Patient Participation in Nursing Care:  
A Focused Ethnography

Georgia Ann Tobiano  
RN, BN (Hons)

School of Nursing and Midwifery  
Griffith University

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Abstract

Patient-centred care has been recognised internationally as a way patients can participate in their nursing care to potentially improve their safety, yet widespread understanding of patient participation and ways to promote it is lacking. Further, nurses’ behaviours sometimes conflict with their reported support for patient participation. The aim of this study was to understand patient participation in nursing care in medical wards and the barriers to and facilitators of patient participation.

This study was a focused ethnography. Two hospitals participated in the study. Site 1 was located in Queensland and catered for public patients, while Site 2 was located in Victoria and catered for private patients. The setting for this study was four medical wards, two from each hospital. Patients and nurses were observed in practice and participated in semi-structured interviews. Observational field notes were analysed using both deductive and inductive content analysis. Interviews were transcribed and analysed using inductive content analysis.

Deductive analysis of observations of practice showed that the most frequent types of participation were in the categories ‘having dialogue with health care staff’ and ‘sharing knowledge’. Patients participated less frequently in the categories ‘partaking in planning’ and ‘managing self-care’. Inductive analysis of field notes demonstrated that nurses exerted control over care, evident in the category ‘maintaining control of work’.

Findings from 20 patient interviews, revealed four categories. In the category ‘valuing participation’ patients spoke about wanting to participate and seeing it as beneficial. The categories ‘exchanging intelligence’ and ‘on the lookout’, were ways patients reported participating in care. The final category ‘power imbalance’, revealed patients’ difficulty in enacting participation.

Analysis of 20 nurse interviews resulted in five categories. In the first category, ‘acknowledging patients as partners’, nurses valued the role patients could have in their care. However, the next category ‘managing risk’, showed nurses sometimes restricted participation due to safety and rules perceptions. The categories ‘enabling participation’ showed nurses’ verbal tactics to encourage participation and ‘hindering participation’ demonstrated nurses’ difficulty encouraging patients with certain characteristics. The final category, ‘realising participation’ showed ways patients participated in care.
Recommendations based on the barriers and facilitators found in this study are discussed in relation to the Theoretical Domains Framework. Major recommendations for nursing include strategies that address nurses’ social and professional role and identity, nurses’ beliefs about consequences, the environmental context and resources, and social influences at all levels of the hospital system. Future research endeavours suggested include qualitative and quantitative designs, projects that test and refine the conceptual framework and behaviour change projects to enhance practices of patient participation.

This study has contributed to new knowledge by providing understanding of how patient participation is perceived and enacted, the barriers to and facilitators of it and provided conceptual clarity of patient participation in nursing care. The preliminary conceptual framework proposed, shows meaningful interactions and exchanging clinical communication as foundational for patient participation. Next, nurses’ tailoring of care and approach towards the patient determines how patients participate in care activities. The framework has a feedback loop, showing nurses’ approach enhances meaningful interactions and clinical communication, but also that nurses must constantly cycle through the framework to ensure patients participate in care activities at an appropriate level. This study was set against a background of growing awareness to improve the safety of nursing care. Nurses should embrace and encourage patient participation to reap the benefits of a patient-centred approach to care.
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

(Signed)

Georgia Tobiano
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Acknowledgment of Papers included in this Thesis and Extent of Assistance

Included in this thesis are papers included in Chapter 2 and 4, which are all co-authored with other researchers. My contribution to each co-authored paper is outlined at the front of the relevant chapter. The bibliographic details (if published or accepted for publication)/status (if prepared or submitted for publication) for these papers including all authors, are:

Chapter 2


Chapter 4


(Signed) __________ (Date) __________
Georgia Tobiano

(Countersigned) __________ (Date) __________
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Presentation of study


Conference awards


Top student award, at International Society of Communication and Medicine Conference. 15-16 June, 2015. Montecatini Terme, Italy.
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I am in awe of how truly blessed I am to be surrounded by such wonderful people.
Chapter 1: Introduction

Introduction

Frequent adverse events occurring in hospitals highlight the importance of investigating strategies to improve patient safety. Patient participation in care is an approach that enables patients to engage in nursing activities and potentially enhance safety. However, little is known about patients’ and nurses’ perspectives on, and behaviours towards, patient participation in nursing care. Without this knowledge, the potential contribution that patients and nurses could make to patient participation may be overlooked.

