest in the project expressed by the Nurse Unit Manager (NUM). The Director of Nursing (DON) was advised that ethics approvals to field-test RHEPORT had been received (see Appendix G), and the NUM of IPU A was contacted for permission to begin.

During their planning discussions, the Advisory Group agreed that to ‘give everyone a voice’, all patients and visitors would be approached during the interview period to participate in the study. This decision was supported by literature suggesting that random or self-selection of participants in patient experience trials has tended to represent extreme views and overestimation of overall patient satisfaction (Barron et al. 2014; Mazor et al. 2002). Also, self-selection tends to result in low response rates (Coulter et al. 2014). Josh, one of the Registered Nurses in the Advisory Group, suggested that I should, however, “*approach the*

NUM or CNE (Clinical Nurse Educator) to identify patients who should not be approached based on their current condition". The Advisory Group agreed this was a good idea.

During the planning phase for this Action Cycle, I decided, in conjunction with my research supervisors, that despite hospital approval to display negative feedback publicly, senior hospital staff (specifically NUMs and CNEs) would be afforded the opportunity to view negative comments before the posters were created. They could then choose whether these comments would appear unaltered, in a modified form, or be removed. This decision was based on the assumption that senior staff would be ideally placed to identify potential issues for their specific IPU. While the goal was to be transparent in presenting feedback, we were also very conscious of not causing harm to staff, other patients, or the hospital's reputation. For example, if a patient identified a staff member by name, or if the patient could be identified from his or her story, the comment would be modified. Similarly, comments which may harm the reputation of an individual or the organisation would be deemed too negative and would be altered or removed. The Advisory Group were informed of this decision and, upon reflection, decided that we should flag all negative comments for review by senior staff. The Advisory Group decided that if a key comment contained both negative and positive feedback, the comment would be flagged as 'negative'. Similarly, if a key comment was a suggestion for a change, it would be flagged as 'negative' on the assumption that a suggestion implies a less-than-optimal experience.

Based on the Advisory Group's desire to ask participants to choose an emoji to accompany their comments on the posters, this required an emoji template to be set up during the planning phase of this Action Cycle. I developed the template and emailed it to the Advisory Group for approval (see Appendix Q). From this document, the field test participants could choose an emoji which they felt best represented their experience. Members of the Advisory Group surmised that there would be a common understanding among patient and visitor participants of the emojis' meanings, and therefore decided that I would not advise patients of the precise meaning. Instead, I would let the participant choose the image based on the meaning they ascribed to it (in other words, the emojis' names, such as 'sad emoji' did not appear on the template). The Advisory Group's rationale was based on their desire to identify whether nurses, patients, and visitors would agree on the emojis' connotations.

Consent cards (discussed in section 4.7, above) were used in the recruitment process. While participation would be voluntary, participants were advised that once they gave final approval for the key comments to be displayed, it would not be possible to remove their comments

later, because it would not be possible to match the comments with participants once they had been anonymised. An interview guide was created with input from the Advisory Group to capture patient and visitor feedback (see Table 14, below). Question 1 was the primary question, with prompt questions to be asked if the previous question yielded little feedback.

Table 14 RHEPORT V1 Interview Guide

1	Can you tell me something memorable about your experience here so far?
2	If your friend or family phones or comes in, what will you tell them about your experience here?
3	Take me through what has happened during your stay.
4	Thinking about the ideal hospital experience, tell me about the reality.
5	Can you tell me your feelings associated with your hospital experience?

To facilitate data collection, a template document was created to record participant consent, status (patient or visitor), gender, age-range, key comments, and field notes (see Appendix R). A separate list of bed numbers was also created, which I would use to ensure that each patient bed had been visited during the interview period. If a room or bed were empty, it would be revisited later in the day or the next day. Excel spreadsheet templates were created to store collected feedback data. Poster templates (see Appendix S) were also designed so that key comments could be easily and quickly inserted into the speech bubbles. This allowed rapid production of posters.

Immediately after sharing their experiences, field study participants (patients and visitors) would be asked for their opinions regarding the sharing of real-time qualitative feedback. This **evaluation interview** was centred on the key question ‘What do you think about this [RHEPORT] as a way of capturing experience feedback?’ This question enabled the participants to share their perceptions of RHEPORT V1. It was also agreed with the Advisory Group that the effectiveness of the feedback posters should be evaluated in a brief **poster evaluation interview**. Once the posters were up for display, people (patients, visitors, or clinical nurses on the unit) looking at the posters would be asked ‘What do you think about these posters?’ To capture as many responses as possible, it was planned that I would attend IPU A for three hours in the morning and three hours in the afternoon each day the posters were displayed. Also, clinical nurses were to be given the Nurse Evaluation Survey (see Appendix K) as designed by the Advisory Group. It was planned that the RHEPORT Protocol evaluation data (the Nurse Survey and the evaluation interviews with patients and visitors) would be shared with the Advisory Group members as soon as possible after collection to allow them time to consider the findings before the next Action Cycle.

Implement

Field-testing of RHEPORT V1 commenced in March 2016 and took 11 days. The sequence of events is outlined in Figure 11, below.

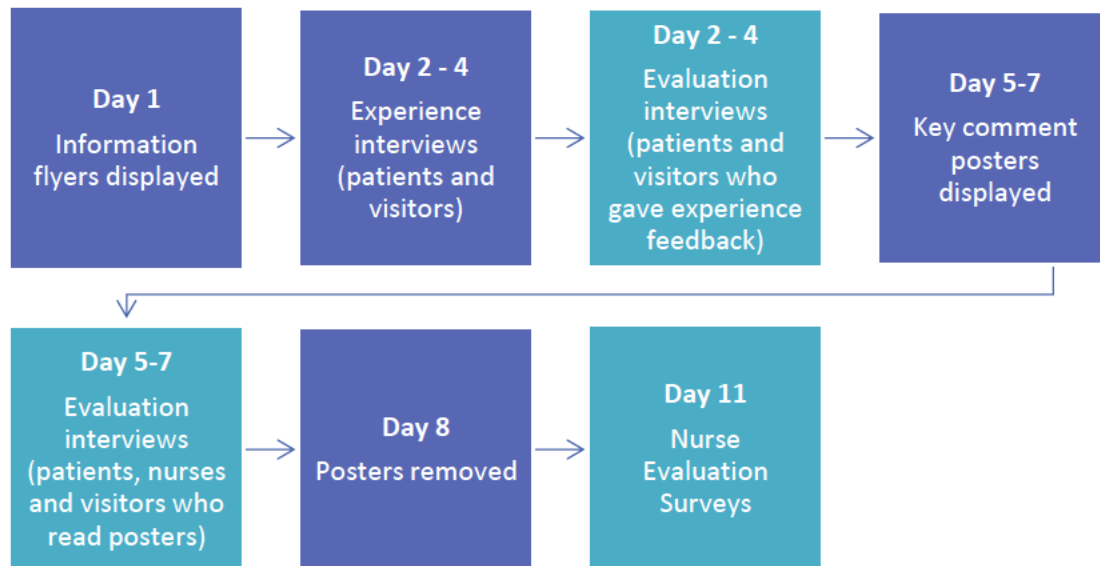


Figure 11 RHEPORT V1 process and evaluation

Information flyers were displayed around IPU A advising that a research study would be taking place (see Appendix T). The NUM or CNE was consulted before I approached any patients or visitors. This was to ensure that the patient was in a physical and mental state to receive an invitation to participate in the field test. Patients and visitors were then approached and given the opportunity to consent to participate in the RHEPORT experience interviews. When a patient and visitor were present together, both were given the option to be interviewed together or separately. A choice of interview location was then offered, in the patient's room, in a common area within the unit, or in a private room away from the unit.

During the experience interviews, I took notes about the participant's experiences and then read these back to the participant for clarification and approval. Participants then chose the exact wording of the 'key comments' to appear on the poster, often selecting one or two short messages. Based on discussions at the Advisory Group workshop, I initially attempted to obtain key comments in the participant's handwriting. After only three attempts, it became apparent that this approach was futile. Participants struggled with writing their key comments. Concerns raised included perceived "poor handwriting" and "spelling" mistakes. Attempts to convince participants took a considerable amount of time. Following immediate consultation with the Advisory Group (after the third experience interview), this plan was quickly discarded. Subsequently, I transcribed participants' key comments and read them

back to the participant. All participants were asked to choose an emoji that would 'represent their overall experience'. Negative comments were flagged and emailed to senior staff and members of the Advisory Group for approval or modification before poster production. It is important to note that all participants who provided key comments were advised that their comments could be removed or edited by an external Advisory Group or senior staff member if this was considered necessary. Notes from the experience interviews, key comments that were recorded for presentation on the posters, and my corresponding field notes (which I took in private after each experience and evaluation meeting) were transcribed daily into an Excel spreadsheet at the end of each data collection session.

Findings of experience interviews

Forty-nine participants from IPU A were approached, and all agreed to participate; however, one patient then declined to make a key comment. Participant interviews lasted, on average, 34 minutes 45 seconds each, with a range of 10 to 112 minutes. Twenty-nine key comments were deemed to be positive and 19 negative (see Figure 12). While several interviews contained both positive and negative comments, no participant in this Action Cycle chose to include both positive and negative feedback as their key comment. Moreover, there was little variation between the overall experience feedback that participants provided and their key comments. For example, if the participant spoke at length about the quality of food at the hospital, their key comment was invariably about this same issue.

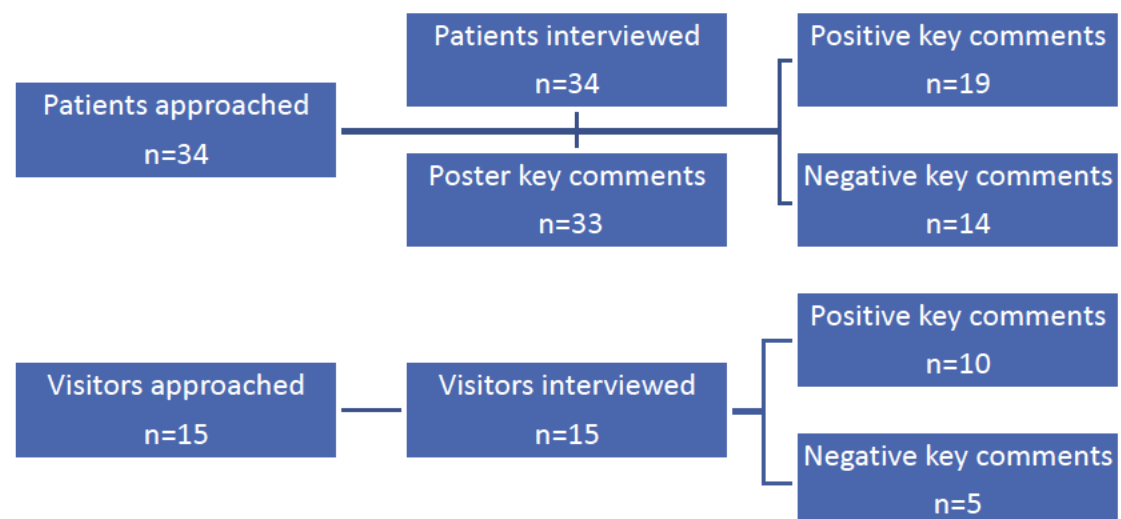


Figure 12 RHEPORT V1 hospital experience participants

Forty-five posters were created to display one key comment each (see Appendix U). The NUM requested that three key comments which had been flagged for her review not be posted. These included comments referring to single rooms as opposed to shared rooms, and or the

noise of the cardiac monitors. For example, the following comment was flagged for NUM review: *“I was told I would have a single room... after I was admitted, I was told there wasn’t one available”* (patient). The NUM explained her reasons for not including the comment via email:

[I] spent a lot of time talking with patients or being yelled at by patients and or their relatives about this matter. I would prefer that other patients and families did not read these comments and add fuel to the fire.

At the request of the NUM, an additional key comment was modified from *“he has a nice room by himself”* to *“he has a nice room”*. Two key comments regarding noise from the cardiac monitors were removed as the NUM stated that *“cardiac monitors are essential for patient care”*. Other key comments which were flagged for the NUM’s review, however, were approved for inclusion: *“Doctors can be so rude, they don’t even introduce themselves to you, and they talk in doctor terms”* (visitor); *“I rang the buzzer. I waited twelve minutes, it’s shocking”* (patient).

Forty-two participants chose an emoji to accompany their key comment. When questioned about their understanding of the chosen emoji, 15 diverged from the official meaning. For example, all participants ($n=3$) who chose the ‘tears of joy’ emoji (see Figure 13) and provided negative feedback took this emoji to represent a negative emotion. Several of the nurses reading the posters identified this emoji as expressing happiness. As such, they stated that it did not ‘make sense’ to see it paired with a patient or visitor’s negative comment. Most patient and visitor participants found it challenging to choose an emoji, with seven not choosing one at all. As one patient said: *“no emojis for me, I’m too old”*.



Figure 13 RHEPORT V1 ‘tears of joy’ emoji

Evaluate

Participant evaluation, group evaluation, and personal reflections

Immediately after their hospital experience interview, patients and visitors were asked for their evaluation of RHEPORT V1 as a means of capturing and delivering hospital experience feedback. These participants had given experience feedback and had viewed example posters. They were asked *“What do you think about this as a way of capturing experience feedback?”* Additional RHEPORT evaluation data were collected from people reading the posters (patients, visitors, clinical nurses). These evaluation interviews took place during the poster display period. These patients, visitors and clinical nurses were advised of the study, consented by way of consent cards, and were then simply asked *“What do you think about these posters?”* To capture as many responses as possible, I attended IPU A for three hours in the morning and three hours in the afternoon each day during the poster display period. I conducted a preliminary analysis of evaluation data (from participants who had provided experience data and participants who had simply read the RHEPORT posters) at the end of each day. This information was then relayed to the Advisory Group. Data from the Nurse Survey were also reported to the Advisory Group. In total, 71 evaluation responses about RHEPORT V1 were obtained, but only one Nurse Evaluation Survey was returned (see Figure 14, p97).

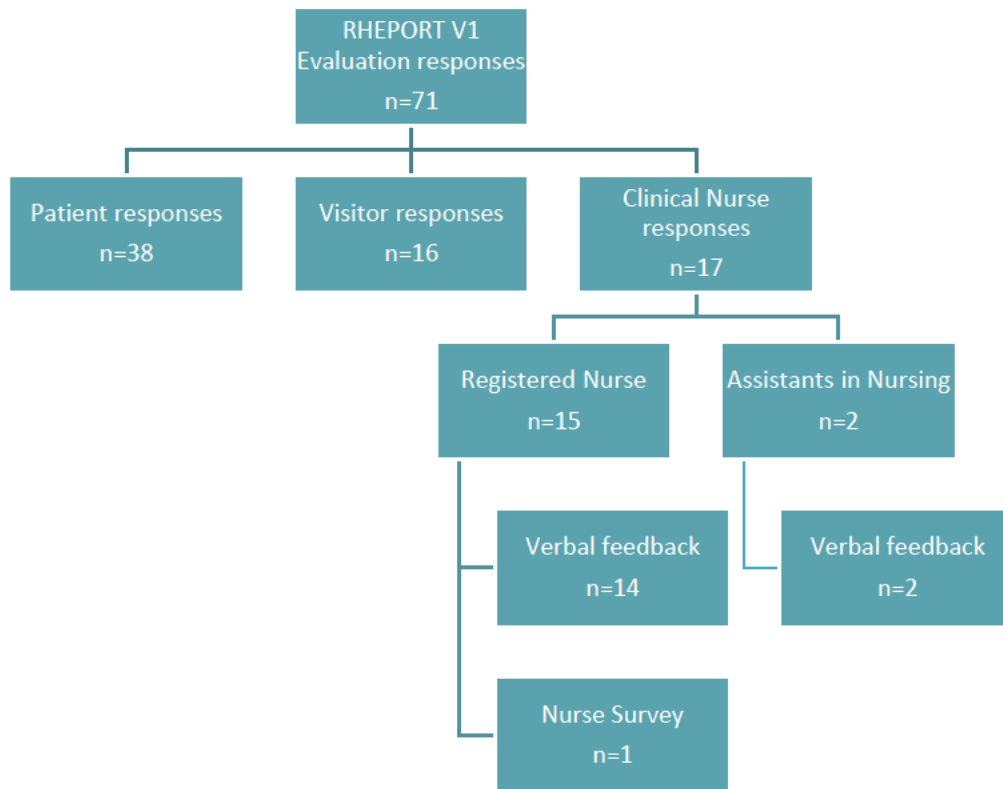


Figure 14 RHEPORT V1 evaluation responses

All patient and visitor participants agreed RHEPORT V1 was a good way to capture current hospital experience feedback and to deliver it to clinical nurses. Several patients specified that actually *“talking”* to an individual was a benefit over *“filling out a form[,] because it was more personal”*. Interestingly, several patients were very keen to know what other people had written about their experience before the posters were displayed. Two patients asked if they could read my handwritten notes from other patient interviews, as they were being discharged before the posters went up. One patient said: *“I’m going home today. I would really like to know what they say”*. I explained that this was not possible because it deviated from the protocol.

All participants reported that they enjoyed reading the positive comments. For example, one patient stated: *“I’ve read them all. It’s good. I’ve got nothing else to do. I’ve read them twice”*. As I collected feedback from the patients and visitors, I also noticed that nurses who stopped to read the posters appeared to be scanning them, as if deciding what to read. I asked one of the nurses what she was searching for, and she replied, *“I’m looking for the bad stuff”*. It became evident very quickly that clinical nurses were displeased at seeing negative comments on the posters. I noticed that their non-verbal language (facial expressions and

gestures) changed markedly after reading negative comments. Upon reading a poster mentioning the nurses being late responding to a buzzer, one nurse said to me:

I don't mind seeing the positive things, but they don't know what's behind it. It's too difficult. This is too in your face. How would you like to come to work and see a poster about how bad a job you are doing?

The visitors who read posters appeared equally displeased with the display of negative comments, with one stating:

I don't know if things like this need to be said? I don't think visitors to the hospital need to know about the bad things other people say?

Interestingly, patients reading the posters were either amused or only slightly displeased after reading negative comments (even patients who were interviewed about their experience and happy for their own negative comments to appear). One such patient said:

I think it's unfair comments. It's stupid to complain about staff, [...] saying negative things. If something happens, it's not the staff's fault [...] I don't think visitors to the hospital need to know the bad things people say.

Another patient also indicated his displeasure like this: “This hospital is great. A lot of these things here are grossly exaggerated. This place is paradise”. Upon reading a key comment that stated “the fruit is like a piece of steel”, this same patient laughed: “Come on, I mean, this is ridiculous. Fruit today is horrible anyway”.

At the end of the display period, 35 evaluation surveys were distributed to the CNE for the IPU's clinical nurses. Only one nurse survey was completed and returned, despite numerous visits to the hospital over seven days and several personal reminders to the CNE to try and encourage participation. The sole clinical nurse respondent answered the question regarding whether any comments surprised them as follows:

[...] their experiences are all different [...] some patients have pre-existing expectations of healthcare, and they are unrealistic. Some people have never been sick before and they don't know what to expect. There are so many variables, so no [no comments surprised me].

This clinical nurse also wrote that none of the comments caused them to reflect on their practice. However, they did write that seeing the patient's feedback and emojis made them feel “uncomfortable”, because “emojis are very gen-Y. It's not something I can really relate to. Maybe I am too old”. When specifically asked if RHEPORT V1 was a good way to provide current IPU-specific feedback, the nurse chose the ‘no’ option:

I don't think hanging criticisms in the hallway is very productive. It breeds resentment amongst the staff – and even in patients, too [...] I would put it in a booklet format and leave it at the nurses' station to be read.

The Advisory Group members were kept up to date with the progress of the RHEPORT V1 field-test and evaluation findings via email while fieldwork was in progress. Aware of the difficulty experienced in obtaining key comments in the participants' handwriting, the Advisory Group quickly chose the font *Lucida Handwriting* for the poster. The Advisory Group reasoned that this font was similar to handwriting, which could draw readers' attention to the message. Based on my observations while on IPU A, I suggested to the Advisory Group that it was also likely that the emojis signposted comments as positive or negative, which enabled nurses to identify and read only the negative comments only – rather than having to consider each comment.

A final evaluation report was sent to the Advisory Group, along with specific participant comments at the completion of the field test. Included in this report were my observations based on my fieldwork notes and journal. I relayed to the Advisory Group that clinical nurses were not only upset with the display of feedback, but it also appeared that they were upset with me. I shared the following journal entry with the Advisory Group:

It seems like nurses are no longer willing to talk to me. As a nurse, I feel like I am being met with hostility. They [the nurses] were very defensive – they were also concerned with their short fallings being highlighted to the other patients and to the public. The nurses I spoke to dismiss the feedback as irrelevant. Even my supervisor has heard via the grapevine about how unhappy nurses on this Unit are – yet no-one is saying anything directly to me. (Action Cycle 2, Day Four)

Each day it is as if they have become angrier with me [...] I feel like they don't even look me in the eye anymore [...] One nurse was clearly angry with me. I tried to tell her this is just how one patient feels at one moment in time, it's just so you know what they are thinking [...] I don't think she listened. (Action Cycle 2, Day Six)

After reading the evaluation feedback and my reflections, Advisory Group members were invited to respond to my emails either directly to me or to the group. Three members responded directly, and I then collated their comments and relayed them to the group anonymously. Several members did not reply and were contacted individually, with three electing to make no further comment in this Action Cycle. They said they had nothing to add.

Most Advisory Group members were surprised by the content of my journal entries, which highlighted the level of displeasure among the nurses upon reading the negative feedback. Via email, a group discussion about this issue ensued. Amelia (a clinical nurse) wrote that she could not understand why nurses would be so upset as “*nurses receive feedback all the time*”. Josh (also a Registered Nurse) suggested that “*perhaps there is not a culture of getting negative feedback on this ward? Maybe they never hear about it?*” Another member, Sarah, who also happened to be a clinical nurse on IPU A added some additional context:

It's been a particularly heavy couple of weeks on [IPU A]. We have all had full care patients, lots of arrests [...] I think the nurses are just exhausted?

Sarah's rationale was of particular interest to me. I wrote this in my journal:

[...] there are nurses who have not even seen the posters who are telling me how terrible it was to have the posters up. There is a 'collective' displeasure. Even Sarah, who helped design RHEPORT, told me how hurtful it has been to have these negative comments up, yet she didn't work that week and didn't even see the posters up on the wall! Her colleagues have obviously told her. (Action Cycle 1, Day Eight)

Action Cycle 2 summary

The Advisory Group members who participated in this cycle's evaluation (via email) agreed that posters were a quick and easy way to communicate patient and visitor feedback. However, there were questions raised about the effectiveness and meaningfulness of the posters to staff if clinical nurses were opposed to them displaying negative feedback. The Advisory Group members agreed that this was an issue that required further exploration. The group also concluded that the use of emojis was not as effective as had been hoped. While using emojis was designed to improve the clarity of the messages on the posters, as Selena (a patient) said, “*they had the opposite effect*”. Because of this, the Advisory Group queried whether an accurate snapshot of patient and visitor experience was being received by the clinical nurses. Additionally, the impact of negative comments on the nurses was greater than the Advisory Group had expected. We had believed that anonymity would mitigate the possibility of nurses taking ownership of the negative comments. It became apparent that we had overlooked the possibility of their taking ‘collective ownership’. Not only were nurses displeased at reading negative comments, their unhappiness had also perhaps resulted in the poor response rate to the Nurse Evaluation Surveys.

Based on the findings from Action Cycle 2, the lessons learnt and questions raised from Action Cycle 2 are summarised in Table 15, below.

Table 15 AC 2 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
EMOJIS	Most participants found emojis confusing	Should we continue to use emojis?
KEY COMMENTS	<p>Participants were happy to identify key comments</p> <p>Senior staff appreciated the opportunity to review and remove comments</p>	
POSITIVE KEY COMMENTS	All participants reacted positively to reading positive comments	
NEGATIVE KEY COMMENTS	All clinical nurses interviewed, and some patients and visitors, reacted negatively to reading negative feedback	Should we continue to display negative feedback?
EVALUATION FEEDBACK	<p>All participants interviewed about their experience (patients and visitors) agreed that RHEPORT V1 was a good way to capture and deliver feedback. Clinical nurses did not</p> <p>There was minimal response to the nurse survey</p>	How can we increase the Nurse Evaluation Survey response rate?

Action Cycle 3 – field-testing RHEPORT V2

(March – May 2016)

Aim

The aim of Action Cycle 3 was to revise RHEPORT V1 based on lessons learnt and questions raised in Action Cycle 2, and to field-test RHEPORT V2.

Plan

Planning to field-test RHEPORT V2 on IPU B (a cardiology ward) began in March 2016.

Discussions within the Advisory Group during this time were based on the findings, evaluation, reflections, lessons learnt, and questions raised in Action Cycle 2. In addition, I conducted literature searches regarding best practice in the use of emojis in healthcare.

Specific issues for discussion via email amongst the Advisory Group members were:

1. The use of emojis
2. The display of negative feedback, and
3. Lack of clinical nurse feedback.

Based on these discussions, and on literature searches relating to health literacy, font choice, and communication using emojis, two further topics were discussed:

4. Poster specifics, and
5. Experience interview questions.

Use of emojis

At the request of the Advisory Group, I sought additional evidence on the use of emojis in a healthcare setting. While there was little research on the use of emojis in healthcare in 2016, we did know that one in four adults worldwide were regularly accessing social media, and frequently complementing their text-based communication with emojis (Hewis 2015; Pew Research Center 2014). The use of emojis, however, did not seem to enhance understanding among those reading the posters during Action Cycle 2. The Advisory Group nevertheless decided that we should continue to use emojis in Action Cycle 3, as we could not rule out that difficulties may have been IPU-specific.

Negative feedback and lack of clinical nurse feedback

The issues of the nurses' adverse reactions to negative feedback again elicited robust discussion among the Advisory Group during email planning meetings. Wallace (a Registered Nurse) queried whether the issue was IPU-specific when he asked, "*perhaps it was just [IPU*

A] nurses who can't take criticism?" Other Advisory Group members shared concerns about the nurses' negativity. For example, Selena (a patient) stated:

As a patient (at [another hospital]) I would love seeing these comments! I hope there is a way to keep this going and to get the nurses on board. Surely it is a given that nurses are loved, so these are minor quibbles in the scheme of things?

Irena, another patient, said:

I think it is great – both the positive and negative comments. It humanises the situation. I think it is unfortunate that the staff seem to take the negative comments personally rather than seeing them as an opportunity to learn what the patients are feeling.

The issue of potential vulnerability and exposure was also raised by Miranda (family member):

In terms of the comments, it seems to me that the nurses are suffering from the usual thing where seeing/hearing one negative comment overweighs ten positive ones. Perhaps part of the not wanting the negative comments shown is that it makes the nurses feel vulnerable and that others are more likely to criticise once criticisms are public, however, the reason the patients liked it is probably because we tend to like other people showing their vulnerability [...]

Based on its discussions and evaluation, the Advisory Group resolved to continue to display negative comments during this upcoming unit to be field-tested (IPU B). The rationale being that these feelings of negativity may also be unit-specific.

After discussing the inadequate response regarding the Nurse Evaluation Surveys, the Advisory Group surmised that if the clinical nurses resented the negative feedback, they may choose not to participate in giving evaluation feedback. However, Andrea (a patient) and Alexia (a Registered Nurse) offered another point of view when they suggested that clinical nurses may not have completed the surveys because the surveys were simply too long, "*given how busy the nurses are*". The Group agreed, and the survey was shortened, then re-approved by the Advisory Group and by the relevant ethics committees (Appendix K and G).

Based on the desire to capture more nurse evaluation feedback, I suggested to the Advisory Group that I would try to collect more verbal feedback from nurses whenever I saw them reading the posters. The Advisory Group agreed this was a good idea. I also suggested to the Advisory Group that we could forewarn the nurses before the posters were displayed that there may be negative feedback. I made this suggestion based on literature that highlighted the importance of 'buy-in' from healthcare providers to 'support' and understand the

benefits of negative feedback (Care Quality Commission 2009). As a strategy to support staff buy-in, it was agreed that I would attend one of the unit's bi-monthly education sessions and present the goals and objectives of RHEPORT V2, which included the importance of negative feedback, to the clinical nurses before displaying the posters.

Poster specifics

Following the Advisory Group's reflections on copies of the posters that had been displayed during Action Cycle 2, Mette (a patient advisory group member) suggested in an email that the phrase 'you said' (see poster examples Appendix O) may be too direct:

I can't make up my mind about the phrase "This week you said" [...] slight air of accusatory?? I know it's not meant that way and nobody else will have the same thought, in which case being overly sensitive. Anyway, I just mention it. Have yet to come up with an alternative.

The Advisory Group then considered using the phrase 'you told us,' however, I shared with the group my concerns that 'us' may be taken to imply the hospital. I felt that this had potential ethical implications, as it could suggest to participants that the 'hospital' gathered or endorsed the comments displayed – which was not the case. As such, it was agreed that we should continue to use the phrase 'you said' for RHEPORT V2.

Experience interview questions

During this planning phase, I relayed to the Advisory Group that two patients from the previous Action Cycle had told me that they would recommend the hospital to others when asked about their experience. I was aware from my literature review that the Friends and Family Test (FFT) (National Health Service 2014) was considered to be representative of a patient's hospital experience. As discussed, a patient's willingness to recommend a hospital has been seen as such a relevant measure of patient experience that since 2013 the UK has collected over 48 million pieces of feedback using their Friends and Family Test (FFT) (National Health Service 2018). By merely asking patients how likely they are to recommend the hospital to a friend or family member, I explained to the Advisory Group, we would get an overall sense of their hospital experience. I suggested to the Advisory Group that it might be valuable to also ask this FFT question to our patient and visitor participants. I assumed that positive key comments would result in a recommendation and negative comments in no recommendation. This would be an ideal opportunity to test that hypothesis. The Advisory Group were keen to test this theory and agreed that I should also ask patients and visitors

providing experience feedback if they would recommend the hospital to their friends and family.

Implement

IPU B (a cardiology medical and surgical ward) was chosen to field-test RHEPORT V2, and this commenced in May 2016. The sequence of events is outlined in Figure 15, below.

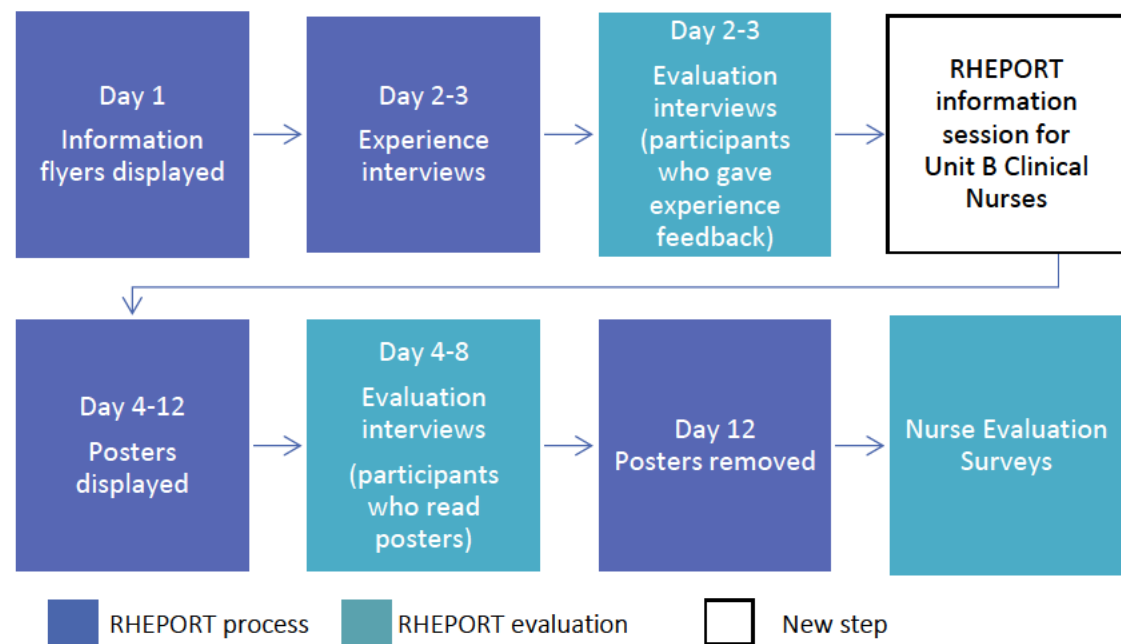


Figure 15 RHEPORT V2 process and evaluation

Findings

Thirty-Six participants (patients and visitors) were approached to provide experience feedback, and all agreed to participate (see Figure 16, p106). Participant interviews lasted, on average, 24 minutes each, with a range from ten to 86 minutes. Six participants did not want to choose an emoji to accompany their key comments, and again, those who did found the process difficult. From the data provided, 25 key comments were deemed to be positive and 12 negative. All 36 participants (including those who made negative key comments) stated they would recommend the hospital to their friends and family.

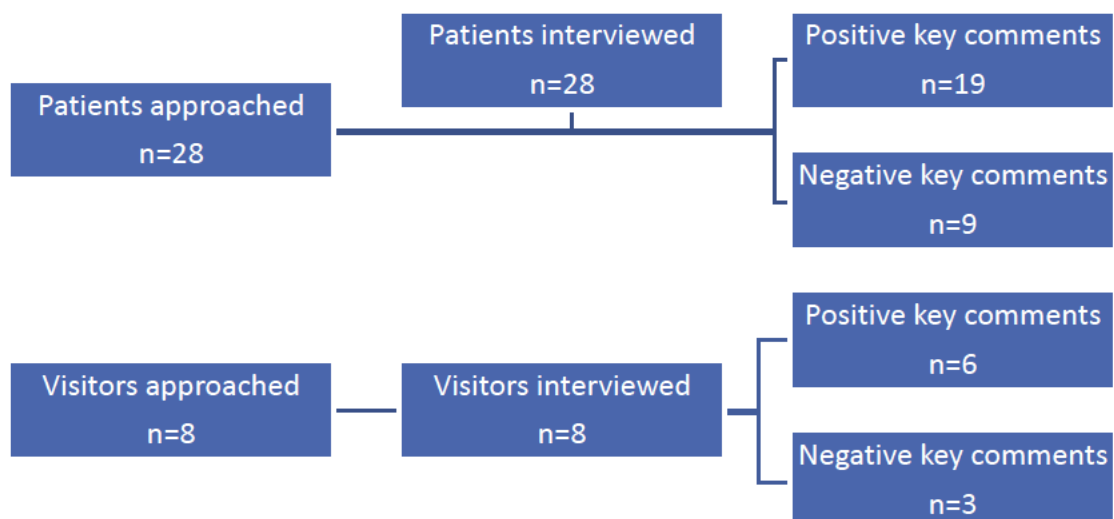


Figure 16 RHEPORT V2 hospital experience participants

The NUM of IPU B requested to see all key comments (positive and negative) before poster display. She agreed to all negative comments appearing, but did not want the following positive key comment to be included: *“The NUM took the time to talk to you. She talked you through [a form] at 5 pm. I work in a hospital – that’s pretty impressive”* (Visitor). The NUM’s reason for excluding this was that she felt it was *“only for her”*, stating *“I get plenty of negative comments, too. No-one needs to see this”*.

Before the posters were displayed, an information session was held (during one of IPU B’s bi-monthly education sessions) with six clinical nurses. These nurses were informed of the study goals and were shown examples of the posters. I discussed with the nurses some of the previous negative and positive comments, and impressed upon them that the comments were a perception of events, and that participants may perceive experiences differently. The nurses did not have any questions about the study, and from my observations of their expressions and body language they appeared ambivalent. There were no comments made other than ‘ok’ by one nurse as he left the room.

Evaluate

Participant evaluation, advisory group evaluation, and personal reflections

All patients and visitors interviewed about their experience were then immediately interviewed about their evaluation of RHEPORT V2. Subsequent evaluation interviews with patients, visitors and clinical nurses took place once the posters were up. Evaluation responses were obtained from 34 patients, eight visitors and 21 clinical nurses (including two assistants in nursing (AIN) and one NUM from another unit). Eight nurses completed the

revised Nurse Survey (see Appendix K). In total, 63 responses were obtained evaluating RHEPORT V2 (see Figure 17)

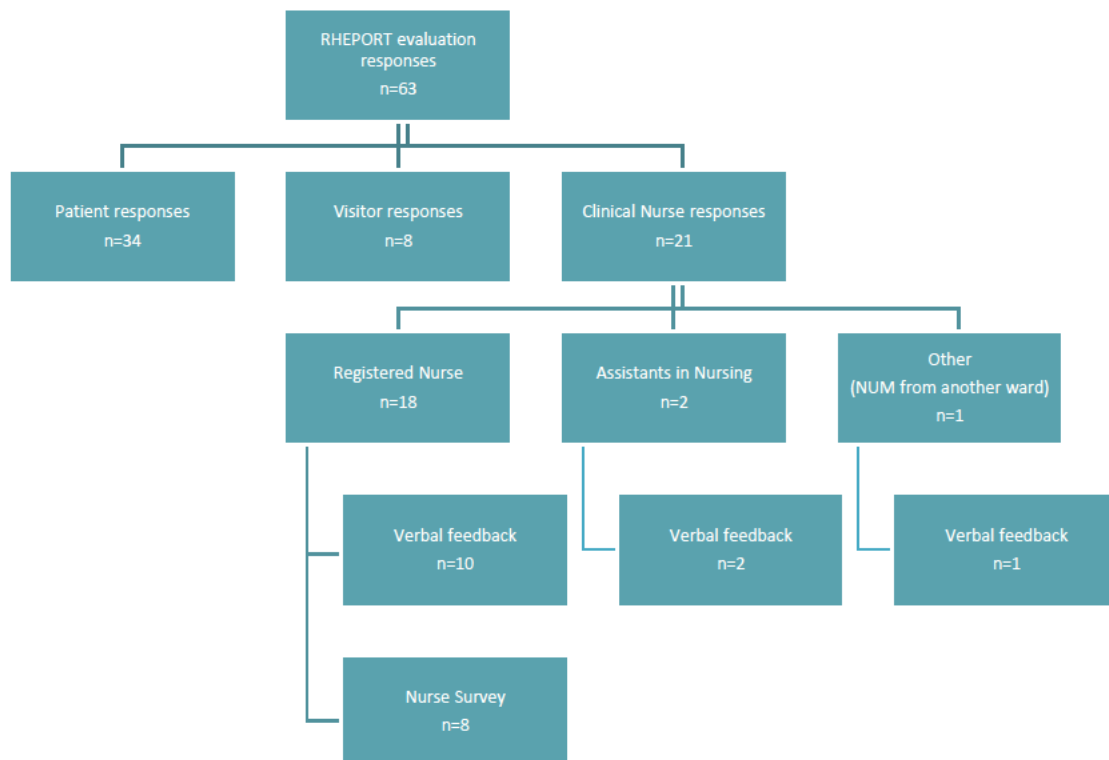


Figure 17 RHEPORT V2 evaluation responses

All visitors and all but one patient stated that RHEPORT V2 was a good way to capture current feedback and deliver it to nurses. One patient said, *“It’s a good idea to show the good and the bad like this”*, and another that *“These posters are a good idea”*. The patient who was not happy with the RHEPORT method was not pleased that we collected patient experience feedback in general:

I’m upset that we spend so much money on experience in the hospital system [...] [this is] beyond acceptable. This whole place. The room is twice as big as it should be. We spend too much money on the wrong things.

Interestingly, despite this patient’s negative feedback and evaluation, he responded that he ‘would definitely’ recommend the hospital to others when asked the FFT question. Members of the Advisory Group were quite surprised to learn that all participants stated that they would recommend the hospital, despite many having given negative experience feedback.

To capture as many evaluation responses as possible, I attended IPU B for three-and-a-half hours in the morning and three-and-a-half hours in the afternoon each day the posters were displayed. All responses from patients, visitors and clinical nurses indicated that they liked

reading the positive comments and found the feedback useful. Overall, staff were positive in their verbal feedback about RHEPORT. For example, when I asked one of the nurses for their opinion, they stated: “The general feeling is good [...] I’ve noticed lots of the visitors reading them”. Moreover, an NUM from another unit approached me in the foyer of the hospital, and their feedback also highlighted the usefulness of RHEPORT as a mechanism to improve patient care:

I read that comment yesterday [on IPU B] about the fans. This reminds [us] we need to get better at feeding back to the unit what happens with fans. If someone orders a fan, we search for it in the hospital, but we might not get back to the nurses.

The above example was specifically relayed to the Advisory Group as a concrete example of how RHEPORT could improve communication between staff and in turn, improve patient experiences of care.

When patients and visitors on IPU B were questioned about the negative comments, most seemed at ease with them. For example, one patient thought it was “a good idea to show the good and bad”. Similarly, one of the visitors said, “these posters are a really, really good idea”. Three patients expressed that the poster font was too hard to read, and one patient in a wheelchair reported that they found the posters “impossible” to read because they were placed too high. The NUM from another IPU also expressed concern that the posters were “taking up too much wall space”.

With respect to the display of negative feedback, clinical nurses were seen to actively search for negative comments. I shared a specific encounter from my journal with the Advisory Group, in which a clinical nurse confirmed that he was trying to identify the negative comments based on the emoji that accompanied them:

Most nurses witnessed to be reading posters seemed to be scanning them as if looking for specific comments to read. When I asked how they chose what to read, one said he was looking for the ones with ‘negative emojis as they must be the negative comments?’ I started to look more closely at all the people reading the posters. When questioned, several other nurses admitted to ‘skipping over positive comments’ and focusing on negative ones (Action Cycle 3, Day Six)

Despite the clinical nurses actively seeking out negative comments, unlike in Action Cycle 2, very few verbally expressed any displeasure after reading those comments. One nurse, after reading all the comments, said: “these must be edited so that we only see the good comments?” She was quite shocked to learn that the comments were unedited. Another

exchange I had with three clinical nurses reading the posters highlighted the lack of any apparent displeasure. I recorded this conversation in my journal:

[Nurse 1] read the poster ‘...older nurses are more thorough’ and looked at me and smiled, stating: ‘did you know that older nurses are more thorough?’ [Nurse 2] joined in the conversation and laughed about older nurses being more thorough. [Nurse 3] then replied, laughing, ‘what are you talking about? You are the nurse who never got the fan!’ (Referencing another poster comment she had obviously read earlier). The three nurses then laughed. (Action Cycle 3, Day Four)

Nurses from IPU B also appeared to be more engaged with the feedback, and with discussing the feedback with their colleagues:

The nurses on Unit B seem to read the posters in groups of two or more nurses and then share their perceptions, which was not witnessed on the previous inpatient unit. Several nurses took guesses at who said what, asking me if they were right. (Action Cycle 3, Day Six)

After relaying the above journal entries, along with my observations regarding clinical nurses’ reactions to the comments, to the Advisory Group, Simon (a Registered Nurse) suggested that perhaps this apparent acceptance of negative feedback was due to a “*more open collegial culture*”.

I also shared accounts from my journal in which I had recorded that nurses had continued to focus on looking for negative comments instead of positive ones. Moreover, the perception that only positive comments were being displayed was further apparent during an interaction I had with a clinical nurse on IPU B several weeks later (well after the field-testing of RHEPORT V2). I recorded this interaction in my journal:

A nurse approached me in the hospital on another inpatient unit and stated ‘you must tell us the negative things, too. I think you only told us the positive things people said on our ward’. I explained that there were twelve negative comments, and reminded her of some of the specific comments, to which she replied, ‘but those comments weren’t really negative.’ While there were slightly fewer ‘negative’ comments on this [B] than the previous one [A], they were still very similar in content. Another nurse who had also seen the posters on unit B stated that he ‘didn’t see the bit about recommending the hospital, but then I only glance over the positive ones.’ (Journal Entry on Action Cycle 3)

I also fed back to the Advisory Group how, during the fieldwork, I noticed that the attitude towards me among nurses on unit B was in complete contrast to the previous Action Cycle.

Reflective of a more positive attitude to the display of feedback, one nurse approached me after reading the comments and said, *"I wanted to thank you for doing this study"*.

Amended Nurse Evaluation Surveys

The amended (shortened) Nurse Evaluation Survey was given to all clinical nurses present on IPU B on Day 12, with the remainder distributed via the CNE. Six completed surveys were returned. Five of the six nurses stated that they remembered the RHEPORT posters. One nurse wrote that he or she read 'all comments', three indicated that they had read 'most', and one only read 'some' comments. Responses about reading positive or negative comments varied, but two nurses stated that they only remembered reading positive comments.

When asked how many negative comments were displayed, one nurse said there were three, two said there were two, and one that there was only one negative comment. There were, in fact, 12 negative comments displayed. Only two nurses reported that the posters caused them to reflect on their practice. One stated that the comments reminded them *"to keep doing what we are doing"*, while the other stated the comments made them think about *"patients' perceptions compared to nurse's perceptions"*.

Two clinical nurses indicated that they felt 'neutral', as opposed to 'comfortable' or 'uncomfortable', about seeing the experience comments on display; however, one wrote *"some of the comments made me laugh. I enjoyed reading them"*. Three nurses felt 'comfortable' about seeing the comments on display, and wrote:

when you constantly strive for excellence, there's nothing to hide from. I've found the negative comments to be trivial, e.g. "the nurse took too long to find a fan"!!

When questioned whether the presentation of patient and visitor feedback was valuable, two nurses reported that they felt 'neutral', and the remainder considered the feedback valuable. One nurse suggested that *"feedback promotes improvement in practice as long as it's constructive. Nobody likes to be bashed verbally"*. Another added: *"It is always good to see something from someone else's point of view"*. Four of the five nurses who saw the posters indicated that they would not change anything about the RHEPORT Protocol. One nurse reported that they would change the posters so that only positive comments appeared, suggesting that we ought to *"send negative comments privately to the NUM to feed back to the staff!"*

Given the low response rate to the evaluation survey among clinical nurses, I was concerned that they might be simply reading the posters but not engaging with the feedback, nor with the method of delivery, and as such not participating in RHEPORT's evaluation. Clearly, this would have implications for achieving the overall aim of the study. I relayed this concern to the Advisory Group and asked them *'how we could change practice based on insights from clinical nurses if these same nurses were unwilling to provide insight'*. In response, members of the Advisory Group agreed that we needed to explore additional ways of capturing clinical nurse evaluation feedback about the RHEPORT process.

Action Cycle 3 summary

Based on the findings from field-testing RHEPORT V2 and the reflections and evaluation, lessons learnt and questions raised from Action Cycle 3 are summarised in Table 16, below.

Table 16 AC 3 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
PRE-FEEDBACK INFORMATION SESSION	Well received by clinical nurses.	
EMOJIS	Participants continue to find emojis confusing. Clinical nurses are using the emojis as identifiers of negative or positive comments and are then only reading the negative comments.	Should we continue to use emojis?
POSTERS	Font style and poster placement are not accessible to all participants.	Should we change font and poster placement height?
FRIENDS AND FAMILY TEST (FFT)	All participants interviewed would recommend the hospital to friends and family – even those who had negative experiences.	Why would patients who make negative key comments recommend the hospital?
NEGATIVE KEY COMMENTS	Some nurses interviewed, and some patients and visitors, reacted negatively to reading negative feedback.	Should we continue to display negative feedback?
EVALUATION FEEDBACK	Nurse evaluation response rate remains low.	How can we collect more evaluation feedback from nurses?

Action Cycle 4 – Field-testing RHEPORT V3

(April – June 2016)

Aim

The aim of Action Cycle 4 was to revise RHEPORT V2, based on the lessons learnt and questions raised from Action Cycle 3, and to field-test RHEPORT V3.

Plan

Planning for the field-testing of RHEPORT V3 began in April 2016. Discussions with the Advisory Group during this time were based on the findings, evaluation, and reflections from Action Cycle 3, plus subsequent literature searches regarding issues raised. Specific topics for discussion and planning were:

1. The continued use of Emojis
2. Poster specifics (font style and poster placement)
3. Understanding the Friends and Family Test (FFT) recommendations
4. The display and reaction to negative feedback, and
5. Clinical nurse evaluation feedback.