The purpose of this research was to understand patient participation from the perspective of both patients and nurses, including the perceived barriers to and facilitators of participation. Additionally, an understanding of how participation occurs in practice was sought. Patient participation is viewed as a process, as it is transactional in nature where patients and nurses collaborate to provide care. As a process, it is made up of technical and interpersonal aspects. Thus, in this study an understanding of the process of patient participation is being sought, including how it is perceived, how it is behaved and what are the barriers and facilitators to this process. In order to understand the context for this research a description of adverse events, the patient safety movement and patient-centred care is provided. Next the aims of the study are outlined, followed by assumptions of the research and then the significance of the research. Finally a summary of the thesis chapters and format is given.

Background

Hospitals are not safe

Evidence of the burden of adverse events on hospitalised patients was established in early work, in two classic US studies that used randomised chart review (Brennan et al., 1991; Thomas, Studdert, Newhouse, Zbar & et al., 1999). Adverse events are characterised by two defining elements: first, patient injury occurs and second, the injury is caused by medical management rather than patient disease or harm (Brennan et al., 1991). US researchers discovered that up to 98,000 acute care patients suffered an
adverse event (Brennan et al., 1991; Thomas et al., 1999) with 6.6% to 13.6% of these adverse events resulting in death and 2.6 to 7.4% resulted in permanent disability (Brennan et al., 1991; Thomas et al., 1999). More than half (51%) of the cases of adverse events were preventable, at an estimated cost to US healthcare organisations of more than $US600 million (Thomas et al., 1999).

Adverse events also occur in Australian hospitals. In the landmark ‘The Quality in Australian Health Care Study’, 14,655 patient records were assessed and it was identified that 16.6% of admissions were associated with an adverse event and 4.9% resulted in patient death (Wilson et al., 1995). Compared to the US, Australian data demonstrated higher rates of permanent disability (13.7%) attributed to adverse events (Wilson et al., 1995). In Australia more than half of the adverse events identified were preventable (Wilson et al., 1995) and predicted to cost the Australian health care system an estimated $AU438 million (Rigby, Clark & Runciman, 1999). The cost of these preventable adverse events is substantial in terms of monetary loss, human lives, and permanent physical harm.

Researchers in Australia have used a variety of methods to assess the frequency of adverse events since ‘The Quality in Australian Health Care Study’ (Appendix A). These studies are not directly comparable due to the different methods used but provide a sense of the adverse events occurring in Australian hospitals. Researchers undertaking chart review or using hospital datasets suggest an adverse event rate of 6.9–16.6%. Select groups like surgical populations have higher rates of adverse events (15.5–23.1%) (Hauck, Zhao & Jackson, 2012; Kable, Gibberd & Spigelman, 2008; Kable, Gibberd & Spigelman, 2002; Moje, Jackson & McNair, 2006), and cardiac patients have the highest rate of adverse events (36.9%) (Ehsani, Duckett & Jackson, 2007). These data were mostly collected in hospitals in New South Wales and South Australia. Australia-wide hospital data on adverse event rates are reported biennially by the Australian Institute of Health and Welfare (AIHW). From 2000–2014, an adverse event rate of around 5% for hospitals was reported. However, the AIHW may under-report adverse event rates due to their coding system (Australian Institute of Health and Welfare, 2015), which relies on adverse events being coded under a list of present diagnoses and some adverse events are not identifiable using these codes.

The outcomes of these frequent adverse events are problematic for Australian hospitals. The cost of adverse events ranged from an estimated $AU42–460 million per
annum (Ehsani et al., 2007; Ehsani, Jackson & Duckett, 2006), which may be attributable to the extra 7–10 bed days created by adverse events (Ehsani et al., 2007; Ehsani et al., 2006; Kable et al., 2002). In terms of permanent disability, the results are variable depending on the method of data collection. Researchers undertaking chart review suggest up to 17% of adverse events resulted in permanent disability (Kable et al., 2002), while researchers’ observing patient transfers between hospital settings, witnessed no transfers that resulted in disability (McLaughlin, Leslie, Williams & Dobb, 2007). Mortality rates are variable depending on how data were collected; hospital data sets and charts suggest around 4–5% of patients die due to adverse events (Ehsani et al., 2007; Kable et al., 2002) supporting ‘The Quality in Australian Health Care Study’, while patients observed during hospital transfers had higher rates of death due to adverse events (11.7%) (McLaughlin et al., 2007). Interestingly, like ‘The Quality in Australian Health Care Study’, around half of the adverse events were considered preventable (Kable et al., 2002; McLaughlin et al., 2007).

More recent publications demonstrate that adverse events are problematic worldwide. A systematic review that included studies from developed countries, like Australia, Canada, New Zealand and the United Kingdom, showed 9.2% of patients experienced an adverse event; 43.5% of these adverse events were preventable. Of those patients who suffered an adverse event, 7% died or suffered permanent disability (de Vries, Ramrattan, Smorenburg, Gouma & Boermeester, 2008). Average adverse event rates in developed countries are comparable with developing and transitional countries, where 8.2–10.5% of patients experience an adverse event. However, these adverse events were deemed more preventable (60–80%) (Aranaz-Andres et al., 2011; Wilson et al., 2012). In terms of nursing, 2699 patient charts from 22 acute medical wards in 11 Canadian hospitals were reviewed for six nurse-related adverse events (D’Amour, D'Amour, Dubois, Tchouaket & Clarke, 2014). Researchers discovered 1 in 7 patients (15.3%) experienced a nurse-related adverse event, which were most frequently falls or medication errors (D’Amour et al., 2014). Dutch researchers suggest adverse event rates may be improving due to patient safety initiatives in their country, as preventable adverse event rates have dropped by 45%, from 2.9% to 1.6% during the period 2008 to 2011–2012 (Baines, Langelaan, de Bruijne, Spreeuwenberg & Wagner, 2015). Thus, both seminal research and recent analyses show adverse events continue to occur in hospitals.
**Patient safety movement**

In light of a startling frequency of adverse event publicised in the late 1990s, a patient safety movement began to try to ensure patients received safe and quality care when hospitalised. One of the most monumental reports was the Institute of Medicine’s (IOM) (1999) work “To Err is Human: Building a Safer Health System”, which advocated a systems approach towards safety, acknowledging that upstream deficiencies influenced adverse events, rather than individual clinician factors. In turn, many national bodies advocated a systems approach (Donaldson, 2002). Australia responded by establishing the Australian Council for Safety and Quality in Healthcare in 2000, now the Australian Commission on Safety and Quality in Healthcare (ACSQHC), who developed action plans to address hospital system deficiencies (Australian Institute of Health and Welfare, 2013). Overall, these historic international groups provided first-steps in challenging healthcare practice to reduce adverse event rates.

International and national strategies closely aligned in their proposed actions to achieve safer hospitals. For instance, mandatory reporting was advocated to increase transparency in hospital care, thus enhancing investigation of errors to learn from mistakes (Kohn et al., 1999; National Health Service, 2000; The Australian Council for Safety and Quality in Health Care, 2000). In addition, practice standards were enforced to help prevent errors (Kohn et al., 1999; The Australian Council for Safety and Quality in Health Care, 2000; The Department of Health, 2002). Importantly, health care systems required reconfiguration (National Health Service, 2000; The Australian Council for Safety and Quality in Health Care, 2002). The influential report ‘Crossing the Quality Chasm: A New Health System for the 21st Century’ addressed service reconfiguration, stating that health care systems needed to epitomise the core values of safe, effective, patient-centred, timely, efficient and equitable care to improve delivery of care (Institute of Medicine, 2001). Today, many national programmes are based on these broad and multi-faceted strategies.