Emojis

The use of emojis to represent patient and family member experience during Action Cycle 3 continued to cause confusion among field-test participants and nursing staff who read the experience posters. We referred to the literature to understand the findings from Action Cycle 3, and found the most commonly confused emoji was 'tears of joy' (see Figure 13, p95), which is somewhat surprising, considering that the Oxford English Dictionary named the 'tears of joy' emoji its 'word' of the year for 2015, suggesting that it should have had a wide appeal and broad comprehensibility (Willoughby & Liu 2018). Nevertheless, the Advisory Group decided to abandon the use of emojis.

Poster specifics

Several field test participants stated during Action Cycle 3 that the font used on the posters was challenging to read, regardless of size. In response to this, the Advisory Group looked to the National Health Service (NHS) font guidelines for help in choosing an appropriate typeface (National Health Service 2016). As a result, **Arial** was chosen for its consistency with the NHS guidelines for easy readability, and because it did not incur a cost to use.

The Advisory Group, and I in particular, also made a note to be more mindful of poster height placement for the upcoming field test after the participant in a wheelchair reported that they

could not read the posters at their previous height. The Advisory Group also agreed to reduce the poster size (but not the font size), based on senior staff members' feedback, from A3 to A4.

Understanding willingness to recommend

When reflecting on the willingness to recommend data from Action Cycle 3, the Advisory Group was surprised that the 12 patients and visitors who gave negative feedback all said that they would recommend the hospital to their friends and family. As a possible rationale for this response, Becca, one of the advisory group members who identified as a 'family member', said, "*Maybe it's the Devil you know*", suggesting that perhaps patients would prefer to stick with a hospital they already knew rather than recommend another. While the Advisory Group considered this to be plausible, we decided that we needed to better understand the reason(s) behind participants recommending the hospital despite giving negative feedback. As such, it was decided that during the upcoming field test I would ask participants who gave negative feedback and yet recommended the hospital why they would do so.

The display of and reaction to negative feedback

The visible and verbal reactions of the clinical nurses with regard to negative feedback during the previous Action Cycle was in direct contrast to Action Cycle 2. Clinical nursing staff, in general, did not appear to be concerned with negative feedback. The Advisory Group surmised that the pre-feedback information sessions might have helped prepare the clinical nurses for negative feedback. As such, the Advisory Group decided to continue to display negative feedback for this cycle.

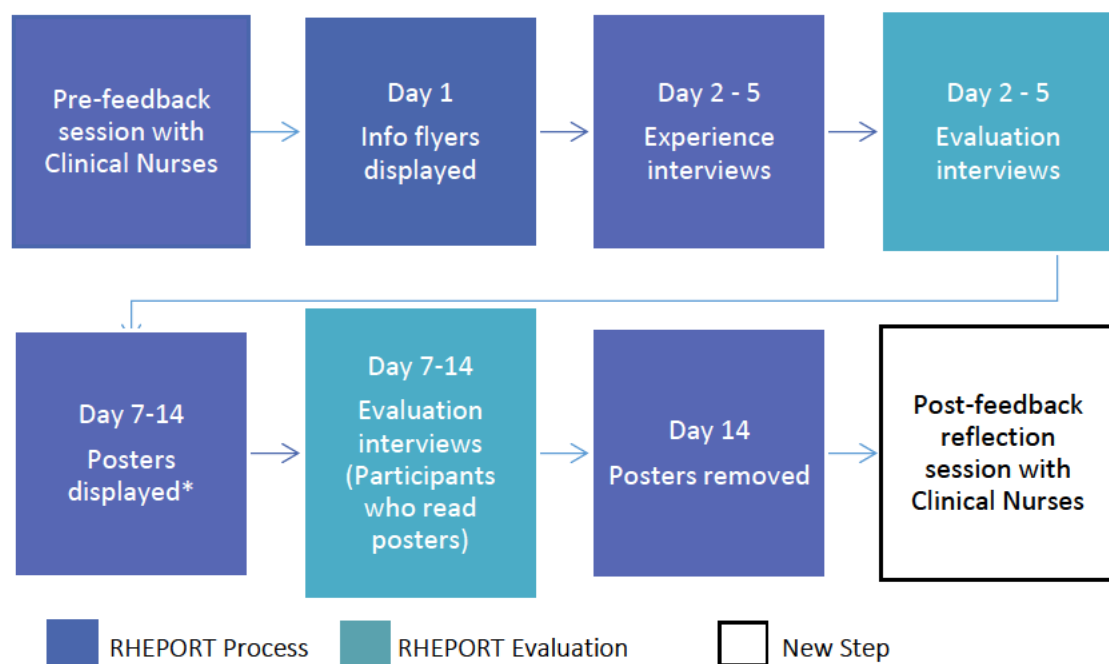
Nurse evaluation feedback

Disappointed with the continued low Nurse Survey response rate, the Advisory Group agreed to discontinue written surveys and consider alternative methods to capture clinical nurse evaluation data. The Advisory Group proposed that I hold a guided 'post feedback reflection session' with the clinical nurses at the end of the field test period (after the posters had come down). The plan for the reflection session was to discuss the positive and negative comments and offer a safe space for clinical nurses to reflect on the feedback together. The Advisory Group felt that reflection sessions were an important addition, because they posited that if clinical nurses were not receptive to the feedback RHEPORT provides, then the protocol is of little value. Thus, directly seeking the clinical nurses' evaluation feedback via a face-to-face session would enable the Advisory Group to obtain data on the nurses' perceptions of the acceptability and usefulness of real-time feedback, and of the RHEPORT Protocol itself. I

suggested we base the session on the Point of Care Foundation’s guide for running a staff feedback event – part of their Experience-based Co-design (EBCD) toolkit (The Point of Care Foundation 2016), in which nurses are brought together to discuss and share their views on experience feedback. The Advisory Group agreed.

Implement

Inpatient Unit C (an orthopaedic unit) was chosen as the unit to field-test RHEPORT V3. Field-testing of RHEPORT V3 (see Figure 18, below) commenced in May 2016.



*The NUM of this unit was away during the interview period, hence the three-day lag time between experience interviews and poster display.

Figure 18 RHEPORT V3 Process and Evaluation

Findings

The pre-feedback session for IPU C nurses was held on 11 May 2016, with 13 clinical nurses attending. The nurses were advised that the study would commence shortly. They were asked to try to read as many feedback posters as possible, and were advised that, unlike most traditional patient and visitor feedback processes, this data would be unit-specific. The clinical nurses were reminded that reading positive comments is not only good for morale, but that they also convey what is being done well. I also discussed with the clinical nurses that negative feedback can be quite confronting, and that there had been a mixed reaction from clinical nurses on other units to the posters thus far. The nurses were then advised that they would have a chance to discuss the comments and their feelings about the feedback and the

process at the end of the poster display period in private via a post-feedback reflection session.

Thirty-six participants (patients and visitors) were approached to provide experience feedback, and 35 agreed to participate (see Figure 19, p116). Participant interviews lasted, on average, 20 minutes, with a range of 16 to 42 minutes. Twenty-five key comments were deemed to be positive, and ten were negative. This cycle saw the only instance of a patient giving quite detailed negative feedback about one experience, and yet the key comment she wanted to appear did not relate to that incident. The patient stated that she wanted the following to appear on the poster: *"My nurse didn't seem happy. It was as if it was an effort to be here. The rest have been amazing"*. I immediately asked if she would recommend the hospital to friends or family, to which she replied, *"Of course. It's brilliant here"*.

Again, all participants in this cycle (four), including the ten who made negative comments, said they would recommend the hospital to their friends and family. At no stage did any participant who gave negative feedback provide any unsolicited justification for why they would recommend the hospital despite negative experiences. Reflecting on this issue in my journal, it appeared to me as if the two responses were 'unrelated':

Patients are telling me specific negative experiences, but they still say they would recommend the hospital? When I ask why, they don't refer to the negative things they just told me. It's as if they have nothing to do with one another. (Action Cycle 4, Day Five)

When directly questioned why these patients would recommend the hospital, the most common reasons given were 'good reputation' and long-term custom. As one patient put it: *"we've been coming here for years"*.

Another important finding from this cycle was that Mondays were not ideal for collecting patient or visitor experience feedback in this hospital. There were rarely elective surgeries on the weekends and as a result, many IPU beds were empty on Monday mornings. While the beds filled up as the day progressed, these patients were post-operative, and usually still under the effects of anaesthesia, and as such unable to be interviewed.

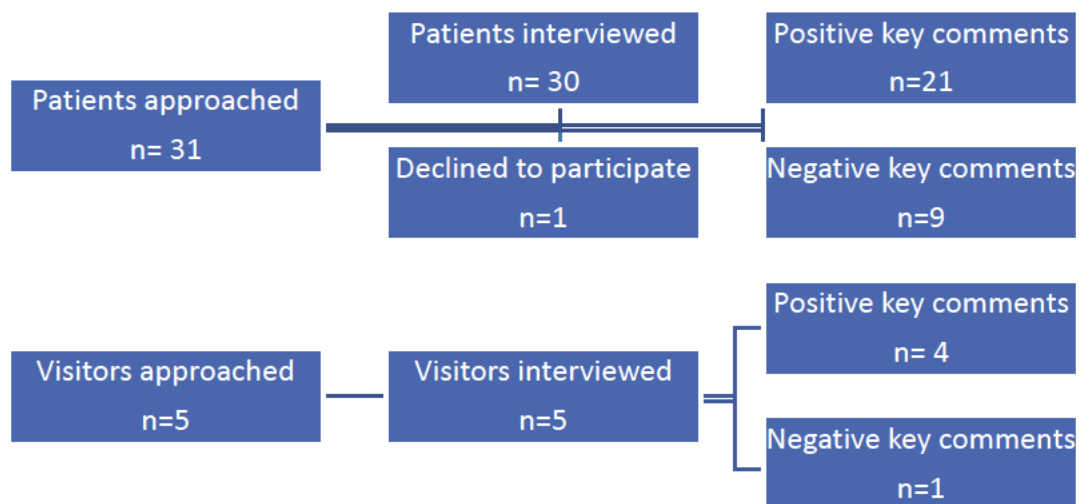


Figure 19 RHEPORT V3 hospital experience participants

Posters were created to display the 36 key comments (see Appendix U). The NUM of this unit also requested to see all feedback before the posters went up and subsequently agreed to all comments being displayed.

Evaluate

Participant evaluation, advisory group evaluation and personal reflections

Following the same format as previous cycles, all participants who were interviewed about their experience were then interviewed about their evaluation of RHEPORT V3. Subsequent evaluation interviews took place once the posters were up. In this cycle, I conducted a post-feedback reflection session with the clinical nurses about the patient and visitor experience feedback. In total, 63 evaluation responses were collected (see Figure 20, p117).

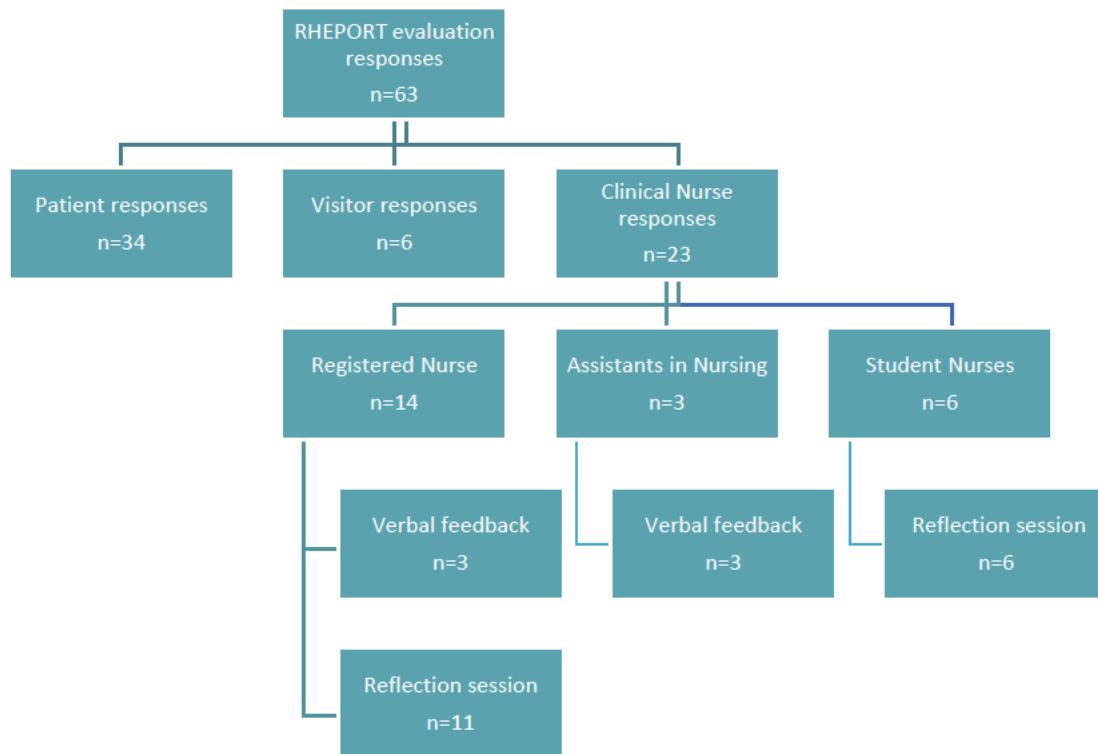


Figure 20 RHEPORT V3 evaluation responses

In this cycle, an extremely low number of patients and visitors were observed reading the posters: four patients, and one visitor. Given that this was an orthopaedic unit, it is likely that the lack of mobility among the participant population meant that few patients were able to ambulate freely and view the posters. Many patients were bedridden. Those who were not often walked along the corridor with the assistance of the physiotherapist. These walks were very focused on the task and, as such, not conducive to stopping to read a poster.

The majority of evaluation responses from patients and visitors, therefore, came from those who were interviewed about their experience. While all patients and visitors again said that RHEPORT was a good way to capture and deliver feedback, and that they were ‘interested’ in reading the comments or ‘liked’ reading them, one common theme among the patients on this unit was a reluctance to see negative comments. When asked if they were keen to read negative comments, only one person stated that they would want to. This was true even for participants who themselves had made a negative comment. The one exception was a patient who informed me that she was a Human Resource manager, who said, *“reading negative comments would interest me”*. The other participants’ reasons for not wanting to read negative feedback had a common theme: not wanting to add to their current *“stress”*, or not wanting to have *“additional worries”* during their hospital stay. Based on these insights, I

began to question the ethical implications of displaying negative feedback as highlighted in my researcher journal;

I think this may potentially cause undue stress to patients and visitors, as well as to the nurses. We can't make patients more concerned. (Action Cycle 4, Day Nine)

Clinical nurse evaluation feedback predominantly came from the reflection session, which was well attended, with 11 Registered Nurses and six student nurses taking part. Overall IPU C nurses seemed to have had a positive perception of RHEPORT V3, as reported in the following journal entry:

I think the warning [pre-feedback sessions] plus the end discussion [post feedback reflection sessions] are a good idea, but they want to know the "upshot" [...] The nurses seem to like it, and I think they have been more engaged. Only one nurse was very quiet. She had more to say during the pre-feedback session [...] Nurses have thanked me again on this Unit [...] I feel they are happy with RHEPORT. (Action Cycle 4, Day 15)

Those present at the reflection session were highly engaged with the discussions, and seemed very keen to hear my views on the experience comments made, and particularly how this compared to other inpatient units. The clinical nurses stated that they read "most" of the RHEPORT posters on the unit. When asked if they saw patients reading the posters, there was a consensus that there very few had been witnessed doing so. One nurse said, "maybe it's the location where you put them or the fact that its ortho – I mean they don't walk far do they?", echoing my explanation. When the clinical nurses were asked how they felt about reading negative feedback, their responses ranged from ambivalence or disinterest to slight irritation. One nurse said "I just assumed it was not about me", with another saying they "preferred to be told about it individually in person".

Potential benefits and shortcomings of the RHEPORT Protocol were identified during this feedback session. One nurse volunteered a story about her experience when reading a poster. The comment she read was "I've had this calf compressor on all day, but it hasn't been turned on" (patient). The nurse said reading it had immediately 'triggered' her memory: "I had a patient that I forgot to take them [calf compressors] off. Great patient-centred care, right?", suggesting that posters may remind nurses of the importance of specific practices.

Conversely, it became apparent that the reflection session was not providing meaningful enough data for the nurses. After discussions about specific key comments, one nurse asked, "well what's the upshot?" I had difficulty answering this question. While I conducted a preliminary analysis of experience feedback at the end of each interview day to ensure the

key comments were meaningful experience findings, I had not yet done any other coding or overarching thematic analysis. This nurse's question, however, prompted me to consider that some level of thematic analysis was warranted to code the experience findings in a way that was meaningful for clinical nurses on the units. This evaluation feedback was relayed to the Advisory Group, as were my reflections (Day 15's journal entry, see above). No Advisory Group members replied directly to this information during this Action Cycle. It occurred to me at this stage that Advisory Group members may have started to disengage from the research. As such, I contacted each member individually. Only six members offered suggestions and/or comments. However, all members said that they were happy with how things were progressing and were keen to move on to the next Action Cycle.

Action Cycle 4 summary

Based on the findings from field-testing RHEPORT V3 and the reflections and evaluation, the lessons learnt, and questions raised from AC 4 are summarised in Table 17, below.

Table 17 AC 4 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
PRE-FEEDBACK INFORMATION SESSION	Was well received	
INTERVIEW TIMING	Monday should be avoided when collecting experience feedback from patients	
POSTERS	Bedbound patients cannot read posters	How can we display feedback to bedbound patients?
FRIENDS AND FAMILY TEST (FFT)	Patients and visitors continue to recommend the hospital regardless of their negative experiences	Why would patients who make negative key comments recommend the hospital?
NEGATIVE KEY COMMENTS	Some clinical nurses interviewed, and some patients and visitors reacted negatively to reading negative feedback	Should we continue to display negative feedback?
POST FEEDBACK REFLECTION SESSIONS	Reflection sessions are well received by clinical nurses and provide a good opportunity to obtain nurse evaluation feedback A method of coding the experience findings is needed	How can we collect more evaluation feedback from nurses? How can we code the experience findings quickly and easily and relay those findings back to the Clinical nurses?

Action Cycle 5 – Developing a method to code feedback

(June 2016 – June 2017)

Action Cycle 5 was conducted in explicit response to the feedback offered by the clinical nurses during the reflection session from the previous Action Cycle (Action Cycle 4). During Action Cycle 4, it became clear that analysis and coding of the experience feedback data was necessary to communicate an accurate summation of the experience comments to the clinical nurses during the reflection session. This section chronicles the development of a method devised by the Advisory Group to achieve this.

Aim

This Action Cycle aimed to develop a method to synthesise and code patient and visitor experience feedback.

Plan

It was always intended that RHEPORT be developed as a replicable mechanism for capturing and delivering feedback. The Advisory Group agreed at the workshop that we would endeavour to create something other nurses and hospitals could benefit from. As a qualitative researcher, I was aware of several methods for coding qualitative findings, such as the experience data collected, but these methods would not be suitable in this case because of the considerable amount of time and expertise required to do the coding. The requirement was that we relay the feedback to the nurses in a timely manner – as close to real-time as possible. Based on my Honours research regarding patient experience (Edwards, Duff & Walker 2014), I suggested to the Advisory Group that we adopt a framework for coding based on patient-centred care and/or patient experience. At the time, there were several such frameworks that could provide a structure within which the patient experience could be considered (National Clinical Guideline Centre UK 2012). Moreover, the use of a framework would assist future facilitators when applying the RHEPORT Protocol to code their experience feedback. The Advisory Group agreed that if RHEPORT was to be replicated in the future by non-researchers, an uncomplicated and rapid method of coding the key experience comments was required.

A number of frameworks were sent to the Advisory Group for their consideration (see full versions in Appendix B). These included:

1. Australian Charter of Healthcare Rights
2. Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS; eight domains to measure patients' perceptions of their hospital experience)
3. Institute of Medicine (IOM) framework for patient-centred care (six domains of patient-centredness crucial to providing quality healthcare)
4. Picker Principles of Patient-Centred Care (eight domains)
5. The National Institute for Health and Care Excellence (NICE) Guidance Development Group for the National Health Service (NHS; six outcomes of good patient experience)
6. Warwick Patient Experience Framework (WaPEF; seven generic domains of experience), and
7. World Health Organisation (WHO) Domains of Responsiveness (seven domains of satisfaction with the health system from the perspective of the patient experience).

Only five members of the Advisory Group stated their preference, and all five of them opted to leave the final choice to me. Selena (a patient) stated in one email, *"I think the Picker and the HCAHPS look quite useful ways of organising the data"*. Mette (a patient and family member) suggested, *"WHO is a bit more inspirational, but also the vaguer categories might be easier to work with? (Or not)"*. Both Selena and Mette highlighted that we should consider the fact that clinical nurses may not have the authority to change certain categories of experience:

I think the driver for the framework will depend on who the recipient is. My initial thought was to say – as a patient – I'd like to see equal importance given to medical procedures as to that other fluffy stuff. Like actually giving me the best drugs and procedures is most important. But then, as you know, nurses don't have total control over this. (Selena)

[...] the framework maybe should include a) only things nurses have control over, or b) have a column for things outside their control. In fact, "b" might address some of the concerns you've been getting from nurses [negative feedback from nurses regarding the public display of negative patient and visitor comments]? (Mette)

Other Advisory Group members raised similar concerns. Moreover, a frequent criticism in the literature, offered by nurses, of patient experience feedback mechanisms is that the issues raised are beyond their control (Adams, Maben & Robert 2018), and that nurses are not regularly involved in the development of policies necessary to address them (Kieft et al. 2014). Rather than merely positioning such findings as 'not applicable to nursing care', I suggested that by including such feedback in the reflection sessions, we could open discussion on how nurses may have some impact on an experience seemingly beyond their control. I gave the example of a frequent complaint voiced by patients in their feedback about hospital food. I also discussed with the group that several aspects of a patient's diet could be modified if a nurse requested it, including portion size, food preference, texture,

assistance required, and delivery time. In response to this, the Advisory Group agreed that all feedback should be included in the coded data to be presented back to the nurses. We decided that the Picker Domains should be used as the framework due to its widespread adoption in Australia and other countries, and its suitability.

To field-test the appropriateness of this method, I planned to code all comments, and I invited all members of the Advisory Group to do the same, and several agreed to participate. I then created a template so that the coders could simply read and then allocate the key comments to a Picker domain or domains, or create a new domain if they felt it necessary.

The following framework of Picker domains (Picker Institute 2013), with examples, was sent to the Advisory Group members to guide their coding:

1. **Respect for patients' values, preferences and expressed needs** (providing dignity, respecting autonomy)
2. **Coordination and integration of care** (coordination of clinical care, support services etc.)
3. **Information, communication, and education** (for example, information on clinical status, information on hospital processes of care, information to facilitate self-autonomy)
4. **Emotional Support and alleviation of fear and anxiety** (anxiety over treatment or outcome, anxiety over financial impact)
5. **Physical Comfort** (includes pain management, assistance with activities, surrounding environment, feeling safe)
6. **Involvement of family and friends** (recognition of the importance of family and friends, and the support given by family and friends)
7. **Continuity and transition** (information regarding discharge, physical limitations)
8. **Access to care** (for example, this could be ease of seeing a doctor or parking issues), and
9. **Additional domains** (Advisory Group members to generate).

Based on the findings from my Honours research, I highlighted to the Advisory Group member coders that most experiences do not fall neatly into only one category (Edwards, Duff & Walker 2014). I gave the example of a patient who discussed his displeasure about the timing of his medication. Medication management issues as framed in the Picker domains are typically considered to be matters of 'coordination of care' (Picker Institute 2013). However, this could also be a lack of 'respect for patients' values preferences and expressed needs', and/or an issue about 'information, communication and education'.

The members were asked to code only the key comments. They did, however, have access to additional supporting data for each comment, such as my field notes. The Advisory Group also decided that, based on the coding, I would then identify the top three domains of

experience which contained the most key comments, regardless of whether they were negative or positive. I would in turn discuss these domains, with examples, at the reflection sessions with the clinical nurses. After coding, I would create a document (see Appendix V) for each inpatient unit, with every Picker domain listed (including additional domains), along with verbatim examples of key comments applicable to each domain. In addition to discussing the top three themes at the reflection meetings with the nurses, I would identify which domain contained the most positive and which the most negative comments – again with examples of each on hand for discussion.

For the production of the RHEPORT posters, key comments would continue to be classified as negative if any part contained a negative remark or suggestion. However, with regard to thematic coding by the Advisory Group members, each comment would be considered in its entirety. For example, when developing the RHEPORT posters, the following comment would be deemed negative and flagged for NUM review: *“Nurses are caring here. If you ask them, they come. Some have been just beautiful. One was a bit abrupt”*. For coding purposes, however, the comment would be attributed to the ‘coordination and integration of care’ domain as a positive example, and to the ‘information, communication and education’ domain as positive *and* as negative. Thus, the same key comment could be assigned to multiple domains, and as both positive and negative to the same domain.

Implement

At the end of each Action Cycle (Six through to Nine), using the Picker Domains as a framework, I coded all key comments, and a random 10 per cent were sent to four Advisory Group members who offered to code the data (see Action Cycle 6). Four Group members sent back their coding at the end of the Action Cycle, with the fifth stating that he no longer had time. Throughout the entire study, seven additional domains were identified by the five Advisory Group coders (me, Irena (patient), Selena (patient), Mette (patient and family member) and Olivia (Registered Nurse):

1. Outcome
2. Reputation
3. Effort
4. Kindness and care
5. Expertise
6. Attitude, and
7. Peer support.

The findings from Action Cycles 2 to 4 were retrospectively coded, but the synthesis of this information was not delivered back to the clinical nurses of their respective inpatient units (A, B and C) as there was no opportunity to do so. Also, a considerable amount of time had passed between capturing those comments and coding them. The coding of these experience comments did, however, allow us to assess whether the coders were reaching similar findings, by using the same coding framework.

Evaluate

Participant evaluation, Advisory Group evaluation and personal reflections

Apart from the one Advisory Group member who stated he no longer had time to code the key comments, the four other members (Mette, Selina, Irena, and Olivia) reported that the coding method using the Picker framework was straightforward. Irena and Mette completed the most coding, with Irena saying that time and complexity were issues to begin with: *“it took longer than expected [...] harder than it looks at first pass!”* Irena, Mette and Serena returned their samples to me within two to three days of receiving them. Olivia returned hers 10 days later. All reported that after ‘coding’ the first batch, the process became more familiar and much more manageable. In all but a few cases, the Advisory Group members coded the data in similar ways to me. Any disagreements were resolved by including all and any domains identified by coders.

Action Cycle 6 – field-testing RHEPORT V4

(June – August 2016)

Aim

The aim of Action Cycle 6 was to field-test RHEPORT V4.

Plan

Planning for the field-test of RHEPORT V4 began in June 2016. Specific topics for discussion and investigation by the Advisory Group were based on Action Cycles 4 and 5:

1. Poster display (How can we display feedback to bedbound patients?)
2. The display of negative feedback
3. Thematic coding of experience feedback, and
4. Reflection sessions.

One new topic was also raised during this cycle’s planning stage:

5. Inclusivity.

Poster display

Very few people were seen reading the posters during Action Cycle 4. The Advisory Group decided that the easiest way to ensure all patients (including immobile patients) had access to the feedback was to create a simple brochure. The brochure would include the same key comments as the posters, and would be placed by each patient's bed. I created a draft version of a brochure, then sent it to the Advisory Group for approval (see Appendix S).

Display of negative feedback

An increasing number of patients by this stage had expressed that they did not want to read any negative comments, citing that reading them might make them feel “worried” or “anxious”. The possibility of causing undue concern or stress to patients was, therefore, raised again with the Advisory Group during this stage. In response, Miranda (a family member) suggested that reading negative comments could actually lead to a negative experience:

An interesting question is perhaps asking patients if seeing negative comments made them notice negative things more or less? Perhaps you asked that, but I'd be interested in the answers to that as I know in feedback sessions at my work public negative comments sometimes seems to lead to more complaints. The balance between helping people to feel comfortable giving negative feedback and not putting ideas into other's heads is an interesting one.

The Advisory Group members who participated in the discussion about the display of negative feedback thought that it should continue to be displayed, and that I should continue to ask patients and visitors how they felt about reading such comments. I again voiced my concerns about this course of action as I thought there were ethical issues to consider and that there was a risk of causing undue stress to patients or their visitors. Following several discussions via email and face to face with individual Advisory Group members, we agreed that negative feedback would continue to be displayed. However, it was agreed that if any patients stated during this cycle that they felt concerned or experienced feelings of stress as a result of reading negative comments, I would remove the relevant posters immediately.

Thematic coding of experience feedback

In this Action Cycle, experience feedback would be thematically coded to the Picker Domains of Care and any additional themes that the Advisory Group members identified. From this

coding, the dominant experience themes and examples could be identified and shared with the clinical nurses during the reflection sessions.

Reflection sessions

The Advisory Group members were pleased that the pre- and post-feedback reflection sessions with the Clinical nurses on IPU C (Action Cycle 4) had been well received, and that the sessions had provided valuable evaluation feedback. As Irena (a patient) commented after reading the evaluation feedback from the Unit C reflection session, *“I think it is great to get this feedback from nurses, it makes the end product better”*. However, she highlighted that including a ‘summary’ of negative feedback, as we planned to do in this cycle, could be a constructive way to engage nurses to consider their practices. She explained: *“maybe the negative comments are not constructive [...] because no solution is offered? Here [during the feedback sessions] the nurses can talk about that”*.

Inclusivity

During this planning phase, Advisory Group member Josh (a Registered Nurse) highlighted the issue that on any given unit there:

may be admitted patients and visitors who were off the ward or unavailable at the time you passed by to conduct experience interviews, and that they may feel neglected when the posters go up?

I agreed this could be a possibility, particularly as most patients I interviewed for evaluation feedback (i.e., those who were reading the posters) then wanted to tell me about their own experience. When presented with this, the Advisory Group agreed we should test Josh’s hypothesis. I developed a blank poster (which I suggested we call the ‘Your Voice Counts’ poster), with a post-it note pad and pen for patients and visitors attached. This poster offered patients and visitors who had not had the chance to be interviewed the chance to leave anonymous feedback (see Figure 21, p127).



Figure 21 RHEPORT V4 Your Voice Counts Poster

Implement

Inpatient Unit D (a medical-surgical gastroenterology unit) was chosen to field-test RHEPORT V4. Field-testing of RHEPORT V4 commenced June 2016 and occurred over 19 days. The sequence of events is outlined in RHEPORT V4 Process and Evaluation (see Figure 22, p128)

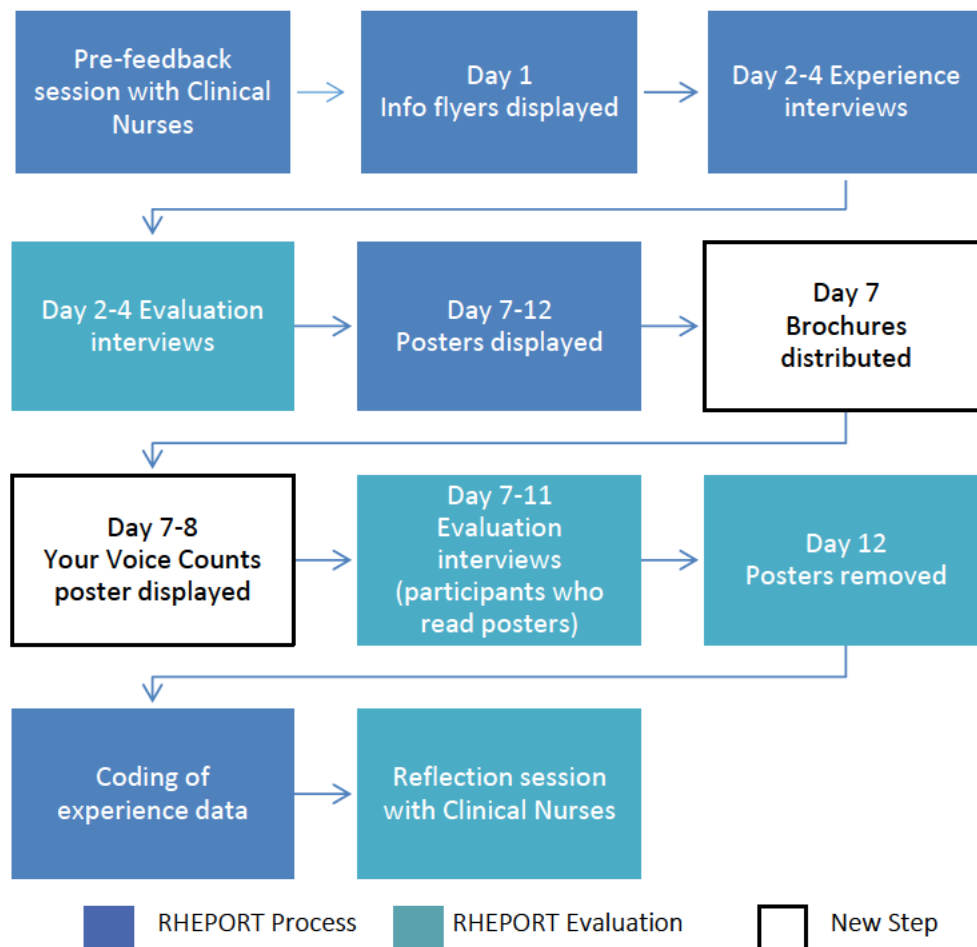


Figure 22 RHEPORT V4 process and evaluation

Findings

Pre-feedback session

The pre-feedback session for Unit D's clinical nurses was held before the patient and visitor experience interview period. The five clinical nurses who attended were advised of the study's format and outputs, and were also reminded that negative feedback would be publicly displayed. They were informed that the feedback that would appear was representative of how *"your patients are feeling about their experience since they have been here"*. I wrote in my field notes that the clinical nurses seemed engaged and eager to see what comments would appear.

Experience comments

Thirty-nine participants were approached to provide experience feedback, and 38 agreed to participate (see Figure 23, p129). Only one participant left a key comment on the Your Voice Counts poster. Participant interviews lasted, on average, 26 minutes, with a range of 18 to 66 minutes. Twenty-six key comments were deemed to be positive and 13 negative. Once again,

all participants said they would recommend the hospital. Comments from participants who gave negative feedback but stated that they would recommend the hospital included: “*from what I have heard about other hospitals I would recommend this one*”, and “*my family insisted I go here and, according to my experiences, I would say the same thing to my friends*”.

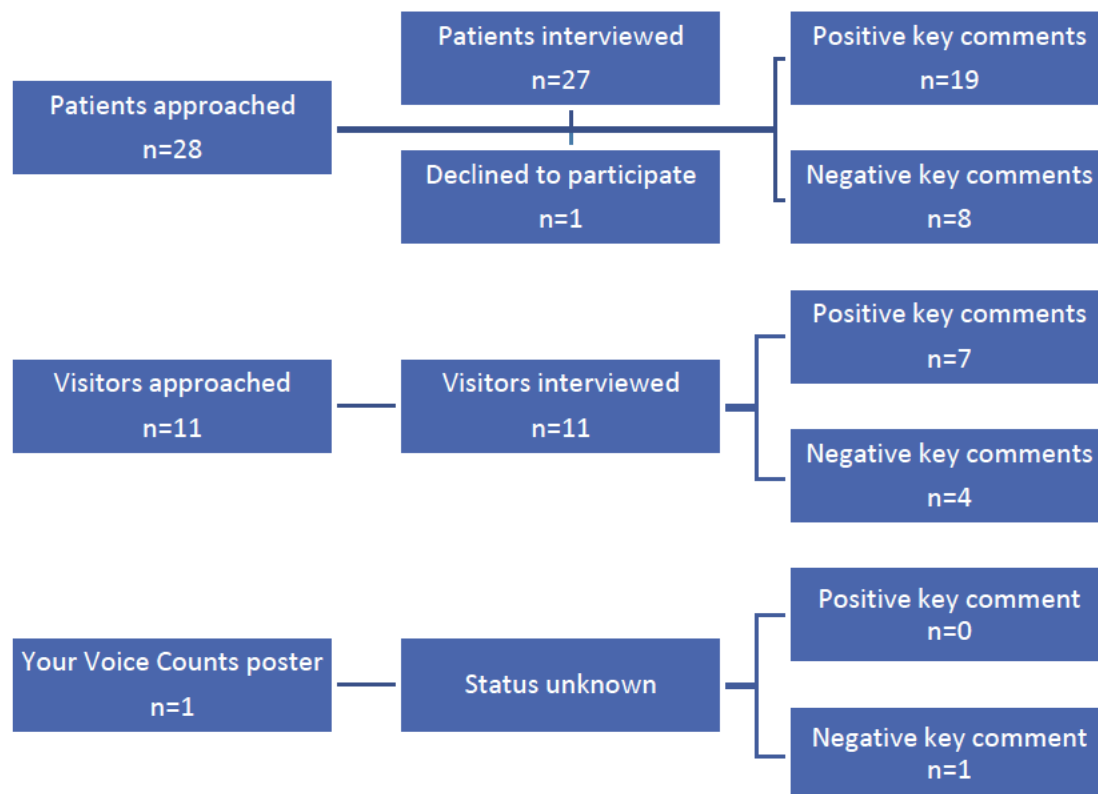


Figure 23 RHEPORT V4 hospital experience participants

The NUM of Unit D vetoed the appearance of all 12 negative comments on posters. While she was aware that we had the Director of Nursing’s approval, she said that she was the one who “*deals with the negative feedback*”. She expressed her understanding that displaying negative feedback was an important element of the study, but said, “*at the end of the shift, nurses who read negative feedback will feel deflated*”. Thus, only the 26 positive key comments appeared on posters. I created a brochure (see Appendix S) including the same positive comments appearing on the poster. Ten brochures were handed directly to patients, and the remainder were left on bedside tables. Several brochures were also placed at the clinical nurses’ stations. The newly created Your Voice Counts poster was displayed alongside the key experience comments posters. On day two of the poster display period, one brief comment, in small handwriting, appeared on a post-it note: “*it sucks*”. As this was quite clearly a negative comment, the post-it note and the otherwise blank poster were removed.

Experience findings

Consistent with the process that had been adopted in Action Cycles 1 to 4, I conducted a preliminary analysis of the key comments at the end of each interview day. The thematic coding was to be conducted by Advisory Group members Olivia, Mette, Irena, Serena and me prior to the pre-arranged reflection session. Unfortunately, no members were available to code the experience findings in this short timeframe. As a result, we were unable to fully assess the acceptability and appropriateness of this method of coding during this Action Cycle. Therefore, I coded the findings into the Picker domains myself, then shared my findings with the Advisory Group (see Appendix V). While we were not permitted to display negative comments, all key comments were coded. In addition to the eight Picker domains of care, additional themes generated from the Action Cycle (Six) field-test were:

1. **Reputation**

Example: *"I've been to other hospitals, but here it is incredible. We told our GP we only wanted to come here"* (Visitor)

2. **Effort**

Example: *"Nurses are very kind. Nothing is too much trouble for them. Nothing is an effort. God bless them"* (Patient)

3. **Kindness and care**

Example: *"I'll tell you a story [...] my niece, who is a nurse, said always be kind to your nurse and they will be kind to you. Last week I wasn't very compliant, but the nurses here were still kind to me"* (Patient)

4. **Expertise**

Example: *"Nurses here are experts – which is good. It makes everyone feel safe"* (Patient)

The three dominant themes from this cycle were:

1. **Kindness and care** (12 comments – all positive)

Example: see 'kindness and care' example, above

2. **Physical comfort** (10 comments – four positive and six negative)

Example:

The nurses here are great – they are always trying to help you. They come I and check on you all the time and ask if I need anything. I'm confined to bed. I depend on them. Sometimes they even help arrange my table without me asking, which is good (Patient)

3. **Effort** (nine comments – seven positive and two negative)

Example: see 'effort' example above

The most common positive comments related to 'kindness and care' (12 comments). The most negative comments pertained to issues of 'physical comfort' (six comments), such as:

They could improve those showers - getting the temperature is impossible. The hard pillows are horrible, they need softer pillows. They do have different ones, but you have to

ask. The size of the cups are too small [...] they can't make a decent cup of tea, you expect a decent cup of tea that's hot. (Patient)

Evaluate

Participant evaluation, Advisory Group evaluation, and personal reflections

Following the same format as Action Cycle 4, evaluation responses were collected from patients, visitors and clinical nurses (see Figure 24).

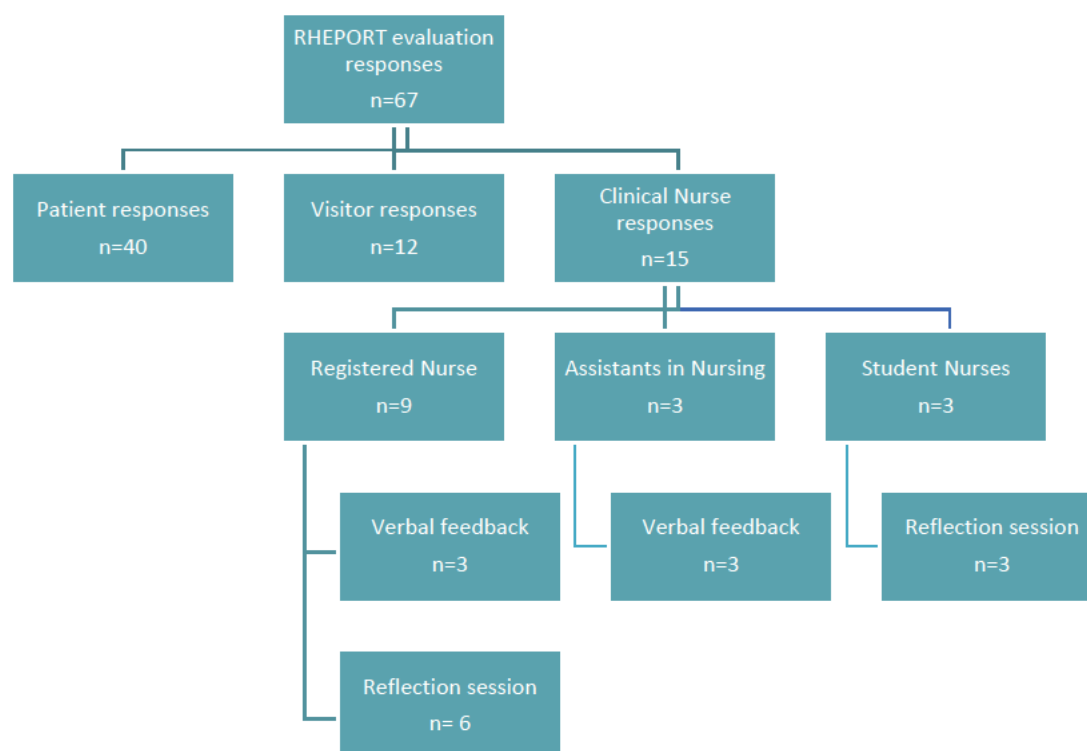


Figure 24 RHEPORT V4 evaluation responses

Evaluation of brochures

The brochures were well received. All patients given a brochure directly read it immediately. Interestingly, several patients then wanted to tell me about their similar positive experiences. One said, *“Yes, yes that’s what I would say too. Do you want me to say that for your next one?”* I relayed this information to the Advisory Group and said that it appeared as if patients were reading the comments and then using them as a *“type of script”* to tell me about their own experience. The patients used the same words that they had just read to express their own experiences. The Advisory Group discussed the potential merit of participants reading these comments not only as an exercise in providing open feedback, but potentially as a way of encouraging (or perhaps priming) the reader to recall their own positive experience. Advisory Group member Miranda (Family member) was particularly interested in this idea:

I love this!! I was sort of worried that giving patients the good news is only priming their comments, but if I can get them to say their own positive comments [...] well, that opens up the whole world of gratitude!

The Your Voice Counts poster

It is difficult to evaluate the success or failure of the Your Voice Counts poster on Unit D, as it was removed on day two. It was assumed that allowing such open access to providing negative feedback could cause reputational harm to both individual staff members and the hospital. The information contained in this case was also of little value. We had no way of knowing whether it was a patient, staff member or visitor who wrote the comment, nor what aspect of the experience they were referring to. Despite my preference for abandoning the Your Voice Counts poster, the other Advisory Group members wanted to continue with it. Andrea (a patient) suggested that I ask a member of staff on the next unit to look at the Your Voice Counts poster periodically and to remove any negative comments as they appeared. The Advisory Group agreed this was the best course of action.

Positive versus negative feedback

I asked all participants who I observed reading the posters from this Action Cycle (Six) whether they would have liked to read negative comments. Only one participant (a patient) wanted to read them. She explained to me that she was a lecturer in philosophy and that matters like this interested her. Reasons provided by other patients for not wanting to read negative comments included a denial that there was anything negative to be said about the hospital, such as: *"I don't want to hear negatives. I've had nothing but positives about this place [...]"*. Self-protection was another reason: *"I've had a hard enough time through getting better. I don't want to read things that bring me down"*. An assumption that 'others know best' was also given as a reason:

I'm simply not interested in seeing what negative comments there are [...] but I want to read the good things. There must be a reason why we are only seeing the positive things.
(Patient)

I went on to ask the above participant *"why do you think they are only showing you the positive things?"*, to which she replied, *"to make us feel better"*. In other words, the participant may have felt that the comments were being selected to improve patients' experience.

I asked a clinical nurse reading the posters how he would feel if there had been negative comments displayed. He replied:

It's always good to hear the negative things [...] but it's the positive things that motivate people. Negative things should be done in private. Negative things here are shown to us in our breakroom.

This nurse then directed me to the private staff room, where both positive and negative comments from previous patient experience reports had been pinned to a notice board. Individual staff member's names and comments were highlighted by the NUM. There were no names attributed to highlighted negative comments. The nurse went on to tell me:

Sometimes it clicks in your mind. This ward is like a family, you can't just say this is not my patient. The NUM here knows the right way to improve things. I think a manager should just tell us the negative things.

I asked if he felt that he was able to hear negative feedback from his NUM because he felt close to or particularly liked this NUM. He replied:

No, it's not that I'm close [...] it's just, well [...] this manager, she always gives everyone a say. If there is something important, she will tell us.

After this evaluation feedback, I advised the Advisory Group that my initial assumption that the NUM of Unit D simply did not want to share negative feedback was incorrect. This NUM, in fact, routinely shared negative feedback with her staff, and had found a mutually acceptable way of doing so.

Reflection session

The statements from the clinical nurses during the reflection session echoed the acceptance of receiving negative feedback privately, and the importance of “*giving everyone a say*”. Nurses stated that the NUM spoke to them privately about any negative feedback, but that generic negative feedback is “*put in the staffroom, so we can all read it*” (Nurse). All clinical nurses at the session stated they had read all the RHEPORT posters or brochures, and they particularly appreciated the opportunity to now discuss the comments.

Using the Coded Experience Comments Guide (see Appendix V), I shared with the nurses that the dominant theme from participant experiences on their unit was ‘kindness and care’, which clearly pleased them. In response to this, the nurses discussed ways they demonstrated care and kindness, with several sharing their own experiences. For example, one nurse stated that they always tried to offer every patient a cup of tea, another said he tried to spend at least five minutes talking to the patient about the patients’ normal life outside the hospital.

I mentioned to these nurses that the negative comments were predominantly about physical comfort. In response, they were quick to state that these were mostly issues beyond their control. For example, in response to comments by patients about feeling cold, one nurse said, *"I hear that all the time, but the hospital controls the temperature"*. Another said, *"well it is winter"*. Rather than simply accept this was beyond their control, I started a discussion about how they could deal with this. One responded: *"Warm blankets, they love them"*, referring to the heated blankets available on this IPU. Another said, *"Sometimes I offer to move the bed slightly, so it's not directly underneath the air conditioning vent"*. At the end of the reflection session, the clinical nurses thanked me for conducting the study on their unit.

I relayed my observations about the nurses' participation and engagement with the feedback in the post-feedback reflection session to the Advisory Group. Based on this data, the Group felt that the method for coding the experience data and sharing it in the reflection session had generated information the nurses found valuable. This display of only positive comments (as per the NUM's request) appeared to have had a positive effect on the clinical nurses, patients and family members reading them. Only patient, and no visitors, said that they wanted to read any negative feedback comments. Also, by providing negative feedback to the nurses in a private space, the nurses appeared more willing to receive, reflect and then discuss it. Reflecting on these findings, the Advisory Group agreed that there was a potential to cause undue stress to patients and nurses by publicly displaying negative feedback, and that negative feedback was better received in private. As such, we collectively decided, commencing with the next Action Cycle, that RHEPORT would specify that negative feedback is to be provided privately.

Action Cycle 6 summary

Based on the findings from field-testing RHEPORT V4, and the reflections and evaluation, lessons learnt and questions raised from AC 6 are summarised in Table 18, p135.

Table 18 AC 6 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
BROCHURES	Brochures have been well received	
POSTERS	The Your Voice Counts poster was not well utilised; potential to cause undue stress	How can we monitor feedback provided on the poster so as not to cause harm?
EXPERIENCE CODING	The devised method was easy to use, but the short turnaround time between poster display and reflection session did not give enough time for Advisory Group member coding	How can we facilitate Advisory Group member coding?
NEGATIVE KEY COMMENTS	Negative key comments were NOT publicly displayed. No participants questioned why there were no negative comments on the posters Patients and visitors stated they did not want to see negative comments Nurses were pleased that negative comments were relayed during the guided reflection session	Should we display negative feedback?

Action Cycle 7 – Field-testing RHEPORT V5

(August – September 2016)

Aim

The aim of Action Cycle 7 was to field-test RHEPORT V5.

Plan

Planning for field-testing of RHEPORT V5 began in August 2016. Specific topics for discussion and investigation by the Advisory Group were:

1. The Your Voice Counts poster
2. Experience coding
3. Negative feedback

And, raised in subsequent Advisory Group email discussions:

4. Reflection sessions.

The Your Voice Counts poster

While the Your Voice Counts poster provided no meaningful findings during the previous Action Cycle, as per Andrea's (a patient) suggestion, I asked the CNE of IPU E to monitor the comments during this field-testing period as they appeared, and to remove any negative ones. The Advisory Group decided to trial the Your Voice Counts poster again.

Experience coding

On further discussion with those Advisory Group members who had initially agreed to code the experience data, it became apparent that this was again not going to be possible, given the short time between data collection and the pre-scheduled feedback sessions. After discussions with my supervisors, we decided that, rather than Advisory Group members coding at every stage, I would provide them periodically with a random 10 per cent of comments which they would code using the same format. It was essential to do this to ensure that this method of coding was both feasible (for people not necessarily familiar with qualitative research coding) and that our findings had a level of internal consistency.

Negative feedback

The Advisory Group decided that negative experience feedback would be provided to clinical nurses in a private setting during this Action Cycle. The Group also decided that participants (patients and visitors) should be advised before they agreed to participate that only positive key comments would be displayed publicly, and that negative key comments would be conveyed to the Nurse Unit Manager (NUM), then discussed with the clinical nurses during a private reflection session.

Reflection sessions

The reflection session, which had also taken place on Units C and D in the previous Action Cycles, was well received by staff, and provided valuable evaluation data. Our method of coding the experience findings and then highlighting the three dominant themes with examples, provided an excellent platform for reflection and discussion. During the planning stage of Action Cycle 7, one member of the Advisory Group (Andrea, a patient) pointed out that it may be beneficial to point out to the clinical nurses instances when the positive comments outnumbered the negative. By simply addressing the dominant themes and then providing a positive and negative example to reflect upon, Andrea suggested I may inadvertently be creating an *"evenly weighted [impression] when that is not the case"*. In response, I developed a facilitator guide to ensure all areas were covered during the

reflection session, including the total numbers of positive and negative comments (see Figure 25).

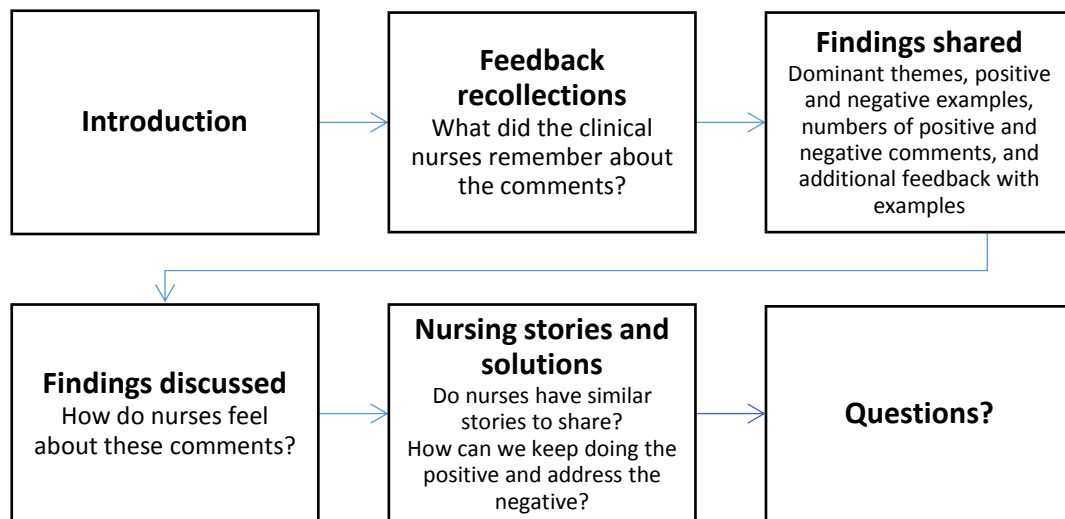


Figure 25 RHEPORT V5 facilitator guide for post-feedback reflection session

Implement

Field-testing of RHEPORT V5 on Unit E (a medical-surgical urology and gynaecology unit) commenced in August 2016, adopting the sequence of events shown in Figure 26.

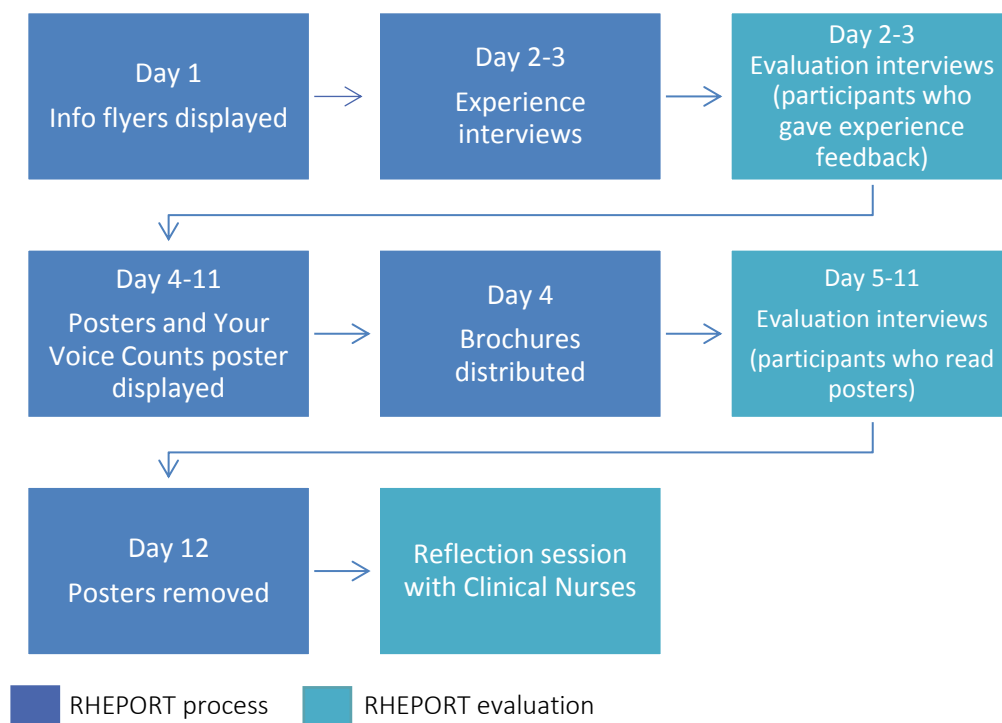


Figure 26 RHEPORT V5 process and evaluation

Findings

Unfortunately, due to scheduling conflicts on the unit, it was not possible to conduct a pre-feedback session. However, information posters were again displayed, advising the patients, visitors, and nurses that a study would be taking place.

Thirty-three participants were approached to provide experience feedback, and all agreed to participate (see Figure 27). Two additional participants left key comments on the Your Voice Counts poster, both negative. Participant interviews lasted, on average, 34 minutes, with a range of 20 to 65 minutes. Thirty key comments were deemed to be positive and five negative. Again, most key comments matched the patients' stories. One patient, however, discussed numerous negative experiences with me for more than 40 minutes about her stay on another IPU during this admission. However, she then went on to dictate a positive key comment for the poster: *"The care here is great. People treat you like a human being. They treat you as an individual"*. When I suggested that this comment seemed at odds with the experiences she described, she said: *"no, no [...] just don't go to [another unit]"*.

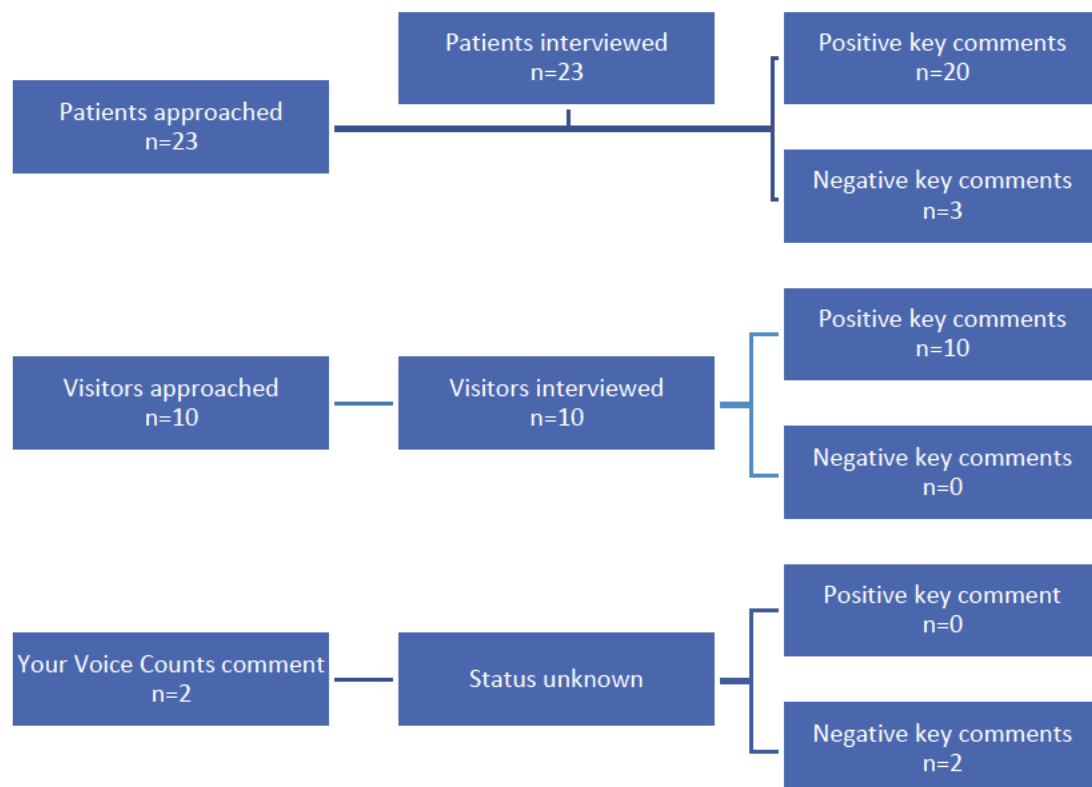


Figure 27 RHEPORT V5 hospital experience participants

All but one participant (a patient) stated they would recommend the hospital to their friends and family. Surprisingly, this participant spoke at length about the positive experience they

had had, and made a positive key comment. When asked why he would not recommend the hospital, he said it was because:

I picked up E. coli [see glossary] in the urine [...] The multi-resistant kind. I think I got it from here. I'm a GP, so I know how bad it is.

All negative comments from interviews were relayed to the NUM of Unit E. Posters were displayed, and 10 brochures handed directly to patients with the remainder left on bedside tables. Brochures were again also placed at the nurse's stations.

The Your Voice Counts poster

On day six of the poster display period, two comments appeared on the Your Voice Counts poster (see Figure 28). One comment said: “*Bed Side Manner of Registrars Not Very Palatable*” (errors and capitalisation in original), and the other “*Dietbetic [sic] diet is the most sugary diet*”. Upon reading the comments, I removed both due to their negativity.

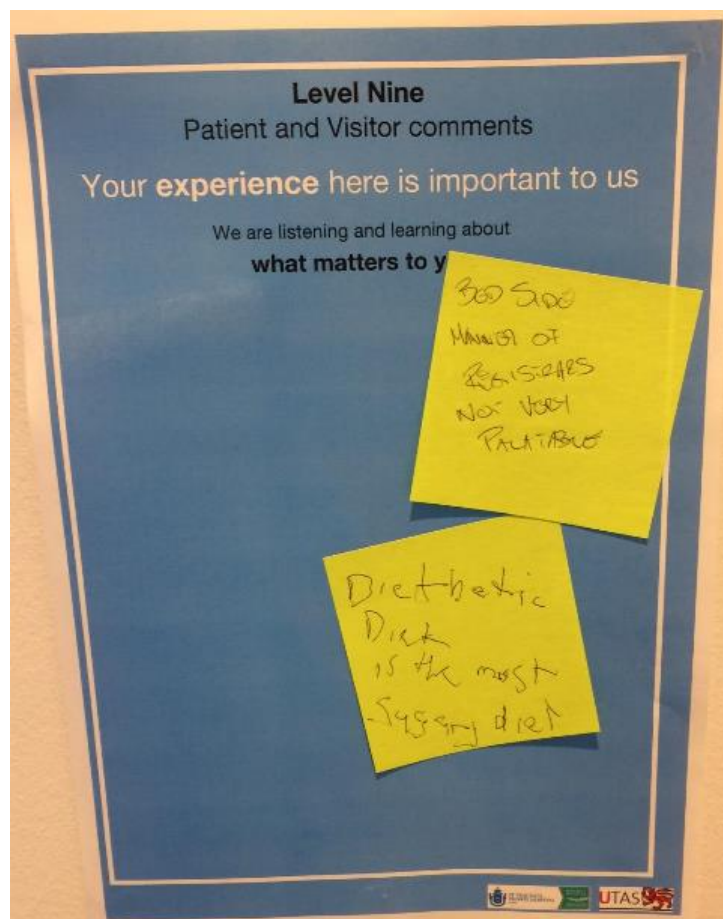


Figure 28 RHEPORT V5 Your Voice Counts poster

Experience findings

I undertook a preliminary analysis of the key comments at the end of each interview day. Again, I conducted thematic coding, and forwarded 10 per cent of the data to four Advisory Group members for them to code (see Appendix V). Using the Picker Domains of Care, the three dominant themes from this cycle were:

1. **Physical comfort**, which includes food and pain control (12 comments; eight positive, four negative)
Example: *"They are interested in me, in my pain level. They say they will come back and they do"* (Patient)
2. **Information, communication, and education** (nine comments; eight positive, one negative)
Example: *"The nurses always introduce themselves. It's professional. I like the whiteboard. I like it tells me what might happen"* (Patient)
3. **Kindness and care** (nine comments, eight positive, one negative)
Example:

Excellent. The nurses are so caring here. They hold your hand. I was asleep, and the nurse was creeping around during the night, and when she realised I was awake, she held my hand and said I'm [name]. (Patient)

The dominant themes above also contained the most positive comments (eight), along with the theme 'effort'. The most common negative comments pertained to physical comfort (four). Three of these comments related to food and one to noise. An example of a comment relating to food was:

It is monotonous. Cold scrambled eggs. You don't come here for a meal anyway. I didn't expect much so I'm not upset. It's a big job to deliver food to all these people. (Patient)

Evaluate

Participant evaluation, Advisory Group evaluation, and personal reflections

Following the same format as the previous Action Cycles, all patients and visitors interviewed about their experience were then asked for their evaluation of RHEPORT. Additional evaluation feedback came from interviews with patients, visitors and clinical nurses seen reading the posters and brochures, along with nurse evaluation data captured during the post-feedback guided reflection session. In addition to the 23 patients and 10 visitors interviewed after providing their experience feedback, a further 10 patients and two visitors gave evaluation input after reading the posters or brochure. In total 61 evaluation responses were collected (see Figure 29, p141).

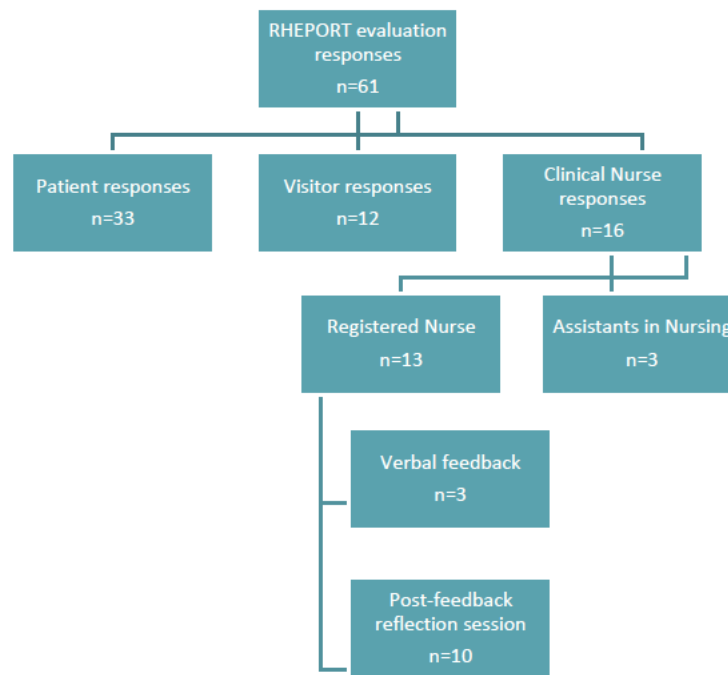


Figure 29 RHEPORT V5 evaluation responses

All patients and visitors confirmed that RHEPORT was a good way to collect and provide experience feedback. The majority of these participants again also confirmed that they did not want to read negative experience comments. The three patients who said they would want to read negative comments volunteered their profession as the reason: *“I’m an IT manager, so I’m interested in people’s different perspectives”*, and *“I’m a professor of organisational behaviour, so I’m interested”*. A third said:

I worked for [airline] and the public service, my field is handling complaints. I’m interested. I tell my staff it’s really a game of perception and you are all actors.

The reasons participants gave for not wanting to read negative feedback were similar to those in the previous Action Cycle, such as avoidance of negative information; *“I’m a visitor, I don’t want to read them. That’s not my truth. My reality is it’s been fantastic”*, and self-preservation, such as *“I don’t want to worry. I don’t want to read about negative things and get nervous”* (patient).

Interestingly, several patients seized this opportunity to speak on behalf of the nurses when they explained why they did not want to read negative comments:

It’s [negative feedback] not appropriate for nurses unless you give a specific example. Some people can lie. Look at the internet. Some reviews are good some are bad, it depends on the personality. (Patient)

It's better for internal review. People [nurses] are vulnerable [...] I don't think negative comments should be in a public forum. You could tell people, though, that negative comments are dealt with by internal review [...] or if you want to access negative comments [...] do it this way. You need to reinforce through encouragement. It needs to be done in a safe environment. Last time I thought morale here was bad, but telling people [nurses] that might make it worse! (Patient)

The three nurses interviewed after reading the posters all said they preferred that negative comments were not displayed. For example: *"Personally I love it [RHEPORT], but I wouldn't want to see negative comments"*.

Upon reading the brochures, several patients were prompted to again share their own experiences with me. While these experience comments did not form part of the coded experience data, relevant information was passed on to the clinical nurses during the reflection session. For example, one patient who read the brochure said:

I wish you had name tags we could read. When they use an acronym, I don't know what that is. We tried to google 'kidney function' but there is a lot to read. They come in and say your kidney function is 16 [...] but we don't know if that's good or bad. I didn't know who to talk to about something I was unhappy with, so I waited for a nurse I felt confident with. They did say I could 'approach the NUM' – but what is the NUM?

The Advisory Group were informed that only two post-it note comments (both negative) had been left on the Your Voice Counts poster. The Group's plan that the negative comments would be removed by the CNE did not eventuate. However, we had no way of knowing when the comments were placed there. I raised with the Advisory Group not only the potential to cause stress or concern to the patients and visitors, but also the potential to cause harm to an individual or to the institution's reputation. There would be no way to prevent a participant from naming individual staff members on this poster. As a result, the consensus was to abandon the Your Voice Counts poster (see Plan – Action Cycle 8).

Ten nurses attended the reflection session. The structure of the session was based on the facilitator guide for post-feedback discussion (see Figure 29, p142). Eight nurses said that they had read the posters, and only one stated she had read the brochure. I was keen to assess whether not having a pre-feedback information session mattered. Most nurses said they had heard about the study via colleagues before it started. When questioned whether the staff saw value in having a pre-feedback session, all responded that they saw no need, with one nurse commenting: *"the hospital collects experience [feedback] all the time"*. This was subsequently relayed to the Advisory Group.

During the reflection session, I shared the dominant themes which emerged from the feedback comments, and highlighted that most comments were positive. The clinical nurses responded favourably to the finding that many of the positive comments pertained to information, communication, and education. For example, one nurse said, *“well that’s what we are about. Positive communication”*. The clinical nurses and I also discussed the comment made by a visitor, which suggested that they did not understand some of the terminology (‘NUM’ and ‘kidney function of 16’). Reflecting on this, there was consensus among the clinical nurses that they had probably made a similar mistake themselves in not explaining clearly to patients what their pathology result numbers or acronyms mean. With regard to the negative comments, the nurses were happy to hear that they were mostly about food, as they saw this as being beyond their control. We did, however, discuss ways in which meals could be experienced more positively. I provided examples of both positive and negative comments on the main themes. Most nurses participated in the discussion, offering their reflections on the comments, or similar stories.

When I asked the clinical nurses if they read all the positive comments, they said that they did, with one stating, *“I don’t take it for granted when reading the positive comments”*, meaning that she didn’t just assume they would all be *“the same”*. All nurses agreed it was preferable to receive negative feedback privately *“like this”*, in a Reflection Session, and would prefer negative comments not to appear on posters or brochures. Reflecting on her experience of the study, one nurse stated, *“I really love it [seeing the positive comments publicly displayed], but I don’t want to read negative comments. It’s hurtful”*. Another stressed the importance of the negative feedback being delivered to the nurses by the person who collected it: *“receiving real-time feedback in this type of setting is best so we can discuss, also it should be given by the person who collects the data, because they can put it into context”*. Another clinical nurse suggested that it *“should always be collected by a nurse, because they can ask the right questions to the patient”*. When asked whether we should display negative comments in a staff-only room, one nurse commented:

[...] not a good idea to just put up negative comments – even in the treatment room, because you can read it and feel bad but not have anyone to talk to about it.

The above evaluation comments were relayed back to the Advisory Group. Reflecting upon the Action Cycle, the members reported a sense of satisfaction that RHEPORT was clearly being well received, and that the reflection session component was productive for both the clinical nurses and the inquiry process. Clinical nurses were able to discuss their

understandings of practice, and the Advisory Group developed a greater insight into the value of providing negative feedback out of the public eye.

During the reflection and evaluation stage of this Action Cycle, I shared with my supervisors and Advisory Group members the personal challenges I had experienced during the recent fieldwork. While I was relieved that the Advisory Group seemed to be re-engaged with the study, I explained that I had struggled with my role and engagement in the research process. At one stage, I felt as if I forgot I was a researcher when I realised how strongly I identified with being a nurse and an employee of the hospital. I wrote about this experience in my researcher journal:

Today a patient said they would not recommend the hospital. I was so shocked because he just finished telling me about how good the hospital was. I didn't even look up as I asked the question, as I assumed I knew the answer. The patient was about to be discharged and I felt as if I had to stop him leaving [...] felt like I had to protect the hospital [...] I actually felt myself standing blocking the doorway, as if it were my responsibility to get him to change his mind [...] (Action Cycle 7, Day Three)

During the subsequent discussion with my supervisors, I questioned whether my reaction was out of loyalty to the hospital, or in fact, 'loyalty to nursing'. One supervisor reminded me that my role as a researcher was to collect the experiences of others, not to justify them.

Interestingly, none of the Advisory Group members seemed to understand why I felt so strongly about a patient not recommending the hospital. I had felt confident the nurses in the group would at least share my surprise, yet they seemed to dismiss it. For example, Sarah (a nurse) said simply, "it probably happens all the time".

Action Cycle 7 summary

Based on the findings from field-testing RHEPORT V5 and the reflections and evaluation, lessons learnt and questions raised from Action Cycle 7 are summarised in Table 19, p145.

Table 19 AC 7 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
BROCHURES	Brochures continue to be well received	
POSTER	The Your Voice Counts poster was not well utilised, and there was the potential for harm	Should we continue to display the Your Voice Counts poster?
PRE-FEEDBACK INFORMATION SESSION	Not conducting a pre feedback information session appeared to have no impact on nursing acceptance	Is the pre-feedback information session necessary?
POST-FEEDBACK GUIDED REFLECTION SESSIONS	Continues to be useful Clinical nurses agreed the experience feedback should be presented by the person who conducted the interviews, ideally a nurse	

Action Cycle 8 – Field-testing RHEPORT V6

(October – November 2016)

Aim

The aim of Action Cycle 8 was to field-test RHEPORT V6.

Plan

Planning for the field-testing of RHEPORT V6 began in October 2016. Specific topics for discussion and investigation by the Advisory Group were:

1. The Your Voice Counts poster, and
2. The pre-feedback information session.

As only two comments were left on the Your Voice Counts poster during Action Cycle 7 (both negative), and the fact that harm could be caused by allowing un-monitored negative feedback to be publicly displayed, the Advisory Group decided that this element of RHEPORT was no longer worth pursuing. Based on findings and lessons learned from the previous Action Cycle, the Advisory Group also decided to remove the pre-feedback information sessions from the protocol. Planning for this Action Cycle was brief, as most of the preparation work had already been attended to during the previous six Action Cycles.

Implement

Inpatient unit F (a neurology and oncology unit) was chosen to field study RHEPORT V6. Field-testing of RHEPORT V6 commenced in November 2016, adopting the sequence of events shown in RHEPORT process RHEPORT evaluation

Figure 30.

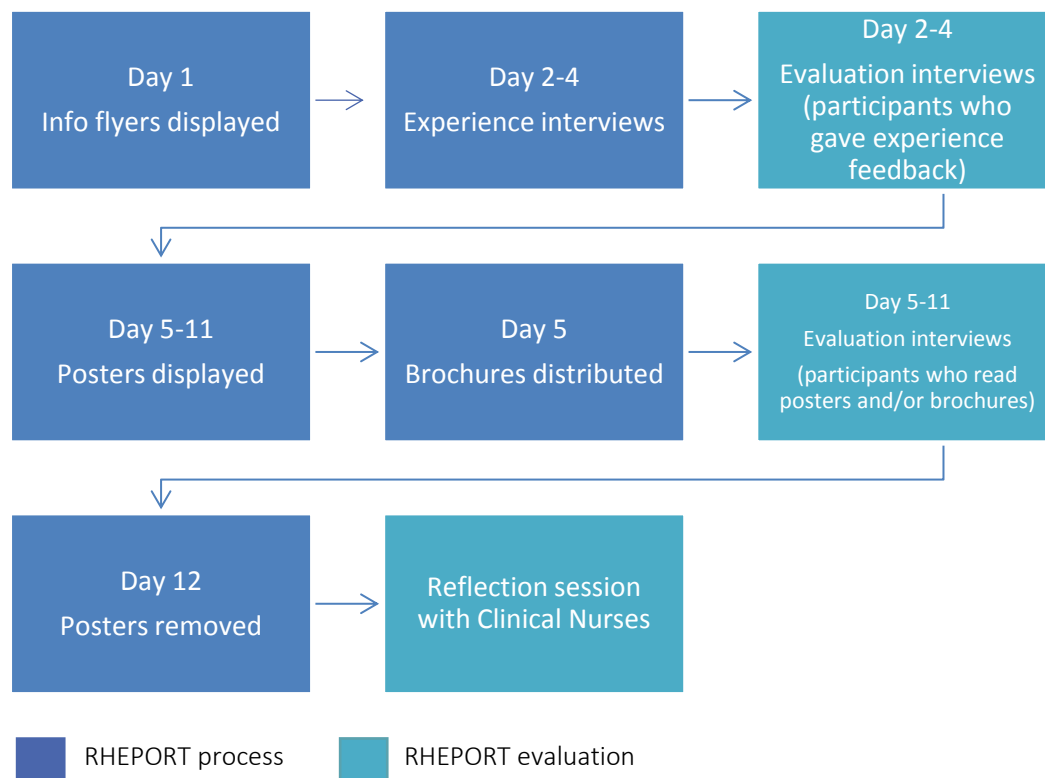


Figure 30 RHEPORT V6 process and evaluation

Findings

Thirty-six participants were approached to provide experience feedback, and all agreed to participate (see Figure 31, p147). Interviews lasted, on average, 22 minutes, with a range of 16 minutes to 90 minutes. One participant who was unable to speak handwritten his feedback. Another patient, who shared his experiences with me during an interview for an hour and a half also emailed me several days later with additional comments. This further feedback was not included in the key comment's posters (as they had already been created), though the comments were relayed to the nurses during the reflection session. His comment is also important to note because of its suggestion that RHEPORT allows the patient's voice to be heard by promoting both agency and autonomy:

I appreciate you taking the time to come by and ask [about my experience] because I think patients don't feel it is there [sic] place [...] Who are we to tell them [the doctors and nurses] how they should do their job? [...] after our chat yesterday I felt empowered to give feedback personally [...] I may need to come in for another treatment and [...] I should try to discuss with my doctors about how I can try to get more sleep. I realise now I can ask about that.

Twenty-three key comments were deemed to be positive and 13 negative. Of the 13, seven also contained positive remarks. All participants stated that they would recommend the hospital to their friends and family. Reasons for supporting the hospital included its positive reputation:

It's fantastic here, you are paying for what you get. You know it is a first-class hospital with good specialists [...] Friends ask, 'why do you go there and spend all that money, you could go somewhere nearby?' I tell them I'm making a choice to come here. I've been coming here for 20 years. You must remember this is [name] Hospital. This is the best hospital in Sydney. (Patient)

Other reasons for recommending the hospital related to the perceived expertise of the healthcare professionals:

Would I recommend this place? I never stop recommending it. My team here are the A-team. They are why I am sitting here talking to you. (Patient)

All comments were sent to the NUM and CNE before the posters and brochures were created. In addition to the posters being displayed, 14 brochures were handed directly to patients and the remainder left on bedside tables and at the nurse stations.

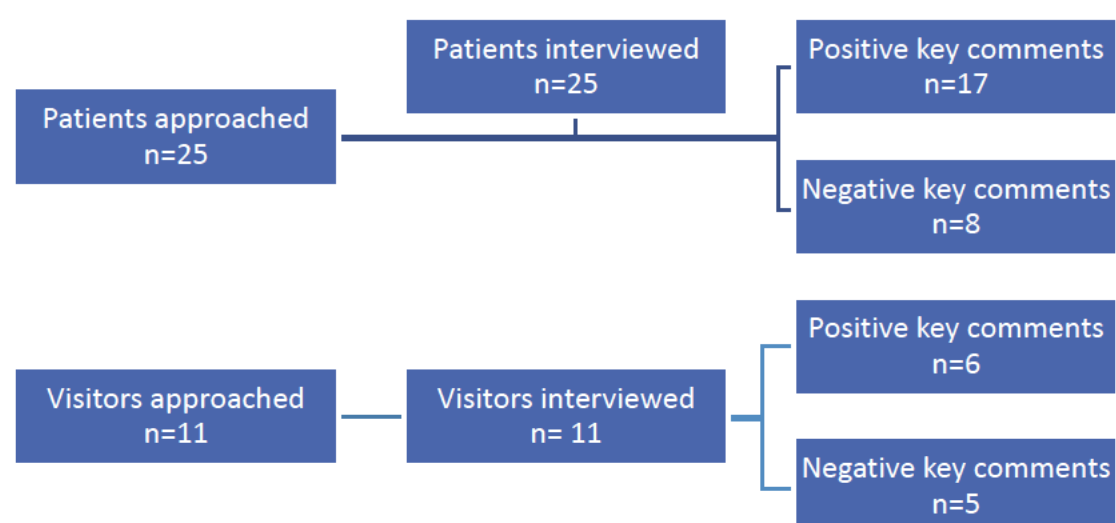


Figure 31 RHEPORT V6 hospital experience participants

Experience findings

The dominant themes from patient and visitor experience data in this Action Cycle were 'information, communication and education', 'respect for patients' values, preferences and expressed needs', 'physical comfort', and 'staff attitude'. The majority of positive comments were related to 'information, communication and education' or 'staff attitude'.

1. 'Information, communication and education' (21 comments; 12 positive and nine negative)

Example:

I've had a total laryngectomy and have been in this hospital for nearly seven weeks. The staff are all very competent as well as kind people. Nothing is too much trouble. For instance, I have to write to them. They patiently try to lip read me and read what I have written and do what I want. (Patient)

2. 'Respect for patients' values, preferences and expressed needs', 'physical comfort' and 'Nurse Attitude' (all with 13 comments each: 'Respect for patients' values, preferences and expressed needs' – seven positive, six negative; 'Physical comfort' – nine positive, five negative; 'Nurse Attitude' – 12 positive, one negative)

Examples:

Respect for patients' values, preferences and expressed needs:

I understand the drug I'm taking is strong, if something were to happen, they would be responsible, however, there are some nurses who think outside the box and are happy to be flexible within reason to help me sleep. I notice that some nurses who feel a bit more comfortable about the treatment have been [names of nurses]. (Patient)

3. Physical comfort:

'[...] I'm living in comfort [...] the meals are top [...]' (Patient)

4. Nurse attitude:

How blessed I am. How fabulous it is here. Everyone is polite. I have not one complaint. We have been here many times...you know, I study them from the sweeper to the cleaner to everyone. It's got everything. They have got everything right [...]' (Patient)

5. 'Information, communication and/or education' received the most positive comments (12), and also the most negative (nine). For example:

It would have been nice for someone to say lunch comes at 12, dinner at [...] I don't know who is who here. I don't know where to go to get someone [...] it would be good to get a mini briefing – no one said here is the button, press this. I wish you had name tags that said nurse, doctor and your name. (Visitor)

No additional themes were identified during this cycle; however, ‘freedom’ was identified as a sub-theme under ‘respect for patients’ values, preferences and expressed needs’. Several participants specifically mentioned the word ‘freedom’ as an essential determinant of their positive experience. ‘Freedom’ for one patient meant an opportunity to become more independent:

They allow me to walk around on my own, which is building up my confidence. I feel comfortable. I feel free. The staff are friendly, and you don’t feel threatened. (Patient)

Visitors also spoke of a sense of freedom when spending time with their relatives:

They let me take her downstairs, but they take my contact details, so we are contactable. That was so important. That gives us a bit of freedom. Freedom following a protocol that protected all of us.

Security, freedom and peace of mind were also raised by another visitor to the unit: “it’s comforting to know she is being looked after. She feels safe, there is freedom, and she is supported”.

Evaluate

Participant evaluation, Advisory Group evaluation and personal reflections

Following the same format as the previous Action Cycles, 64 evaluation responses were collected (see Figure 32).

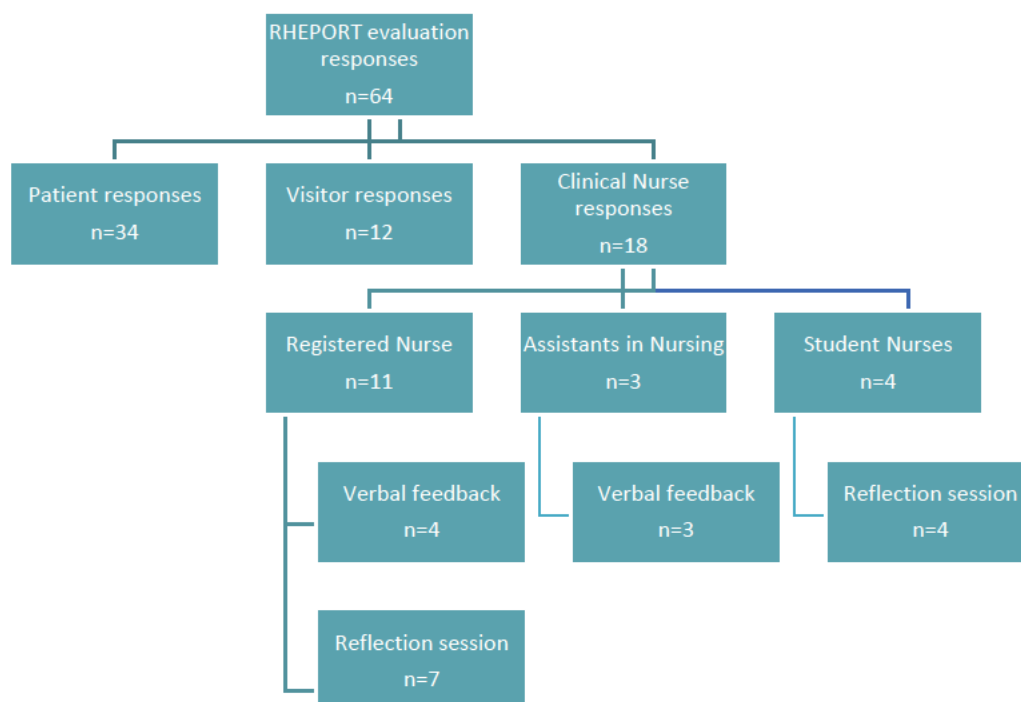


Figure 32 RHEPORT V6 evaluation responses

All participants felt RHEPORT was an effective way to capture and deliver positive feedback to clinical nurses. The rationales for these positive evaluations ranged from seeing feedback as a path to improvement, through to feedback data being considered a blueprint for a gold-standard experience. One visitor said:

I think this is a wonderful idea. You get quick feedback. It gives nurses and staff an uplift, because they have that standard to reach for.

Patients expressed their views that experience feedback was necessary for the nursing staff, with one patient stating, “we can only improve it if someone tells us there is a problem. Quite often, we don't even know there is a problem”. Patients also expressed their positive evaluations of RHEPORT with respect to the quality of feedback it could garner: “doing it [seeking feedback] here gives you richer data [...] [it's] better [...] while I'm in here it is fresh in my mind” (Patient). This comment further confirmed the value of collecting real-time feedback.

Interestingly, several patients compared RHEPORT to other feedback methods;

This [RHEPORT] is an excellent way to collect feedback. A routine survey is useless. There is a five-point scale, and there is such a margin of error. It can only be effective as anecdotal. (Patient)

I think it is good to have a conversational forum like this rather than a form. When you are filling out a form you get sick of it, and you end up filling out yes, yes, yes or 10, 10 10 or whatever just so you can send it off. (Patient)

I asked all evaluation participants on Unit F if they felt that this method allowed them to provide negative feedback. Several were adamant that they would never have a problem giving negative feedback:

If I had something to complain about, I would. At my age, I would speak up for the next generation. I don't have a problem saying what I feel. (Patient)

Another patient suggested: “a spade is a spade to me. I would tell the staff myself [if I had a problem]”. However, others suggested it was our relationship (mine with the participant) that allowed them to express negative feedback: “I do feel like I would tell you negative things, but it's because of you”; another answered: “Yes, I think you have made me feel as if I could say something negative”.

Nonetheless, not all participants felt that they would or could give negative feedback, though this was a minority:

I guess there would be some hesitation to complain to you. I mean, I'm here under your care, and you might tell someone. You are a nurse here. (Patient)

Only one participant (a patient) said that they wanted to read negative feedback. The patient's profession was once again offered as the reason for wanting to do so: *"yes, I want to read other people's experiences. [I] was in business"*. The majority of participants stating that they did not want to read negative feedback again referred to self-preservation: *"I don't want to read anything negative. It would make me anxious"*(Patient).

Reflection session

Seven clinical nurses and four student nurses attended the reflection session. Discussions were based on the facilitator guide (see Figure 25, p137). All staff and students present stated they had read the posters, and it became apparent from the conversations that they had a good recollection of the key comments. All were interested that 'freedom' was a theme. One nurse said, *"that's strange"*, suggesting that this was not something she had previously considered. The nurses were even more surprised to learn that 'freedom' was not raised by any patient or visitor from the other units. The nurses discussed the concept of 'freedom', with one suggesting that perhaps because the nurses had become accustomed to *"allowing"* patients to leave the unit, they routinely advised patients it was an option. They were pleased to know that this practice was well received. With regard to negative comments, the clinical nurses felt that providing negative feedback in a group setting was appropriate. One nurse stated that the Director of Nursing *"tells us negative stuff at ward meetings. But he doesn't really tell us anything specific"*, and suggested that RHEPORT offered a level of specificity that the nurses appreciated.

Action Cycle 8 summary

Based on the evaluation feedback relayed back to the Advisory Group, along with my reflections, the Advisory Group did not identify any areas for further development. RHEPORT V6 – which became known as the 'RHEPORT Protocol', was considered by the Advisory Group to be feasible, acceptable, meaningful, and effective. However, the Group were keen to field-test the protocol in a different setting, specifically within a young adult mental health unit. This desire was initially sparked during the Advisory Group workshop. In the workshop, I shared the fact that current research suggests adolescents are not often included in developing experience feedback strategies (Wiering, de Boer & Delnoij 2017), and that while mental health patient involvement in research has increased over time (Ennis & Wykes 2013), these patients typically have a limited role in experience instrument development (Currie et

al. 2020). In keeping with the project ethos of ‘nothing about me without me’, the Advisory Group were very eager to field-test RHEPORT within this population, and, more importantly, to consider changes based on their feedback.

Action Cycle 9 – Field-testing RHEPORT+

(December 2015 – March 2017)

Aim

The aim of Action Cycle 9 was to develop and field-test RHEPORT in a young adult mental health unit.

Plan

Consultation for planning to field-test RHEPORT amongst young adults (aged 16 to 25) admitted to a private mental health unit began early in December 2015. Inpatient Unit G was a 20-bed private room facility, designed to promote the recovery and psychological wellbeing of young adults with severe and emerging mental health problems. Given the vulnerability of this population, both the CNE and NUM of IPU G were consulted for their input before the initial ethics application submission (see 4.7 Ethical Considerations). In November 2016, the NUM and CNE were advised of the progress and outcomes of field-testing of RHEPORT in units A to F, and further planning ensued. During this planning stage, the NUM, the CNE and me identified several potential issues with RHEPORT as a method of soliciting feedback from the adolescent mental health inpatient population. In consultation with the Advisory Group, we identified modifications so that the RHEPORT Protocol would be fit for purpose. Due to the fact that there would be modifications for this population, I suggested that we refer to this version of RHEPORT as RHEPORT+.

Specific issues identified before field-testing

Participation

As advised by the CNE, patients of IPU G spend many hours a day discussing their experiences in private with unit staff (clinical nurses, psychologists, and psychiatrists) or in facilitated group settings. The CNE suggested that these patients may feel ‘obliged’ to participate in this field study, as they might see me as “*yet another person asking them about their experience*”, albeit not from a therapeutic or treatment perspective. At the NUM and CNE’s suggestion, we decided that I would not directly approach potential participants. Rather, the CNE would

inform the patients about the study at their weekly meetings, and the patients would approach me if they wanted to participate. The Advisory Group were made aware of this change in the way participants would be recruited, and Selena (patient member) suggested that I create a poster to identify who I was, and that I could sit near it while on the unit and wait for potential participants to make contact (see Appendix W).

The CNE and I agreed that if a patient approached me, I would explain the study, and if they wanted to participate, we would arrange a suitable time in the near future for me to interview them. The aim of the strategy was to allow potential participants additional time to reflect on whether they wanted to take part. At the time of the interview, participants were again reminded of the goals, risks and benefits of participation. They were also again offered an opportunity to withdraw or to consent to participate by way of the consent cards.

Privacy

The NUM requested that I not interview patients in their private rooms as this was considered “*their private space*”. As a locked unit, it was agreed that the patient could choose to be interviewed in the internal courtyard, the cafeteria, or the meeting room, all located within the unit. All three areas were visible to healthcare workers, yet, depending on where we sat, others could not hear our conversations.

Poster display

The physical layout, design and decor of IPU G are purposely very different from the other medical-surgical units in the hospital. According to the hospital, unit G was explicitly designed to offer a “bright and engaging atmosphere” (St Vincent's Health Australia 2020). One noticeable difference was the lack of hospital paraphernalia, be it equipment or hospital posters and flyers. The NUM agreed for the RHEPORT+ posters to be displayed in a small area (approximately 150cm x 150cm) located away from the main communal areas, but near the internal courtyard used by the patients. This placement area was far less prominent and visible than in previous units.

Safety

Both the CNE and the NUM were given my assurance that any comments which related to current or potential harm (to self, reputation, property, or others) would be immediately reported back to them. Patients were also to be advised before they began their interview that this would be the case.

CNE advice

Both the CNE and the NUM approved the questions as per the RHEPORT interview guide (identical to the previous Action Cycles, see Table 16), however, the CNE suggested, “[the patients] may need prompting, as these patients are teens and won’t talk much. Also, they are depressed [...] and I’m sure this will influence findings”. When questioned further about what this second comment meant, it became apparent that the CNE assumed that the unit would receive negative feedback from their patients because of the nature of their admission to hospital.

Implement

Field-testing of RHEPORT+ commenced in February 2017. Because we had to wait for participants to self-select, recruitment proved very difficult. In consultation with the Advisory Group, key comments posters were displayed while I was still in the interview phase (which lasted far longer than other cycles, despite a significantly smaller inpatient population). Several changes were also made to the layout and format of the posters over the display period, based on suggestions from the patients themselves (see Figure 33). These changes are discussed in greater detail in the next section.



Figure 33 RHEPORT+ poster display

Unfortunately, it proved impossible to schedule a reflection session with the clinical nurses of Unit G, as there were only ever one or two nurses present on the unit at any time. Therefore, it was agreed that I would relay information to the CNE about the findings, and she would inform the nurses. However, as the Action Cycle progressed, another strategy to present experience findings to the clinical nurses was developed, based on a suggestion from a

patient. The implementation steps of RHEPORT+ are outlined below (see Figure 34), and the aforementioned strategy is referred to at Day 18, the point in the Action Cycle where it emerged.

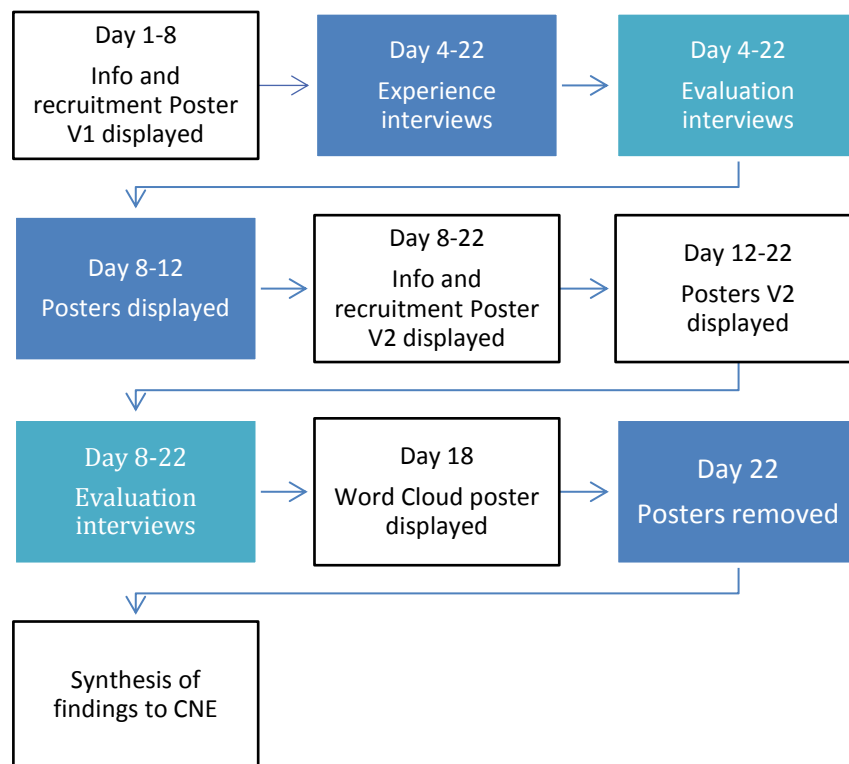


Figure 34 RHEPORT+ process and evaluation

Findings

Recruitment of patients was difficult, and I was unable to recruit any family members. During the field study period, I was present near the recruitment poster during most break times, when the patients were available. However, without being able to approach potential participants, I had to rely on them reading the recruitment poster and then feeling comfortable and or interested enough to approach me for more information. While I did see several visitors during the field-test period, at no time did I witness any of them reading a recruitment poster. In conjunction with my supervisors, a decision was made to cease recruitment after three weeks. For those patients who did express a desire to participate in the study, it was challenging to find a suitable time to interview them as they had little free time during the day. Most experience interviews were therefore conducted during a meal or break time, although this was not ideal, as most participants expressed that it was their only free time.