Leading international organisations like the World Health Organisation (WHO) were instrumental in the patient safety movement. WHO met in 2002, calling for action to make patient safety a priority and in 2004 the World Alliance for Patient Safety was formed, which comprised an international group of people with the combined expertise, research and resources to address the complexity of patient safety issues (World Health Organisation, 2015). The World Health Alliance developed six action areas including
health-care associated infection, patient and consumer involvement, development of patient safety taxonomy, further research in the field, development of solutions and prevention mechanisms and methods of reporting and learning as areas to improve patient safety. One of these action areas, involving patients and consumers, led to the development of a program called ‘Patients for Patient Safety (PFPS)’, recognising that patients can help identify risks in their care and devise solutions. For example, PFPS have recently met to discuss strategies to enhance the patient’s role in participating in the improvement of medication safety.

Researchers have an increasing interest in patient involvement in safety (Peat, Entwistle, Hall, Birks & Golder, 2010), inclusive of patients monitoring their care and reporting errors (Hall et al., 2010; Koutantji, Davis, Vincent & Coulter, 2005; Peat et al., 2010). Promisingly, patients report being receptive to supporting their role in intercepting errors (Schwappach, 2010; Schwappach & Wernli, 2010a; Schwappach, Frank, Koppenberg, Müller & Wasserfallen, 2011; Waterman et al., 2006). Nurses too state they are supportive of patients participating to prevent error (Hor, Godbold, Collier & Iedema, 2013; Schwappach, Frank & Davis, 2013), which may enhance their relationship with the patient (Schwappach, Hochreutener & Wernli, 2010).

However, the enactment of patient participation in safety is complex with many factors hindering success. For instance, patients’ willingness to enhance safety depends on the perceived risk (Rathert, Brandt & Williams, 2012; Schwappach & Wernli, 2010a), trust of nurses (Rathert, Huddleston & Pak, 2011), knowledge (Davis, Jacklin, Sevdalis & Vincent, 2007; Vaismoradi, Jordan & Kangasniemi, 2015), illness factors (Davis et al., 2007) and reluctance to speak up (Schwappach, 2008). In addition, health care workers’ interactions can influence the success of patients’ participation in safety, including their ability to communicate with patients (Giles, Lawton, Din & McEachan, 2013; Hor et al., 2013), their relationship with the patient (Hor et al., 2013) and how facilitating they are (Vaismoradi et al., 2015). Further, the type of error being reported (Davis, Sevdalis, Jacklin & Vincent, 2012) and norms within the setting can have an impact on patients’ involvement (Schwappach & Wernli, 2010b). Despite international attention, patient participation as a means to improve safety is influenced by many factors making it challenging to practice.

**Patient-centred care**
Patient-centred care became internationally recognised as an important dimension of safe care during the patient safety movement, despite being a concept that existed for decades previously. Today, various countries have implemented patient-centred care policies in hospitals (Richards, 2015), with a range of initiatives in place to measure patient-centeredness in practice (Groene, Skau & Frølich, 2008). In Australia, hospitals are guided by ten quality and safety standards, with patient-centred care being inherent throughout all standards (Australian Commission on Safety and Quality in Health Care, 2012). Australian hospitals need to meet these standards to maintain accreditation. Recently, the ACSQHC have released a draft of the second version of these quality and safety standards that also focuses on patient-centred care (Australian Commission on Safety and Quality in Health Care, 2015a). The phrase patient-centred care stirs philosophical debate amongst scholars in regards to accepted terminology and definition. For terminology, much diverse taxonomy is used to describe ‘patient-centred’ (Table 1). Although not coined by the US Institute of Medicine committee, the groups adoption of the term ‘patient-centred’ in their report ‘Crossing the Quality Chasm: A New Health System for the 21st Century’, (Institute of Medicine, 2001), has been instrumental in uptake of this terminology. Today, some well-known not-for-profit organisations that advocate patients’ rights, like Planetree Inc. and Picker Institute Europe, adopt the term patient-centred (Frampton et al., 2008; Picker Institute Europe, 2016). In Australia, the ACSQHC prefers the term patient and consumer centred care (Australian Commission on Safety and Quality in Health Care, 2016). The choice of term is often dependent on the context and the taxonomy ‘patient-centred care’ is often used in hospital systems (Morgan & Yoder, 2012).
Table 1 Taxonomy Used for ‘Patient-Centred’