Ten patients gave experience feedback. Interviews with each patient lasted between 40 minutes and an hour. Contrary to the CNE's assumption that the participants would need prompting to share their experiences, all of them were talkative and highly engaged during the interview. Participants offered detailed experience and evaluation feedback. Interestingly, all participants refused to hear their comments read back to them, with one stating indignantly "*I know what I told you*".

All participants were offered a chance to read the notes I had taken at the completion of the interviews and to choose a key comment they wanted to appear on the posters. However, interestingly, all of the participants stated that they wanted their entire story relayed. This was an unexpected finding. The participants provided extremely personal and often detailed stories, each with a distinctive style and syntax. It was apparent early on in this field-test that the anonymity of participants and others mentioned in their comments would be compromised if the entire narrative was displayed. An example of such a comment was:

I have chronic fatigue and pain like the other girl here [...] I follow the group rules, but she doesn't [...]

Clearly, the above statement would not only allow the participant to be identified, but also the other patient. As a result, in consultation with my supervisors and the Advisory Group, we decided to remove identifying comments and also to split comments into separate quotes on separate posters. For example, we split the comment "I have [...] pain like [another person on this unit]" and "I follow the group rules [...]". We also chose to modify how we identified positive and negative comments, because under the processes used in the previous Action Cycle, all of the participants' comments would have been classified as negative because they all contained negative elements, in spite of the comments, on the whole, being overwhelmingly positive about the participants' experiences. Once we separated the comments, we then identified whether they were positive or negative. All comments were relayed to the CNE. I went to great lengths to ensure that I very carefully separated the comments to try and retain their original meaning; however, there was an inherent risk that I could modify the original intent. The Advisory Group, however, and my supervisors, considered this to be a reasonable risk to take in order to protect the participants' anonymity. Several of the interviews in this cycle also proved challenging. Two patients discussed their illness and diagnosis at length, as opposed to their experience at the facility. Re-orientating these patients to discussions about their hospital experience was challenging. Another patient wanted to provide feedback while seated in the cafeteria, where both staff and patients could

potentially overhear us. When I suggested it may be better to talk in private, he was adamant that there would be a 'cover-up' and wanted to stay where he was. The interview went ahead, and during the interview period several patients and staff members walked into the room and out.

All patients interviewed said that they would recommend this adolescent mental health unit to their friends and family. When asked why they would recommend the unit, all patients said that they felt this hospital was better than others:

I quite like it. This is my fourth admission. I wouldn't be coming back if I didn't like it. I've heard from other people that this place is much better than others. It's by far the best place. It doesn't feel like it's a hospital. I couldn't cope if I had to wear a hospital gown and a hospital band. (Patient)

Experience findings

Even though experience comments were fragmented for the poster displays, they were analysed intact in order to code participant experience findings. The three dominant themes from this cycle were 'physical comfort' (20 comments, eight positive, 12 negative), 'respect for patients' values, preferences and expressed needs' (with 14 comments, six positive, seven negative), and a new theme, 'peer support' (see Appendix V) (10 comments, all positive).

The majority of positive comments pertained to the importance of peer support, for example:

The best thing is the unity here with everyone. Everyone is here for one another. We have all been through the same thing. We are all here for one another [...] It's really youth-orientated here. The ages are 16 to 30. You know you are not alone.

Examples of negative comments largely referred to physical comfort:

the food is not the greatest [...] the last place had a big TV room. We all sat there every night. That was how we all bonded. I have fond memories of that [...] We don't have a place like that. These [chairs] aren't comfortable. We need a space to relax – it would help me bond, and it gets you out of your head. It's a nice way to end the day.

Evaluate

Participant evaluation, Advisory Group evaluation and personal reflections

All 10 patients interviewed about their experience were asked for their evaluation of RHEPORT+ after their interviews. Additional patients and clinical nurses who were witnessed reading the posters were also asked for their assessment (see Figure 35, p158). Over the three weeks I spent at IPU G, I only saw 15 people reading the posters – that said, the Unit's

capacity was only 20 patients. Eight of those 15 participants discussed their evaluation of RHEPORT with me. While I did see visitors come and go, none were witnessed to have read the posters.

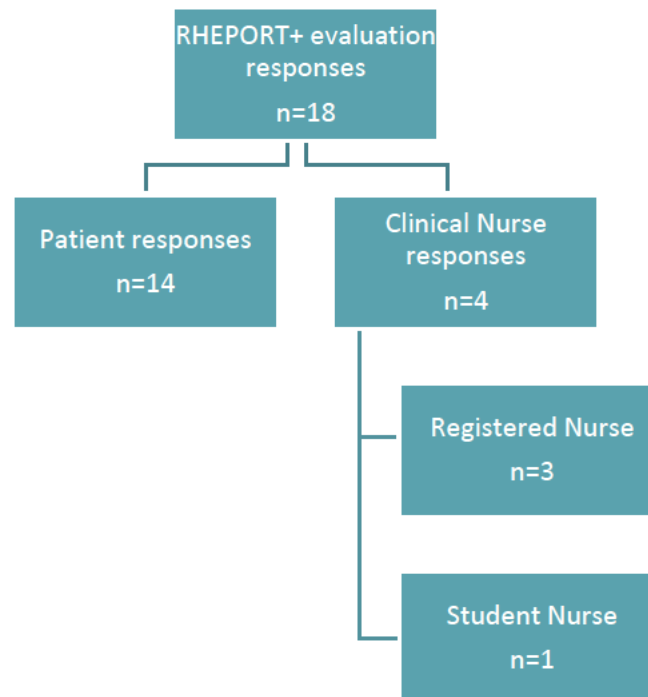


Figure 35 RHEPORT+ evaluation responses

With regard to negative comments, all participants said they would prefer not to read any negative feedback. One said:

I wouldn't want to read negative comments. Everyone experience's negative things, but we are all different. One person's negative might be another person's positive. (Patient)

Another patient suggested that reading the positive comments would have improved their experience, had they read them before coming to the unit: "These are a good idea. I have been here a couple of times, but when you are first admitted this would have made me feel more comfortable". Similarly, another patient said:

They are nice to read. When you come in here, you don't know what to expect, so it is comforting to read this. I think when I first came in it would have been really good to read these. I was nervous and didn't know what to expect. Reading these would have calmed me down. It's definitely a good thing to do.

Suggestions from patients

While all participants (patients and clinical nurses) considered RHEPORT+ to be a valuable idea, most patients suggested specific changes to the posters. Such specific feedback had not

been voluntarily provided by participants on the other field-test units. One patient in particular suggested: *“maybe you should take out the important words and put them up as individual words on their own”*. Unbeknownst to this patient, they had suggested a novel way to present a synthesis of experience comments. This idea also addressed my emerging concerns about how we could provide an accurate summary of the feedback comments to clinical nurses, given that I would not have the opportunity to conduct a reflection session. This patient’s suggestion led to a discussion with several members of the Advisory Group regarding a preliminary analysis being presented back to staff, patients, and visitors using a second poster. During one of these discussions, Selena (a patient member) suggested we could create a word cloud to represent the most commonly used words in the positive key comments. With her help, we identified poignant words used and, using Wordle (a piece of free online software), a visualisation of representative feedback was created and displayed alongside the individual key comments during the field-test period (see Figure 36, below).

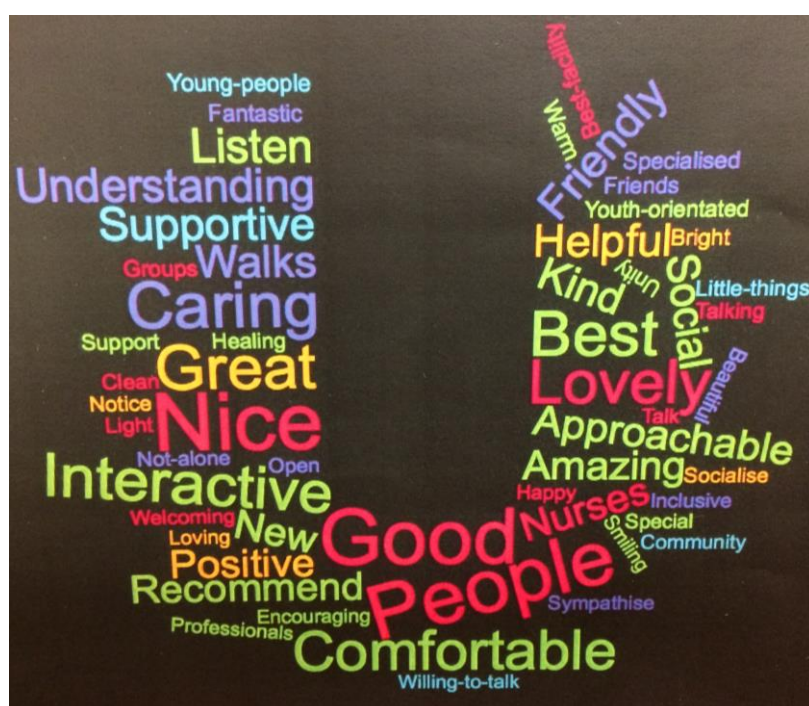


Figure 36 RHEPORT+ word cloud

Given the difficulty in recruitment, the Advisory Group made the decision to display posters during the interview period. The Group reasoned that weeks could pass until a batch of posters were actually displayed, which defeated the aim of the protocol of providing real-time experience feedback. While we were able to react to this issue during the field-test, we were unable to address another concern raised regarding poster location on the unit. A clinical nurse from the unit initially highlighted the problem with the posters’ location:

I've been here for three days, and I don't think they are in a good spot. When you walk by here you are going to break or a meeting, so you have something on your mind. You don't stop and look. They need to be somewhere more centred.

While I agreed, unfortunately we were not permitted to change the location of the posters.

Another patient suggested:

I think you should have a sign bigger saying, 'this is what people said', and don't have posters in the same colour. They look like they will say the same thing, so I didn't bother reading them. You should have speech bubbles cut out or just white.

I took this suggestion back to the Advisory Group during the field-testing period, and we agreed that this was a good idea. As a result, I re-formatted the posters, making each speech bubble (representing a comment) a different colour (see Figure 33, p154).

The Advisory Group were apprised of the evaluation feedback, and there was general agreement that more work was needed to establish a streamlined approach to capturing and disseminating the experience findings for this population. We also decided that the level of consultation with the NUM and CNE before field-testing this specific version of RHEPORT was crucial, and that in future this should form a specific step in the RHEPORT+ Protocol for similar patient populations. Advisory Group member Josh (a Registered Nurse) reflected on the problems with poster location and on the fact that few people actually read them: “perhaps we should have used brochures”, as we had done on the other units. However, this decision was made in response to patients being bedridden, which was not an issue in this unit and thus something we unfortunately did not test. Nonetheless, the Advisory Group agreed this could be an important improvement to enhance participant engagement with the data in future.

Members of the Advisory Group were surprised, and found it “odd” (Selena), that none of the patients wanted to have their comments read back to them. I expressed my concern that perhaps they saw me as another healthcare provider taking notes, and as such, they may have felt they had no ownership. Advisory Group member Sarah (a Registered Nurse) suggested it was most likely because this population were simply “used to speaking while someone was taking notes” and reading notes was something unfamiliar to them. The Advisory Group concluded that this issue also needed further investigation. However, these investigations were outside the scope of this project.

Action Cycle 9 summary

Based on the findings from field-testing RHEPORT+ and the reflections and evaluations, lessons learnt and questions raised from Action Cycle 9 are summarised in Table 20, below.

Table 20 AC 9 lessons learnt, questions raised

	LESSONS LEARNT	QUESTIONS RAISED
RECRUITMENT	The recruitment process was difficult	How can we recruit this population?
EXPERIENCE FEEDBACK	Participants were very willing to provide detailed experience feedback Participants did not want to edit their feedback to identify a key comment Participants did not want to hear their feedback read back to them	Why did this population want every aspect of their experience shared? Why did this population not want to verify the feedback notes?
POSTERS	Poster placement and location is important	Would brochures have been more widely accepted?
EVALUATION	This population was very forthcoming with improvement ideas	

5.4 Summary of Action Cycles 1 to 9

The RHEPORT Protocol created at the Advisory Group workshop (in Action Cycle 1) was refined over a series of eight cycles of planning, implementing and evaluating across three years, thereby respecting the action cycle principles of action research (Cordeiro & Soares 2018).

In total, 238 participants (178 patients and 60 visitors) were interviewed about their hospital experience over a period of two-and-a-half years (three additional people provided feedback by way of the Your Voice Counts poster). Four hundred and seven evaluation responses (227 patient responses, 70 visitor responses, and 110 clinical nurse responses) regarding RHEPORT as a protocol were obtained, in addition to those provided by the 16-member Advisory Group. Based on the findings of the nine Action Cycles, a final RHEPORT Protocol was developed (see Figure 37, p163).

Three principal findings emerged from the fieldwork:

1. **Adopting a pragmatic action research approach resulted in the successful co-creation of a new experience feedback protocol.**

The research approach facilitated the co-creation process so that stakeholders could come together to create a new way for patients' and their families' voices to be

heard. The output of this study, the RHEPORT Protocol, is an inpatient unit-specific, qualitative, real-time hospital experience feedback protocol with an associated method of relaying this feedback to clinical nurses. Experience findings by the Advisory Group from field-testing RHEPORT are consistent with current hospital experience literature.

2. **The RHEPORT Protocol is comprised of five core components:**

Capture memorable experiences

Asking participants to 'describe something memorable' about their hospital experience provides an opportunity and guide for the patient or visitor to discuss what matters to them, rather than being explicitly prompted to discuss positive or negative experiences.

Publicly display positive key comments only

Only positive experience feedback should be publicly displayed. Patients, visitors, and clinical nurses react positively to the public display of positive feedback. Negative experience feedback should not be publicly displayed. Patients, visitors, and clinical nurses respond negatively to the public display of negative feedback.

Consider positive and negative feedback during reflection sessions

Reflection sessions with clinical nurses are essential to enhancing reflective consideration of the patients' and visitors' positive and negative hospital experiences.

Consider the facilitator

RHEPORT requires an appropriate facilitator to prepare clinical nurses for feedback, to elicit experience feedback from patients and visitors to display, to analyse feedback, and to relay feedback.

Understand the population

The target population must be understood to ensure participation in and engagement with the feedback generated by the RHEPORT Protocol. Changes to the protocol may be necessary.

3. **A willingness to recommend the hospital to friends or family is not necessarily representative of a patient or visitor's hospital experience.**

A willingness to recommend question should not be used to measure experience.

Based on the findings from nine Action Cycles, the following RHEPORT Protocol has been developed (see overleaf), along with an explanatory guide to be used in conjunction with RHEPORT based on the lessons learnt from this study (see Appendix X).



Figure 37 The RHEPORT Protocol

Chapter 6 Discussion and Conclusion

The collection of hospital experience feedback has increased dramatically in the past decade (Gleeson et al. 2016; Sheard et al. 2019). This increase has undoubtedly been fuelled in part by consumer-driven demand for excellence in quality healthcare provision. However, the increased costs and negative revenue implications associated with negative consumer experiences have also driven this trend (Betts et al. 2016). Central to high-quality hospital experiences are patients' and visitors' perceptions of the care received (Confederation 2012). Attempts to capture patients' perceptions of care are taking place daily across the globe, from small-scale, one-on-one interviews to country-wide surveys (Davidson et al. 2017; Edwards, Walker & Duff 2015; Gleeson et al. 2016; Sheard et al. 2017). Despite a shift in healthcare ideology that recognises the centrality of patient perspectives (Williams et al. 2017), there is a distinct lack of stakeholder input into the conception, development and evaluation of tools or methods that collect experience feedback. My literature review revealed a lack of peer-reviewed evidence regarding co-created methods that are effective in disseminating experience feedback to frontline staff, particularly clinical nurses (Edwards, Walker & Duff 2015). Despite the imperative to place healthcare recipients at the centre of care, their absence in the design and evaluation of feedback elicitation strategies calls into question the efficacy of the whole process. In an effort to address these concerns, this study aimed to answer the question ***How might we co-create a new protocol designed to collect patient and family hospital experience feedback and share this with clinical nurses so that patients' and families' perspectives can be heard?*** Through a pragmatic action research approach, a novel experience feedback protocol called RHEPORT (Real-time Hospital Experience Posters) was developed.

This chapter considers the findings from Action Cycles 1 to 9 and draws on current healthcare and related literature. In section 6.1, the complexities, and successes of co-creating RHEPORT using a pragmatic action research approach are discussed. The experience findings generated from field-testing RHEPORT will also be briefly examined here. Section 6.2 discusses the five core components of the RHEPORT Protocol with respect to feasibility, appropriateness, meaningfulness, and effectiveness. A willingness to recommend the hospital as an indication of the patient or visitor's hospital experience is examined in section 6.3. Reflections on my role as a novice action researcher are set out in section 6.4. Contributions this research

makes, implications for practice, and limitations are addressed in sections 6.5 and 6.6. Current and future directions are discussed in section 6.7. The thesis concludes with final remarks in section 6.8.

6.1 Co-creation using a pragmatic action research approach

Key finding one

Adopting a pragmatic action research approach resulted in the successful co-creation of a new experience feedback protocol.

A pragmatic action research approach

Action research as a method synergistically combines research and practice whereby research informs practice and practice informs research (Avison, Davison & Malaurent 2018). In this study, the strength of pragmatic action research was that it enabled flexibility in the inquiry and development process. Consistent with Greenwood's (2007) position that situational usefulness should dictate the type of action research approach taken to address a research problem, adopting a pragmatic approach enabled me to shift between technical and practical modes of action research. This 'shifting' meant that I could meet the needs of the stakeholders I was working with, the setting I was working in, and the requirements of completing a Doctor of Philosophy.

As a doctoral candidate, I entered the research field with a specific aim, which was to capture the experiences of patients and family through a new feedback process. Hence, at the beginning of the study, my engagement reflected a predominantly technical mode of action research (Kemmis, McTaggart & Nixon 2014c) through which I was seeking a pre-determined outcome. It was appropriate that I took the lead role in organising the set-up of the project, given that the setting was a greenfield site, and that I organise and conduct the Advisory Group workshop (Action Cycle 1). However, while I entered the field in a technical capacity, it is also important to acknowledge that there was a practical intent early on in this project. The Advisory Group, for example, sought to create a feedback process which encompassed the views and knowledge of multiple stakeholders, thereby respecting what Kemmis (2009, p. 470) refers to as a central tenet of practical action research – remaining "open to the views and responses of others". The Advisory Group also worked together to identify and solve problems while developing understandings of the situation, further demonstrating a practical

intent and a respect for the action research principal regarding knowledge building that considers participants' realities (Cordeiro & Soares 2018).

Adopting a pragmatic action approach allowed for aspects of the project to shift between technical and practical ways of working. In this sense, we adhered to a goal common to action research, which is to remain flexible and agile throughout the inquiry and change process. A common criticism of action research is that, in reality, a *modus operandi* is often developed and then not altered (James, Slater & Bucknam 2011). In this study, however, the pragmatic approach enabled the Advisory Group to maintain close attention to the current situation and respond when problems arose, thereby also adhering to the problem-solving principle of action research (Cordeiro & Soares 2018). An example of this flexibility is demonstrated by the rapid decisions taken during field-testing RHEPORT in relation to how key comments would be displayed – in the participants' own handwriting or not, for example (Action Cycle 2). My decision (while in the field) to transcribe comments rather than have them in patients' or visitors' handwriting can be understood as reflecting a technical interest. This was a decision made with the intention of addressing an immediate problem and moving the research forward. In one sense, this decision was a means to an end in order to collect the data. When I went back to the Advisory Group in Action Cycle 3, a more practical and collaborative approach was adopted, under which the Advisory Group discussed and decided what font to use for the transcribed comments when they appeared on the posters. These types of decisions made throughout the fieldwork demonstrate how a pragmatic Action Research approach was operationalised during the life of the project – from the macro decisions regarding the setup, right down to the micro decisions, such as what font size and type would be used on the posters.

The responsiveness of action research to emergent knowledge (developed through action) further demonstrates the value of a flexible methodology to addressing complex social questions. The evolving nature of action research allows researchers to engage with the knowledge emerging from the issues at hand as collaborators attempt to understand them (Roberts & Dick 2003). Our decision to discontinue the public display of negative feedback, for example, emerged through the iterative generation of knowledge across Action Cycles 2 to 6. Through the successive Action Cycles, the group members were able to test, evaluate, reflect, and retest whether negative feedback should be displayed. Consequently, the findings of this study have demonstrated, consistent with the early mantra of Lewin (Maksimović 2010), that to understand something, one must first try to change it. Change, however, cannot come to fruition without the engagement, or at least participation, of stakeholders.

Accordingly, developing collaborative engagement and facilitating participation was essential to the success of this pragmatic action research project.

Participation and engagement – Successes and challenges

The Advisory Group – Successes

The relevance of action research to solving pertinent real-world problems emerges through the action researcher's collaboration with participants in local settings, where knowledge is generated that is specific to that setting (Levin 2012). Achieving collaborative engagement, whereby people move beyond being mere participants to become part of the process to achieve a shared goal, is crucial to an action research project, particularly if changes are to be maintained (Bartlett & Piggot-Irvine 2008; Molineux 2018). Participation and collaboration are principles of action research (Cordeiro & Soares 2018) and as such, were central to the success of this action research project. Consistent with the collaborative imperative of action research, the formation of a 16-member Action Research Advisory Group was a crucial first step to ensure that key stakeholders were involved and had a voice in this project. The Advisory Group was central to operationalising the pragmatic action research approach, and as such, recipients, and providers (clinical nurses) of healthcare were identified as key stakeholders in this study. Healthcare recipients (patients and their families) are 'experts' on their own care (Realpe & Wallace 2010), and given the fundamental importance to patient-centred care to this project, their involvement was essential. Clinical nurses are central to shaping the healthcare and hospital experiences of patients and their family members (Dempsey, Reilly & Buhlman 2014) and thus are also considered stakeholders. The Advisory Group consisted of eight healthcare recipients (patients and family members) and eight nurses (including me). Bringing the Advisory Group members together in Action Cycle 1 was important to building their engagement with the research question, and with each other, to provide a foundation from which they could work together to co-create a solution.

MacLeod et al. (2017) state that engagement is developed through the formation of mutual trust and respect for one another's views and opinions. Accordingly, I used a range of strategies to support the members of the Advisory Group to develop a sense of reciprocity and trust. These included sharing all ideas with all members of the Advisory Group and giving equal consideration to different ideas as expressed by different members. Other strategies that were designed to foster members' engagement included me contacting members individually to ensure all opinions were heard, providing regular updates regarding the field-testing of new ideas, and regularly requesting input regarding procedural or design changes

to the RHEPORT Protocol. Collaborative engagement, mutual respect and new understandings developed among the Advisory Group's members over the course of the research, starting with the Advisory Group workshop, then continuing during my later meetings with individual Advisory Group members, and in both group and individual email exchanges over the nine Action Cycles. As suggested by McNiff (2013), the domains of change within our action research project related to **changes in our thinking and practice, how we were influencing one another, and how we were developing new insights and practices through our interactions**. These domains were important to consider, as they allowed us to monitor and evaluate change in our action research project (Kemmis 1988; Kemmis, McTaggart & Nixon 2014a).

Evidence of what McNiff (2013) refers to as **changes in thinking and practice** is seen in members of the study's Advisory Group adopting and then using similar words and phrases; a phenomenon often seen in experience and patient-centred care research literature. Over the course of the study, the Advisory Group members commonly referred to 'real-time feedback', 'person-centred care', 'measuring experiences', and 'evaluative data'. Attendance at the Advisory Group workshop demonstrated an early willingness on the part of stakeholders to both participate and collaborate. Participation in workshop activities facilitated the recognition of mutual interest relating to patient experience, and a desire to improve current practice. However, as McNiff (2013) states, action research is about more than problem identification and solution. It is about "realising human potential" and thinking about the influence that we have over one another (McNiff 2013, p.35). This is difficult to achieve in practice, as we must consider our ways of thinking in order to critique them (McNiff 2013). A strength of this study is that it afforded space and opportunity to participants so that they could consider and critique their ways of thinking and work together differently. For example, nurse members of the Advisory Group were able to consider experiences of care from the patient and family's perspectives (as collected through the RHEPORT data). While patient and family members of the Advisory Group were able to examine first-hand how Registered Nurse members of the Advisory Group responded to these comments and made sense of them, this type of collaboration suggests what McNiff (2013) refers to as **change to practice**, such that the Advisory Group participants worked in different ways from their previously prescribed (nurse, patient, or visitor) roles.

The Advisory Group members displayed increasing confidence in their decisions as the Action Cycles progressed. For example, in Action Cycle 4, Advisory Group members disagreed with

my repeated suggestion that we cease showing negative comments. Despite my preference, the Advisory Group consensus was that we would continue with the current course of action. This finding suggests the occurrence of what McNiff (2013) would refer to as **influencing each other**, such that a level of shared control developed through the research process. Therefore, while I instigated the study and conducted the Advisory Group workshop, as the study progressed, Advisory Group members were more comfortable to challenge me and each other. This finding also highlights my respect for stakeholder knowledge and engagement throughout the field work. This shift was reflective of how engagement moved from being based in technical interests, whereby I was initially the decision-maker and driver of the direction of the research, to relations that were more equitable. As the collaboration of advisory group members developed, this in turn further influenced the practices of Advisory Group members and their insights into practice. For example, the involvement of some Advisory Group members in the process of coding and analysing the experience findings demonstrates the development of what McNiff (2013) refers to as **new insights and practices through interactions**.

Advisory Group – Challenges

Although there were numerous successes in terms of collaboration amongst the Advisory Group members, there were challenges and tensions, primarily to do with participation. Several members of the Advisory Group decreased their engagement over the course of the study, and as a result it was difficult to assess how engaged these members were in the research process. At the outset, following the Advisory Group workshop, all members expressed their interest in the research area and their desire for ongoing participation. We had initially planned to meet in person at least three times over the field-test period, but this proved impossible to co-ordinate. All communication after the Advisory Group workshop was by email (group or individual), telephone, or individual face-to-face meetings. By Action Cycle 4, only six members remained actively engaged with the study. From the beginning of the study I was motivated to ensure that the principle of ‘nothing about me without me’ was upheld; ideally, no decision would be made without input from all Advisory Group members. However, this way of operating resulted in delays to field-testing in Action Cycles 2 to 4. It became clear that such delays were not practical in subsequent Action Cycles, given the study timeframe. On the other hand, I also held a desire to adhere to a person-centred approach to the overall research and thus to respect individual needs (such as workloads) and preferences (such as a continued interest). These inherent tensions in conducting action research, where

there are competing interests that can stymie participation, are not unusual (Snoeren & Frost 2011).

In this project, the difficulty in sustaining the participation of the Advisory Group members served to highlight the inherent and competing tensions of conducting an action research study within a complex healthcare setting. Developing collaborative relationships between patients and healthcare professionals is often challenging (Martin & Finn 2011). According to Snoeren and Frost (2011), individual interest and motivation is often an issue in action research projects, while engaging and sustaining stakeholder participation in research depends on interest, funding, time, and other commitments (Froggatt, Heimerl & Hockley 2013). Variability in participant engagement in research advisory groups, in particular, has been well documented, and is affected by a range of factors, such as financial incentives (Smiddy et al. 2015), relationship building (Portalupi et al. 2017), and or a lack of decision-making capabilities (Hayes 2001). It was therefore to be expected that the level of participation would vary throughout the study. In this study, there was no financial incentives for Advisory Group members to participate, though the Registered Nurses were able to claim the Advisory Group workshop day as a paid study day. Despite this lack of financial incentive, Advisory Group members worked together often through email to make decisions. In spite of this, the Patient-Centred Outcomes Research Institute (PCORI) (2014) considers compensation an essential component of value recognition, and as such recommends patient and family members should be paid. A lack of compensation may have explained the Advisory Group members' decreasing participation over the course of the study.

Notwithstanding the democratic and collaborative underpinnings of action research, building relationships and sustaining communication are also fundamental components of experience-based co-design and co-creation (Palmer et al. 2018). Therefore, attempts were made to re-engage specific Advisory Group members who were not actively participating in the research throughout Action Cycles 2 to 5. These attempts took the form of individual phone calls, emails and, at times, face-to-face meetings. Our findings were consistent with the literature, which highlights the key role a facilitator plays in a group's sustainability and success (Cheng & Lee 2014; McCormack et al. 2017; Pharo et al. 2014). While several Advisory Group members disengaged from participation entirely, the remaining members seemed to increase their participation after I encouraged them. For example, 10 members made valuable contributions to re-designing the posters and designing the brochures. These same members also actively participated in the decision to exclude negative comments from public displays.

This success of re-engagement with the study was also evidenced by Advisory Group member input throughout the Action Cycles after prompting, and in particular their participation in coding the data (see Action Cycles 5 to 7), further showing the importance of facilitation.

Limited participation by clinical nurses in RHEPORT evaluation (Action Cycles 2 and 3) was another challenge for the Advisory Group. Upon reflection, it was clear to the Advisory Group that we had neglected to anticipate the implications negative feedback would have for our ability to evaluate RHEPORT. Our initial way of displaying negative experience feedback was, in fact, detrimental to the development process, although we did not fully appreciate this until Action Cycle 6, when the NUM refused to allow any negative comments to appear publicly. An inability to predict such outcomes is not uncommon in action research (James, Slater & Bucknam 2011). However, this finding did require the Advisory Group to consider how we could engage the clinical nurses with both the RHEPORT Protocol and its evaluation. The lack of participation by the clinical nurses in completing evaluation surveys arguably demonstrated their resistance to change. This finding demonstrates that even with well-planned change, the outcomes can be unpredictable and unknown. The Advisory Group's reflections on the clinical nurses' adverse reactions, in turn, challenged our individual assumptions about the nurses, which led to the development of new knowledge. Returning to McNiff's (2013) domains of change, the challenges that the Advisory Group faced in terms of clinical nurse participation during field-testing in fact led to **changes in thinking**, and ultimately practices. We used this knowledge to plan further change. Negative feedback was not displayed publicly but was presented via post-feedback debriefing sessions. This outcome demonstrates the value of developing change through action.

Field-test participants

In addition to Advisory Group members being considered co-creators and collaborators, many patients and visitors provided not only evaluation, but also detailed design suggestions for the RHEPORT Protocol. While co-creation has recently been promoted within the research community, there is widespread scepticism that stakeholder involvement, particularly of patients and family, remains tokenistic (BMJ Publishing Group 2019; Richards et al. 2013; Romsland, Milosavljevic & Andreassen 2019; Snow, Tweedie & Pederson 2018). A success of this study was, therefore, the element of co-creation embedded in the research design. As recently highlighted by Raynor (2019), it is the explicit focus on co-creation in action research that leads to the continual re-defining of the research focus. Knowledge developed in this way (i.e. through action) is a fundamental tenet of action research (Reason & Bradbury 2008),

and a bi-product of conducting it (Sarvestani et al. 2017). Examples of design changes made based on patient and visitor input included poster placement (originally too high for a patient in a wheelchair – Action Cycle 3), font (the original was too difficult to read – Action Cycle 3), and content (Action Cycle 9).

At the beginning of the research, field-test participants were considered by the Advisory Group (myself included) as ‘subjects’ who could provide experience and evaluation data. This perception demonstrates our initial ‘technical’ leanings in the set-up of the project. However, it also later served as a challenge we would have to face as we came to the realisation that field-test participants were more than mere subjects. As the Action Cycles progressed, it became increasingly apparent that we needed to engage with all participants in a more ‘practically’-oriented mode. The Advisory Group needed field-test participants to evaluate the protocol. While patients and visitors provided evaluation data willingly, it was not until the Advisory Group changed our thinking that we started to ask for design input from all field-test participants. This in turn changed the RHEPORT Protocol, and our way of viewing the field-test participants; they went from ‘subjects’ to ‘co-creators’. This is a highly significant outcome, given that reviews of nursing and healthcare action research have identified limited participation by patients and family (Munn-Giddings, McVicar & Smith 2008; Soh et al. 2011). The findings of this study go some way to addressing this gap.

Clinical nurse input into RHEPORT re-design, in turn, also created opportunities for the Advisory Group members to consider different ways of making changes and improvements. The Reflection Sessions provided the forum for the clinical nurses to reflect on experience feedback, but also gave the Advisory Group a way to elicit evaluation input regarding RHEPORT design. The reflection sessions further allowed the Advisory Group to demonstrate that we no longer viewed clinical nurse participants as ‘subjects’. The clinical nurses themselves then began to adopt project-specific terminology during the reflection sessions, such as ‘patient-centred care’ (Action Cycle 4), ‘real-time’ (Action Cycle 7), ‘negative experience feedback’, and ‘qualitative research’ (Action Cycle 8), suggesting a degree of collaboration and co-creation. These findings also demonstrate the value of bringing clinical nurses together to develop shared understandings. Arguably, they also reflect what McNiff (2013) refers to as one of the ‘domains of change’ in action research – **changes in other people’s understandings and practices.**

Moreover, clinical nurses who participated in post-feedback sessions (Action Cycles 4 and 6 to 8) discussed and problematised, how to ‘improve the patient experience’ in response to the

feedback data they received. This suggests enhanced reflective engagement through practice. Based on McNiff's (2013, p. 105) domains of change, this could also be interpreted as the nurses developing "**new insights**" through their "**interactions**". Consistent with the findings of others (Rowe et al. 2013), this study has demonstrated that when clinical nurses are given time for reflection and are encouraged to engage in an open dialogue, not only can resistance to change be minimised, but possibilities for transforming practice can emerge. All 'subjects' therefore essentially came to be seen as expert stakeholders who contributed to shared understandings and to the re-design of the RHEPORT Protocol.

By coming to see nurses and field-tests participants (patients and family members) as expert stakeholders who could contribute to shared understandings and the re-design of the RHEPORT Protocol, this project has shown how the democratisation of knowledge generation can occur within a pragmatic framework. This expert input created opportunities for the Advisory Group to consider different ways of making changes and improvements. Returning to McNiff's (2015) domains of change, it is evident that other people's (field-test participants') thinking and practice, influenced our (the Advisory Group's) thinking and practice. This brought new insights, leading to **changes in practice** (a re-designed RHEPORT Protocol and increasing acceptance of the RHEPORT Protocol among participants). Re-testing these changes in later Action Cycles and specifically asking for evaluative and redesign input also proved to be an effective way of ensuring that RHEPORT met the needs of the clinical nurses, and of the patients and visitors on the IPU. Arguably, by working to engage the clinical nurses, patients, and visitors in conversation – as opposed to seeking their input from a survey or some other more technical means – these participants were able to take on a role as co-creators. Indeed Greenhalgh et al. (2016) argue that when stakeholders work alongside researchers to design components of an intervention or change, those stakeholders essentially become co-creators. As such, we consider the clinical nurses, patients and visitors who field-tested RHEPORT to be co-creators of the RHEPORT Protocol.

Experience themes generated by field-testing RHEPORT

The similarity of results (experience themes and positive comments significantly outweighing negative) between our study and previous work suggests the validity of the process and of the results generated by adopting the RHEPORT Protocol.

The three dominant experience feedback themes the Advisory Group identified during field-testing were:

1. Physical comfort
2. Respect for patients' values, preferences and expressed needs, and
3. Information, communication, and education.

These three themes are consistent with findings from the experience literature, both in Australia and overseas (Brookes & Baker 2017; Grocott & McSherry 2018; Harrison, Walton & Manias 2015; Wolf 2018). 'Comfort, pain and clinical care', and 'the care environment' were identified as dominant themes in Harrison, Walton and Manias (2015) systematic review, and these are consistent with RHEPORT's findings regarding the **physical comfort** experience domain. It is important also to note that RHEPORT uncovered physical comfort experiences which may never have been relayed to nurses. Only a handful of patients in our study (and no visitors) stated that they had complained about the noise (an aspect of physical comfort) to a nurse, yet many more highlighted noise as an issue when they were prompted to share their experience. This is significant, as an absence of complaints may lead nurses and hospital administrators to assume all is well when it is not. RHEPORT facilitated an awareness of what was important to patients and visitors and provided a space in which clinical nurses could discuss possible solutions.

Respect for patients' values, preferences and expressed needs was also a dominant theme in the experience findings of our study. Recent research into consumer perspectives of the patient experience from the United States, Canada, the United Kingdom, the Philippines and Australia found that being treated with courtesy and respect was in the top three most important components of experience (Wolf 2018). **Information, communication, and education** were also consistently identified as a determinant of experience in our study, with communication problems accounting for the majority of negative and positive comments in this category. Likewise 'communication' is often reported, globally, as an essential component of patients' hospital experience (Brookes & Baker 2017; Grocott & McSherry 2018; Tak, Ruhnke & Shih 2014; Wolf 2018). Brookes and Baker (2017) found that communication and interpersonal skills were among the key areas identified in a UK study of that country's National Health Service. A primary driver of their positive feedback was staff being caring and compassionate, and 'knowing' the patient (Brookes & Baker 2017). On the other hand, experiences of nurses not listening and showing apathy were drivers of negative feedback (Brookes & Baker 2017), which also concurs with our findings.

The finding that field-test participants (RHEPORT Versions One to Six) expressed significantly more positive feedback (167 comments) compared to negative feedback (67 comments) is consistent with other feedback research (Brookes & Baker 2017; Hong et al. 2019). While we

do not know why participants made more positive comments in general (the obvious assumption would be that the service offered is of a high standard), our findings are in keeping with the tendency for predominantly positive feedback reported in other studies. Brookes and Baker's (2017) UK study that explored online patient feedback highlighted that the NHS was evaluated positively three times more often than negatively. One explanation for why patients generally provide more positive experience feedback than negative may be offered by social desirability theory. According to Althubaiti (2016), social desirability bias occurs when individuals asked to self-report try to present themselves to the interviewer in a more positive light, particularly when the interviewee perceives that confidentiality or anonymity cannot be guaranteed. Additionally, participants may also want to please the interviewer for fear of confrontation or future ramifications (Brown et al. 2014). Our study did find five patients who expressed concern about their anonymity and the potential consequences of sharing negative feedback. This was evident in a patient's comments during Action Cycle 8.

Notwithstanding these concerns, RHEPORT did elicit negative patient and visitor experience feedback, with more 67 negative comments collected (excluding RHEPORT+). These data suggest that fear of recrimination or a desire to present oneself in a positive light may not have had a significant impact on participant responses. In a project where feedback was sought from patients about GPs (Desborough et al. 2008), the authors reported no difference in content (negative or positive) of feedback, whether patient questionnaires were returned to the respondent's medical practice or to an independent interviewer. This supports our finding that fear of recrimination if feedback was delivered directly to a healthcare provider is not necessarily an issue. Similarly, it is argued that people may well only report positive experiences out of a belief that negative experiences are beyond the control of those directly involved in their experience (Brown et al. 2014). Participants did, however, report experiences to do with food, parking, and visiting hours (see Appendix V), suggesting this was not the case in our study.

The timing of data collection may well have affected the number of positive experience results. Barron et al. (2014) found that early responders are more likely to give positive evaluations. Arguably, our participants were *very* early responders, because they were being interviewed about their experience while they were experiencing it. Most other feedback elicitation strategies gather data post-discharge (Edwards, Walker & Duff 2015). Our findings may indicate that real-time feedback from patients and family members tends to be more positive about the service than feedback gathered after discharge. However, more research is

needed to confirm this. An implication of this finding is that ‘review lag time’ may have an effect on hospital experience feedback which it does not in other settings. Hospitality experience research, for example, has found that the sooner after their experience customers post reviews, the more detailed and negative they are. With time increasing, customers tend to focus on the overall experience and come to a more positive view (Stamolampros & Korfiatis 2018). This is significant because healthcare has become increasingly consumer-driven, and healthcare providers are looking to other industries, particularly hospitality, in hope of improving consumer experiences.

When considering experience findings, it is essential to note that multiple factors (such as age, sex, and culture) influence responses (Russell 2013; Sizmur, Graham & Walsh 2015), and that experience comments are time- and context-bound. Thus, while we can compare RHEPORT to other feedback findings to demonstrate validity, had data been collected at a different time, even with the same participants, we may well have gotten different results. This is, however, equally true for most other methods and studies. Experiences and satisfaction are also shaped by expectations, which are in turn shaped by a variety of factors, including cultural norms and health status (Coulter, Fitzpatrick & Cornwell 2009; Newell & Jordan 2015). RHEPORT offers a window into how patients and visitors experience and re-telling their hospital experiences (positive and/or negative) at a given moment. Therefore, the validity of the RHEPORT Protocol is that it offers a way of collecting information about what matters to patients and family members about their experience at a specific time. For their part, too, clinical nurses can reflect on this information to develop a greater understanding of patient and visitor experience and how the care nurses deliver affects that experience.

6.2 The RHEPORT Protocol: Core components

Key finding two
The RHEPORT Protocol comprises five core components

Findings from the nine Action Cycles enabled us to identify five components that were central to the feasibility, acceptability, meaningfulness, and effectiveness of the RHEPORT Protocol. These five components are: 1. capture memorable experiences; 2. publicly display positive key comments only; 3. review positive and negative feedback during private reflection sessions; 4. consider the facilitator; and 5. understand the target population. In keeping with the perspectives of Blase and Fixsen (2013) and Fixsen et al. (2009), implementation scholars, we argue that these core components are essential elements which should be actioned or

considered to produce the desired outcome – in this case, relevant and meaningful experience data.

1. Capture memorable experiences

Key finding three

Asking participants to ‘describe something memorable’ about their hospital experience provides an opportunity for the patient or visitor to discuss what matters most to them.

Asking patients and visitors to ‘describe something memorable’ while they were in hospital was found to be an effective way to engage participants. This is an important finding because previous research (Edwards, Duff & Walker 2014) has reported that merely asking a participant to ‘tell me about your experience’ can be met with silence or a response to the effect of ‘what do you want to know?’ Moreover, asking specific questions, that have historically appeared on inpatient feedback tools such as ‘tell me about your room cleanliness?’ does not necessarily give scope for the patient or visitor to discuss what they may want healthcare providers to know. Rather, such questions focus the conversation on what the providers want to know. Additionally, questions that have traditionally been adopted in experience surveys, such as ‘What could we improve on?’ or ‘What did we do a good job on?’, can be understood as prompting the participant to give an exclusively negative or positive response. Through RHEPORT, we aimed to elicit narrative accounts from participants and so avoided binary prompts. Grob et al. (2019) highlight that patient narratives can convey what matters most to the individual. Additionally, Brown, Botti and Hutchinson (2018) argue that personal stories provide more significant insights into the individual needs of patients than other methods. Consistent with the positions of these authors, we found that asking participants to share something memorable gave them the agency to discuss what mattered most to them and to focus on that point or event in their narrative. From these memorable experiences emerged key comments which appeared on the posters.

Our findings demonstrate that patients and visitors are able to identify and discuss pivotal points of experience when presented with the open-ended question ‘Tell me something memorable about your experience?’ As such, our findings do not support the suggestions made by The Point of Care Foundation (2019c) that when asking patients to give experience feedback, both positive and negative feedback must be actively sought. The Foundation’s rationale for this guidance is that “if the patients only offer positive feedback, they will not be

able to contribute to the key aim; to improve services” (The Point of Care Foundation 2019c). Indeed, if improving patient-centred care is based on identifying what matters most to the individual, then feedback must focus on the pivotal points of that experience. Hence the findings of this study do not support actively seeking out positive and/or negative feedback as a central mechanism for improving services. Instead, they argue for engaging people in a dialogue to understand what matters most to them during their hospital experience. In addition, given that RHEPORT yielded experience data that was consistent with other studies, this finding suggests that the question asked regarding ‘memorable experiences’ was appropriate and sensitive enough to produce meaningful and relatable findings.

‘Tell me something memorable about your experience?’ could be considered a ‘global question’ in that it asks a participant to consider their whole experience up to that point. Larsson and Larsson (2002) argue that global questions, as opposed to specific enquiries, may lack validity, as they depend on the respondent’s mood at the time and, to some degree, on their personality. Solomon (2014), however, suggests that specific questions also elicit responses which are affected by overall experiences. For example, the responses to ‘How often were your room and bathroom kept clean?’ (HCAPS surveys) show that we tend to be more lenient in our specific answers if we have had a good experience overall. As Solomon (2014) explains, ‘Always’ is often the response given, even though this is technically impossible. He (Solomon 2014) argues that people may respond ‘always’ because they have had a positive experience overall. Mood, personality, and a positive or negative overall experience can influence answers to all experience questions (Larsson & Larsson 2002), but this does not invalidate the findings of RHEPORT. RHEPORT captured ‘perceptions of experience’, and as previously stated, there is no ‘absolute’ truth of an experience other than that which is expressed by the person who experienced it. Asking a patient what is ‘memorable’ elicits their perception of experience and is in keeping with valuing the patient’s voice. It is a global question that prompts specific responses.

If a healthcare provider takes the time to ask a patient or family member about their experience, that person may assume the provider cares about their experience. Knowing this can prompt the consumer to feel valued, thereby potentially improving the experience. Research suggests that asking questions about behaviour can affect behaviour (Wilding et al. 2016; Wood et al. 2016). For example, students who were asked about their intentions to exercise had increased their exercise rates by the time they were contacted again two months later (Godin et al. 2008). Similarly, asking a patient or visitor about their experience can improve it (Ziebland & Wyke 2012). Ziebland and Wyke (2012) also state that asking

about experience can enhance a patient's sense of agency, and this in turn can positively influence their experience. One patient response in our study illustrates this finding. A patient from Action Cycle 8 stated he felt *"empowered to give feedback personally [to staff in future]"* as a result of our interview about his experience. This patient's comment, and previous research regarding experience questions, agency and autonomy, suggests that RHEPORT may also be beneficial in this area.

Finally, the Advisory Group considered asking patients and visitors to share 'a memorable experience' in a face-to-face interview to be crucial to capturing rich and nuanced qualitative accounts. However, Ross (2017, p. 8) suggests that in such an interview situation, there is a potential to reinforce the notion that "participants are less powerful than researchers who ask the questions". While this concern cannot be discounted, I would argue that RHEPORT shifts the participant into a more equitable position by valuing their voice and providing them with the opportunity to convey what is most meaningful for them. Our findings suggest that asking someone to describe their 'memorable experiences' both guides and provides an opportunity to convey what matters to them at a particular time. Unbeknownst to the Group, several studies in hospitality experience research also looked at 'memorable incidents' and the effect these have on clients (Black & Kelley 2009; Lundqvist et al. 2013; Ryu et al. 2018, p. 22). These studies further support our finding that capturing 'memorable experiences' is feasible, appropriate, meaningful, and effective.

2. Publicly display positive key comments only

Key finding four

Only positive experience feedback should be publicly displayed. Patients, visitors, and nurses react positively to the public display of positive feedback. Negative experience feedback should not be publicly displayed. Patients, visitors, and nurses respond negatively to the public display of negative feedback.

Positive feedback

Our findings demonstrate that the public display of positive feedback was well received by patients, visitors, and clinical nurses alike. Not only was this display beneficial in relaying the feedback to clinical nurses in particular, but the effect of reading the positive feedback was also favourable. Clinical nurses were more willing to engage with me and with the Protocol when the displayed feedback was positive. They also made clear in their evaluations that they

found reading positive feedback beneficial to their practice. This is not surprising, as positive feedback can both inform practice and boost morale (Duffin 2013). As reported in Action Cycle 3 (see the journal entry for Day Six), when negative comments were posted alongside positive comments, clinical nurses tended to dismiss the positive and focus on the negative. When only positive comments were publicly displayed, however, nurses willingly read them (see Action Cycle 6). To date, I have found no literature that has specifically addressed the impact that removing negative comments has on the number of people reading the exclusively positive reviews. Despite this, one way to understand these findings is to consider the relationship between emotion and reflection.

According to Jones et al. (2019), reflection on practice (a re-evaluation of past experiences) is triggered when feedback is personally relevant and emotionally salient (Jones et al. 2019). However, reflective learning (making sense of learning experiences) involves an interaction between emotion and cognition, which can be seen as “two sides of one coin” (Imbir 2016, p. 43). It is this relationship between negative emotions and reflective learning which triggered the change in RHEPORT to displaying only positive comments. The purpose of delivering experience feedback to nurses is so that they can reflect on other people’s experiences and learn from them. Unfortunately, our research confirms the findings of Carlson, Guha and Daniels (2011), which suggest that negative reviews are read more often despite an increased number of positive reviews being available. Reading only negative reviews is problematic for two reasons. Firstly, positive feedback tells us what we are doing right, and secondly, reading only negative reviews may harm our ability to learn from feedback. Clore, Schiller and Shaked (2018) suggest that a positive affect serves as a vehicle to access thoughts and mental processes, whereas a negative affect essentially halts this process. Therefore, in addition to not reflecting on positive feedback, the negative responses may have halted acceptance of any information being relayed and, as a result, degraded reflective learning. It is arguable that the public display of positive feedback only, in our study created a more favourable mental state for the nurses, allowing them to better receive and process information (Clore, Schiller & Shaked 2018).

Patients and visitors also responded favourably to reading the positive feedback of others. This most likely triggered a feeling of satisfaction and validation in their hospital choice (Loria 2019); though reading positive feedback had other repercussions for patients and visitors in our study. The public display of positive feedback seemed to allay patients’ fears, arguably improving the experience (see Action Cycle 7). In fact, patients themselves assumed this was the reason we were displaying positive feedback (Action Cycle 6). Patients also stated that

reading the positive comments during or just before admission would have had a reassuring effect (Action Cycle 9). After reading favourable comments, several patients wanted to tell me about their own positive experience, and often used the exact words or phrases they had just read (see Action Cycle 6). To make sense of these findings about patient and visitor reactions to positive comments, I looked to psychology, and specifically to what is known as ‘priming’.

As discussed in Chapter One, priming refers to the effect that exposure to a related message can have on a person’s perceptions and/or actions (Barutchu, Spence & Humphreys 2018; Elgendi et al. 2018). Elgendi et al. (2018) offer the example of someone choosing not to smoke as a result of exposure to the word ‘cancer’. Priming refers to a “behaviour outside of awareness” which can affect “behaviour, choices and actions” (Elgendi et al. 2018, p. 1). There is also evidence to suggest that consumer narratives have the ability to stimulate positive behaviour change and elicit what have been referred to as ‘story-consistent attitudes’ not dissimilar to priming (Falzon et al. 2015; Van Laer et al. 2013; Willoughby & Liu 2018, p. 76). Not only does the concept of priming explain why people’s experiences may be improved by reading positive comments, it may also explain why patients and visitors reading the comments in our study later wanted to tell me about positive experiences of their own. The display of positive feedback may have led to participants presenting what could be understood as ‘story-consistent attitudes’. The fact that the feedback was in other patients’ and visitors’ own words may have been the catalyst that primed these patients to express similar sentiments. Koester et al. (2016) found that participants who were exposed to positive narratives and stories of other patients reported significantly more positive user experiences than those who were not. Positive priming strategies are widely used in other fields for this very reason. Successful marketers, for example, use priming to influence purchasing decisions, and it can also improve brand recall (Bressoud, Lehu & Russell 2010; Dens, De Pelsmacker & Verhellen 2018). It is possible, therefore, that in displaying positive comments RHEPORT not only captured and disseminated the patient’s and visitor’s voice, but also that it had a positive (priming) effect which can improve the experiences of others who read the feedback.

The near-real-time delivery of the positive comments may also have been a factor in their being well received by clinical nurses, patients, and visitors. Patient comments such as *“reading positive comments would have calmed me down”* and *“made me feel better”* suggest that negative experiences may be moderated in real-time by reading about the positive experiences of others (see Action Cycle 9). As discussed in Chapter One, the stories we recall

and relay to others are, in fact, memories of our experience. It is, therefore, the memory of a positive experience which improves the outcome (such as clinical and safety outcomes; (Price et al. 2014)). Memory researchers Shaw and Porter (2015) suggest that it is possible to manipulate memories. Their study demonstrates that 70 per cent of participants exposed to specific suggestive interview techniques went on to generate a false memory, with more than three quarters being able to provide vivid detail of the false memory. Morgan III et al. (2013) found that memories of stressful events were modifiable based on exposure to positive information. Our findings raise the possibility that negative hospital experiences could potentially be mitigated by exposure to the positive experiences of others. While we are in no way advocating the creation of false memories, our research findings suggest there is merit to bringing positive experience memories to the fore, particularly if positive memories of experience affect health outcomes.

Positive priming and memory manipulation are both already being field-tested in healthcare. The ‘false memory diet’, for example, demonstrates how new (albeit false) memories can have health benefits. Bernstein, Pernat and Loftus (2011) found that false memories about a particular food, for example, can influence what a person later consumes. False memories are not limited to adverse events (Strange, Sutherland & Garry 2006), and nor are they necessarily distinguishable from actual events (Laney & Loftus 2008; Stark, Okado & Loftus 2010). This again leads to the potential of priming patients for a positive experience both before and during admission. There are ethical implications to consider in both priming and memory manipulation. However, our research does suggest that there may be merit in displaying the positive experiences of others to reduce the impact of and or memory of negative experiences.

Negative feedback and radical transparency

Despite the trend towards disclosure and transparency in healthcare (Desai et al. 2017; Lee 2017), this study found that the public display of negative feedback from patients and visitors was not well received, by patients, visitors or clinical nurses. Displaying negative feedback publicly reflected our attempts at transparency. During the initial planning phase of the project (Action Cycle 1), the Advisory Group members felt that a side-by-side display of negative and positive feedback would provide what Hardavella et al. (2017) describe as a ‘feedback sandwich’, where critical feedback is sandwiched between positive comments. It was anticipated that this would moderate the impact of negative feedback. When RHEPORT was field-tested, however, evaluation data from Action Cycles 2 to 5, revealed that clinical

care nurses skimmed over positive comments and actively sought the negative. Doing this meant that nurses focused on negative feedback, thereby giving more weight to what was wrong than to what patients or visitors considered good. While identifying negative experience comments may improve practice (The Point of Care Foundation 2019a), the findings of this study are consistent with Buckingham and Goodall (2019), who argue for the need to focus on what healthcare providers are doing right to help them continue to do so. This tendency to prioritise negative feedback means that if clinical nurses are not reading the positive comments, displaying those comments for their benefit is pointless. Only feedback which is taken on board can affect change (Buckingham & Goodall 2019), so feedback must be presented in a manner which facilitates that acceptance.

The Advisory Group anticipated a level of displeasure at reading publicly displayed negative comments. It has been reported that nurses can mistrust experience data, becoming either defensive or dismissive of negative feedback (Asprey et al. 2013; Cornwell 2015; Sheard et al. 2017). The level of annoyance and the collective displeasure the clinical nurses expressed during Action Cycle 2, however, was not anticipated. Nurses from IPU A (Action Cycle 2), where RHEPORT was first field-tested, were extremely opposed to the negative feedback offered by patients and visitors. Clinical nurses expressed feelings of shock, humiliation, and disbelief regarding this feedback. One explanation for this may be, as Cornwell (2015) suggests, that feedback draws attention to behaviours and attitudes. In this study, the specificity of feedback may have been a real barrier to acceptance. While clinical nurses could assume the feedback did not relate to them personally, they could not escape the knowledge that the feedback was specific to the clinical nurses on their unit. Previous research has reported that frontline staff tend to consider findings of broader organisational surveys as not applicable or relevant to their setting (Gleeson et al. 2016). The very purpose of RHEPORT was to ensure that feedback was highly specific at a unit level, and this specificity may have been confronting.

It is interesting to note that the initial reaction from clinical nurses in Action Cycle 2 was particularly adverse (compared to the next two Action Cycles), yet the number and content of negative experience comments were very similar to the other units. It is possible that staff on the subsequent field-test units (for example, unit B – Action Cycle 3) heard informally about the study, which could have gone some way to forewarning them about the likelihood of receiving negative feedback. In turn, this forewarning, albeit informal and not initiated through the project, may have mediated the reactions of unit B's staff. Interestingly, nurses from IPU A, who had not personally seen the feedback, only having heard about it from their

colleagues, expressed similar sentiments about the display of negative feedback. This collective displeasure at the very idea of negative feedback was unexpected. It suggests that someone does not have to personally view the public display of negative feedback to be affected by it. As is the case with online reviews (Adams 2011; Patel et al. 2015), it would seem that negative feedback can be shared and therefore amplified, with detrimental implications. This is yet another reason why negative feedback should not be publicly displayed, as the impact is further reaching than expected.

Regardless of the reasons, the nurses' reactions to the negative feedback (in Action Cycles 2 to 4) suggested that the feedback was not delivered in a way that was appropriate or acceptable to them. When staff are mistrustful or dismissive of feedback, they tend to disregard it (Hardavella et al. 2017). The clinical nurses also refused to participate in the evaluation surveys, further indicating rejection of the feedback and of RHEPORT as a whole. As demonstrated in Action Cycles 6 to 8, clinical nurses became far more willing to engage with the feedback posters and participate in the evaluation of RHEPORT once we displayed positive comments only. According to Adams, Maben and Robert (2018), the experience of patients complaining is highly emotive for frontline staff, because nurses see these comments as damaging to their relationships with their patients and to themselves (Adams, Maben & Robert 2018). One can surmise that this was the case in our study, particularly as nurses in the study conducted by Adams, Maben and Robert (2018, p. 608) expressed very similar emotions ("devastation", "awful shame", "disbelief" and "shock") regarding complaints made about them or their colleagues.

In considering the findings of Action Cycles 2 to 6, the Advisory Group members were most surprised, however, by the patient and visitor reactions to the public display of negative feedback. Our study found that, while patients and visitors were happy to give negative feedback (knowing that it would be publicly displayed), the majority did not want to read the negative comments of others (Action Cycles 6 and 7). The patient and visitor reactions may be explained by further considering why patients read other peoples' feedback in the first place. Up to 72 per cent of healthcare consumers in the United States use online reviews as their first step in choosing a healthcare provider and, as discussed, more than 19 per cent use feedback reviews to validate their choice once made (Loria 2019). Drawing on Loria's (2019) findings, negative comments may have challenged patients' and visitors' decisions and perceptions of their own hospital experience, bringing the realisation that others around them may be experiencing the hospital very differently.

Conversely, displeasure expressed by patients and visitors at reading negative feedback may again have been due to the quantity as opposed to the specific content. There were far fewer negative key comments captured or displayed than positive comments during each of the nine Action Cycles (67 negative to 167 positive). As discussed above, this ratio of positive to negative feedback is not uncommon in healthcare (López et al. 2012; Loria 2019). There are also many more positive reviews online than negative in related sectors, such as hospitality (Melián-González, Bulchand-Gidumal & González López-Valcárcel 2013; Pantelidis 2010). Research suggests, however, that negative reviews are often more salient to consumers than positive ones, on the basis that customers pay more attention to negative reviews (Chen, Fay & Wang 2011; Papathanassis & Knolle 2011; Sparks & Browning 2011). Wu (2013) suggests that it is the scarcity of negative comments which leads people to attribute more weight to them. Wu (2013) further explains that, under such circumstances, individuals consider rarity of comments to correlate with higher quality. This may also explain why clinical nurses appeared to prioritise negative comments when both negative and positive were displayed. While further research is needed in this area, these findings do suggest the importance of not displaying negative feedback publicly.

One final reason identified by the Advisory Group not to display negative feedback was related to potential detrimental ramifications on the carer–patient relationship. I observed that clinical nurses tried to guess which patient or family member had written which negative comment (see the journal entry for Action Cycle 3, Day Six). The Advisory Group reasoned that identification, whether correct or incorrect, could harm the nurse’s relationship with the patient. Negative feedback was therefore perceived as not only damaging to healthcare professionals, and patients and visitors themselves, but also potentially to their relationships with each other. Adams, Maben and Robert (2018) examined how healthcare professionals make sense of complaints, and found that they were almost always seen as damaging to care relationships. The Advisory Group incorrectly assumed that anonymity would guard against any potential damage, but we neglected to consider that nurses would at least wonder who made the comments and possibly form their own conclusions. In Locock et al.’s (2020) study, participants (staff members of the Aberdeen Royal Infirmary) highlighted instances where they might attempt to de-anonymise anonymous patient feedback. While those participants reported understanding why patients preferred to remain anonymous, they felt ‘uncomfortable’ and ‘challenged’ by anonymised feedback, often questioning the veracity (Locock et al. 2020). Collins et al. (2020) also found that while patients want anonymity and confidentiality when providing information relating to negative experiences; nurses view

anonymity as a barrier to overcome. This phenomenon is known as the ‘anonymity paradox’ (Speed, Davison & Gunnell 2016). Patients can be concerned that future care may be jeopardised if they provide identifiable feedback. In contrast, healthcare providers are fearful that, without identification, consumers can ‘say anything’, and thus damage providers’ reputation (Speed, Davison & Gunnell 2016). This is a tension with enhancing the agency of patients and visitors. Overall, the display of negative comments in no way benefited the experience of the patient or visitor, nor did it facilitate a sharing of feedback to the clinical nurses. It is for this reason that a core component of the RHEPORT Protocol is to publicly display positive comments only.

3. Review positive and negative feedback during reflection sessions

Key finding five

Post-feedback guided reflection sessions for the clinical nurses are essential to enhancing their reflective consideration of the patient and visitor’s hospital experience.

In response to the findings from Action Cycles 2 to 4, reflection sessions were developed, field-tested with clinical nurses, and evaluated by the Advisory Group. While the positive feedback served as a platform for further inquiry, simply excluding negative feedback was not an option for two reasons. Firstly, the intention of this project was not merely to present positive comments, but rather to develop a process whereby the patient’s and visitor’s voice could be heard. Thus, in an effort to respect this ethos, both positive and negative feedback was provided in a sensitive and respectful way so that nurses could consider it.

The formal steps within the reflection sessions were refined over four Action Cycles (Four to Eight), and the sessions were well-received by all clinical nurses. For RHEPORT to be an authentic feedback protocol, it became apparent during Action Cycle 4 that a specific mechanism to support the clinical nurses to reflectively engage with positive and negative feedback was needed. The concept of reflection and reflective practice is well-engrained in nursing literature and education (Choperena et al. 2019). However, clinical staff rarely have time to reflect upon their own experiences (Flanagan et al. 2020). Despite the literature suggesting that Registered Nurses must reflect upon practice (Bladon & Bladon 2019; Dickson 2016), this is often difficult for nurses to embrace (Oluwatoyin 2015). The day-to-day time pressures associated with nursing usually mean that coming together to reflect on the workings of the unit is often neglected (Hung et al. 2018).

The reflection sessions in RHEPORT provided a safe space for clinical nursing staff to better understand, consider and discuss the experiences of their patients and visitors, which is essential to transforming practice. The clinical nurses responded favourably to these reflection sessions. Our findings here are similar to those of Reeves, West and Barron (2013), who found that nurses are more engaged with patient experience feedback during 'reflective meetings' as this counters the challenges associated with nurse scepticism regarding the relevance of the feedback to their practice. According to Bladon and Bladon (2019), the sharing of stories can create an opportunity for people to consider their practice and learn from others. The benefits of bringing people together in a collaborative space to discuss their practice and reflect on opportunities for improvement has been well documented (Bevan 2013; Kemmis 2001; Lea et al. 2017; Rönnerman & Salo 2018).

Purposeful reflection provides an opportunity for nurses to both consider and develop new knowledge (Caldwell & Grobbel 2013; Chong 2009). Additional benefits of reflection sessions are that they allow nurses a space to establish a sense of engagement and agency, and to enhance professional expertise, such as critical thinking ability (Lawrence 2011; Yu, Ling & Hu 2019). Evidence of this taking place in our study is demonstrated via the discussions clinical nurses had about how they could solve problems expressed by patients to do with physical comfort or food. Moreover, according to Webster (2010), reflection sessions of this kind are essential, as reflection promotes empathy. The storytelling of real experiences is also beneficial in teaching empathy (Leonard, Zomorodi & Foster 2018). While change in empathy was not assessed, insight into how the patient and family members are experiencing their care is essential to recognising issues in practice and to enhancing patient-centred care (Archer et al. 2018). RHEPORT's reflection sessions enabled the patient's voice to be heard and, more importantly, considered by the clinical nurses.

The reflection sessions stimulated discussion about patient experience, and also evaluation discussions regarding the evaluation of the RHEPORT Protocol. These sessions generated new knowledge that could be returned to the Advisory Group. As a result, Advisory Group members were able to make changes to the RHEPORT Protocol based on these new understandings. Knowledge gained in this way strengthens confidence in the research findings, as it internally validates and enhances the applicability of both the research and the intervention (Israel et al. 2019). Such a collaborative space for reflection was also crucial in establishing the legitimacy of RHEPORT's development, as it provided data on the meaningfulness, effectiveness, and appropriateness of the protocol. Learning from experience (either directly or from others) is central to both action research and reflective

practice (Coghlan & Branick 2010). The value of the Reflective Sessions was particularly evident when clinical nurses reflected on positive feedback and were able to discuss ways in which they delivered care with 'kindness' or 'respect'. According to Buckingham and Goodall, (2019), positive feedback can enhance desired behaviour, and reflection can promote and reinforce optimal care provision. However, Buckingham and Goodall (2019) also highlight that, amidst the competing demands of practice, employees need help to 'see what's working', in order to learn from this as opposed to what they are doing poorly.

Dixon-Woods et al. (2014) point out that there is a difference between the elicitation of feedback for 'problem-sensing' and for 'comfort-seeking'. Problem-sensing aims to identify issues using multiple sources of information (Dixon-Woods et al. 2014). Comfort-seeking aims to gain reassurance that all is well, and that staff are perceived to be performing up to or beyond expectation (Dixon-Woods et al. 2014). However, when staff consider feedback elicitation exercises to be more focused on comfort-seeking (for example, only providing positive feedback), they become disengaged and see the activity as pointless (Dixon-Woods et al. 2014). While negative feedback does not have the same impact on learning as positive performance (Buckingham & Goodall 2019), it is still important to share, because patients and visitors deserve for their stories (positive and negative) to be heard.

Negative feedback should not be ignored, but questions about the appropriateness of 'transparency' in healthcare in general were raised during this study. There is a growing discourse on the dangers of negative feedback in industries outside healthcare. For example, Bridgewater Associates, a large American investment firm, and Netflix, an American media services provider, have adopted cultures of 'radical transparency', whereby multiple sources of feedback (from subordinates, colleagues, supervisors, and even customers) are gathered and presented to the employee (Buckingham & Goodall 2019). Buckingham and Goodall (2019), however, believe that these methods are not productive, mainly because negative or critical feedback can be perceived as a threat by staff, which produces strong negative emotions, provoking a negative perceptual, cognitive, and emotional impact. They suggest that rather than enabling learning, negative feedback may impair it. Our findings indicate that this was the case in the clinical setting, and that transparency requires a more nuanced approach if engagement and participation are to be fostered.

Findings from this study indicate that versions of RHEPORT (see Action Cycle 6 to 8) facilitated learning by not only delivering negative feedback sensitively, but also highlighted positive feedback in a way that was meaningful. The feedback process is ultimately "driven by the

learner” (Henderson et al. 2019, p. 1402), suggesting that the recipient of feedback ultimately determines receptivity. As demonstrated, however, RHEPORT provides a road map to facilitate an acceptance of both positive and negative feedback by ‘the learner’. It would appear, though, that a delicate balance is required, even when highlighting positives, which leads to the critical role the facilitator plays both in actioning RHEPORT and during the reflection sessions.

4. Consider the facilitator

Key finding six

RHEPORT is a facilitated process. The role of the facilitator is crucial to the success of the feedback protocol and as such, RHEPORT requires an appropriate facilitator.

The facilitator was a critical factor in the success of RHEPORT. A core component of the RHEPORT Protocol is, therefore, the selection of a suitable facilitator or facilitators to collect experience feedback from patients and visitors, analyse the feedback, display it, and relay it to clinical nurses in reflection sessions. Our findings suggest that a Registered Nurse is uniquely positioned to take on a facilitator role. Patients and visitors (see Action Cycle 8), on the whole expressed that, they felt comfortable to provide feedback to me (a Registered Nurse) as a facilitator, despite knowing that I was also a nurse employed at the hospital. Moreover, patients and visitors were forthcoming with negative feedback, and even those patients who only provided positive feedback stated that they felt comfortable to provide negative feedback. While previous research has suggested that patients may be reluctant to provide feedback, for fear of reprisal or out of a sense of futility regarding any expected change (Chan et al. 2018), the findings of our study suggest that this may not always be the case. Likewise, our findings do not support the suggestions of the King's Fund (Coulter, Fitzpatrick & Cornwell 2009) that experience data should be collected and organised by a non-staff member – such as trained volunteers or professional researchers – as a way to avoid patients’ and visitors’ hesitancy to comment negatively to staff. We did not however field test RHEPORT using any other interviewer and acknowledge that hesitancy to comment negatively may have been mitigated altogether had we done so.

Given that the purpose of capturing experience feedback at an inpatient unit level is to improve the patient and visitor experience, nurses are however uniquely positioned to identify and address issues raised which require immediate attention. As discussed in Chapter

One, when a 'service recovery' takes place (when issues identified by consumers are addressed swiftly), consumers are potentially converted into loyal customers (Hübner, Wagner & Kurpjuweit 2018). However, for such service recovery to occur, the facilitator ideally needs to have 'insider knowledge'. This knowledge allows the facilitator to identify (and possibly address) negative experiences in near-real-time, thus improving the experience. According to the service recovery paradox theory discussed in Chapter One, if the experience is improved beyond expectation, it is then often recreated as a more positive experience than had the negative event not occurred (Hübner, Wagner & Kurpjuweit 2018; Mount 2012). In addition, an improved experience may result in a commitment to recommend. When a patient or visitor justifies his or her intention to recommend or return to the hospital in the future, should the need arise, the healthcare provider or hospital may benefit, and the memory of the experience for the healthcare consumer is then often recreated as a more positive experience (Cowley 2008; Flacandji & Krey 2018). This is important given that future intention to choose a hospital, repeat patronage, and recommendations are based on the memory of an experience, as opposed to the actual experience (Flacandji & Krey 2018; Pedersen, Friman & Kristensson 2011; Stragà et al. 2017).

Insider knowledge is therefore essential to consider when choosing a RHEPORT facilitator. The clinical nurses in this study valued having the feedback presented to them by the person who interviewed the patients and visitors, and by a Registered Nurse (see Action Cycle 7). Participatory action researchers Herr and Anderson (2014), in similar research, support the inclusion of those with insider or local knowledge, and suggest that a patient or family member may be a suitable facilitator. This would, however, necessitate a level of training which may be beyond the scope of a unit or organisation wishing to adopt RHEPORT. Our findings suggest that the facilitator must understand the inner workings of the hospital hierarchy to be able to highlight issues that are relevant to people or departments outside the unit. Also, research suggests that people tend to accept feedback from those they respect (Hardavella et al. 2017), suggesting that an unfamiliar person may not be able to garner respect from the clinical nurses immediately. McCormack et al. (2013), in their systematic review about change agents, suggest that facilitators are in fact agents for change, and that staff respect for the change agent is crucial. In this study, clinical nurses had the option to attend the facilitated feedback sessions, but were not required to. Their attendance suggests a level of respect for both the source of the feedback (patients and visitors) and the facilitator.

5. Understand the target population

Key finding seven

The target population must be understood to ensure active participation and engagement with the RHEPORT Protocol.

To facilitate participation and engagement with RHEPORT, the target participant population must be considered, which includes both the nurses, and patients and visitors. It is generally accepted that experience instruments must be developed to be sensitive to local healthcare systems, cultural needs, and patient expectations (Wong, Coulter, Cheung, Yam, Eng-Kiong, et al. 2013). Factors to examine, therefore, include nurses' awareness of the importance of patient experience feedback strategies, as well as the patient and visitor population, and hospital policies.

Nursing population

The results of this study demonstrate that to facilitate clinical nurses' participation and engagement with the experience findings generated by RHEPORT, they must first have an understanding of the value of such data. The importance and benefits of real-time, unit-specific hospital experience feedback must be effectively conveyed to, and understood by, the clinical nurses (Carter et al. 2016; The Point of Care Foundation 2019b). In the absence of this, clinical nurses' 'buy-in' to RHEPORT is likely to be minimal, reducing the feasibility, meaningfulness and effectiveness of the process. The acceptance and approval of frontline staff is also essential to the running of any co-creation or patient experience collection strategy (Larkin, Boden & Newton 2015; Robert & Cornwell 2013). Thus, the Advisory Group developed the pre-information sessions. While the sessions were initially well received by the clinical nurses, in subsequent iterations of RHEPORT, most nurses felt they were not necessary. This may, however, have been context-specific. Clinical nurses in this hospital were aware that patients and visitors were routinely surveyed about their experience, but this may not be the case in other hospitals. Existing awareness coupled with my initial presentation to the nursing forum regarding RHEPORT meant that most clinical nurses were aware of our study taking place. The introductory information sessions, however, provided an opportunity to convey the importance of real-time, unit-specific feedback. We would, therefore, caution that participation in and engagement with the feedback depends on clinical buy-in. As such,

some level of information regarding RHEPORT feedback collection strategies should be relayed to clinical nurses before patient and visitor feedback is collected.

Patient and visitor population

Respect for patient experience and patient-centred care requires an appreciation for the uniqueness of the individual patient or visitor. The findings of RHEPORT should, therefore, be presented in a way that respects and acknowledges the uniqueness of patients and visitors. There are three points to consider here: first, how the feedback is collected; second, how the feedback is displayed publicly so that all patient and visitor participants have access; and third, how the feedback is thematically coded to ensure it is reflective of the specific patient and visitor population. With regard to feedback collection, this may mean that qualified interpreters are needed when the patient population consists of linguistically diverse and/or deaf or hearing-impaired individuals. Similarly, posters and brochures may need to be made available in different languages, braille, and/or in font sizes suitable for people with vision impairment. Our findings suggest that hospital experience feedback brochures should be made available to all patients, visitors and clinical nurses, in addition to the publicly displayed posters. While those patients, visitors and nurses who were interviewed after they read the posters reported that they were an excellent way to relay experience feedback, we have no data on how many patients, nurses and visitors in total actually read the posters or brochures. Moerenhout et al. (2013), however, found that 93 per cent of respondents stated they read the leaflets (brochures) in their physician's waiting rooms. These are, however, health education messages, which may or may not be similar enough to suggest experience feedback readership. The multiple modes of relaying RHEPORT feedback are to ensure all stakeholders have equal access, not necessarily equal readership.

The framework for thematically coding data must also be reflective of the patient and visitor population. In this study, the Advisory Group elected to adopt the Picker Domains of Experience as a framework for quickly coding experience feedback in a way that was easily presentable back to nurses. Categorising experience content into pre-existing and recognised themes in this way is not new (Edwards, Duff & Walker 2014; Silvera, Haun & Wolf 2017). While overly deductive approaches should be avoided, frameworks are a good starting point, particularly with participants not accustomed to traditional research methods. Gleeson et al. (2016) systematic review of approaches to using patient experience data for quality improvements in healthcare settings found a lack of expertise in collecting qualitative data,

and a need for data analysis training for staff in order for them to understand feedback results fully. We suggest that coding to a framework addresses both concerns.

The RHEPORT Protocol guide (see appendix X) states that the facilitator or facilitators code the data (unless there is a Research Advisory Group established for that purpose). The facilitator or Advisory Group would then choose an appropriate framework. While the Picker Domains of Experience are purportedly universal, and as such fitting scaffolding for data analysis, we suggest that other aspects, dimensions, or principles of care could be taken into account (see Action Cycle 5, Frameworks for Consideration), which may better reflect the patient and visitor population. Alternatively, hospital charters, policies, mission statements, and/or performance indicators such as McCance et al.'s (2015) person-centred nursing and midwifery key performance indicators (McCance, Hastings & Dowler 2015; McCance et al. 2020; McCance et al. 2012) for example, could guide the initial framework adopted. The framework should reflect both the findings and the patient and visitor population in question.

Patient population – Young adult mental health

The use of patient experience feedback as a way of evaluating outcomes in adolescent health has been encouraged in recent years. Inclusion of this population in the development of experience procurement strategies, however, has been lacking (Wiering, de Boer & Delnoij 2017). Experience-based co-design and co-creation are still relatively new in the field of mental health (Larkin, Boden & Newton 2015). However, there are examples of consumer and carer involvement (Banfield et al. 2018; Larkin, Boden & Newton 2015). These studies informed the development of RHEPORT for this population. In mental health user-led research, the evidence suggests that the quality and reliability of results is enhanced when studies are conducted by the patients themselves (Tambuyzer & Van Audenhove 2015). Despite this, there is little evidence that strategies designed to elicit patient experience feedback have been created by and specifically for those suffering from mental illness (Gallan & Shattell 2015). This study provided an opportunity to engage this population, and to address some of these concerns.

It is difficult to draw broad conclusions regarding the validity of RHEPORT for this population, given the limited participation in giving evaluation responses ($n=18$; see Action Cycle 9). A brief discussion about Action Cycle 9's findings offers some interesting points for future consideration. For example, all participants in Action Cycle 9 were very forthcoming in their evaluation of RHEPORT, and with suggestions on how to improve it. In fact, despite predictions from senior staff that this patient population would "*not say much*", these

participants were far more responsive than others. They were very keen to make design changes, but the goal was not aesthetic. Instead, it was to improve meaningfulness and readership. Recent research suggests that young adults value the opportunity to ‘think outside the box’ when participating in collaborative research on mental health service redesign (Allan et al. 2017). Also, the opportunity to help others through research involvement is a dominant motivation in this population (Mawn et al. 2016).

What is also of interest here is the level of participants’ engagement with the evaluation and redesign process. These patients wanted to improve the protocol for the benefit of others. They said that the sharing of ideas and opinions was of benefit to their peers, and also to themselves. Similar sentiments have been reported elsewhere in mental health research, where young service users have expressed the strong need to share their experiences with other patients in similar situations (Nakarada-Kordic et al. 2017). Banfield et al. (2018), in their model for meaningfully engaging mental health consumers and carers throughout the research process, identified that discussing experiences and ideas with other consumers was valuable.

Traditionally, research on this young population has considered participants to be ‘developing beings’ and not yet adults, with data often collected by a proxy or adult close to the adolescent (Claveirole 2004). Arguably, inclusion in this study allowed participants to have their voice heard. Because our research valued their input, these young adults were very willing to be involved. Once again, the cyclical nature of action research allowed for changes to the protocol based on comments from this population. Unlike other inpatient units, which were exposed to one version of RHEPORT, the Advisory Group had the opportunity to field-test several changes to RHEPORT+ (based on participant suggestions) during an unusually long Action Cycle. The participants were then able to see their ideas implemented. This was important, because it demonstrated that their participation was not tokenistic and that their voices were being heard. Despite limited numbers, the level of involvement and engagement with the study among young mental health participants is considered a success of the study. Further refinement and field-testing of RHEPORT+ is, however, required before it is ready for use in the wider young adult mental health population.

The core components of RHEPORT have been discussed in this section. Several other logistical points to consider have been identified as a result of this study, and while they need not be discussed here, they are covered in the RHEPORT Guide (see Appendix X). Examples include the importance of modifying interview times based on admission and discharge patterns or

adjusting posters and their placement based on unit traffic patterns. The accompanying RHEPORT guide is intended to be used in conjunction with the RHEPORT Protocol to facilitate the latter's adaptation as required. The final RHEPORT Protocol meets the initial evaluation criteria, as discussed in Chapter Three. RHEPORT is feasible because the intervention has been piloted successfully, and it is practical, as demonstrated by its use in the field-tests. It is appropriate in that it was designed specifically for patients, family members and clinical nurses at the inpatient unit level. RHEPORT is meaningful because local experiences guided its development, and RHEPORT is effective because it produces experience data in keeping with the experience literature. Therefore, RHEPORT is a suitable protocol to elicit unit-specific real-time experience feedback from an adult (medical and or surgical) inpatient unit within a hospital, and to relay such feedback to clinical nurses.

6.3 Hospital experience and willingness to recommend

Key finding eight

A willingness to recommend a hospital to friends or family is not necessarily representative of a patient's or visitor's hospital experience.

This study highlights that patient's and visitor's responses to being asked if they will recommend the hospital to their friends or family are not necessarily indicative of the nature of their experience. At the beginning of Action Cycle 3, the Advisory Group decided that all patients and visitors who provided experience feedback would be asked whether they would recommend the hospital to their friends and family. As discussed in Chapter One, a willingness to recommend question is based on work out of the UK (the Friends and Family Test) and the United States (the Net Promoter Score). A single question is used to identify a willingness to recommend or promote the hospital ('Would you recommend this hospital to your friends and family?'), with the results purportedly indicative of experience (National Health Services 2014; Wilberforce et al. 2019). Our findings demonstrated that patients and visitors would recommend the hospital to friends and family, despite having had negative experiences. These findings sit in contrast to the initial intent of the willingness to recommend question, which was that patient loyalty and retention are linked to positive experiences (Browne et al. 2010). Our findings disagree with the commonly stated hypothesis (Krol et al. 2015) that pledging loyalty to a hospital (by way of the NPS or FFT) would be the result of a positive hospital experience. Out of the 67 negative experience comments made over Action Cycles 2 to 8, only one participant stated that they would not recommend the hospital. Surprisingly, this participant gave an overwhelmingly positive account of his hospital

experience and provided only a positive key comment for display. Based on these findings, willingness to recommend is arguably not representative of a patient or visitor's hospital experience. Moreover, having had a negative experience is not necessarily incompatible with recommending the hospital. A willingness to recommend could, for example, be based on the perception that the hospital is better than available alternatives. This sentiment was evidenced by one patient, who said: "*the hospital near me is nothing like this*" (Action Cycle 7). Our findings demonstrate that we cannot assume that a patient or visitor has had a positive experience simply because they would recommend the hospital.

This is a significant finding in terms of hospital experience research. Both the NPS and the FFT have been touted as a rating of, or collective judgement regarding, experience (Krol et al. 2015; National Health Service 2014). The FFT and NPS have been advocated as a means of summarising patient experiences, with many researchers referring to it as a 'game-changer' (Iacobucci 2013) or "the ultimate question" (Krol et al. 2015, p. 3100), and many others adopting it into their patient satisfaction and experience measures. Despite this, Krol et al.'s (2015) research supports our findings. They found that the NPS, in particular, does not reflect survey results about the experience and, as such, is a less valid score for summarising patient experiences. Despite this, the willingness to recommend question remains a staple of patient experience surveys in the United States, Europe, and Australia (Krol et al. 2015; Leggat 2016; Robert, Cornwell & Black 2018; Wilberforce et al. 2019). Most recently, there has been an increasing critique of the willingness to recommend question in healthcare. Robert, Cornwell and Black (2018) suggest that the FFT should no longer be mandatory as it generates little insight for practitioners. Marsh et al. (2019) argue that the lack of qualitative detail with which to contextualise results makes it unfit for purpose. Based on our research, we would agree, and would also suggest that searching for such a response is of little benefit to improving the patient and visitor experience.

Interestingly, in late 2019 (after the completion of field-work for this study) a decision was made that the NHS would no longer include the FFT question based on recommendations from their patient experience surveys (Service 2020). Instead, the question was replaced with a broader one that focused on experience: "Overall, how was your experience of our service?" (Service 2020). There are six response options, from "very good" to "very poor" or "don't know" (Service 2020). The new question is designed to be asked at any time during a patient's journey, so that the feedback captured relates to immediate and specific issues – though it is currently unclear how this collection will take place in practice. Additionally, the NHS also now asks a follow-up question: "Please can you tell us why you gave your answer?"

and “please tell us about anything that we could have done better” (National Health Service 2019, p. 12). The rationale behind these changes is focused on “exploring a more effective question that works better for patients”, “so that people can tell us what they want us to know in their own words” (National Health Service 2019, p. 3). In fact, this is what our study set out to do in 2015.

The findings of our study further support that experience is multi-faceted and cannot be reduced to a single number or response. Both the FFT and NPS’s usefulness in the healthcare industry is being increasingly questioned (Graham & Maccormick 2012; Manacorda et al. 2017; Robert, Cornwell & Black 2018). While the NHS has seemingly recognised flaws in the FFT, the continued adoption of the NPS around the world further advances the reductionist agenda surrounding patient experience. The nuances of experience simply cannot be expressed by a number. Based on the findings, I suggest that the willingness to recommend question not be used in conjunction with the RHEPORT Protocol. In fact, nor should it be used in isolation as a measure of experience; our data demonstrate that it is not reflective or indicative of experience.

6.4 Reflections on my role as a novice action researcher and facilitator

The task of facilitating an action research study as a novice action researcher was both daunting and exciting. Initially, I was blissfully ignorant of the tensions and practicalities of conducting an action research study. Similarly, I was unaware of the challenges of completing a PhD based on action research. This meant, however, that I commenced the project with boundless optimism. Action research as a methodology was well-suited to answering the study question, and the tenets of action research resonated with my personal beliefs: that patients and their family are experts in their health, and that their voices should be the loudest. Just as the healthcare provider is but one voice in patient-centred care, in action research, the researcher is in fact “one voice amongst equals in the team that conducts the research” (James, Slater & Bucknam 2011, p. 8). Appreciative of this view, I was not, however, prepared for the issues that arose from the insider–outsider duality.

From the outset, I occupied both ‘insider’ and ‘outsider’ roles. I was an insider in that I was a Registered Nurse employed by the hospital where the field-tests took place. However, I was also an outsider in that I was a PhD candidate conducting research. I assumed recognition of this duality would suffice, and that alternating between these roles would be easy. The tensions created by this dual status, however, became apparent early on when soliciting

patient experience feedback. I was confronted by patients and visitors, criticising both the hospital and my peers (many of whom were friends). This was challenging, because I felt compelled to rationalise to the participant why they may have had a negative experience, and to 'protect' the nurses, though I refrained from doing so. At the same time, I was also alienated from my nursing peers, as an outsider, and was considered the bringer of bad news (negative feedback). Greenwood and Levin (2007) make a clear distinction between the practical knowledge of insider community members and outsiders such as academics. Jacobs (2017), however, suggests that an insider–outsider demarcation in action research is actually more fluid than traditional action research suggests. Herr and Anderson (2014) also indicate that it is not unusual to occupy both roles, but that tensions exist. Jacobs (2017, p. 589) suggests that it is not the clear division of roles (insider or outsider) but the “crossing of boundaries” that actually facilitates collaboration in action research. While my supervisors encouraged me to ‘step away from the data’ and not become personally involved with it, it was the Advisory Group members who provided perspective. They were more distant from the data, and perhaps not as emotionally invested in the staff reactions to RHEPORT as I was. It was by sharing my experiences with members of the Advisory Group that I was able to gain greater insight into my own actions and an acceptance of crossing boundaries.

By adopting a patient-centred approach to the study as a whole, I was very much aware that the Advisory Group could potentially give a voice to the patients and visitors at the expense of the clinical nurses. Navigating the existence of these possibilities as a nurse myself further challenged my ability to facilitate the process. I found it extremely difficult, for example, to listen impartially to patients and families complain about their hospital experience without apologising or attempting to improve the experience. I found it equally difficult to accept the apparent dismissal of patient and visitor negative feedback by individual nurses. When I relayed these sentiments and the harsh feedback from the nurses to the Advisory Group, none of the members volunteered that any of the comments were difficult to hear. It was through these discussions with the Advisory Group members that I was able to see the situation from a new perspective. Nurses in the Advisory Group suggested, for example, that some nurses just refuse to hear feedback, and patient and family Advisory Group members reminded me that I am not responsible for their experience. Feedback from the Advisory Group made me consider my positionality in the study, and the limits of my responsibility in the construction of knowledge. Self-reflection, as action research dictates, enabled my facilitation of the process.

Most challenging to accept and adjust to for me was the declining participation of some individual Advisory Group members. I was fearful throughout the research that without everyone's input at every stage, the study would somehow be less robust. Montgomery, Doulougeri and Panagopoulou (2015) systematic review of implementing action research within a hospital setting found that the role of the researcher was not mentioned in many studies. As such, I had little to draw upon. Again it was one of my supervisors who pointed out that the declining participation was, in fact, a finding worth reporting. de Wit et al. (2018) highlight that there is very little literature available to support researchers in their role as facilitators in action research, despite the growing emphasis on patient and public involvement (PPI) in research which ultimately relies on it. The authors (de Wit et al. 2018) also highlight that PhD candidates face numerous challenges in engaging participants. It was the work of Snoeren and Frost (2011) which reminded me that equitable and just participation does not necessarily mean equal participation. It was with this realisation that I was able to take responsibility for specific activities, and to accept that this allowed the Advisory Group members to focus on areas they chose to participate in.

I believed I entered the field with a keen appreciation and respect for the insider knowledge that patients and family hold. It was only when field study participants (clinical nurses, patients and visitors), started providing suggestions to the design of RHEPORT that I realised I had not even considered these stakeholders as co-creators. Evaluation data were solicited from all participants, but I had maintained that the design (co-creation) process sat with me and the Advisory Group. This recognition of my taken-for-granted assumptions led to the realisation that I had unwittingly merely paid lip service to inclusivity, despite my statement of its importance when setting up the study. This contradiction only emerged when I engaged in field-testing RHEPORT. It was through trying to change something that I gained a clearer insight into how we could foster greater inclusivity of patients and visitors in the research by actively soliciting their design input.

Finally, action research, as a research approach for a PhD, adds a layer of complexity and emotion. As the project progressed, my facilitation role changed. However, the university requirements meant that time was a luxury I did not have. I went from recruiting members of the Advisory Group and educating them on action research and their participation as co-creators, to supporting the members to engage in the process. Supporting stakeholders (Advisory Group members) to have meaningful (rather than tokenistic) engagement with the research meant that the local knowledge of these members was harnessed to make improvements to the design of RHEPORT. At the same time, however, 'support' often

translated to ‘friendly reminders’ to Group members to ‘please participate’ as research deadlines were encroaching. I wholeheartedly agree with Greenwood (2007, p. 146) when he states “the trouble with programmatic descriptions of action research is that they sound very sanitary, rational, and unemotional, but that is not my experience”. My experience of action research is that it is like learning to fly a plane while flying it. It is not easy, but the journey and destination make it worthwhile.

6.5 Contributions and implications

This section reflects upon this study’s contributions to the field of patient-centred care and hospital experience. Broader contributions concerning the research methods, specifically co-creation of a new protocol using action research, will also be considered, as will the implications for practice.

RHEPORT offers a new way to collect and disseminate hospital experience feedback. While numerous approaches exist to collect patient experience feedback, most are quantitative, collect data after the hospital experience, and have no inbuilt feedback mechanism to relay that information to clinical nurses in a meaningful way (Edwards, Walker & Duff 2015). The findings of this study are significant because they open opportunities for capturing patient and visitor experiences so that they can be heard. As such, this opens up broader considerations for organisations around alternative measures of success. The ever-changing needs and experiences of patients and visitors differ significantly across the inpatient spectrum, so flexible and responsive feedback collection processes are necessary (Käsbauer et al. 2017). RHEPORT is one such strategy.

While it is accepted that healthcare users should be involved in the development of outcome measures, we continue to use approaches with little or no patient or visitor involvement (Wiering, de Boer & Delnoij 2017). RHEPORT contributes to the current methods attempting to increase this involvement. Healthcare providers must work towards improving the experiences of their patients and families. Global Chief Experience Officer at PwC, David Clarke (2018), suggests positive experiences are particularly influential in healthcare purchasing decisions (i.e., which hospital to choose). Also, positive experiences affect outcomes (Cliff 2012; Epstein et al. 2010; Wolf, Ekman & Dellenborg 2012). Accordingly, the future success of companies may well be determined by ROX (return on experience) rather than the traditional ROI (return on investment) (PwC 2019). If this is the case, then RHEPORT can offer a way in which to highlight what is working well, and what needs improvement.

Most public reporting of performance measures is difficult for consumers to make sense of (Schlesinger et al. 2012). A strength of RHEPORT is that positive comments are presented in a way which is easy for all stakeholders to understand. RHEPORT provides qualitative data, which will allow healthcare providers to better understand their patients' healthcare experiences. Patients, their families, and staff will ultimately benefit from this increased awareness of what matters to patients and family during their hospital experience. Identified barriers to clinician acceptance of patient feedback, such as insufficient dissemination of results, lack of discussions of the results, and lack of qualitative feedback (Barry et al. 2016; Boyer et al. 2006), have also been addressed by RHEPORT.

RHEPORT is a real-time patient and visitor feedback protocol with a mechanism for disseminating that feedback in a timely manner and in a way which is positively received by all stakeholders. RHEPORT offers current, unit-specific feedback which ideally, can then be used to make evidence-based improvements to the patient and family experience, and in the provision of patient-centred care. Various other real-time options are available to collect experience feedback (such as iPads, standalone kiosks, hospital websites, etc.). Real-time collection using technology such as handheld devices, however, is not without its barriers, including familiarity, connectivity, positioning, and initial and ongoing costs (Käsbauer et al. 2017). RHEPORT is non-hardware-dependent, and thus also minimises start-up costs, and has no ongoing costs other than the facilitator's time. RHEPORT is a 'low-tech' approach which could be easily replicated in large and small hospital inpatient units. In this way, the protocol contributes a feasible and available method to capture real-time qualitative hospital experiences and feed it back to nurses.

While the virtues of real-time feedback have been discussed above (see Chapters One and Two), the potential of real-time information to allow service recovery is another reason why the findings from this study matter. By identifying negative experiences in real-time, hospital care providers have the opportunity to go above and beyond what their patient or family members may have been satisfied with in improving their experience. Corrective actions, however, need to happen close to the time of the event. Xu, Liu and Gursoy (2018) found that compensation for a negative airline experience only ameliorates negative emotions if provided for the current trip, not for future trips. This suggests that hospital experiences must be identified and dealt with, ideally, before the patient leaves the hospital. RHEPORT is one way to facilitate this. What is perhaps most pertinent for healthcare administrators, especially in our increasingly litigious environment, is that positive employee attitudes and behaviours,

along with prompt service recovery actions, generate more positive emotions associated with the experience than does financial compensation (Xu, Liu & Gursoy 2018).

Patient experience is a cornerstone of quality healthcare (Montgomery, Doulougeri & Panagopoulou 2015). The specific experience findings that the RHEPORT field-testing generated contribute to the existing research. Physical comfort, respect for patients' values, preferences and expressed needs, and information, communication and education have repeatedly been identified as determinants of a positive or negative hospital experience. The co-creation of the RHEPORT Protocol, using a pragmatic action research approach to capture and reflect upon real-time, qualitative hospital feedback in a meaningful way, not only gives patients and visitors a voice, but also provides a process for their voices to be heard. Patients, visitors, nurses, hospital administrators, and researchers will collectively benefit from the findings of this study.

6.6 Limitations

Findings generated from this research were context-specific and based solely upon qualitative inquiry. RHEPORT was field-tested in one private hospital with Magnet Recognition (suggesting excellence in nursing care), and the findings may be reflective of this. As such, the findings should be interpreted with caution. As a private, Magnet-recognised hospital, the expectation of patients and visitors may have been that the care experience would be high. This expectation may, in turn, have affected the experience findings. The increased ratio of positive to negative key comments provided may also be context-specific, and thus a limitation of this study. Although, as previously highlighted, this ratio is not an unusual finding when compared to other studies examining patient and hospital experience.

While RHEPORT was field-tested in a private hospital setting, the Advisory Group members who co-created it had experienced both private and public hospitals. Their input, therefore, was arguably reflective of both experiences. However, field-testing in the public sector and other settings, such as rehabilitation, critical care, and aged care, is warranted. In addition, characteristics such as the level of experience of the Registered Nurses in the Advisory Group may have impacted engagement and the RHEPORT protocol however this data was not collected.

As a qualitative study, the findings may be relatable but not generalisable to other settings. Adopting a pragmatic action research approach allowed for an open-ended approach to questioning. We solicited free-flowing narrative from field-test participants and real-time

member checking, but the impact of eliciting narrative accounts on the perception of experience cannot be discounted. Human beings ascribe significance to experiences we or others have had by way of storytelling. Being human is entwined with the need to tell and listen to stories (Andrews 2017). Because of this, the act of asking someone about their experience, asking them to share their narrative, can affect the very experience they are asked to discuss. As discussed, by asking someone about their experience, we are essentially saying that we value their opinion. This, in turn, may make the participant feel more valued and more positive about their experience. There are positive associations between patient involvement and satisfaction (Tambuyzer & Van Audenhove 2015), so the act of participation may increase their positivity about an experience. A limitation of this study is, therefore, the impact that asking a participant about their experience has. However, no alternative exists.

Finally, despite the social movement towards recognising and respecting the patient as a partner in both healthcare delivery and research, inequitable power relations still exist within this setting (Griscti et al. 2017). Traditionally, a common area for investigation in action research is the presence of power (Donnelly & Morton 2019), with critical action research specifically focusing on addressing injustice and disempowerment (Kemmis, McTaggart & Nixon 2014c). Because this study adopted a highly pragmatic approach and did not have a critical or emancipatory intent, we did not examine power. As such this can be understood as a limitation for the study. Future research should focus on how power relations impact on the collection of real time experience feedback at organisational, professional, and patient levels.

6.7 Current and future directions

Today, in 2020, it seems we were not alone in our quest to develop a new real-time qualitative hospital experience feedback protocol. Since the commencement of this study in 2015, several large studies have been commissioned to create and evaluate new methods to capture what is referred to as ‘specific episode of care feedback’, qualitative feedback, and/or feedback in real-time. In the United States, the Agency for Healthcare Research and Quality (2019) funded and developed the Patient Narrative Elicitation Protocol (PNEP), designed to capture ‘salient’ and ‘concise’ narratives about patients’ experience of hospital care. In 2017, a beta version was released, and an evaluation commenced of a template for feeding experience comments back to healthcare providers. In the UK, Beattie et al. (2016) have developed the Care Experience Feedback Improvement Tool (CEFIT), where survey items have been developed based on five domains (or elements) of quality healthcare (safe, caring,

effective, timely, and enables system navigation). These CEFIT domains are not dissimilar to the Picker Framework domains we used to code RHEPORT data.

With striking similarities to several aspects of our research, Mills, Lawton and Sheard (2019) have just published their work examining the new Patient Experience Toolkit (PET) designed to enhance the use of patient experience feedback by healthcare professionals in the NHS. There are many similarities between their study and ours in the approach taken and the challenges identified. Their team adopted an action research methodology to co-design, implement, evaluate and refine their toolkit. 'Participating ward teams' attended workshops to develop their toolkit, and adopted guiding principles to encourage reflection. Upon realising that feedback was not available to healthcare providers in a useable form during their field-testing of the toolkit, they summarised data as we did. They also organised the feedback into topics (again not dissimilar to our framework for coding), referring to this as a "collective interpretive process" (Mills, Lawton & Sheard 2019, p. 5). They field-tested across six hospital units, and eventually included a 'guided reflection stage' to assist healthcare professionals with considering the feedback. One key aspect of their toolkit was that 'live' (real-time) qualitative data were collected and made available at ward (unit) level. It would seem that the only area in which our study method and findings differ is in Mills, Lawton and Sheard (2019) finding that staff and service pressures limited healthcare providers' use of the toolkit, with the toolkit ultimately being deemed too bulky and time-consuming. In contrast, the final RHEPORT Protocol was well-received by healthcare providers and recipients alike.

In 2014, shortly after this study began, the Australian Health Ministers' Advisory Council (AHMAC) funded the development of core patient experience questions for overnight admitted hospital patients (including at private hospitals). Before this, the Australian Bureau of Statistics (ABS) population survey data was used for the mandatory reporting of patient satisfaction and experience indicators. Criticisms of such methods were that results were limited in usefulness as they could not be attributed to particular episodes of care or particular facilities. In 2017, the Australian Commission on Safety and Quality in Health Care (2017) (ACSQHC) published the summary of development and testing. The core questions were developed from two sources: a review of qualitative patient experience literature conducted by the Sax Institute for the ACSQHC (Harrison, Walton & Manias 2015), plus a series of focus groups. Their literature review included 39 studies, one of which being work that stemmed from my research on this subject in 2014 (*What really matters? A multi-view perspective on one patient's hospital experience* (Edwards, Duff & Walker 2014)), which prompted the creation of RHEPORT. The Sax Institute created a 15-member expert advisory

group, with two healthcare consumers, to guide the project. The reason for doing so was the fact that, at that time, there were no patient experience question sets developed using qualitative research with stakeholders across Australia. The resulting Australian Hospital Patient Experience Question Set (AHPEQS) asks respondents to give answers to experience questions such as 'Always', 'Mostly', 'Rarely', or 'Very good', 'Good' or 'Average'. I would suggest that RHEPORT is certainly not made obsolete by the introduction of AHPEQS, as each collects and provides very different data.

As discussed, due to a lack of data, the findings from RHEPORT field-testing in a young adult mental health unit cannot adequately inform a protocol for this target population. RHEPORT is therefore not ready for practical application with this population. While young adult mental health patients helped develop RHEPORT by providing evaluation feedback regarding RHEPORT+, recruitment issues need to be addressed. With regard to the specific research facilitators for this population, Banfield et al. (2018) suggest that, ideally, consumers and carers should interview this population. This idea also needs exploration in future research, as it may bolster participation.

It is important to highlight that change in practice regarding improvements in care experiences, as a result of feedback provided by RHEPORT was not examined in this study. There is increasing concern that experience feedback is not directly being used to improve the experiences of patients (Coulter et al. 2014; Flott et al. 2016; Sheard et al. 2019). Indeed, Dawson et al. (2019, p. 34) argue that "effective feedback needs to demonstrate effect." Future directions in the field of patient and hospital experience will no doubt include improving experience and service recovery based on feedback. We know that consumers characterise their experience based on touch-points or cues that they pick up at every step of the experience journey (Zomerdijs & Voss 2010). We should, therefore, consider the cues that occur outside the admission period when we attempt to positively prime or prepare the patient and family, as the hospital experience actually begins before admission and extends well beyond discharge (Edwards, Duff & Walker 2014). Positive stories set the stage for a positive experience, touchpoints along the experience journey determine how the patient and family member will ultimately perceive their experience. This priming for experience is about setting the stage, setting the expectation, and pre-empting a positive experience. Disney, for example, designs its experiences around experience cycles that begin with anticipation and arrival (Zomerdijs & Voss 2010). In healthcare, positive experience priming could be a way of preparing the patient or family member for a positive experience in hospital; reminding them of positive experiences while they are in hospital, and again even

after they have been discharged. As our findings suggest, patients and visitors enjoyed reading about the positive experiences of others, experiences they may not have considered. A proactive and creative approach on the part of healthcare providers will be necessary to manage service recoveries and to cultivate positive experiences ('Cultivating service excellence: Service recovery critical for positive patient relations' 2019). Resources to improve and manage experiences, however, are limited (Agency for Healthcare Research and Quality 2018). As our findings have suggested, positive experience priming using the RHEPORT Protocol may, therefore, be a low-cost way to add to the patient experience improvement armoury.

Patient experience commentary is transforming and dictating the future behaviour of healthcare consumers (Schlesinger et al. 2015). Informing clinical nurses of patient and family experience feedback is a vital step in providing quality patient-centred healthcare and improving healthcare experiences for patients and their families. For feedback to truly influence the behaviour and practice of all healthcare providers, policy-level actions and leadership are required for patient and visitor feedback to be incorporated in care quality improvements (Kumah, Ankomah & Kesse 2018). Ultimately, the fact that positive patient experiences are associated with higher profitability, and vice versa (Richter & Muhlestein 2017), may well pave the way for future applications of the RHEPORT Protocol, and for further research into improving the patient and family member hospital experience.

6.8 Concluding remarks

Patient-centred care has emerged as the chief approach to healthcare delivery (Delaney 2018), with experience an indicator of care quality. As we attempt to challenge the biomedical models of the past, where the patient was neither recognised nor solicited as an expert in their healthcare journey, we search for new ways to ensure the patient and their family have a voice in their care, and also in the research which affects that care. Genuine patient-centred care and co-creation in healthcare research necessitate a change in the role of the healthcare provider from a 'fixer of problems' to a facilitator who 'finds solutions' by working with patients and their families (Realpe & Wallace 2010). While this approach undoubtedly gives the patient and family member a more prominent voice, certain conditions must be met for their involvement to be meaningful and non-tokenistic. A pragmatic action research approach can facilitate such involvement, and is ideally suited to the co-creation of a new hospital experience feedback protocol. Identifying what matters to the patient and their family continues to be the way forward for improving the experience.

RHEPORT provides an opportunity for patients' and families' perspectives on their hospital experiences to be heard by those who can improve that experience. Studies have demonstrated that engagement with experience feedback is increased when descriptions of clinical encounters in the patient's own words are used (Kanouse et al. 2016; Lagu et al. 2013). RHEPORT facilitates a process for capturing and disseminating the patient's and family's experiences in their own words. By conducting interviews with patients and visitors about their experiences, RHEPORT participants are also afforded the opportunity to provide information about what matters to them, as opposed to questions healthcare providers may want to answer.

The successful development of RHEPORT was the result of adopting a pragmatic action research approach. Local knowledge informed action and action informed knowledge. The result was a new feedback protocol designed to capture unit-specific, qualitative, real-time feedback with a mechanism to subsequently relay that feedback to clinical nurses. The core components of the protocol are that: memorable experiences should be captured; only positive key feedback should be publicly displayed; positive and negative feedback should be discussed during reflection sessions; and both the facilitator and population should be considered. Finally, despite its continued widespread use, willingness to recommend a hospital to friends and family is not necessarily indicative of positive hospital experience. If improving patient-centred care is based on what matters most to the individual, then we must focus on the pivotal moments which impact that experience. RHEPORT is a feasible, acceptable, meaningful, and effective way to achieve this.

Appendices

Appendix A Instruments to measure the inpatient hospital experience: A literature review



2015

Instruments to measure the inpatient hospital experience: A literature review

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Instruments to measure the inpatient hospital experience: A literature review

Cover Page Footnote

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Instruments to measure the inpatient hospital experience: A literature review

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Abstract

Healthcare professionals worldwide are increasingly broadening their focus to include the experiences of patients and their family members as a means of assessing quality patient centered care. This paper seeks to identify and discuss instruments specifically designed to measure the inpatient hospital experience. A literature search focusing on pre-identified instruments as per the Health Foundation's *Helping Measure Patient Centered Care* database of measurement instruments (de Silva, 2014) and additional health databases (CINAHL, ERIC, EBSCO, HAPI, MEDLINE, PubMed and Psych INFO) was undertaken. Thirteen relevant instruments and seventeen associated studies (regarding instrument development and/or validation) were identified. These instruments provide generalizable but less descriptive experience data, are predominantly based on post hospital discharge data and do not have identified feedback to staff mechanisms. Further research is warranted to co-develop an inpatient hospital experience instrument, designed to capture real time descriptive data with a corresponding feedback process to frontline clinicians. Ideally such an instrument could be designed using a participatory research methodology, whereby patients, friends, family and healthcare clinicians are equal co-developers.

Keywords

Patient experience, measurement, patient centered care, patient-centered outcome research

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Healthcare professionals worldwide are increasingly broadening their focus to include the experiences of patients and their family members, as a means of assessing quality patient centered care. Prior to 1995 experience research consisted of small scale studies using predominantly qualitative methods ¹. Today with substantially larger sample sizes, methods are mostly quantitative ^{1,2}. Government mandates and experience dependent remuneration schemes have further propagated an abundance of quantitative experience surveys particularly in the hospital sector. In recent years developments in the science of measuring patient experience have been made, and as such a range of approaches are available to measure experience ³. These fall broadly into survey, patient feedback processes or narrative methods (interviews and patient stories) ^{4,5}. Approaches can further be divided into generalizability and the depth of information provided ⁶. The Health Foundation ⁷ contend that these strategies for measuring

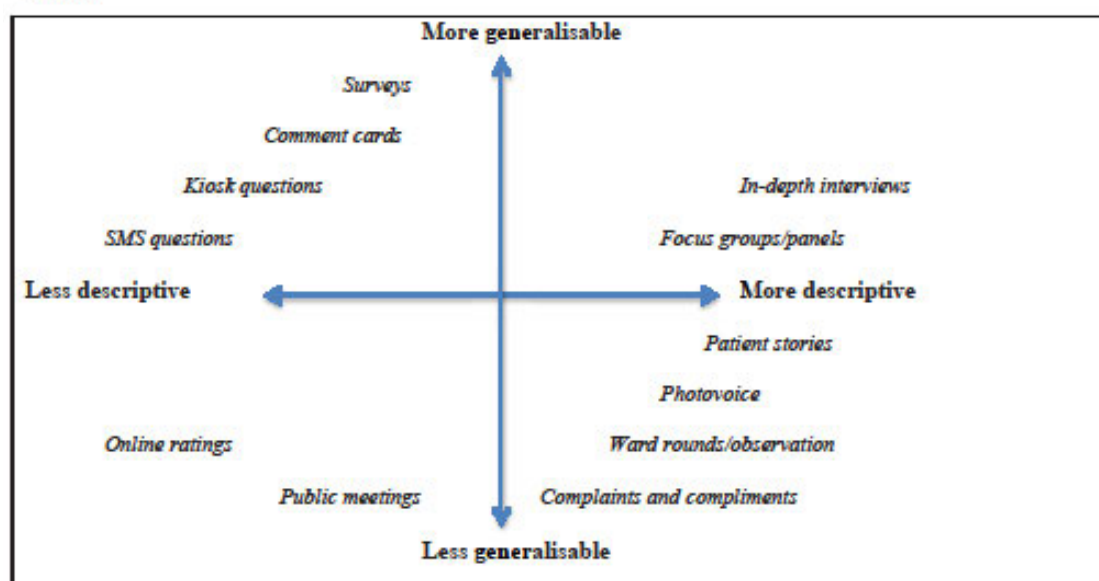
patient experience are on a continuum (See Figure 1). Meaningful measurement of experience however, is intrinsically problematic given its multifaceted and subjective nature and as such no gold standard measurement instrument exists. The main purpose of this paper is to identify published instruments designed specifically to capture experience data of the hospital inpatient.

Method

Search Strategy

A three-stage search strategy was used. Stage one focused on pre-identified instruments as per the Health Foundation's *Helping Measure Patient Centered Care* database of measurement instruments ⁶. The Health Foundation ⁷ has produced a database of commonly used validated tools for measuring patient centered care, based on screening over 200,000 studies published between 2000

Figure 1 The Health Foundation (de Silva 2013) Examples of methods used to measure patient experience of health services



and 2013. Using the 'category' filter, instruments used to explore specifically 'experience' were identified.

The following databases were then searched for additional instruments published between 2000 and 2015:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Education Information Resources Center (ERIC)
- EBSCO
- Health and Psychosocial Instruments (HaPI)
- Medical Literature Analysis and Retrieval System (MEDLINE)
- PubMed
- Psychology and Behavioural Sciences Collection (PsychINFO)

With the following search strategies:

((T1 experience AND ((patient or person or family) AND (centered))) OR ((MH 'patient satisfaction' OR (MH 'Patient attitudes') OR 'patient experience*')) AND (Patient satisfaction OR patient experience*)) AND (reliabil* OR validat* OR development) OR (questionnaire* OR survey* OR tool* OR instrument*)

OR
TI((reliabil* OR validate* OR development)) AND
ti((experience* OR satisfaction)) AND (questionnaire* OR survey* OR tool* OR instrument*)

Finally, articles regarding development or validation of each identified instrument were then searched using the above search strategies limiting results to studies published between 1990 and 2015.

Selection Criteria

Titles and abstracts were initially considered using a modified version (see Table 1) of Beattie and colleagues' 'Inclusion Selection Questions' for instruments to measure patient experience of healthcare quality in hospitals.

Only primary, peer-reviewed studies (print, online, journal or report) in English, which directly reported on the development and/or validation of a patient reported hospital experience instrument published in a print, online journal or report were included. General research regarding experience and what matters to patients and their family members was not included, as the focus was on instruments for measurement rather than findings using the measurement.

Studies primarily concerned with specific events or issues (such as patient discharge or safety) were not included. Studies examining measurements for specific specialist areas within the hospital setting were included. The reason for inclusion is based on the aim of identifying measurement instruments regardless of the patient's reason for admission. Instruments designed specifically for

Table 1 Inclusion Selection Questions

1. Does the study report the development and/or validation of Patient Reported Experience Measure instrument?	Yes Go to question 2	No Reject
2. Is the context a hospital setting or intended for use in a hospital setting?	Yes Go to question 3	No Reject
3. Is the population adult inpatient, or adult inpatient family member?	Yes Go to question 4	No Reject
4. Is the study measuring the patient, family member perspective of the patient's experience of care?	Yes Go to question 5	No Reject

participants with intellectual disabilities or psychiatric disorders were excluded based on the assumption that these have likely been developed for their specific needs.

Results

Thirteen relevant instruments and seventeen associated studies (regarding development and/or validation) were identified (See Table 2). Two instruments were developed in the United States (HCAHPS, PAQ5-ACV), one in Hong Kong (HKIEQ), one in Ireland (INPQCS), five in the United Kingdom (NSNS, NHS NAIS, PFE-15, howRwe, ICE), one in Australia (PEECH), one in Norway (PEQ), one in Sweden (QPF) and one joint development in Norway, Sweden, Iceland and Denmark (NORPEQ). The number of participants in each study ranged from 25 (HIEQ) to 19720 (HCAHPS).

Instrument development consisted primarily of literature reviews, focus groups followed by item generation, pilot testing and appraisal. The theoretical or guiding principles were only identified for eight of the thirteen instruments ((The Institute of Medicine for HCAHPS, Picker domains for HKIEQ and NHS NAIS, Grounded theory for PEECH, PAQ5-ACV, QPF, Patient Centered Care for PFE-15 and the concept that all patients want high quality service from staff and the organisation as a whole for howRwe). All studies included patients only as participants and intended users of the instruments. The aims of all studies were to develop, test and/or report on a patient experience approach. Patients and/or family members were involved in the development of at least eleven instruments (HCAHPS, HKIEQ, INPQCS, NSNS, NHS NAIS, PEECH, PEQ, PAQ5-ACV, PFE-15, QPF, howRwe).

All but three instruments (PEECH, ICE & NORPEQ) were developed and tested using mixed method approaches. Qualitative methods were predominantly used for item generation (interviews and focus groups) with quantitative and qualitative methods used to test and analyse the instruments. All instruments identified are survey based providing predominantly quantitative data with items ranging from four questions (howRwe) to ninety-five (INPQCS). Two instruments include comment

sections (HKIEQ and NHS NAIS), and two included comment sections for each item (PEECH and howRwe).

Eight instruments used a paper based only survey mode (NSNS, NHS NAIS, PEECH, PEQ, PAQ5-ACV, PFE-15, QP and NORPEQ). Two instruments use a telephone only mode (HKIEQ and INPQCS). The HCAHPS instrument uses four modes (Mail only, telephone only, mail with telephone follow-up, and interactive voice response (IVR) mode). HowRwe is designed for use with multiple modes - paper, touchscreen device (such as kiosks, smartphones and tablets), web browsers, and telephone. Touchscreens were used for testing. It is not clear from the literature what mode one instrument was tested using (ICE). None of the articles identify a corresponding feedback mechanism (that is how the information provided by the instrument is to be fed back to clinicians).

Data was designed to be collected during hospital admission for five instruments (NSNS, PEECH, PAQ5-ACV, QPF and howRwe) and post discharge for the remainder (ranging from immediately post discharge to up to twelve months post discharge). Nine instruments provide the recipient with quantitative data (HCAHPS, INPQCS, NORPEQ, NSNS, PEQ, PAQ5-ACV, PFE-15, QPF, and ICE), four provide quantitative and limited qualitative data (HKIEQ, NHS NAIS, PEECH, howRwe), with none providing qualitative data only. All instruments fall into the more generalizable, less descriptive approach (See Figure 2).

Discussion

As the desire to practice patient centered care has gained prominence, numerous institutions are increasing their efforts to capture patient experience data. Most OECD (Organization for Economic Cooperation and Development) member and partner nations are endeavoring to obtain experience data at national, state or institution level¹. Many hospitals outsource larger scale studies to companies such as Press Ganey, Gallup, Dr. Forster, and the Picker Institute, while others solely use in house approaches⁹. While thousands of studies are published regarding patient experience, often information

provided regarding the method of collection or instrument used is limited¹⁰. Despite this obvious real world practice of capturing experience data, there are very few validated and published instruments designed specifically to examine the hospital experience (thirteen), and even fewer designed to capture data during the episode of care (five).

Direct patient feedback is the core method for measuring patient experience¹¹. The literature confirms the view that quantitative structured questionnaires or surveys are the most common approach published^{1,9,11-13}. Such quantitative research however is not capable of providing rich and nuanced information regarding individual experience, and for this reason patient interviews are becoming increasingly popular as a means of obtaining qualitative experience data¹⁴⁻¹⁷. Cleary and colleagues¹⁸ suggest qualitative research is in fact the optimal scholarly means of understanding patient experience, while Russell¹ purports information gleaned from surveys make them potentially 'useless for improving patient's experience'. Experiences cannot be reliably evaluated by using standard questions¹¹, nor by solely focusing on individual aspects of the overall experience¹⁹. Accordingly experience data collection requires multiple approaches to enhance validity¹. Many hospitals and larger institutions do use multiple approaches to collect data¹. Despite this adoption of qualitative approaches and expert opinion regarding the

importance of qualitative approaches, it is difficult to understand why there are no published qualitative instruments. This view is echoed by de Silva⁴ and Russell¹ who have identified research regarding the testing and validating of survey tools but very limited research on qualitative techniques.

While four instruments (HKIEQ, NHN NAIS, PEECH, howRwe) do contain comment sections (providing limited qualitative data) all instruments identified are considered to be less descriptive and more generalizable. Such surveys are not suitable for those with low literacy, and as such have the potential for self-selection bias¹¹. Surveys have also tended to reflect concerns of administrators, often representing manager or clinician agenda¹¹. Six instruments were developed using patient focus groups, however the resulting surveys of this type can only represent the issues identified by patients other than those completing the questionnaire. As such survey approaches cannot provide in depth data nor are they well suited to cover sensitive issues⁴. Despite these limitations most hospitals continue to use standardised surveys as they provide administrators with the benefit of allowing for comparison and benchmarking against other institutions²⁰. This is potentially of limited value to the individual patient or the health care provider caring for them.

Figure 2 Experience instruments identified to measure patient experience in hospital

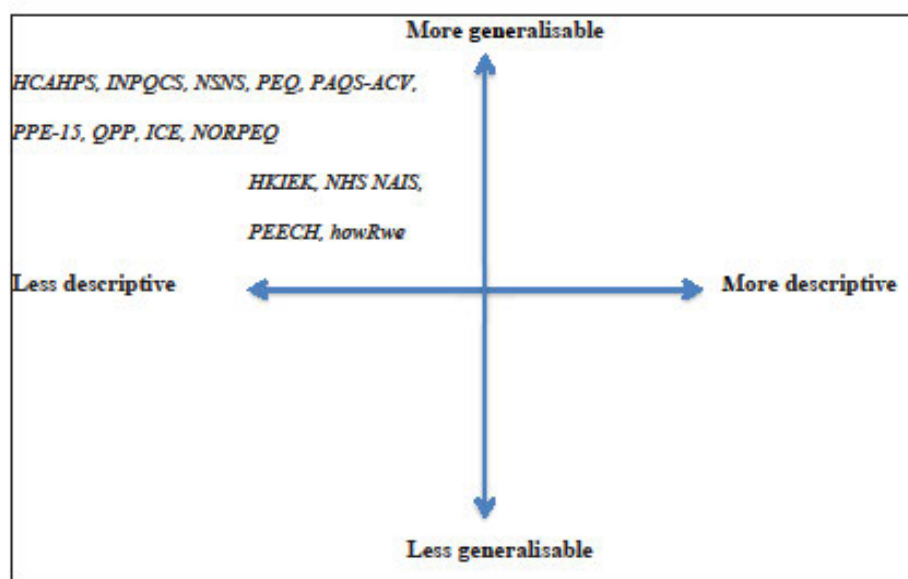


Table 2 Experience Data Collection Instruments and Associated Studies

Approach Name	Study Authors	Study Title
Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)	Giordano, Elliott, Goldstein, Lehman & Spencer 2010	Development, Implementation and Public Reporting of the HCAHPS Survey
	Goldstein, Farquhar, Crofton, Darby, Garfinkel 2005	Measuring hospital care from the patients' perspective: an overview of the HCAHPS Hospital Survey development process
Hong Kong Inpatient Experience Questionnaire (HKIEQ)	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013	Validation of inpatient experience questionnaire
	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013b	Item generation in the development of an inpatient experience questionnaire: a qualitative study
howRwe	Benson & Potts 2014	A short generic patient experience questionnaire: howRwe development and validation
Intensive Care Experience ICE questionnaire (ICE)	Rattray, Johnson & Wildsmith 2004	The intensive care experience: development of the ICE questionnaire.
Irish National Perception of Quality of Care Survey (INPQCS)	Sweeney, Brooks & Leahy 2003	Development of the Irish National patient perception of quality of care survey.
NHS National Adult Inpatient Survey (NHS NAIS)	Reeves, Coulter, Jenkinson, Cartwright, Bruster & Richards 2002	Development and Pilot Testing of Questionnaires for use in the Acute National Health Service (NHS) Trust Inpatient Survey Programme
Newcastle Satisfaction with Nursing Scale (NSNS)	Thomas, Macmillan, McColl, Priest, Hale & Bond 1995	Obtaining patients' views of nursing care to inform the development of a patient satisfaction scale
	Thomas, McColl, Priest, Bond & Boys 1996	Newcastle satisfaction with nursing scales: an instrument for quality assessments of nursing care
Nordic Patient Experiences questionnaire (NORPEQ)	Olteidal, Garratt, Bjertnaes, Bjørnsdottir, Freil & Sachs 2007	The NORPEQ patient experiences questionnaire: Data quality, internal consistency and validity following a Norwegian inpatient survey
Patient's Assessment of Quality Scale - Acute Care Version (PAQS-ACV)	Lynn, McMillen & Sidani 2007	Understanding and Measuring Patients' Assessment of the Quality of Nursing Care
Patient Evaluation of Emotional Care during Hospitalisation (PEECH)	Murrells, Robert, Adams, Morrow, Maben 2013	Measuring relational aspects of hospital care in England with the 'Patient evaluation of emotional care during hospitalisation' (PEECH) survey questionnaire
	Williams & Kristjansson 2009	Emotional care experienced by hospitalised patients: development and testing of a measurement instrument
Patient Experience Questionnaire (PEQ)	Pettersen, Veenstra, Guldvog & Kolstad 2004	The patient experiences questionnaire: development, validity and reliability
Picker Patient Experience Questionnaire (PPE-15)	Jenkinson, Coulter & Bruster 2002	The picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries
Quality from the Patient's Perspective Questionnaire (QPP)	Larsson & Larsson 2002	Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire

The solution to obtaining richer data does not lie with more detailed surveys. While surveys tend to have positive response rates, length of survey can actually be a deterrent to completion thereby impacting response and value of

information²¹. The United Kingdom NHS NAIS survey for example has seen response rates decline from 64% in 2001²² to 49% in 2013²³. Shorter survey instruments reduce participant burden, which was a guiding driver

behind the establishment of the howRwe³⁰ and QPP instruments²⁴. Not surprisingly however a comparison between PPE-15 and PEECH Instruments, found that the longer PEECH Instrument, provided more data regarding interpersonal aspects of quality care than the shorter Picker Institute Instrument²⁵.

National, state and even hospital wide surveys usually provide non-attributable experience data. That is they don't necessarily reflect the care delivered by the provider or providers who were directly responsible for the experience²⁶. The recent focus on improving experience²⁷ suggests that data collected at the episode of care and collected at individual team level may have the greatest impact on services¹. Slow feedback to staff is also an ongoing criticism of patient experience surveys²⁸. By the time frontline clinicians receive information, they may well argue that such practices have now improved²⁹.

Collecting real-time data (when the patient is in the hospital) or near-time (immediately post discharge) is the most effective way to capture meaningful experience data¹ however only five instruments (NSNS, PEECH, FAQ5-ACV, QPP, howRwe) are validated based on collection in real time, and one in near time (ICE). The leisure industry have been using real time methods to elicit data for decades however the healthcare industry has been slow to adopt this practice³⁰. Timing of data collection is crucial as it provides the recipient with 'fresher' information³⁰. Staff in particular perceive timely information as having greater validity³⁰. Two studies which used the PEECH instrument – one administered while patient was in hospital³¹ and one post discharge²⁵ found that differences in findings could be influenced by recall bias. Such recall bias is often an issue with data collected post discharge²⁴. The United Kingdom Department of Health now requires all hospitals to collect 'real-time' or 'rapid' feedback from hospital patients³².

There are naturally ethical and validity concerns regarding real-time collection of data. There may be a tendency for patients to offer positive results regarding satisfaction for fear of jeopardising treatment^{1,4,33}. Experience research however differs from satisfaction research in that it does not ask patients to rate their quality of care, rather it seeks to capture the patient's perception of what did or did not happen during an episode of care. Results from the NSNS found that answers did not differ between hospital and home, suggesting patients can be asked about their experiences before they leave hospital without biasing results^{34,35}.

The perception of improving experience for other patients is also powerful incentive to offer truthful real time feedback, and we must not underestimate today's healthcare consumer³⁰. The existence of online communities such as PatientsLikeMe and

HealthTalkOnline suggest that large numbers of the patient population are in fact willing to share their experiences³⁶. The value of real time data also appears to be outweighing any ethical concerns, with more and more hospitals seeking real time data. In select United Kingdom hospitals experience trackers (hand held devices) are being used that allow patients to answer five multiple choice questions³⁰. The Picker Institute's Frequent Feedback system also makes use of real-time hand held devices³⁰. Customer Research Technology (CRT) provide a range of products to hospitals including hand held devices and touch screen kiosks for real-time purposes³⁰. Other approaches available for real-time include: patient stories/interviews, paper based methods, stand-alone kiosks, telephone and online systems³⁰. While the majority of instruments identified in the review are paper based, only five could be considered real-time instruments.

As patient centered care models and attention to patient experience show no sign of abetting, timely and effective feedback to those providing the care is imperative as 'we [healthcare clinicians] might think we are delivering care that looks like one thing, but in reality it is quite another'³⁷. While most articles in this review did not discuss the importance of reporting or feedback to staff mechanisms, Picker state that reporting the findings to patients and staff is extremely important and suggest a collect, communicate, act strategy where results are readily available to staff³⁸. Only one study discussed feedback to staff (INPQCS). The staff were informed of the interviews to be carried out in the INPQCS and were advised that they (staff) would have access to the information once collated, although methods of doing so were not discussed³⁹.

There is little evidence available on how best to use and disseminate patient experience data¹¹. Clinicians tend not to feel ownership of results from surveys; often claiming 'that doesn't happen on my ward'⁴⁰⁻⁴². Yet none of the studies identified a preferred feedback to clinician mechanism. These clinicians are disproportionately responsible for day to day decision making that impacts the patient's experience yet survey results tend to be communicated to senior hospital administrators then trickle down slowly through the hierarchical channels^{43,43}.

Commitment from every employee is required to optimise a patient's experience⁴⁴ however clinicians often report difficulty in interpreting quantitative results⁴⁵. The Francis Inquiry into Mid Staffordshire NHS Foundation Trust reported that 'results and analysis of patient feedback including qualitative information needs to be made available to all stakeholders in as near-real time as possible'³⁸. Experience feedback also needs to be ward specific, rapid, and staff need the opportunity to discuss the findings⁴³. The instrument used should also only include

items which are under the day to day control of staff and management²⁰. Given these findings it is difficult to understand why none of the experience instruments appear to have been designed with specificity, speed nor staff in mind.

Systematic reviews, highlight the large volume of studies purporting to measure satisfaction, with or experience of specific aspects of care^{1,46}. The volume of different measurement approaches however, makes it difficult to compare findings, which also explains why so few studies are then eligible for systematic reviews on issues regarding experience^{1,47}. Hudson and colleagues⁴⁷ systematic review for example identified over 3000 articles regarding patient perceptions of patient centered care however only 26 articles met the inclusion criteria.

Similarly, one of the major criticisms of patient satisfaction surveys and surveys from a validity point of view is their lack of theoretical foundation²⁴. Guiding theories or principals were identified in the associated experience instrument literature for only eight studies. HKIEQ and NHS-NAIS were based on Picker Domains (See Table 3). The Institute of Medicine (IOM) domains (See Table 4) were the guiding principles for the creation of the HCAHPS instrument. Patient centered care and the assumption that all patients want high quality service from staff and organisations as a whole were the basis upon which the FPE-15 and howRwe instruments were developed respectively. Only three instruments (PEECH, PAQS-ACV, QPF) mention the theoretical model upon which the instrument is based, all of which being

grounded theory.

The NHS recommends bringing staff and patients together to design improvements¹¹, while Brown Davidson and Ellins³⁰ state that patients must be involved in the design of experience measure instruments. While all instruments involved participants in the development process at some stage it is unclear whether patients specifically were involved at every stage. 'Authentic and genuine consultation with stakeholders' is key to developing experience instruments¹⁸ suggesting a participatory research methodology is well suited to developing such an instrument. It is interesting to note that while most instruments were developed with some stakeholder input, none identified as having been based upon a participatory research method.

Conclusion

Current perspectives in healthcare suggest a fundamental tenant of patient centered care is patient experience. The future drive towards patient centered care suggests capturing patient experience data will take on even more importance over the coming decades. Progress has been made in the last decades regarding the science of measuring patient experience³. This review demonstrates that, while there are a numerous approaches available, there is not a large body of literature regarding instruments designed to capture experience data of the hospital inpatient, with no validated instruments designed to capture qualitative data. Only quantitative methods in the

Table 3 Picker Domains of Patient Centered Care

- Respect for patients' values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support and alleviation of fear and anxiety
- Involvement of family and friends
- Transition and continuity

Source: Picker Institute <http://pickerinstitute.org/about/picker-principles/>

Table 4 The Institute of Medicine Domains of Quality Healthcare

- Safe
- Effective
- Patient Centered
- Timely
- Efficient
- Equitable

Source: Agency for Healthcare Research and Quality
<https://cahps.ahrq.gov/consumerreporting/talkingquality/create/sixdomains.html>

form of surveys are represented in this review. This is not to say that qualitative methods are not being used in the healthcare arena or that there are a substantial number of studies using qualitative methods to capture experience data. It simply highlights the gap in the literature regarding validated qualitative instruments.

The instruments identified are able to provide generalizable but less descriptive data, which is predominantly collected post hospital discharge. While this appears to be common practice⁴⁰, experience data needs to be captured as close to the experience as possible to exclude recall bias⁴⁹. The lack of discourse surrounding instrument preferred feedback to staff mechanisms is also apparent. Further research is warranted to co-develop a patient experience instrument, designed to capture real time data with a corresponding feedback process to frontline clinicians. Ideally such an instrument could be designed using participatory research methodology.

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Appendix B Frameworks of experience

The Australian Charter for Health Care Rights

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

1 Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.

2 The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.

3 Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.



For further information please visit
www.safetyandquality.gov.au

**AUSTRALIAN COMMISSION ON
SAFETY AND QUALITY IN HEALTHCARE**

What can I expect from the Australian health system?

MY RIGHTS

WHAT THIS MEANS

Access

I have a right to health care.

I can access services to address my healthcare needs.

Safety

I have a right to receive safe and high quality care.

I receive safe and high quality health services, provided with professional care, skill and competence.

Respect

I have a right to be shown respect, dignity and consideration.

The care provided shows respect to me and my culture, beliefs, values and personal characteristics.

Communication

I have a right to be informed about services, treatment, options and costs in a clear and open way.

I receive open, timely and appropriate communication about my health care in a way I can understand.

Participation

I have a right to be included in decisions and choices about my care.

I may join in making decisions and choices about my care and about health service planning.

Privacy

I have a right to privacy and confidentiality of my personal information.

My personal privacy is maintained and proper handling of my personal health and other information is assured.

Comment

I have a right to comment on my care and to have my concerns addressed.

I can comment on or complain about my care and have my concerns dealt with properly and promptly.

(Australian Commission on Safety and Quality in Health Care 2012)

Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) (Centers for Medicare & Medicaid Services 2020)

Eight domains to measure patients' perceptions of their hospital experience:

1. Communication with nurses
2. Communication with doctors
3. Responsiveness of hospital staff
4. Pain management
5. Cleanliness and quietness of hospital environment
6. Communication about medicines
7. Discharge information
8. Overall rating of hospital

Recently updated to:

1. Communication with Nurses
2. Communication with doctors
3. Responsiveness of hospital staff
4. Communication about medicine
5. Cleanliness and quietness of hospital environment
6. Discharge information
7. Care transition
8. Hospital rating

Institute of Medicine (IOM) Framework*

Patient Centred Care is one of the six domains of healthcare quality and aims for improvement in *Crossing the Quality Chasm: A New Health System for the 21st Century* (Institute of Medicine (IOM) 2001). The IOM's six dimensions of Patient Centred Care are based on Gerteis et al. (1993) work *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*:

1. Respect for patients' values, preferences and expressed needs
2. Co-ordination and integration of care
3. Information, communication, and education
4. Physical comfort
5. Emotional support—relieving fear and anxiety
6. Involvement of family and friends

*Now known as the National Academy of Medicine (NAM)

Pickler Principles of Patient-Centred Care: Core domains of experience (Pickler Institute 2013; Sizmur & Redding 2010)

1. Respect for Patients values, preferences and expressed Needs
2. Coordination and integration of care
3. Physical comfort
4. Information, communication, and education
5. Emotional support and alleviation of fear and anxiety
6. Involvement of family and friends

7. Transition and continuity
8. Access to care

Recently revised to The Eight Picker Principles of Person-Centred Care (Picker Institute Europe 2020):

1. Fast access to reliable health advice
2. Effective treatment delivered by trusted professionals
3. Continuity of care and smooth transitions
4. Involvement and support for family and carers
5. Clear information, communication, and support for self-care
6. Involvement in decisions and respect for preferences
7. Emotional support, empathy, and respect
8. Attention to physical and environmental needs

National Institute for Health and Care Excellence (NICE) (2012) Guidance Development Group for the National Health Service (NHS)

Developed by the Guidance and Development Group as a directive to all National Health Services (NHS). Themes for patient experience recommendations and quality standards:

1. Knowing the patient as an individual
2. Essential requirements of care
3. Tailoring healthcare services for each patient
4. Continuity of care and relationships
5. Enabling patients to actively participate in their care

Warwick Patient Experiences Framework (WaPEF) (Staniszewska et al. 2014)

Seven generic domains of experience

1. Patient as active participant
2. Responsiveness of services
3. An individualized approach
4. Lived experience
5. Continuity of care and relationships
6. Communication
7. Information and support

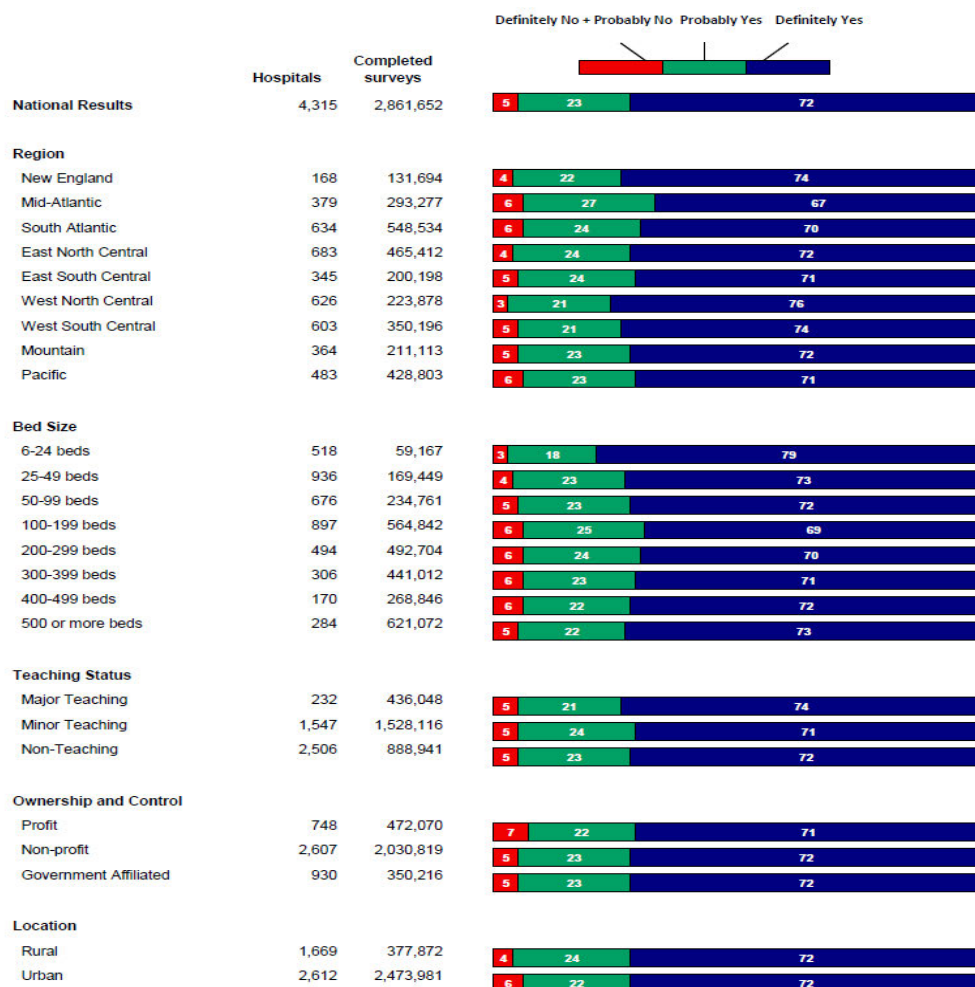
World Health Organisation: Domains of Responsiveness (Bleich, Özaltin & Murray 2009). Seven domains of satisfaction with the health system from the perspective of patient experience:

1. Autonomy
2. Choice
3. Communication
4. Confidentiality
5. Dignity
6. prompt attention,
7. Quality of basic amenities

Appendix C HCAHPS Hospital characteristics comparison chart

HCAHPS: Recommend the Hospital

(Represents patients discharged between July 2017 and June 2018)



www.hcahponline.org

Originally Posted: 04-24-2019

The hospital characteristic variables utilised to create the HCAHPS Hospital Characteristics

Comparison Charts were derived from a survey of hospitals in 2015 that was conducted by

the American Hospital Association See: <<https://hcahponline.org/globalassets/hcahps/summary-analyses/characteristics/july-2015--june-2016-discharges.pdf>>

Appendix D Approval to use publication in thesis

Re: Request to include publication in PhD dissertation



Jason Wolf <jason.wolf@theberyl institute.org>

Tue 12/11/2019 12:04 PM

Kelly Edwards; Lindsay Nelson <lindsay.nelson@theberyl institute.org> +1 other



Kelly – This would be ok to include and congratulations on your dissertation!

Jason

Jason A. Wolf, Ph.D., CPXP

Founding Editor | Patient Experience Journal

President & CEO | The Beryl Institute

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Patient Experience: The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care. - The Beryl Institute

Re: Request to include publication in PhD dissertation

From: Kelly Edwards <kelly.edwards@utas.edu.au>

Date: Monday, November 11, 2019 at 4:11 PM

To: The Beryl Institute - Info <info@theberyl institute.org>

Subject: Fw: Request to include publication in PhD dissertation

Dear Jason Wolf

Re: Request to include publication in PhD dissertation

I am the lead author of the following paper which was published in the Patient Experience Journal

Edwards, Kelly J.; Walker, Kim; and Duff, Jed (2015) "Instruments to measure the inpatient hospital experience: A literature review," *Patient Experience Journal*: Vol. 2 : Iss. 2 , Article 11. Available at: <https://pxjournal.org/journal/vol2/iss2/11>

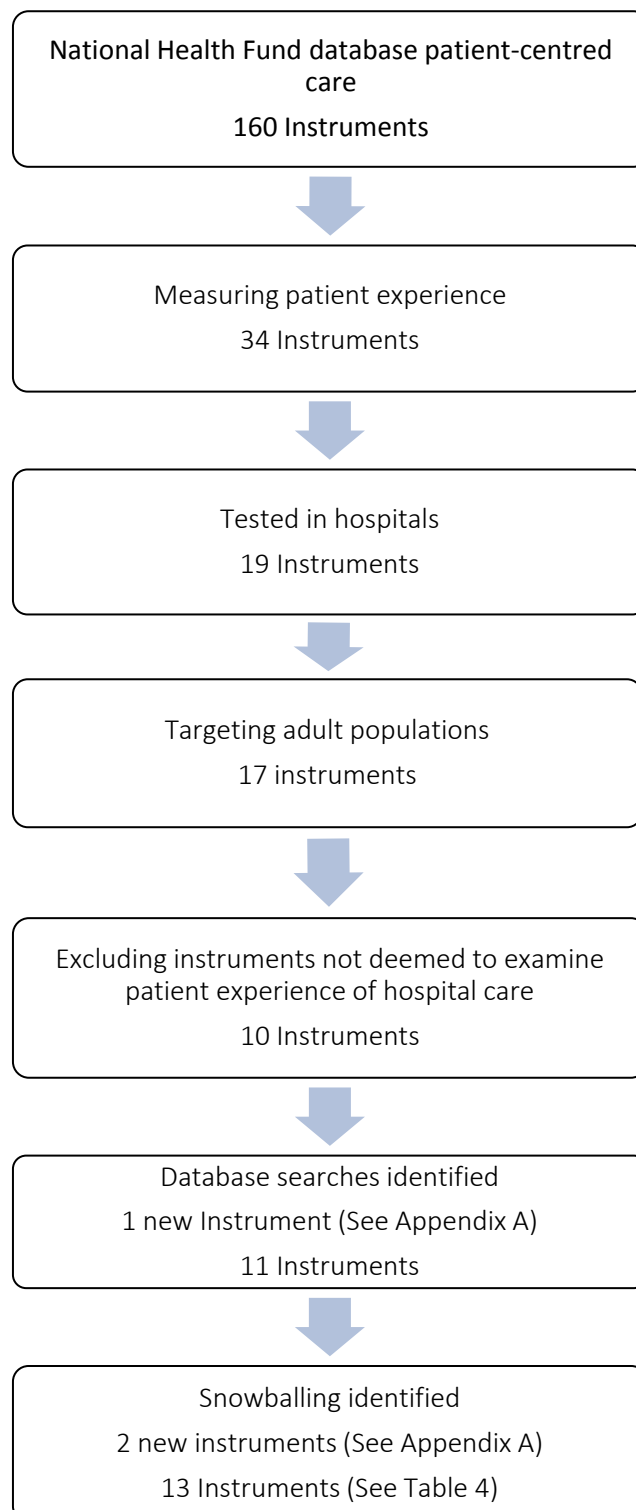
I am seeking permission to include this publication in my PhD dissertation, which will be submitted for examination February 2020. I am seeking permission to include the full text PDF in an appendix, and will include a statement acknowledging permission has been granted in the dissertation.

I look forward to hearing from you.

Kind regards,

Kelly Edwards

Appendix E Results flowchart



Appendix F Literature review evidence table

Instrument Name	Study Authors	Instrument Country Development	Study Title	Study Sample Size
Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)	Giordano, Elliott, Goldstein, Lehrman & Spencer 2010	United States	Development, Implementation and Public Reporting of the HCAHPS Survey	n=19720
	Goldstein, Farquhar, Crofton, Darby, Garfinkel 2005		Measuring hospital care from the patients' perspective: an overview of the HCAHPS Hospital Survey development process	
Hong Kong Inpatient Experience Questionnaire (HKIEQ)	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013	Hong Kong	Validation of inpatient experience questionnaire	n=500
	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013b		Item generation in the development of an inpatient experience questionnaire: a qualitative study	n=25
Irish National Perception of Quality of Care Survey (INPQCS)	Sweeney, Brooks & Leahy 2003	Ireland	Development of the Irish national patient perception of quality of care survey	n=1950
Newcastle Satisfaction with Nursing Scale (NSNS)	Thomas, Macmillan, McColl, Priest, Hale & Bond 1995	United Kingdom	Obtaining patients' views of nursing care to inform the development of a patient satisfaction scale	n= 150
	Thomas, McColl, Priest, Bond & Boys 1996		Newcastle satisfaction with nursing scales: an instrument for quality assessments of nursing care	n=1920
NHS National Adult Inpatient Survey (NHS NAIS)	Reeves, Coulter, Jenkinson, Cartwright, Bruster & Richards 2002	United Kingdom	Development and Pilot Testing of Questionnaires for use in the Acute National Health Service (NHS) Trust Inpatient Survey Programme	n=2250
Patient Evaluation of Emotional Care during Hospitalisation (PEECH)	Murrells, Robert, Adams, Morrow, Maben 2013	Australia	Measuring relational aspects of hospital care in England with the 'Patient evaluation of emotional care during hospitalisation' (PEECH) survey questionnaire	n=423

	Williams & Kristjanson 2009		Emotional care experienced by hospitalised patients: development and testing of a measurement instrument	n=132
Instrument Name	Study Authors	Instrument Country Development	Study Title	Study Sample Size
Patient Experience Questionnaire (PEQ)	Pettersen, Veenstra, Guldvog & Kolstad 2004	Norway	The patient experiences questionnaire: development, validity and reliability	n=19678
Patient's Assessment of Quality Scale - Acute Care Version (PAQS-ACV)	Lynn, McMillen & Sidani 2007	United States	Understanding and Measuring Patients' Assessment of the Quality of Nursing Care	n=1470
Picker Patient Experience Questionnaire (PPE-15)	Jenkinson, Coulter & Bruster 2002	United Kingdom (using data from United Kingdom, Germany, Sweden, Switzerland, USA)	The picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries	n=62925
Quality from the Patient's Perspective Questionnaire (QPP)	Larsson & Larsson 2002	Sweden	Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire	n=162
howRwe	Benson & Potts 2014	United Kingdom	A short generic patient experience questionnaire: howRwe development and validation	n=828
Intensive Care Experience ICE questionnaire (ICE)	Rattray, Johnson & Wildsmith 2004	United Kingdom	The intensive care experience: development of the ICE questionnaire.	Study 1 n=34 Study 2 n=109
Nordic Patient Experiences questionnaire (NORPEQ)	Olteidal, Garratt, Bjertnaes, Bjørnsdottir, Freil & Sachs 2007	Norway, Sweden, Iceland, Denmark.	The NORPEQ patient experiences questionnaire: Data quality, internal consistency and validity following a Norwegian inpatient survey	n=500

Instrument Name	Study Aim	Instrument Development
HCAHPS	Review of the history, development and implementation of HCAHPS.	Public call for measures, multiple Federal Register notices soliciting public input, literature review, meetings with hospitals, consumers and survey vendors, cognitive interviews with consumer, a large-scale pilot test in three US states and consumer testing and numerous small-scale field-tests.
	To describe the developmental process for the CAHPS Hospital Survey.	
HKIEQ	To assess the acceptability, reliability and validity of the HKIEQ.	Modified from the General Inpatient Questionnaire using the item Picker Patient Questionnaire, three focus groups and 7 in depth individual interviews.
	To report on the item generation in the development of HKIEQ.	
INPQCS	To develop a methodology suitable for assessing patient's perception of quality care.	Literature review, focus group, steering committee.
NSNS	To develop a bank of items for inclusion in subsequent scale.	Individual and focus groups for item generation and theme generation.
	To test the validity and reliability of scales for measuring patients experiences and satisfaction wit nursing care.	
NHS National Adult Inpatient Survey (NHS NAIS)	To develop, refine and pilot test the Picker adult inpatient questionnaire for use in the NHS patient survey programme.	UK Picker adult inpatient questionnaire (based on British derivation of the Picker questionnaire originally developed for the US market). 4 page and 12 page pilot test questionnaire sent to patients. Focus group, cognitive interviews with patients, refinement of questions, pilot 8 page and 16 page questionnaire.
PEECH	To validate the Patient evaluation of emotional care during hospitalisation' (PEECH) in English hospitals and to compare against the PPE 15.	Authors developed questionnaire using adapted PEECH tool and PPE 15.
	To describe the development and psychometric testing of the PEECH instrument.	Developed from the qualitative work of Williams (2003) and Williams and Irurita (2004). Construction of instrument, testing.

Instrument Name	Study Aim	Instrument Development
PEQ	To describe the development of the PEQ and to evaluate reliability and validity of constructed summed rating scales.	Five phase. 1. Preliminary work - first generation questionnaire 2. Development of questionnaire 3. Exploratory factor analysis 4. Constructing summed rating scales 5. Assessing validity and reliability.
PAQS-ACV	To develop the PAQS-ACV to provide a mechanism through which patients can evaluate nursing care.	Interviews with patients, data bit translated into items. Sample testing
PPE-15	To develop and test a core set of questions to measure patients' experiences of in-patient care.	Qualitative research to develop questions regarding aspects which are important to patients. Instrument - systematic review of literature, consultation with panel experts, patient focus groups, in-depth interviews in five countries with patients to test first draft questionnaire. Redraft and pilot.
QPP	To test a short version of an established questionnaire (QPP).	Based on original QPP. Questions formulated in the words of patients. Pilot test.
howRwe	To develop a short generic questionnaire for tracking patient experience.	Literature review, informal focus groups with patients and staff, pilot studies, resulting in 50 distinct versions.
ICE	To describe the development of an intensive care experience questionnaire.	Study 1: questionnaire development (patient interview - and completion of preliminary ICEQ), Study 2: questionnaire evaluation pilot study.
NORPEQ	To describe the development of a questionnaire designed for comparisons of patient experiences of hospital care within the Nordic countries.	Review of existing questionnaires, consultations with researchers, health personnel, and health bureaucrats with knowledge of or interest in patient experiences measurement. Pilot Study with six patients.

Instrument Name	Theoretical Underpinning/ Guiding Principles	Stakeholder Development	Study Context/ Target
HCAHPS	Institute of Medicine domains of quality healthcare	Yes. Stakeholder input sought throughout development.	Hospital/ Generic
HKIEQ	Picker Domains	Yes, focus group discussions and individual interviews.	Hospital/ Generic
INPQCS	Not reported within article	Yes. 'Steering committee - 6 members representing cross section of health care disciplines'. Focus groups of patients recently hospitalised determined characteristics of quality care.	Hospital/ Generic
NSNS	Not reported within article	Yes. Patients seen as 'expert informants.'	Hospital/ Generic
NHS National Adult Inpatient Survey (NHS NAIS)	Picker Domains	Yes. Expert advisory group, in-depth interviews with patients, focus groups, testing of draft versions with patients.	Hospital/ Generic
PEECH	Grounded theory	Not reported within article.	Emergency Admission unit, maternity, medicine for the elderly department, haemato-oncology unit
		Yes. Expert panel then pilot tested with patients.	Hospital/ Generic

Instrument Name	Theoretical Underpinning/ Guiding Principles	Stakeholder Development	Study Context
PEQ	Not reported within article	Yes. Review of patient comments, interviews, focus group with former patients.	Hospital
PAQS-ACV	Grounded theory approach - determination of the quality of nursing care must include the patients perspective and that patients judge the worth of care received.	Yes. Qualitative interview with patients, expert panel.	Hospital/ Generic
PPE-15	Patient centred care. Patient interactions with healthcare providers, institutions and systems; subjective experience of illness; patient perspectives.	Yes. Qualitative interviews with patients, expert panel	Hospital - acute care
QPP	Grounded theory approach - quality care from the patient perspective based on previous qualitative study (Wilde et al 1993).	Yes. Questions formulated from the words of patients.	Hospital/ Generic
howRwe	The core premise of the instrument is that all patients want high quality service from staff and the organisation as a whole.	Yes. Informal interviews with patients and staff.	Hospital - Pre-operative assessment clinic (PAC)/ Generic
ICE	Not reported within article	Consultation with intensive care nurses. Not reported whether patient involvement - however ICEQ was amended based on patient interviews during Study 1.	Hospital - Intensive Care Unit (ICU)
NORPEQ	Not reported within article	Health personnel, health researchers. Not reported if patients involved in development.	Hospital

Instrument Name	Study Participants	Methods Used To Develop /Test or Analyse Instrument	Instrument First implemented	Instrument Description
HCAHPS	Patients, >18 years, non-psychiatric, overnight stay or longer.	Qualitative (interviews with consumers) & Quantitative (Pilot trials, Randomised Mode Experiment)	2006	Survey - 27 items, 7 domains
HKIEQ	Patients, >18 years, Hong Kong citizen.	Quantitative (Cross sectional validation survey.)	2007	Survey -54 items, 9 dimensions, plus open ended comment section
		Qualitative (focus group, individual interviews. Thematic analysis.).		
INPQCS	Patients, Adults, non-psychiatric, non-detox,, cognitive impairment.	Qualitative (Focus group) & quantitative (pilot study survey).	1999	Survey 95 items - 8 domains
NSNS	Patients, currently in hospital and discharged within the preceding three weeks.	Qualitative (patient interviews, focus group. Thematic analysis)	1996	Survey - 26 items
	Patients, >18 years, hospital admitted for > 2 nights, able to participate.	Quantitative (Survey pilot test. Construct validity and internal consistency)		
NHS National Adult Inpatient Survey (NHS NAIS)	Patients aged 16 years or older, with at least one overnight stay. Non-maternity, psychiatric, day case, private (non-NHS)	Qualitative (focus groups & interviews) & quantitative (survey pilot studies.)	1998 original version.	Survey - 78 items, 7 dimensions plus open ended section
PEECH	NA	Quantitative (Survey fielded Exploratory factor analysis and confirmatory factor analysis.)	NA	Survey - 48 items
	NA	Qualitative (Expert panel content validity) & quantitative (Survey pilot study)	2005	36 items, 3 subscales, all questions have comment section

Instrument Name	Study Participants	Methods Used to Develop /Test or Analyse Instrument	Instrument First implemented	Instrument Description
PEQ	Patients, 16 years or older, discharged from medical or surgical ward	Qualitative (focus groups or interviews with patients, clinicians & staff) & quantitative (survey Pilot studies. Exploratory factor analysis)	1996	Survey 35 items
PAQS-ACV	Patients, 18 years or older, hospitalised for at least 48 hours, non psychiatric disorder	Qualitative patient (interviews) & Quantitative (Pilot testing of questionnaires. Content and validity of items as deemed by panel).	1996	Survey - 45 items, 5 factors
PPE-15	"all patients" random sample.	Qualitative patient (focus groups) & Quantitative (Pilot testing of questionnaires. Validity, reliability).	1987	Survey - 15 items, 8 dimensions
QPP	Patients, 16 years or older, able to communicate, understand Swedish, in hospital for at least 2 days.	Quantitative (survey - reliability)	2001**	Survey - 22 items, 6 factors
howRwe	Not reported in article	Qualitative (interviews with patients & staff) & quantitative (survey Pilot testing. Internal consistency, validity)	2013	Survey - 4 items - all with comment sections
ICE	Patients, Non elective, 18 years or older, ICU stay of 24 hrs or greater	Quantitative 1. Cross sectional retrospective study. Study 2 prospective longitudinal design (reliability, internal consistency and validity)	1998	Survey - 31 items, 5 domains
NORPEQ	NA	Qualitative (cognitive interviews with six somatic inpatients) & quantitative (internal consistency, test-retest reliability, construct validity)	2006	Survey - 8 items

Instrument Name	Instrument Time of Completion	Instrument Concepts Measured
HCAHPS	Development phase: Post discharge (48 hours to 42 days)	Satisfaction and experience (communication with nurses, communication with doctors, responsiveness of hospital staff, pain management, communication about medicines, discharge information, cleanliness of hospital environment, quietness of hospital environment, overall rating of hospital, willingness to recommend this hospital)
	Not identified within article.	
HKIEQ	Post discharge, within 30 days.	Experience of admission to hospital, staying in the hospital and ward (environment, food and facilities; hospital staff; patient care and treatment), the process of leaving hospital, and the overall impression of hospital care
	Post discharge -within 48 hours to one month.	
INPQCS	Post discharge - within 3 - 6 weeks.	Overall impression, admission procedure, information given, care and assistance, tests and operations, pain management, physical environment and discharge procedure.
NSNS	During admission, within three weeks post discharge	Experiences of and satisfaction with nursing care in hospital.
	Day of discharge, prior to discharge (or returned via mail post discharge)	
NHS National Adult Inpatient Survey (NHS NAIS)	Post discharge - 'two to three months post discharge...up to nine months' NB: Not reported within article*	Information, communication and education; Respect for patient values, preferences and expressed needs; Emotional support; Physical comfort; Coordination of care; Involvement of family and friends; Continuity and transition.
PEECH	Post discharge	Experience: Relational aspects of care and functional and transactional aspects of care.
	During admission	Experience of emotional care in hospital (level of security, level of knowing, level of personal value).

Instrument Name	Instrument Time of Completion	Instrument Concepts Measured
PEQ	Post discharge - 6 weeks	Information on future complaints; Nursing services; Communication; Information examinations; Contact with next-of-kin; Doctor Services; Hospital and equipment; Information medication; Organisation and general satisfaction
PAQS-ACV	During admission	Experience: Measurement of quality care
PPE-15	Post discharge	Measurement of experience; condition, demographic details, aspects of healthcare experience.
QPP	During admission	Perceived quality of care; medical-technical competence of caregivers; physical-technical conditions of the care organisation; degree of identity-orientation in the attitudes and actions of the caregivers: socio-cultural atmosphere of the care organisation.
howRwe	During admission	Perceived experience - clinical care and the organisation of care.
ICE	At discharge, and 6 months and 12 months post discharge	Perceived experience - memories, awareness, information, feelings and environment
NORPEQ	Post discharge, within three weeks.	Experience; Whether the doctors were understandable; Doctors' and nurses' professional skills; Nursing care; Whether the doctors and nurses were interested in the patient's problems, and Information relating to tests.

Instrument Name	Instrument Mode	Instrument Example Question	Instrument Feedback Mechanism
HCAHPS	4 Modes - Mail only, telephone only, mail with telephone follow-up, interactive voice response (IVR)	During this hospital stay, how often did nurses treat you with dignity and respect? Never, Sometimes, Usually, Always.	Current data reported via internet website (www.hospitalcompare.hhs.gov) available to public
HKIEQ	1 mode - Telephone - person to person	Were you given enough privacy when discussing your condition, treatment or condition? Yes always, Yes sometimes, No	Results published in the Hong Kong Medical Journal (http://www.hkmj.org/article_pdfs/hkm1210p371.pdf) and publicly available report (https://www.ha.org.hk/haho/ho/pred/Executive_Summary_ENG_TXT1.pdf)
INPQCS	1 mode - Computer aided telephone system (CATI)	Do you feel you received the right amount of pain medication? Right amount, Too little, Too much.	Current results available online http://www.isqsh.ie
NSNS	1 mode - paper survey	Nurses gave me information when I needed it? Disagree completely, a lot, a little, Neither agree nor disagree, Agree a little, Agree a lot, Agree completely	Instrument has been revalidated for specific populations (ie. maternity, Brazil, Turkey and Poland) and results published in various academic journals.
NHS National Adult Inpatient Survey (NHS NAIS)	1 mode - postal survey (telephone interpretation service available)	When you had important questions to ask, did you get answers you could understand? Yes always, Yes sometimes, No, I had no need to ask. Open ended section.	Findings originally reported back to Trusts. Results of the NHS Inpatient survey today available http://www.cqc.org.uk
PEECH	1 mode - paper survey	I have had the opportunity to get to know the staff as people. All, Most, Some, None..	Not identified within article.
			Not identified within article.

Instrument Name	Instrument Mode	Instrument Example Question	Instrument Feedback Mechanism
PEQ	1 mode - paper survey	How did you experience lying in a corridor bed? I did not mind. It was a very pleasant experience.	Not identified within article.
PAQS-ACV	1 mode - paper survey	The nurses knew my expectations. Strongly disagree, Disagree, Agree, Strongly Agree	Not identified within article.
PPE-15	1 mode - paper survey	Sometimes in hospital a nurse will say one thing and another will say something quite different. Did this happen to you? Yes often, Yes sometimes, No.	Not identified within article.
QPP	1 mode - paper survey	I talked to doctors in private when I wanted to. 'Do not agree at all' to 'Completely agree' (4 point scale)	Not identified within article.
howRwe	Multiple modes - paper, touch screen device (such as kiosks, smart phones and tablets), web browsers, and telephone. Touch screen used for original testing.	How are we doing? See me promptly. Excellent, Good, Fair, Poor.	Not identified within article.
ICE	NA	I was constantly disturbed. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree.	Not identified within article.
NORPEQ	1 mode - paper survey	NA	Not reported within article

Instrument Name	Data or findings provided by Instrument
HCAHPS	Quantitative
HKIEQ	Quantitative/ Qualitative
INPQCS	Quantitative
NSNS	Quantitative
NHS National Adult Inpatient Survey (NHS NAIS)	Quantitative/ Qualitative
PEECH	Quantitative/ Qualitative
PEQ	Quantitative
PAQS-ACV	Quantitative
PPE-15	Quantitative
QPP	Quantitative
howRwe	Quantitative/ Qualitative
ICE	Quantitative
NORPEQ	NA


NA Not available

* Personal correspondence Chris Graham - Director of Research and Policy (Picker Institute Europe)

**Personal correspondence with author Bodil Wilde-Larsson

Appendix G Ethics approvals

Appendix Ethical approval letters (re: H0015021 & H001556) from the University of Tasmania
Human Research Ethics Committees (HREC)

<p>Social Science Ethics Officer Private Bag 01 Hobart Tasmania 7001 Australia Tel: (03) 6226 2763 Fax: (03) 6226 7148 Katherine.Shaw@utas.edu.au</p>	
HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK	

17 June 2015

Dr Jed Duff
UTAS Research Centre
St Vincent's Hospital Sydney

Student Researcher: Kelly Edwards

Sent via email

Dear Dr Duff

Re: MINIMAL RISK ETHICS APPLICATION APPROVAL
Ethics Ref: **H0015021 - Nothing about me without me: The co-creation of a new patient experience measurement and feedback process**

We are pleased to advise that acting on a mandate from the Tasmania Social Sciences HREC, the Chair of the committee considered and approved the above project on 13 June 2015.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

A PARTNERSHIP PROGRAM IN CONJUNCTION WITH THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or human.ethics@utas.edu.au.
3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.
5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**
6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely



Katherine Shaw
Executive Officer
Tasmania Social Sciences HREC

Social Science Ethics Officer
Private Bag 01 Hobart
Tasmania 7001 Australia
Tel: (03) 6226 2763
Fax: (03) 6226 7148
Katherine.Shaw@utas.edu.au



HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

2 March 2016

Dr Jed Duff
School of Health Sciences
University of Tasmania

Student Researcher: Kelly Edwards

Sent via email

Dear Dr Duff

Re: MINIMAL RISK ETHICS APPLICATION APPROVAL
Ethics Ref: **H0015566 - Field testing RHEPORT (Real-time Hospital Experience POster Tool)**

We are pleased to advise that acting on a mandate from the Tasmania Social Sciences HREC, the Chair of the committee considered and approved the above project on 02 March 2016.

This approval constitutes ethical clearance by the Tasmania Social Sciences Human Research Ethics Committee. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approval of other bodies or authorities is required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

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6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely



Katherine Shaw
Executive Officer
Tasmania Social Sciences HREC



ST VINCENT'S
PRIVATE HOSPITAL
SYDNEY



22 July 2015

Kelly Edwards
UTAS Research Centre SVPHS
230 Barcom Ave
Darlinghurst 2010

Dear Kelly,

Re: Project R 45

I write to inform you that your protocol entitled: *Nothing about me without me: the co-creation of a new patient experience measurement and feedback process* has been defined as 'low risk' and is therefore exempt from full HREC review and has been approved by the SVPH Practice Development & Research Council.

On completion of the study could you please forward to my office a copy of the final report/draft manuscript for publication for our files please?

Kind regards,



Professor Kim Walker RN, PhD
Professor of Healthcare Improvement

Appendix H Advisory Group participant recruitment flyers



St Vincent's Private



Patients, friends, family
We NEED YOU!

Help us improve the hospital experience

We are looking for people to join
a Research Advisory Group.

Together we will create a new way of identifying what matters most to individual patients, their friends and family during their hospital stay, and how best to quickly relay that information to nurses.

For more information please contact Kelly Edwards on 8 _____ or
Kelly.edwards@svha.org.au



This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 2763 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [Hxxxxx].

Kelly Edwards
Phone 8362 4631
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St Vincent's Private



NURSES We NEED YOU!

Help us improve your patient's hospital experience

**We are looking for Registered Nurses to join
a nurse and consumer led Research Advisory Group.**

(This will count towards CPD points and looks good in your professional portfolio)

Together we will create a new way of identifying what matters most to patients, their family and friends during admission, and how best to quickly relay that information to the nurses in charge of their care.

For more information please contact Kelly Edwards on 8
Kelly.edwards@svha.org.au

or



This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 2763 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [Hxxxxx].

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Appendix H Advisory Group information and consent forms

Group member (patient or family) information sheet



Consumer Information Sheet [V3] [June 9 2015]

CONSUMER INFORMATION SHEET

Nothing about me without me: The co-creation of a new patient experience measurement and feedback process

You are invited to participate in an advisory research group and study.

The aim of the group will be to develop a new way of:

- **Obtaining real time patient experience feedback**
- **Relaying that feedback to nurses**

This study is being conducted by Kelly Edwards, RN, a University of Tasmania (UTAS) PhD Candidate under the supervision of Dr. Jed Duff (Senior Research Fellow) and Professor Kim Walker (Professor of Health Care Improvement) at St Vincent's Private Hospital, Sydney NSW.

Kelly Edwards is currently employed as a Registered Nurse at St Vincent's Private Hospital. This research is being conducted as partial fulfillment of a PhD degree for Kelly Edwards.

What is the purpose of this study?

The purpose of this advisory group is to design and evaluate a new patient experience measurement and feedback process.

Why have I been invited to participate?

You or your friend or family member has been admitted within the last year to St Vincent's Private Hospital.

Do I have to participate?

Your involvement is voluntary. There are no consequences should you decide not to participate. As a patient or friend or family member, non-participation will not affect your relationship with your doctor/s, staff, the University of Tasmania nor the Hospital.

What will I be asked to do?

Before you participate you will be asked to complete the Consumer Consent Form (attached).

You will be asked to participate in group discussions at the hospital. We understand that there may be times that you will be unable to attend these meetings. In this case the information discussed will be forwarded to you via email for your input. The discussions will focus on creating and then evaluating a new experience measurement and feedback process. The plan is to jointly create a new method, trial it in the hospital, and then together evaluate the trial.

The meetings will be audio and or video recorded, and then transcribed.

Consumer Information Sheet [V3] [June 9 2015]

It is expected that the group will meet ten times over the next twelve months (July 2015 – July 2016).

Are there any possible benefits from participation in this study?

A new experience feedback instrument will allow nurses to better understand their patient's healthcare experiences. Patients, their family and staff will ultimately benefit from this increased awareness; however it may not directly benefit you.

Are there any possible risks from participation in this study?

There is a foreseeable risk of inconvenience giving up time to participate. We will endeavor to arrange a time which suits the majority of participants.

It is unlikely that you will experience any feelings of anxiety and or distress during the meetings, however if discussing your experience leads to such feelings you may at any time cease participation in the meeting. Pastoral care is available should you wish to discuss these feelings. Alternatively you may contact Kelly Edwards or Dr Jed Duff (83824831) as soon as possible, who will assist you in arranging an appropriate referral.

Your comments, opinions and suggestions will form the basis of the development of this new measurement and feedback process, and while every effort will be made to protect your identity, elements of your personal stories shared during the meetings may be recognisable to certain members of your community should this study be published.

What if I change my mind during or after the study?

You are free to withdraw at any time during the study and may do so without providing an explanation. Please note that it will not be possible to retrospectively remove data.

What will happen to the information when this study is over?

Raw data (audio and or video recorded focus groups and transcripts) will be kept in a secure location within the University of Tasmania Research Department for five years from the date of first publication.

How will the results of the study be published?

The results of this study will be published as a thesis. We plan to also publish the results in a peer reviewed journal/s, present at conferences and/or professional forums. Results of the study will be provided to you if you wish.

Will I be personally acknowledged or identified in any publications?

The author/s would like to personally thank you in the acknowledgement section of the thesis. Should you wish to be excluded from this acknowledgment please indicate this on your consent form.

As a member of the Research Advisory Group, you will not necessarily be individually acknowledged in any other published works, nor will you be considered



Consumer Information Sheet [V3] [June 9 2015]

as a co-contributor or co-author in published works. The group as a whole will be acknowledged when possible.

The authors intend to also publish articles/ presentations regarding the group workings, and as such pseudonyms will be used.

What if I have questions about this study or require more information before I agree to participate?

Please contact Dr Jed Duff or Kelly Edwards 8

This information sheet is for you to keep

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 2763 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [Hxxxxxx].

Group member (patient or family) Consent Form



ST VINCENT'S
PRIVATE HOSPITAL
SINCE 1857
CARE BELONGS TO THE FUTURE OF OUR PATIENTS



Consumer Consent Form [V3] [June 9 2015]

PARTICIPANT CONSENT FORM

Nothing about me without me:

The co-creation of a new patient experience measurement and feedback process

1. I agree to take part in the research study named above as a member of the Research Advisory Group.
2. I have read and understood the Consumer Information Sheet for this study, which explains why I have been selected and the aims of the study.
3. The nature and possible effects of the study have been explained to me.
4. I understand that the study involves me participating in an action research group where I will be asked for my opinions and advice on the creation, development, testing and evaluation of a new patient experience measurement and feedback process. I understand that the Research Advisory Group will meet at least ten times from July 2015 until July 2016 and I will attend those meetings when possible.
5. I understand that these meetings will be video and/or audio recorded, and that statements I make may then appear in published works (including but not limited to a university thesis, journal articles, conferences, books).
6. I understand that the results of the study will be published, and that every effort will be made so that I cannot be identified, however elements may be recognisable to members of my community.
7. I understand that as a member of the Research Advisory Group, I will not necessarily be individually acknowledged in any published works, nor will I be considered as a co-contributor or co-author in published works.

Consumer Consent Form [V3] [June 9 2015]

8. I understand the author/s intend to personally thank me in the acknowledgement section of any thesis publication. I agree to this_____ I do not agree to this_____(Please initial preference).
9. I understand that participation involves the risk(s) of inconvenience, and that I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation, and that I have received satisfactory answers.
10. I understand that all research data will be securely stored on the University of Tasmania and St Vincent's Private Hospital Research Department premises for five years from the publication of the study results, and will then be destroyed unless I give permission for my data to be archived.

I agree to have my study data archived. Yes ☐ No ☐
11. Any questions that I have asked have been answered to my satisfaction.
12. I understand that the researcher(s) will maintain confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of the research and subsequent publications.
13. I understand that my participation is voluntary and that I may withdraw at any time without any effect or prejudice to my relationship with St Vincent's Private Hospital or the University of Tasmania.
14. I understand that if I have any questions relating to my participation in this research, I may contact Kelly Edwards 8
15. I acknowledge receipt of a copy of this Consumer Consent Form and the Consumer Information Sheet.



**ST VINCENT'S
PRIVATE HOSPITAL**
SYDNEY
CARELIVING IN THE INTEREST OF OUR PATIENTS



Consumer Consent Form [V3] [June 9 2015]

Participant's name: _____

Participant's signature: _____

Date: _____

Witness name: _____

Witness Signature: _____

Date: _____

Statement by Investigator

I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Investigator's name: _____

Investigator's signature: _____

Date: _____

Group member (Registered Nurse) information sheet



Registered Nurse Information Sheet [V3] [June 9 2015]

REGISTERED NURSE INFORMATION SHEET

Nothing about me without me: The co-creation of a new patient experience measurement and feedback process

You are invited to participate in an advisory research group and study.

The aim of the group will be to develop a new way of:

- Obtaining real time patient experience feedback
- Relaying that feedback to nurses

This study is being conducted by Kelly Edwards, RN, a University of Tasmania (UTAS) PhD Candidate under the supervision of Dr. Jed Duff (Senior Research Fellow) and Professor Kim Walker (Professor of Health Care Improvement) at St Vincent's Private Hospital, Sydney NSW.

Kelly Edwards is currently employed as a Registered Nurse at St Vincent's Private Hospital. This research is being conducted as partial fulfillment of a PhD degree for Kelly Edwards.

What is the purpose of this study?

The purpose of this advisory group is to design and evaluate a new patient experience measurement and feedback process.

Why have I been invited to participate?

You are a Registered Nurse (involved in direct patient care) currently employed at St Vincent's Private Hospital, Sydney, NSW.

Do I have to participate?

Your involvement is voluntary. There are no consequences should you decide not to participate. Non participation will not affect your relationship with the University of Tasmania nor the Hospital.

What will I be asked to do?

Before you participate you will be asked to complete the Registered Nurse Consent Form (attached).

You will be asked to participate in group discussions at the hospital. We understand that there may be times that you will be unable to attend these meetings. In this case the information discussed will be forwarded to you via email for your input. The discussions will focus on creating and then evaluating a new experience measurement and feedback process. The plan is to jointly create a new method, trial it in the hospital, and then together evaluate the trial.

The meetings will be audio and or video recorded, and then transcribed.

Registered Nurse Information Sheet [V3] [June 9 2015]

It is expected that the group will meet ten times over the next twelve months (July 2015 – July 2016).

Are there any possible benefits from participation in this study?

A new experience feedback instrument will allow nurses to better understand their patient's healthcare experiences. Patients, their family and staff will ultimately benefit from this increased awareness; however it may not directly benefit you.

For Registered Nurses, participation can be counted towards CPD points, and you may wish to include participation on your professional portfolio.

Are there any possible risks from participation in this study?

There is a foreseeable risk of inconvenience giving up time to participate. We will endeavor to arrange a time which suits the majority of participants.

It is unlikely that you will experience any feelings of anxiety and or distress during the meetings, however if discussing your experience leads to such feelings you may at any time cease participation in the meeting. Pastoral care is available should you wish to discuss these feelings. Alternatively you may contact Kelly Edwards or Dr Jed Duff (83824831) as soon as possible, who will assist you in arranging an appropriate referral.

Your comments, opinions and suggestions will form the basis of the development of this new measurement and feedback process, and while every effort will be made to protect your identity, elements of your personal stories shared during the meetings may be recognisable to certain members of your community should this study be published.

What if I change my mind during or after the study?

You are free to withdraw at any time during the study and may do so without providing an explanation. Please note that it will not be possible to retrospectively remove data.

What will happen to the information when this study is over?

Raw data (audio and or video recorded focus groups and transcripts) will be kept in a secure location within the University of Tasmania Research Department for five years from the date of first publication.

How will the results of the study be published?

The results of this study will be published as a thesis. We plan to also publish the results in a peer reviewed journal/s, present at conferences and/or professional forums. Results of the study will be provided to you if you wish.

Will I be personally acknowledged or identified in any publications?

The author/s would like to personally thank you in the acknowledgement section of the thesis. Should you wish to be excluded from this acknowledgment please indicate this on your consent form.



Registered Nurse Information Sheet [V3] [June 9 2015]

As a member of the Research Advisory Group, you will not necessarily be individually acknowledged in any other published works, nor will you be considered as a co-contributor or co-author in published works. The group as a whole will be acknowledged when possible.

The authors intend to also publish articles/ presentations regarding the group workings, and as such pseudonyms will be used.

What if I have questions about this study or require more information before I agree to participate?

Please contact Dr Jed Duff or Kelly Edwards 8

This information sheet is for you to keep

This study has been approved by the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 2763 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [Hxxxxx].

Group member (Registered Nurse) Consent Form



ST VINCENT'S
PRIVATE HOSPITAL
SYDNEY
GOVERNED BY THE BOARD OF ST VINCENT'S SOCIETY



Registered Nurse Consent Form [V3] [June 9 2015]

REGISTERED NURSE CONSENT FORM

Nothing about me without me:

The co-creation of a new patient experience measurement and feedback process

1. I agree to take part in the research study named above as a member of the Research Advisory Group.
2. I have read and understood the Registered Nurse Information Sheet for this study, which explains why I have been selected and the aims of the study.
3. The nature and possible effects of the study have been explained to me.
4. I understand that the study involves me participating in an action research group where I will be asked for my opinions and advice on the creation, development, testing and evaluation of a new patient experience measurement and feedback process. I understand that the Research Advisory Group will meet at least ten times from July 2015 until July 2016 and I will attend those meetings when possible.
5. I understand that these meetings will be video and/or audio recorded, and that statements I make may then appear in published works (including but not limited to a university thesis, journal articles, conferences, books).
6. I understand that the results of the study will be published, and that every effort will be made so that I cannot be identified, however elements may be recognisable to members of my community.
7. I understand that as a member of the Research Advisory Group, I will not necessarily be individually acknowledged in any published works, nor will I be considered as a co-contributor or co-author in published works.



ST VINCENT'S
PRIVATE HOSPITAL
SYDNEY
GOVERNED BY THE BOARD OF ST VINCENT'S SOCIETY



Registered Nurse Consent Form [V3] [June 9 2015]

REGISTERED NURSE CONSENT FORM

Nothing about me without me:

The co-creation of a new patient experience measurement and feedback process

8. I understand the author/s intend to personally thank me in the acknowledgement section of any thesis publication. I agree to this _____ I do not agree to this _____ (Please initial preference).
9. I understand that participation involves the risk(s) of inconvenience, and that I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation, and that I have received satisfactory answers.
10. I understand that all research data will be securely stored on the University of Tasmania and St Vincent's Private Hospital Research Department premises for five years from the publication of the study results, and will then be destroyed unless I give permission for my data to be archived.

I agree to have my study data archived. Yes ☐ No ☐
11. Any questions that I have asked have been answered to my satisfaction.
12. I understand that the researcher(s) will maintain confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of the research and subsequent publications.
13. I understand that my participation is voluntary and that I may withdraw at any time without any effect or prejudice to my relationship with St Vincent's Private Hospital or the University of Tasmania.



ST VINCENT'S
PRIVATE HOSPITAL
SYDNEY

AS RECOGNISED BY THE AUSTRALIAN DEPARTMENT OF HEALTH



Registered Nurse Consent Form [V3] [June 9 2015]

14. I understand that if I have any questions relating to my participation in this research, I may
contact Kelly Edwards 8

15. I acknowledge receipt of a copy of this Registered Nurse Consent Form and the Registered
Nurse Information Sheet.

Participant's name: _____

Participant's signature: _____

Date: _____

Witness name: _____

Witness Signature: _____

Date: _____

Statement by Investigator

I have explained the project and the implications of participation in it to this volunteer and I
believe that the consent is informed and that he/she understands the implications of
participation.

Investigator's name: _____

Investigator's signature: _____

Date: _____

Appendix J Advisory Group workshop agenda

1. Welcome to Country and acknowledgment of traditional owners
2. Brief introduction about me
3. PowerPoint presentation – background re subject including findings from literature review
4. Agenda run through
5. Aims of the research, research methodology, methods
6. Introductions– identified roles, employment skills you can bring, why you are the expert, why you are involved
7. Identified proposed ground rules
 - a) Discussion here should not leave this room
 - b) Only discuss details you are comfortable sharing
 - c) Try to keep focused
 - d) Try to keep momentum
 - e) We will all try to obtain closure or consensus
8. Morning Tea
9. Activity: Current Practice
10. Activity: Entertainment Practice/ Transport practice/ Dining practice
11. Activity: Specific Services Practice
12. Lunch
13. Activity: Current patient experience feedback practice vs ideal experience feedback practice
14. Brainstorming new process: who, how, what, and where
15. Summary
16. How shall we continue? How shall we communicate?

Appendix K Nurse evaluation surveys

Version one



Nurse Survey [xxx] [xxx xxx]

Registered Nurse Survey

You are invited to participate in a research study: Nothing about me without me. The co-creation of a new patient experience measurement and feedback process (RHEPORT (Real-time Hospital Experience POster Tool) field test).

The purpose of this survey is to obtain your feedback as a Registered Nurse regarding recent posters displayed on your ward. **Participation is voluntary and anonymous** (please do not write your name on this survey). Please return survey to your ward reception.

WARD:

Please circle
answer

1. Have you already completed one of these surveys?

YES NO

If YES or NO Go to Question 2

2. Do you remember seeing posters on the wards with speech bubbles like the example below?

YES NO



OR



If YES go to question 3

If NO go to question 15

3. Do you remember any specific comments and/or emojis? (Circle all that apply)

YES Comment

YES Emojis

None

If YES go to question 4

If None go to question 5

4. What comments or emojis do you remember? (Please write anything you remember even if you cannot remember the entire comment).

5. Were you surprised by any of the comments/emojis (even if you don't remember specifics)? (Please circle your answer below)

- a. Very Surprised
- b. Somewhat surprised
- c. Neutral
- d. Not very surprised
- e. Not surprised at all
- f. I don't remember how I felt at the time

6. Please give a reason for your answer.

7. How many comments/ emojis surprised you? (Please circle your answer below)

- a. All of them
- b. Two or three
- c. Only one
- d. None of them

8. Did any of the comments/ emojis cause you to reflect on your own practice? (Please circle your answer below)

- a. No, none of the comments made me reflect on my practice
- b. One or two of the comments made me reflect on my practice
- c. Yes all of the comments made me reflect on my practice
- d. I don't remember if any of the comments did or did not make me reflect on my practice.

If A,B or C go to question 9

If D go to question 10

9. If the comments/ emojis caused you to reflect on your own practice, what did you think about?

10.How did you feel about seeing the patient's comments/ emojis on display?

- 1. Very comfortable
- 2. Somewhat comfortable
- 3. Neutral
- 4. Uncomfortable
- 5. Very uncomfortable

Please explain why you chose this answer?

11.Do you think this type of patient feedback information is valuable to you?

- 1. Not valuable at all
- 2. Somewhat valuable
- 3. Neutral
- 4. Valuable
- 5. Very valuable

Please explain why you chose this answer?

12. Do you think these posters are good way of providing nurses with current, ward specific patient experience feedback?

1. Yes they are an excellent way of providing nurses with feedback.
2. Yes they are a good way of providing nurses with feedback.
3. Neutral
4. No they are not a good way of providing nurses with feedback.
5. No they are a terrible way of providing nurses with feedback.

Please explain why you chose this answer?

13. Would you change anything about the posters (layout, location, colour etc.)?
YES NO

If YES go to question 14

If NO go to Question 15

14. What would you change?

15. Do you have any additional comments or suggestions?

16. How long did it take you to complete this survey?

- a. Less than five minutes
- b. Five to ten minutes
- c. Ten to fifteen minutes
- d. Greater than fifteen minutes

Thank you for participating.



Nurse Survey [V6] [xxx]

Registered Nurse Survey

You are invited to participate in a research study: Nothing about me without me. The co-creation of a new patient experience measurement and feedback process (RHEPORT (Real-time Hospital Experience POster Tool) field test).

The purpose of this survey is to obtain your feedback as a Registered Nurse regarding recent posters displayed on your ward.

Participation is voluntary and anonymous

(Please do not write your name on this survey).

Please return survey to your ward reception or CNE.

If you have any questions about this study or require more information please contact: Dr Jed Duff or Kelly Edwards 8 or Kelly.edwards@svha.org.au. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. Please quote ethics reference number H0015566

Patient Care Level:

Please circle answer

1. Have you read the most recent Press Ganey patient Satisfaction or Patient Experience report located on your ward? YES NO



2. Do you remember seeing posters on the wards with speech bubbles like the example below?

YES NO



If YES go to question 3

If NO go to question 13

3. Did you read:
- a. All comments
 - b. Most comments
 - c. Some comments
 - d. None
 - e. I don't remember

4. Did you focus on reading the

- a. Positive comments
- b. Negative comments
- c. Positive and negative
- d. I didn't read any

5. How many negative comments do you remember there being?

(Please write a number) _____

6. Did any of the comments on the posters cause you to reflect on your own practice?

- a. No, none.
- b. Yes, one or two.
- c. Yes all of the comments.
- d. I don't remember.

If A,B or C go to question 7

If D go to question 8

7. If the comments caused you to reflect on your own practice, what did you think about?

8. How did you feel about seeing the patient's comments on display?

- a. Very comfortable
- b. Somewhat comfortable
- c. Neutral
- d. Uncomfortable
- e. Very uncomfortable

Please explain why you chose this answer?

9. Do you think this type of patient feedback information is valuable to you?

- a. Not valuable at all
- b. Somewhat valuable
- c. Neutral
- d. Valuable
- e. Very valuable

Please explain why you chose this answer?

10. Would you change anything about the posters (layout, location, colour etc.)?

YES NO

If YES go to question 11

If NO go to Question 12

11. What would you change?

12. Do you have any additional comments or suggestions?

13. How long did it take you to complete this survey?

- a. Less than five minutes
- b. Five to ten minutes
- c. Ten to fifteen minutes
- d. More than fifteen minutes

Thank you for participating - Please return survey to your ward reception or CNE.

Appendix L Evaluation checklist

Feasible	Is it practical or viable?
Appropriate	Is it acceptable to those who will use it?
Meaningful	Is it associated with positive experiences? Is it not associated with negative experiences? Is it perceived to be useful?
Effective	Is it beneficial? Does it achieve what it is supposed to? Are experience findings generated in keeping with current experience literature?
Patient Centred Care aim	Is it respectful of, and responsive to, the preferences, needs and values of the individual?
Nothing about me without me	Does it give patients and their family members a voice?

Appendix M Ethical conduct evaluation table

Ethical considerations (Tripp 2005)	Evaluation inquiry questions	Advisory Group	Field-test study participants
Addresses topics of mutual concern	How will I ensure this is a topic of mutual concern?	Group consensus	Participant consent and willingness to provide feedback
Is based on a shared commitment to performing research	What will a 'shared commitment' entail?	An agreed collective goal or shared purpose shared language and 'active' participation.	Participation in evaluating RHEPORT
Enables those involved to actively participate as they wish	How will I know if there is voluntary participation?	Group members consent to participation and may actively participate as much or as little as they like.	Participant consent
Shares control over research processes as evenly as possible	How will I know if there is shared control?	Every idea will be listened to, and action or change will be dependent upon consensus	Every idea will be listened to and relayed to the Group

Appendix N Consent card

If you have any questions about this study or require more information, please contact: Dr Jed Duff or Kelly Edwards 8 or Kelly.edwards@svha.org.au. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. Please quote ethics reference number H0015566

Appendix O RHEPORT poster examples presented to field test participants



THIS WEEK
YOU SAID

Your experience here is important to us.
We are listening to you and learning.

THIS WEEK
YOU SAID

Your experience here is important to us.
We are listening to you and learning.

'I'm not very happy today.

My x-ray got cancelled.'

Patient, Level Six

'I'm not very happy today.

My x-ray got cancelled.'

Patient, Level Six






THIS WEEK
YOU SAID

Your experience here is important to us.
We are listening to you and learning.

THIS WEEK
YOU SAID

Your experience here is important to us.
We are listening to you and learning.

'I'm worried about surgery tomorrow'

Patient, Level Nine



'I'm worried about surgery tomorrow'

Patient, Level Nine








Appendix P Advisory workshop findings

Activity	Action	Findings	Participation
Current Practice	Group members were asked to name ways in which we currently give service feedback	<ol style="list-style-type: none"> 1. Blogging 2. Face to face 3. Facebook 4. Photos – Instagram 5. Social Media 6. Story Telling 7. TripAdvisor 	Group
Entertainment Practice	Group members were asked to identify ways we could give feedback after a day at Disneyland	<ol style="list-style-type: none"> 1. Email 2. Facebook 3. Phone call 4. Word of Mouth 	Small group
Transport Practice	Group members were asked to identify ways we could give feedback after a long-haul flight?	<ol style="list-style-type: none"> 1. Email 2. Face to face 3. Phone call 4. Text 	Small Group
Dining Practice	Group members were asked to identify ways we could give feedback after dining at a new restaurant?	<ol style="list-style-type: none"> 1. Face to face 2. Trip Advisor 	Small Group
Specific Services practice	Group members were asked to list specific services they have used in the last six months and what were their associated feedback practices?	<p>Banking</p> <ol style="list-style-type: none"> 1. Verbal rating <p>Education</p> <ol style="list-style-type: none"> 1. Evaluation form 2. Feedback form 3. Online form 4. Online scale 5. Online survey <p>Employment</p> <ol style="list-style-type: none"> 1. Evaluation form 2. Feedback form 3. Online form 4. Online scale 5. Online survey <p>Health, fitness & Beauty</p> <ol style="list-style-type: none"> 1. Email surveys <p>Telecommunications</p> <ol style="list-style-type: none"> 1. Email questionnaire 2. Verbal score out of ten <p>Training and Professional development</p> <ol style="list-style-type: none"> 1. Evaluation form 2. Feedback form 3. Online form 4. Online scale 5. Online survey 	Individual
Patient Experience	Group members were asked how we currently provide hospital feedback and/ or how could we provide feedback specifically to nurses	<p>Current Practice</p> <ol style="list-style-type: none"> 1. Cards 2. External reports 3. Face to face 4. Letters <p>Other possibilities</p> <ol style="list-style-type: none"> 1. Audio recording 2. Posters 3. Telephone calls 	Group

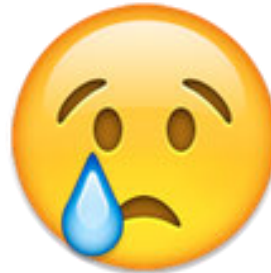
Appendix Q Emojis



Slightly Smiling Face



Confused Face



Crying Face



Worried Face



Angry Face



Face with Open Mouth



Grinning Face



Fed-up Face



Neutral Face



Tears of Joy Face



Thinking Face



Sleeping Face

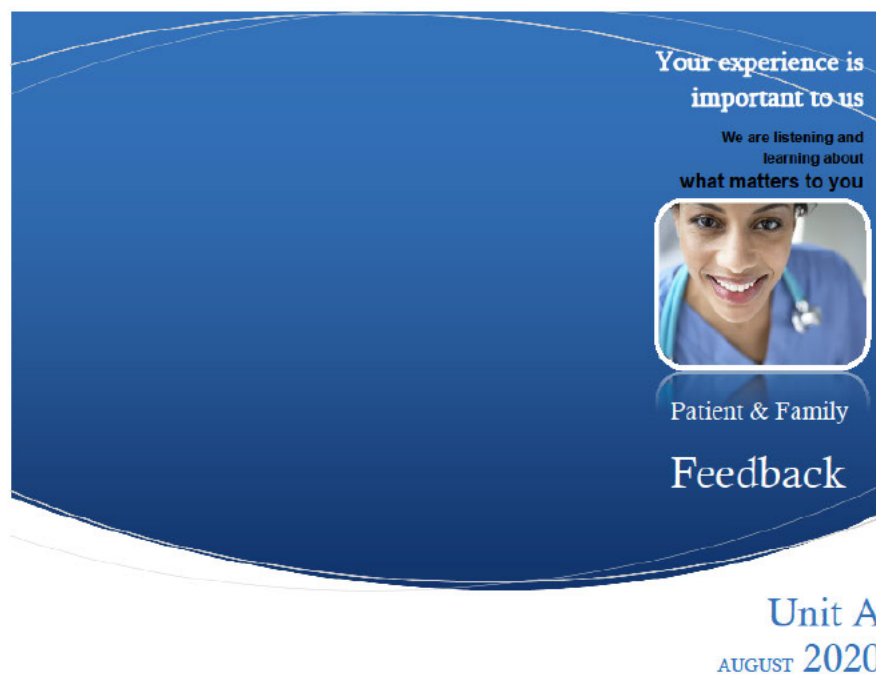
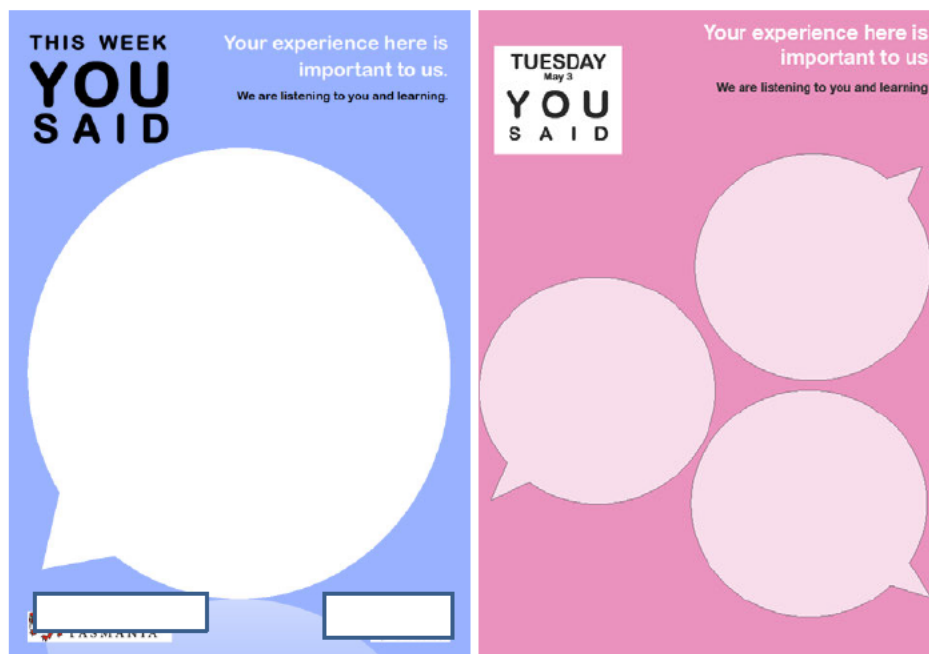
Appendix R Data collection template

RHEPORT Data Unit:	Patient or Visitor:
Date	
Consent	
Consent card given to participant	
Age range	
Time interview started	
Time interview completed	
Participant has read and confirmed key comment to appear on poster	
Flagged for review	

[illegible]

Key Comment:

Appendix S RHEPORT Poster and Brochure template examples



Appendix T RHEPORT Study advisement flyer



Participant Flier [V5] [February -]

A research study will be
taking place on this ward today.

If you do not wish to be approached by a
researcher, please inform your nurse or ward
reception.

This study has been approved by the SVPH PDRC and the Tasmanian Social Sciences Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, please contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. Please quote ethics reference number [H0015566].

Appendix U Poster displays



Appendix V Coded experience comments

Action Cycle 2 (RHEPORT V1) Unit A Experience Findings

The three dominant themes identified based on key comment feedback from Unit A (Action Cycle 2) were:

4. Physical Comfort (sixteen comments)
Example: 'I'm very happy. Its only my third day and I'm practically running with my new knee.' (Patient)
5. Information, communication, and education (thirteen comments)
Example: 'When I call they [nurses] come - it's fantastic and they are friendly. They chat to you.' (Patient)
6. Respect for patients' values, preferences and expressed needs (eleven comments)
Example: 'The nurses acknowledge you and are interested. That makes me feel I'm not a number, I'm a human being.' (Patient)

The most common positive comments pertained to the same themes:

1. Physical comfort (six comments)
2. Information, communication, and education (six comments)
3. Kindness and care (six comments)

The most common negative comments (ten) also referred to physical comfort, an example being 'there should be deodorants in the bathroom. It's very distressing when you have to go to the toilet and you are embarrassed.' (Patient)

Table 21 Coded experience key comments Action Cycle 2 (RHEPORT V1) Unit A

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	11	6 P* 0 V* Total 6	'The nurses acknowledge you and are interested. That makes me feel I'm not a number, I'm a human being.' (Patient)	3 P 2 V Total 5	'The nurse came in and said 'I'll be back' but didn't return for three hours. It's annoying because I could see her sitting at the computer.' (Patient)
Coordination and integration of care	4			3 P 1 V Total 4	'It's unfortunate when you fall asleep you get woken up for medications.' (Patient)
Information, communication and education	13	2 P 2 V Total 4	'When I call they [nurses] come - it's fantastic and they are friendly. They chat to you.' (Patient)	5 P 4 V Total 9	'Doctors can be so rude, they don't introduce themselves to you and they talk in doctor terms.' (Visitor)
Physical comfort	16	5 P 1 V Total 6	'I'm very happy. Its only my third day and I'm practically running with my new knee.' (Patient)	8 P 2 V Total 10	'There should be deodorants in the bathroom. It's very distressing when you have to go to the toilet and you are embarrassed.' (Patient)

Emotional support and alleviation of fear and anxiety	4	0 P 2 V Total 2	'The nurses have been helpful - because mum has been apprehensive about her operation.' (Visitor)	2 P 0 V Total 2	'I'm frightened I won't get better.' (Patient)
Involvement of family and friends					
Continuity and transition	2	0 P 1 V Total 1	'The nurses introduce themselves - that is very nice. They told us they were going to look after [patient] until ten pm tonight.' (Visitor)	1 P 0 V Total 1	'Why do you change your staff so much? We just get to know someone, and they leave.' (Patient)
Access to care	2			1 P 1 V Total 2	'Your carpark is terrible. It's so stressful to come and visit.' (Visitor)
Outcome					
Reputation	1	0 P 1 V Total 1	'If I had to come to hospital I'd come here.' (Visitor)		

Effort	1	1 P 0 V Total 1	'It's a great ward. It deserves an award.' (Patient)		
Kindness and Care					
Expertise					
Attitude	6	5 P 1 V Total 6	'Everyone has been wonderful - polite, friendly (Patient)		

Action Cycle 3 (RHEPORT V2) Unit B Experience Findings

The three dominant themes from Unit B (Action Cycle 3) feedback were:

1. Physical Comfort (thirteen comments)
Example: 'I call this place my five-star hotel.' (Patient)
2. Effort (ten comments)
Example: 'The NUM took the time to talk you through (a form) at 5pm. I work in a hospital - that's pretty impressive.' (Visitor)
3. Information, communication, and education (nine comments)
Example: 'The nurses acknowledge you and are interested. That makes me feel I'm not a number, I'm a human being.' (Patient)

The most common positive comments pertained to the same themes:

1. Effort (eight comments)
2. Physical comfort (seven comments)
3. Respect for patients' values, preferences and expressed needs (seven comments)

The most common negative comments pertained to issues of information, education and communication (ten comments) for example: 'Some nurses are easier to communicate with...' (Patient)

Table 22 Coded experience key comments Action Cycle 3 (RHEPORT V2) Unit B

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	8	5 P* 2 V* Total 7	'I haven't seen anyone miss out on something I've observed.' (Patient)	1 P 0 V Total 1	'Beyond acceptable - this whole place. The room is twice as big as it should be. We spend too much money on the wrong things. We need more doctors in the health system.'
Coordination and integration of care	4	3 P 0 V Total 3	'They don't treat me like an old lady. They are caring. They are efficient' (Patient)	1 P 0 V Total 1	We asked for a fan. They said they would look but we haven't heard anything.' (Visitor)
Information, communication and education	9	1 P 2 V Total 3	'The doctors have taken the time to explain everything to mum.' (Visitor)	6 P 0 V Total 6	'Some nurses are easier to communicate with...' (Patient)
Physical comfort	13	7 P 0 V Total 7	'I call this place my five-star hotel.' (Patient)	6 P 0 V Total 6	'They need to update the TV. They need channel ID and widescreen.' (Patient)

Emotional support and alleviation of fear and anxiety	1	1 P 0 V Total 1	'All the specialists joked about football teams with me during my procedure. It lifted the feeling in the room and was a happy moment.' (Patient)		
Involvement of family and friends					
Continuity and transition					
Access to care					
Outcome					
Reputation					
Effort	10	6 P 2 V Total 8	'The NUM took the time to talk you through (a form) at 5pm. I work in a hospital - that's pretty impressive.' (Visitor)	2 P 0 V Total	'The older nurses tend to be a bit more thorough' (patient)
Kindness and care	3	3 P 0 V Total 3	'The interpreters are really kind to my mother. The nurses are great. The services are really good. They have loaned me a laptop and there is free wifi.' (Visitor)		

Expertise	1	1 P 0 V Total	'Nurses are so well educated here. They know about a lot of diseases. They know stuff. Whoever is hiring them - congratulations. I didn't expect that much.' (Patient)		
Attitude	4	2 P 0 V Total 2	'The warmth of the care is exceptional. The philosophy of the hospital is reinforced by the nurses' (Patient)	2 P 0 V Total 2	'I don't want to complain because I might have to come back, but I don't like the person who took me to my MRI. He was very gruff. He took me back again...he must have cheered up' (Patient)
Peer Support					

Action Cycle 4 (RHEPORT V3) Unit C experience findings

The three dominant themes Unit C (Action Cycle 4) were:

1. Attitude (Thirteen comments)
Example: 'I swear by the staff, the hospital and the way they treat the patients. It's clean - all the staff wash their hands all the time. Everyone is helpful and pleasant.'
(Patient)
2. Respect for patients' values, preferences and expressed needs (eight comments)
Example: 'The physios are great. The way they treat you - they do push you, but not too much.'
(Patient)
3. Physical comfort (eight comments)
Example: (See Attitude example above)

Again, the most common positive comments pertained to the same themes:

1. Attitude (eleven comments)
2. Kindness and care (six comments)
3. Physical comfort (four comments)

The most common negative comments pertained to issues a Respect for patients' values, preferences and expressed needs, such as; 'I don't want to complain - it's not in my nature and I might need to come back. Everyone has been great. It's just that one person who upset me (Patient).

Table 23 Coded experience key comments Action Cycle 4 (RHEPORT V3) Unit C

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	8	1 P* 1 V* Total 3	'The physios are great. The way they treat you - they do push you, but not too much.' (Patient)	5 P 0 V Total 5	'I don't want to complain - it's not in my nature and I might need to come back. Everyone has been great. It's just that one person who upset me. (Patient)
Coordination and integration of care	5	2 P 0 V Total 2	'Everyone has been so friendly. They come almost immediately when you call which is really good.' (Patient)	3 P 0 V Total 3	'My experience hasn't been that great. I was on another ward and asked for a single room. They told me no-one was coming in to my room but then the next nurse said someone was, eventually I moved here. No-one knew what was going on...I feel like I'm project managing my own care.' (Patient)
Information, communication and education	4	2 P 0 V Total 2	'I've been waiting a long time, but my nurse has kept me informed.' (Patient)	2P 0 V Total 2	'I asked the nurse if she liked the TV show I was watching and then I said, 'oh you are probably too busy with your kids.' The nurse said "I make it quite clear I am here to work not to socialise." I was so upset she cried.' (Patient)
Physical comfort	8	4 P	'I swear by the staff, the hospital and the way they treat the patients. It's clean - all the staff wash their	4 P	'Sometimes the machines beep for a while longer than you would expect, but it can't be helped.' (Patient)

		0 V Total 4	hands all the time. Everyone is helpful and pleasant.' (Patient)	0 V Total 4	
Emotional support and alleviation of fear and anxiety	1	0 P 1 V Total 1	'The staff are really helpful. They have made sure [my partner] is relaxed and OK. They are always popping in just to make sure everything is OK.' (Visitor)	0 P 0 V Total	
Involvement of family and friends	1			1 P 0 V Total 1	'Visiting hours are attuned to people who are working, but older people who come in have to be in the city all day, so it may not suit them.' (Patient)
Continuity and transition	1	1 P 0 V Total	'The Nurses are amazing. It's the same staff year after year here. It must be a good recipe.' (Patient)	0 P 0 V Total	
Access to care					
Outcome					
Reputation	3	3 P 0 V	'Overall I give this place and A+ rating. You only have to go somewhere else to know how good it is here' (Patient)		

		Total 3			
Effort	4	2 P 0 V Total 2	'I can't complain about a thing. I will write to the CEO that everyone has been great. They are all polite, caring. Not one person has not been accommodating. There are also great medical staff.' (Patient)	1 P 1 V Total 2	'...My nurse didn't seem happy. It was as if it was an effort to be here. The rest have been amazing' (Patient)
Kindness and care	6	5 P 1 V Total 6	'Kindness is a language the blind can see and the deaf can hear.' (Patient)	0 P 0 V Total	
Expertise	3	3 P 0 V Total 3	'I've been here many times. I always receive excellent treatment...' (Patient)		
Nurse Attitude	13	10 P 1 V Total 11	'I swear by the staff, the hospital and the way they treat the patients. It's clean - all the staff wash their hands all the time. Everyone is helpful and pleasant.' (Patient)	2 P 0 V Total 2	'Nurses are caring here. If you ask them they come. Some have been just beautiful. One was a bit abrupt.' (Patient)
Peer Support					

Table 24 Coded experience key comments Action Cycle 6 (RHEPORT V4) Unit D

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	8	1 P* 3 V* 0 U* Total 4	'The staff are so kind...they always involve me' (Visitor)	3 P 1 V 0 U Total 4	'Nurses have procedures to get things done which are very rigid and there are personal issues which might not actually be what the patient wants. I feel a bit poked and prodded all day long' (Patient)
Coordination and integration of care	8	P 2 V 2 U 0 Total 4	'I was in here months ago and they had people looking at my knee, my stoma, my heart. The co-ordination of care was amazing' (Visitor)	3 P 1 V 0 U Total 4	'The nurses said they would get a gown but didn't. She [patient] wanted to get up but no-one did' (Visitor)
Information, communication and education	4			P 3 V 1 U 0 Total 4	'I can't fault anything here. They were so helpful downstairs too with information... I was in the foyer and upset. [He] waved at me and looked after me. He asked "Are you OK?" when I said I was worried what would happen when we went home, he told me there are people who can help me and he put me directly in touch with them' (Patient)

Physical comfort	10	P 4 V 0 U 0 Total 4	'The nurses her are great - they are always trying to help you. They come I and check on you all the time, and ask if I need anything. I'm confined to bed. I depend on them. Sometimes they even help arrange my table without me asking, which is good' (Patient)	P 5 V 1 U 0 Total 6	'They could improve those showers - getting the temperature is impossible. The hard pillows are horrible, they need softer pillows. They do have different ones but you have to ask. The size of the cups are too small...they can't make a decent cup of tea, you expect a decent cup of tea that's hot' (Patient)
Emotional support and alleviation of fear and anxiety	6	P 3 V 1 U 0 Total 4	'They are very caring staff. They get you up, and always attend to you. I'm not worried. They are special	P 2 V 0 U 0 Total 2	'I had a nurse, there was something about her. I thought "oh god", I was surprised she was a nurse here, but then found out she was an agency nurse, and she didn't have the same approach. I felt anxious' (Patient)
Involvement of family and friends	4	P 1 V 1 U 0 Total 2	'They are really good with the visiting hours - they are flexible. It is an important step to recovery having your family with you' (Patient)	P 1 V 1 U 0 Total 2	'Patients and support staff should be empowered to put more controls around visitation. Visitors feel compelled to come, but I just wanted them to leave me alone. We should be able to appoint a visitor co-ordinator and all visitor requests should go through them. It could be a member of the family' (Patient)
Continuity and transition	0				
Access to care	0				

Outcome	0				
Reputation	2	P 1 V 1 U 0 Total 2	'I've been to other hospitals but here it is incredible. We told our GP we only wanted to come here' (Visitor)		
Effort	9	P 5 V 2 U 0 Total 7	'Nurses are very kind. Nothing is too much trouble for them. Nothing is an effort. God bless them' (Patient)	P 2 V 0 U 0 Total 2	'When you are not feeling well...little things which don't probably bother you become important. You do have a natural affinity with some nurses. Sometimes though they walk in and you get a sinking feeling. The training should include being open to people you are going to see. Some nurses you feel like you would be able to talk to them and some you feel like you might be considered a nuisance' (Patient)
Kindness and care	12	P 9 V 3 U 0 Total 12	'I'll tell you a story...my niece who is a nurse said always be kind to your nurse and they will be kind to you. Last week I wasn't very compliant, but the nurses here were still kind to me' (Patient)		

Expertise	5	P 4 V 1 U 0 Total 5	'Nurses here are experts - which is good. It makes everyone feel safe' (Patient)		
Nurse attitude	0				

*(P) Patient (V) Visitor

Table 25 Coded experience key comments Action Cycle 7 (RHEPORT V5) Unit E

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	8	4 P* 3 V* 0 U* Total 7	'The care here is great. People treat you like a human being. They treat you as an individual.' (Patient) "I feel I've had a positive experience. We are called by our name, never 'honey', 'love' or 'bunny'. A generic term. Some may find that endearing. But I find it disrespectful.' (Visitor)	1 P 0 V 0 U Total 1	Re ICU 'The nurse said 'you can go to bed at 6.30 all the patients do. No orientation, no reassurance. All you need is a bit of warmth and understanding. You don't need more stress than you are already going through. I feel so strongly about it that she doesn't deserve a job in the unit. I found the whole experience soul destroying. I felt like a nobody. I didn't have a voice' (Patient)
Coordination and integration of care	6	3 P 3 V 0 U Total 6	'The level of care is excellent. The nurses and doctors are responsive. If something goes wrong, they turn up immediately.' (Patient)		
Information, communication and education	9	5 P 3 V 0 U	'The nurses always introduce themselves. It's professional. I like the whiteboard. I like it tells me what might happen.' (Patient)	0 P 0 V 1 U	'Bedside manner of registrars not very palatable' (Unknown)

		Total 8		Total 1	
Physical comfort	12	6 P 2 V 0 U Total 8	'...They are interested in me, in my pain level. They say they will come back and they do.' (Patient)	3 P 0 V 1 U Total 4	"It is monotonous. Cold scrambled eggs. You don't come here for a meal anyway. I didn't expect much so I'm not upset. It's a big job to deliver food to all these people.' (Patient)
Emotional support and alleviation of fear and anxiety	4	3 P 0 V 0 U Total 3	"I can't fault it here. The doctors are great. The nurses always ask how you are feeling.' (Patient)	1 P 0 V 0 U Total 1	'I was in a grey room, no clock, and no colour TV, or a TV that didn't work. I felt lost. I'm still very distressed about the experience' (Patient)
Involvement of family and friends	1	0 P 1 V 0 U Total 1	'It's been excellent. It is very fast. The nursing staff have been wonderful. They are very attentive. Showing interest. They are interested in him as a person not just as a patient. He felt like a human. They explained everything and put him at ease. They have allowed me to sit in this room for three hours [while he has surgery]. I can sit here and work and I've got access to the internet.' (Visitor)		

Continuity and transition	0				
Access to care	3	2 P 1 V 0 U Total 3	'What matters to me is when you ring for a nurse one comes fairly quickly here.' (Visitor)		
Outcome	0				
Reputation	1	1 P 0 V 0 U Total 1	'It's a great level. It's premier for bladder and prostate. There are great nurses here. It's the excellent medical attention you get. It's the only thing that matters. (Patient)		
Effort	8	3 P 5 V 0 U Total 8	'They anticipate what's wrong. They said you look hot. He didn't have a temperature, but they brought a cold towel for his forehead. They volunteered how to use the TV, the internet.' (Visitor)		

Kindness and care	9	5 P 3 V 0 U Total 8	“Excellent. The nurses are so caring here. They hold your hand. I was asleep and the nurse was creeping around during the night, and when she realised I was awake she held my hand and said I'm [name]’ (Patient)	1 P 0 V 0 U Total 1	‘I had an asthma attack...I went to ICU...I felt totally disorientated...I made a complaint and they said they will let the manager know but it is bullshit. I don’t think [Unknown name] will ever hear about it. Asthma is terrifying. That woman showed no decency, and kindness. She didn’t care. They need to rethink the model. They assume everyone is unconscious.’ (Patient)
Expertise	5	3 P 1 V 0 U Total 4	‘The surgeons are matter of fact, but the nurses are knowledgeable about what to expect. They are more practical.’ (Patient)	1 P 0 V 0 U Total 1	‘They are not proficient, but they generally care’
Nurse Attitude	7	5 P 2 V Total 7	‘The nurses have been exceptional. They are attentive, patient. It must be hard working with sick people. They are always upbeat and positive, and that’s good’ (Patient)		

Table 26 Coded experience key comments Action Cycle 8 (RHEPORT V6) Unit F

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	13	4P* 3V* Total 7	'...I understand the drug I'm taking is strong, if something were to happen, they would be responsible however there are some nurses who think outside the box and are happy to be flexible within reason to help me sleep. I notice that some nurses who feel a bit more comfortable about the treatment have been [name]' (Patient)	6P 0V Total 6	'... the medications are at the wrong time. They are late...[I] normally takes them at seven and three...' (Patient)
Coordination and integration of care	7	3P 1V Total 4	'...The best moment is when X came in and said, "this is what's going to happen." It was comforting. Patients love it when we get a plan' (Visitor)	3P 0V Total 3	'...I have a habit with my medications and this does throw me. It should be a shared decision'
Information, communication and education	21	8P 4V Total 12	'I've had a total laryngectomy and have been in this hospital for nearly seven weeks. The staff are all very competent as well as kind people. Nothing is too much trouble. For instance, I have to write to them. They patiently try to lip read me and read what I have written and do what I want...' (Patient)	6P 3V Total 9	"It would have been nice for someone to say lunch comes at 12, dinner at... I don't know who who is here. I don't know where to go to get someone...it would be good to get a mini briefing - no one said here is the button, press this. I wish you had name tags that said nurse, doctor and your name.' (Visitor)

					<p>And</p> <p>'Someone accused me of "refusing" Panadol. I didn't 'refuse' that sounds so aggressive. I discussed the decision with the nurse. I felt like the other nurse was then saying it's my fault I was now in pain...'</p>
Physical comfort	13	7P 2V Total 9	<p>'...I'm living in comfort...the meals are top...'</p> <p>(Patient)</p>	4P 1V Total 5	<p>"They should have Foxtel. I spend a lot of time in hotels. Anywhere in the world you can get BBC or CNN, you would think its second rate if you didn't. This is like a hotel, but people are sick. I would have thought you would have the same access and purchasing power as a hotel.' (Patient)</p>
Emotional support and alleviation of fear and anxiety	6	5P 1V Total 6	<p>'Everyone has been brilliant. It's a roller coaster of things I'm experiencing. I've had anxious times but they talk me through it. They are friendly and positive. That positive energy feeds into me. The fact that I know I can ask them anything is good. I've never been to hospital...The treatment is working, but it's not just the treatment. They keep me calm. They are the ones with me. Having experienced</p>		

			staff is so good. I didn't realise nurses have so much knowledge.' (Patient)		
Involvement of family and friends	3	1P 1V Total 2	'We had a nurse yesterday who told us about herself and it made us feel like she was our friend.' (Visitor)	0P 1V Total 1	'They should have a vending machine on the ward. I had to go down the road to get a can of soft drink. We don't know the area. A vending machine would be a brilliant idea for guests.' (Visitor)
Continuity and transition	1			1P 0V Total 1	"I never know if I can go to the bathroom, or if I have to stay so someone can take my BP...I like when I have the same nurse..."(Patient)
Access to care	1			0P 1V Total 1	'Also I'm upset about the parking It is so expensive. You used to get free parking in the private after four but not anymore. It's tough on country people. We know people who go to the [name withheld] now instead because they can't park here. Maybe they need a shuttle bus or a bus you can book from a carpark' (Visitor)
Outcome	0				
Reputation	5	4P	'I've been to other hospitals...but right from the word go it's been good here. If my daughter rings at		

		1V Total 5	home, she says "you know the rule. If anything happens you go to the airport. You get on a plane and you come to St Vincent's." I tell my mates. I give them my doctor's card. I tell them "get on a plane and go and see them."" (Patient)		
Effort	8	6P 2V Total 8	'St Vincent's has a history with country people. I'm in awe of the nurses here that they actually have a chat with you. It means a lot...when they take the time to have a conversation.' (Patient)		
Kindness and care	6	5P 1V Total 6	'...When I first got here, they told me what was going to happen. It was a bit scary, but they told me what to expect. They were so caring, actually I'm amazed at how caring the male nurses are...' (Patient)		
Expertise	11	10P 1V Total 11	'...They are so good at their jobs. I cannot think of anything they could do better. The machines they use block up and they all have enough knowledge to fix them on the run.' (Patient)		
Nurse Attitude	13	10P	'How blessed I am. How fabulous it is here. Everyone is polite. I have not one complaint. We	1P	"I don't dislike this hospital. But they need more bedside manner and not a robotic bedside manner. It's

		2V Total 12	have been here many times...you know, I study them from the sweeper to the cleaner to everyone. It's got everything. They have got everything right...' (Patient)	0V Total 1	a bit like Chinese whispers. I don't feel involved in the handover process' (Patient)
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*(P) Patient (V) Visitor

Table 27 Coded experience key comments Action Cycle 9 (RHEPORT V+) Unit G

	Total	Positive	Example	Negative	Example
Respect for patients' values, preferences and expressed needs	14	6	'...If I had a problem I would tell the nurses. Most of them are very open and happy to listen. They might tell you there is nothing they can do to fix it but they would listen. They will take my suggestions on board. If there is nothing they can do they will sympathise.'	7	'.....the nurses had an issue with me – usually we have a physical group, but because of my chronic pain, it was put to me that "maybe this isn't the right place for you?" That was hard. I go to pain places and they say "we will treat you when you get your mental health checked" and then I go to mental health and they say "we will treat you when you get your pain checked."'
Coordination and integration of care	4	3	'You know the nurses care about you because if you had a bad day, they remember three hours ago you might feel down and then come by and check on you. They follow through.'	1	'Admission is a really tedious process when you have been here thirty times. An hour of questions...'
Information, communication and education	7	3	'The interactive groups are good – it's not like a lecture. It's not like they are talking at us. They involve us, and ask our opinion... I've spoken about this and that and they listen. They are taking it in. They	4	'Hand-overs can be annoying. All the nurses are involved and so no-one can come out and help you during that time. The nurses talk about the patients during handover...Handover is done just between the nurses – they go in the office. I don't know what they say...but it's just one of those things I guess. It's their way of doing it.

			come across as very caring. At other places you talk and it's just "yeah, yeah"		
Physical comfort	20	8	'...I like the rooms, they are very very nicely done. We have our own reading den. I love sitting there. I have always wanted that since I was a little girl. We get our own bathroom. It's good because you don't get nervous taking too long. It's not uncomfortable.'	12	'...the food is not the greatest...the last place had a big TV room. We all sat there every night. That was how we all bonded. I have fond memories of that. We all sit here (pointing to the dining/ common area). We don't have a place like that. These (chairs) aren't comfortable. We need a space to relax – it would help me bond, and it gets you out of your head. It's a nice way to end the day.'
Emotional support and alleviation of fear and anxiety	5	5	'The facility in general, the physical environment and you know...you feel supported, you feel comfortable here. The mix of being around people with similar issues is good. It's a friendly and social environment.'		
Involvement of family and friends	0				
Continuity and transition	0				

Access to care	0				
Outcome	0				
Reputation	3	3	'In reality this is the best facility in the Southern Hemisphere for young people with mental health issues. A couple have popped up based on [this unit] ...but It's so specialised here.'		
Effort	3	3	'nurses will notice here if you are struggling...'		
Kindness and care	3	3	'The staff her are kind and warm. The psychologists, the social workers and the nurses, they are all kind. They are very understanding if you need advice...everyone is so nice including the cleaners and the kitchen people.'		
Expertise	3	2	'The nurses are fantastic. They are really helpful with anything you need. The groups are really helpful too. They are run by good people. I get a lot out of it.'	1	'We are discovering a link between physical and mental health. This unit is having to adjust – there are loads of people coming in here with disabilities. They could get better at that though. In 2013 everyone was still learning the correlation between illness and

					symptoms, understanding that depression can be secondary. Each admission here is better. Even within this unit.'
Attitude	5	3	'...I like it here. The nurses are very approachable and friendly. I've been in other places and its not like this. If I'm down, they come over and talk to me. The other places – the nurses are just there to enforce the rules and give medication. They encourage us to talk here, because the doctors aren't always available.'	2	'The approachability of nurses...I feel like sometimes I can't approach them, Unless it's a simple problem. Some can be quite dismissive...they are very...they minimise what you are going through. That could be a strategy?'
Peer support	10	10	'The best thing is the unity here with everyone. Everyone is here for one another. We have all been through the same thing. We are all here for one another...It's really youth orientated here. The ages are 16-30. You know you are not alone.'		

We would love to hear about:

YOUR experience at USPACE

and/or

What you think about these posters?

Please come and talk to me now



Kelly Edwards
Researcher UTAS/ SVPH

Appendix X RHEPORT Guide and Protocol

2020 | Edwards



RHEPORT

Hospital Experience Feedback Guide

RHEPORT (Real-Time Hospital Experience Posters)

Real-Time Hospital Experience Feedback

Capturing patient and family hospital experience feedback, highlights areas of successful patient and family centred care and areas that need improvement. This guide details a step-by-step process to eliciting and disseminating real-time qualitative hospital experience feedback.

Who is this guide and protocol for?

This guide is written for healthcare staff who care about patient and family experiences, the impact hospital nursing staff have on experience, and for those who want to engage clinical nurses in improving patient-centred care. The RHEPORT protocol is designed to be facilitated by a nurse or nurses at an in-patient unit (unit) level within a hospital setting.

RHEPORT development and purpose

RHEPORT was developed by a 16-member Action Research Advisory Group over a three-year field test period (2015-2017). An Action research methodology was used to co-create RHEPORT, whereby nine iterative cycles of planning, acting (field testing), evaluating and reflecting were undertaken, with each cycle informing the next. RHEPORT was co-created and field-tested at a major metropolitan private hospital in Sydney, Australia. Two hundred and forty-one (n=241) participants (178 patients, 60 visitors, and three status unknown) provided hospital experience data. Four hundred and seven evaluation responses (227 patient responses, 70 visitor responses and 110 nurse responses) regarding the RHEPORT protocol were collected, and the data was shared with the sixteen-member Advisory Group for their reflection and evaluation. This RHEPORT guide will explain why and how we should capture, relay and reflect upon **real-time, qualitative, unit specific** patient and family experience feedback.

Why does patient experience matter?

Healthcare decision makers around the world have been keen to adopt various strategies to implement and measure patient and family centred care (Australian Commission on Safety and Quality in Healthcare (ACSQHC), 2011; Luxford, Safran, & Delbanco 2011). The *Australian Safety and Quality Framework for Healthcare* (ACSQHC 2011) suggests that patient centred care is essential for safety, high quality and outcome improvement and that measuring patient experience is an essential means of assessing such care.

What is patient experience? The Beryl Institute, world leaders in the field of human experience in healthcare define patient experience as:

'The sum total of all interactions, shaped by an organisations culture, that influence a patient's perceptions, across the continuum of care'

(Wolf et al. 2014, p.8)



Patient experience Vs patient satisfaction

Satisfaction is a rating of care, whereas patient experience is a perception of what did or didn't happen during that episode of care (Browne et al. 2010; Russell 2013).

Satisfaction is an aspect of a patient's experience relative to expectation. Satisfaction scores however do not tell us why someone had a good or bad experience, nor how to improve care.

Real-time: Collecting experience feedback during the patient's hospital admission, as opposed to after they have been discharged is referred to as 'real-time' data collection.

Traditionally interventions have been based on retrospective healthcare experiences, with data collected post discharge. Real-time data collection is a proactive, rather than reactive model of healthcare improvement. Capturing feedback while the patient is still in hospital is the most effective way to capture meaningful experience data (Russell 2013). Real-time feedback collection also allows for service interventions. When an issue is raised in real-time, it presents the opportunity for healthcare providers to **address and improve** the experience, fostering both loyalty and satisfaction.

Qualitative: Ensuring we measure or **identify what matters most** to patients is essential to improving the patient's experience (Coulter 2017). Qualitative experience data as opposed to quantitative data provides descriptive, richer and more useful experience findings (Cleary et al. 2014; Lees 2011; Russell 2013). Studies also demonstrate that engagement with experience feedback is increased when descriptions of clinical encounters in the patient's own words are used (Kanouse et al. 2016; Lagu et al. 2013). Qualitative data provides information regarding *what* patients and visitors think, but also *why* they feel the way they do.

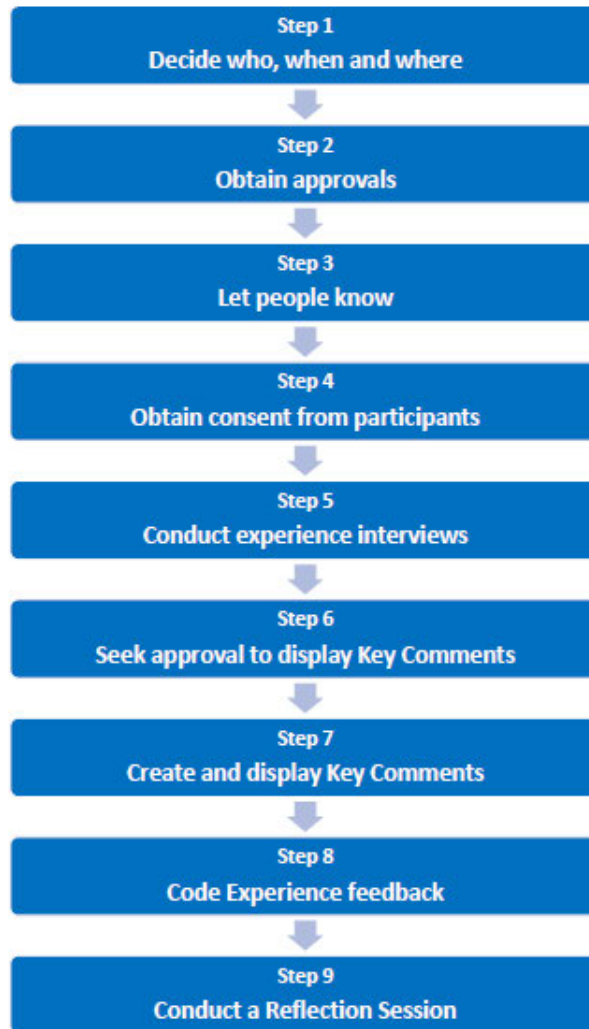
Unit specific: A common criticism and barrier to acceptance of experience feedback by nurses is that survey findings are not specific to individual units. **Specific experience data** is required to enhance acceptance by clinical nurses and to drive quality improvement at a unit level.

What do patients and family want from their hospital experience?

The Picker Institute (2020), leading international researchers on experiences of care, have identified the following issues to be the most important components of a patient's experience:

- **Fast access to reliable health advice**
- **Effective treatment delivered by trusted professionals**
- **Participation in decisions and respect for preferences**
- **Clear, comprehensible information and support for self-care**
- **Attention to physical and environmental needs**
- **Emotional support, empathy, and respect**
- **Involvement and support for family and carers**
- **Continuity of care and smooth transitions**

The RHEPORT Protocol



Step 1: Decide who, when and where

Who

The facilitator/s will be responsible for:

- Running RHEPORT
- Obtaining approvals
- Engaging clinical nurses and conducting information sessions with nurses and hospital staff
- Conducting interviews with the patients and their family members about their experiences
- Identifying 'negative comments'
- Creating and displaying posters
- Coding the experience findings
- Running feedback sessions

The facilitator can be one or several people. If there is more than one person involved, we suggest one person is designated as the primary Facilitator. We suggest a nurse or nurses within the organisation be the designated facilitator, although not necessarily from the same unit. **Why?** Nurses have 'insider knowledge' which allows them to recognise and help address problems in real-time. They can also escalate identified issues through the relevant channels.

The patients and family members: It is imperative to consider the cultural, language, and religious make-up of the patient and visitor population you will be interviewing.

'Effective communication coupled with identification of and respect for cultural differences is essential to the delivery of culturally competent care.' (White, Plompen, Tao et al. 2019)



Tips for success

- **Be aware of non-verbal clues**
However, do not jump to conclusions. A lack of eye contact for example may not mean that a person is disinterested.
- **Ask about relevant customs or traditions**
- **Avoid assumptions**
Check what has been discussed has been properly understood.
- **Ask for clarification** when needed
- **Consider an interpreter** or a **support person** for the participant

When

Depending upon how many patients and family members you interview, the process will take around two weeks to complete from obtaining approvals to the final post feedback guided reflection session. In the interests of capturing a complete experience snapshot we suggest you aim to visit every patient in the designated inpatient unit over the interview period.



Consider the day and time you plan on interviewing people

Consider admission and discharge patterns, staffing levels, rest hours, visiting hours and therapy hours. Most elective surgeries for example happen on weekdays, in the mornings. This means that many patient beds are empty Monday mornings, awaiting post-operative patients.

Where

RHEPORT is designed to be conducted in an individual medical or surgical inpatient unit.

Step 2: obtain approvals

It is essential to gain administrative approval, and Nurse Unit Manager approval before you commence this process of capturing and displaying patient and family feedback.

Ethical implications - The requirement for ethical approvals can vary depending on your purpose and your jurisdiction. Please seek advice from your local quality department.

Step 3: let people know

Clinical nurses

It is important that the clinical nurses are aware of the upcoming gathering and display of experience feedback and feel comfortable with it. A pre-information session with the nurses can be helpful to explain the details of the process and provide an opportunity for the nurses to discuss any questions or fears associated with the collection of feedback, particularly with the public display of feedback.

Patients and family members

Display information flyers* to advise nurses, patients, and family members that you will be shortly be conducting patient and family experience interviews on the unit.

Step 2: obtain consent from participants

After the information flyers have been displayed for at least one day, patient and family interviews can commence. Always check with the nurse in charge or the nurse looking after the patient if they feel the patient and/or family visitor is physically and mentally able to be approached to participate.

It is important to explain to the patient and or family member:

- Who you are
- The purpose of your visit
- How their comments will be used

Consent Script:

Hello my name is [name]. I am a registered nurse here at the [hospital name].

We are asking everyone on the ward [Unit] the same question today – ‘Can you tell me something memorable about your experience here so far?’

If you choose to participate, I will interview you about your experience and then I will read back to you the notes I have taken based on your comments. From those notes you can choose what your ‘key comments’ are. Any positive key comments will appear on a poster here on the unit, and brochures will be distributed for [number] of days. Negative key comments will be discussed with the unit nurses during a private meeting.

This feedback is anonymous. We will not use your name on the posters or brochures, nor will I collect or record your name. If you do consent and give approval to use your comments, we cannot however remove them at a later date.

You do not have to participate, and your care will not be jeopardised as a result of not participating.

Would you like to ask me any questions before you make a decision?

Step 5: conduct experience interviews

Question 1 is the **primary question**, with subsequent prompt questions to be asked if the previous question yields little feedback.

Question 1

*Can you tell me something **memorable** about your experience here so far?*

Asking about something memorable prompts the patient or family member to tell you about an experience they recall, rather than try and think of something positive or negative to tell you. Encourage the participant to discuss any and all memorable experiences. Highlight that something seemingly simple may be very meaningful.

Question 2

If your friend or family phones or comes in – what will you tell them about your experience here?

Question 3

Take me through what has happened during your stay

Question 4

Thinking about the ideal hospital experience - tell me about the reality

Question 5

Can you tell me your feelings associated with your hospital experience?

Allow the patient or family member to talk to you about their experiences, while you take notes. Experience interviews can take between 15 to 60 minutes. Once you feel the patient or family member has finished, read back the notes you have taken and ask them to identify 'key comments.' You may need to assist them with this. Key comments are the specific comments to appear publicly – or to be discussed during the nurse reflection sessions. You may need to highlight to the patient or family member specific words or stories from the notes taken.



Tip for success

Keep track of people interviewed by using a separate room or bed list*, rather than a list with patient names as this could jeopardise anonymity. Use the list only to ensure you have visited all patients. Do not use this form to take experience notes.

Using the RHEPORT Key Comments Template * enter the key comments into the excel spreadsheet. Flag key comments for review.



Remember not to collect any identifying data, and to remove any parts of the story which may compromise anonymity of the patient and or a staff member. Ideally this should be done in conjunction with the patient at the time of collecting the feedback and key comment.

Step 6: seek approval to display key comments

It is important to consider who will decide upon what is deemed negative? We suggest the interviewer flag negative comments and suggestions for review. Ideally Nurse Unit Managers and or the Nurse Educators should be given the courtesy of final approval regarding which comments appear publicly prior to display.

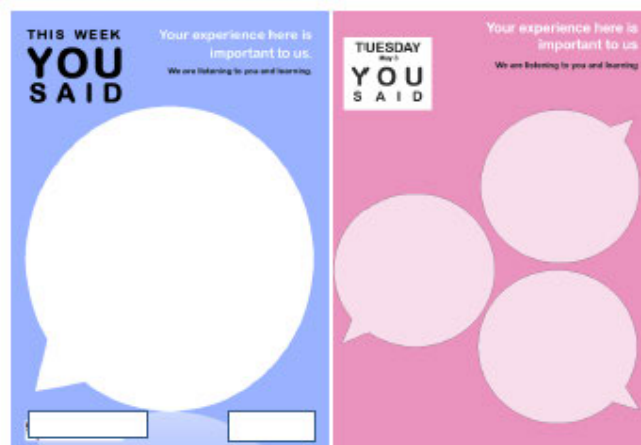


Patients, family members and nurses react positively to the public display of positive patient and family feedback. It is important that only positive key comments are publicly displayed (and this should be clearly conveyed to each patient or family after you have collected their experience feedback and decided upon their key comment). Patients and family should be advised that any negative comments and or suggestions they made will be discussed with senior staff and raised with the Unit nurses.

Step 7: create and display key comment posters

Using the poster and or brochure templates* create posters and brochures containing the positive key comments.

Poster Template Examples



Brochure Examples



Tips for success

- Simply cut and paste positive key comments from your RHEPORT Key Comments spreadsheet to the poster templates.
- Select a commonly used easy to read font such as **Arial**, **Helvetica**, **Times New Roman** and **Garamond**
- Ensure the font size is **LARGE** enough for easy reading at a distance
- Consider the poster placement height – can wheelchair users read the posters?
- Make sure the poster comments are not in the same order as interviews as this may increase the risk of non-confidentiality

Remember Make sure there are no identifying remarks about a patient, visitor or staff member.

Even identifying a staff member positively can have a detrimental effect on other staff members who may feel neglected as a result.

Only display positive comments.

Displaying negative comments has a negative impact on staff, and patients and visitors.

Step 6: code the key experience feedback

You will collect a substantial amount of qualitative feedback, both positive and negative and it is important to relay this feedback back to the nurses on the unit. While the nurses will have the opportunity to read the positive comments on the posters and brochures, a level of synthesis of all the comments is required in order to provide the nurses with a complete picture of how their patients and families are experiencing their hospital admission on their unit. In order to do this, you will need to deductively 'code' the data. Ideally two people would do this independently.

We suggest using the 'Picker dimensions of care' as a way to code the comments:

1. **Respect for patients' values, preferences and expressed needs** (providing dignity, respecting autonomy)
2. **Coordination and integration of care** (coordination of clinical care, support services etc.)
3. **Information, communication, and education** (for example information on clinical status, information on hospital processes of care, information to facilitate self-autonomy).
4. **Emotional Support and alleviation of fear and anxiety** (anxiety over treatment or outcome, anxiety over financial impact)
5. **Physical comfort** (includes pain management, assistance with activities, surrounding environment, feeling safe)
6. **Involvement of family and friends** (recognition of the importance of family and friends, and the support given by family and friends)
7. **Continuity and transition** (information regarding discharge, physical limitations)
8. **Access to care** (for example this could be ease of seeing a doctor or parking issues)

Plus

9. **Additional dimensions** (Facilitator/s to choose)

Using the RHEPORT Coding template (see example extract below), the facilitator or facilitators should read all the key comments along with the notes taken and decide which Picker domain of experience they relate to. Colour code the comments – in the example below blue is a positive comment, red is negative.

Key Comments Unit A		1	2	3	4	5	6	7	8	9
"When I call they [nurses] come - its fantastic and they are friendly. They chat to you"	Patient	X			X					
"The nurse introduce themselves - that is very nice. They told us they were going to look after [patient] until ten pm tonight"	Family			X	X			X		
"I had a pear that was like a piece of steel. It nearly broke my teeth."	Patient					X				
"The nurses acknowledge you and are interested. That makes me feel I'm not a number, I'm a human being"	Patient	X			X					
"There should be deodorants in the bathroom. Its very distressing when you have to go to the toilet and you are embarrassed"	Family				X	X				
"They could improve those showers - getting the temperature is impossible. The hard pillows are horrible, they need softer pillows. They do have different ones but you have to ask. The size of the cups are too small...they cant make a decent cup of tea, you expect a decent cup of tea that's hot. The nurses make it bearable here. They all smile at you. Nothing is too much trouble. They are very patient."	Patient	X				X				X

As demonstrated above key comments can be allocated to one domain or multiple domains.



Individual key comments can contain BOTH positive and negative feedback. For example:

'I think the nurses are kind and caring they really listen to me, but the food is terrible'

'I think the nurses are kind and caring they really listen to me...' could be coded under 'Respect for patients' values, preferences and expressed needs' and 'information, education and communication' as an example of positive feedback.

Whereas '...but the food is terrible' would be coded to 'physical comfort' an example of a negative comment.

After coding the experience feedback, identify the three domains with the most comments allocated to them (positive or negative). These are the dominant experience feedback themes for the unit.

Also identify the domain with the most positive comments, and the domain with the most negative comments.

In addition, it is important to identify any feedback considered as 'important'. Important feedback may be dealt with by the Unit manager and/or discussed with the staff during the feedback session.

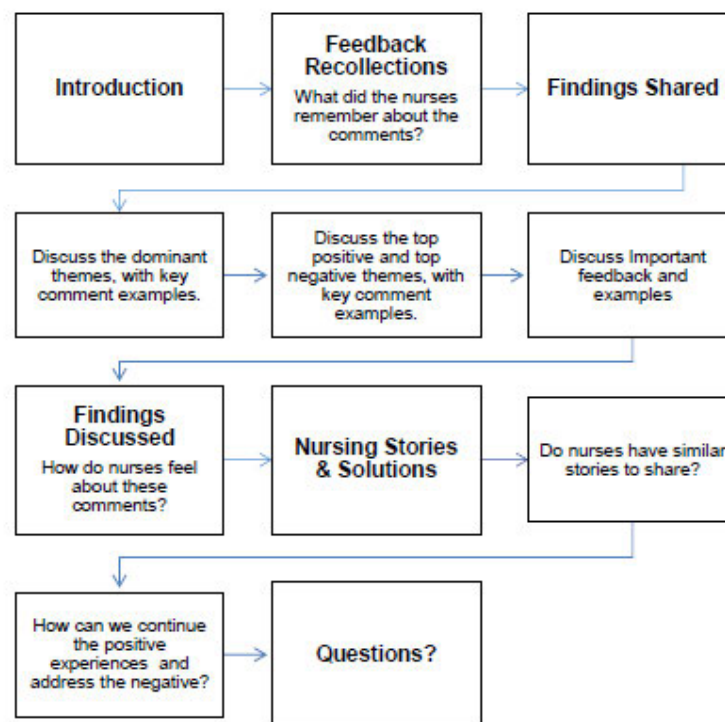
Examples of 'important' feedback include issues relating to a breach in safety and or policy regardless of how many times this was raised by patients or visitors. For example, a patient may state *'The nurse left the syringe in the tray in my room, so I put it in the bin in my room.'* This issue is significant enough to be brought to the attention of the manager and staff and should be discussed at the Reflection Session.

Step 8: conduction reflection session

Providing this valuable feedback to nurses and allowing for adequate discussion and reflection of both positive and negative feedback has the potential to improve the patient and visitor's experiences of care.

While it is good for staff morale to see the positive feedback, it is equally important that nurses are made aware of the negative feedback in a way that is non-accusatory and safe. This is achieved by running a post-feedback guided reflection session.

Shortly after displaying the posters during a staff meeting or education session conduct a Reflection Session following the steps below:



* Additional information and resources can be made available by contacting kellyed@bigpond.net.au

Thank you

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