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<td>Family-</td>
<td>(Kuo et al., 2012; Mitchell, Chaboyer, Burmeister &amp; Foster, 2009; Shields, Pratt &amp; Hunter, 2006)</td>
<td>- focused</td>
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<td>Individual-</td>
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<td>Patient-and-family</td>
<td>(Institute for Patient- and Family-Centred Care, 2010)</td>
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<td>Person-</td>
<td>(Edvardsson, Sandman &amp; Rasmussen, 2008; Ekman et al., 2011; McCormack, 2004)</td>
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<td>Relationship-</td>
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In terms of defining patient-centred care, researchers continue to undertake literature reviews in an attempt to clarify what patient-centred care represents. Three reviews were identified in which researchers included literature from a range of sources and settings that was applicable to a variety of health-care professionals (Hughes et al., 2008; Kitson, Marshall, Bassett & Zeitz, 2013; Scholl, Zill, Harter & Dirmaier, 2014). Two were narrative reviews (Hughes et al., 2008; Kitson et al., 2013; Pelletier, 2014), while one was systematic (Scholl et al., 2014). Cross analysis of these reviews highlights similarities in the defining elements of patient-centred care, suggesting some important elements for achieving patient-centred care.

First, respect for the patient is essential to patient-centred care. This entails acknowledging the patient as a unique person with certain values, beliefs, preferences and needs that need to be understood within the patient’s wider biopsychosocial world.
Patient-centred communication is the second element for patient-centred care; healthcare professionals need to communicate effectively, which incorporates openness, being interactional and attentive listening. Further, communication exchanges need to include both patients’ and healthcare professionals’ expert knowledge. Third, a relationship between the patient and healthcare professional is required. The relationship needs to be therapeutic, genuine, collaborative and reciprocal, and further, trust and rapport needs to be built. Finally, patient participation is a key feature of patient-centred care. Nurses need to partner with patients by sharing responsibility for care through activating and empowering patients to undertake care activities where possible, but also allow patients autonomy and choice. These four concepts of patient-centred care are all influenced by context. The context needs to be supportive, in terms of organisational and policy support, coordination of care across settings, but also teamwork, ultimately creating a therapeutic environment for patient-centred care to occur.

For many, family are viewed as an extension of the patient, who cannot be disconnected from the patient. The definition of family-centred care offered by Shields et al. (2006) emphasises this point, describing family-centred care as an approach that is “…planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients” (p. 1318). The Institute of Patient- and Family-Centre Care (2010) further supports this, describing family as a natural link and support for patients, especially those populations viewed as dependent, such as children, older patients and patients with chronic illness. Similarities between principles of patient-centred care and family-centred care are evident. Kuo et al. (2012) conducted a review, comparing multiple definitions of family-centred care. Like patient-centred care, family-centred care is characterised by respect for family members’ preferences, skills and expertise, communication and information-sharing and partnership and collaboration between family members and nurses (Kuo et al., 2012). Instead of participation, family-centred care researchers use the term ‘negotiation’, meaning the outcomes of care are flexible (Kuo et al., 2012). However, Shields et al. (2006), links negotiation to parent participation in care, by outlining the nurse’s role in assessing parents’ willingness and ability for participation in the child’s care. The importance of context is also highlighted in family-centred care literature, including family member involvement in all contexts, as well as taking in the child and family’s larger social life (Randall, Munns & Shields, 2013).
The importance of context in patient-centred care has been highlighted by many researchers. For instance, researchers who have conducted reviews of patient-centred care specific to the rehabilitation setting, emphasise the nurse as wholistic, encouraging patients to be involved in self-management and preparations for home-life (Lepelge et al., 2007; Morgan & Yoder, 2012). On the other hand, Hobbs’ (2009) review of patient-centred care in the acute care setting, suggested nurses were more controlling when the patient was vulnerable and unable to conduct self-care. Patient acuity may be a specific challenge in the acute care environment (Hobbs, 2009). Likewise, long-term care institutions approach to patient-centred care may have a slightly different focus. Enacting patient-centred care in long-term care institutions emphasises encouraging ‘everydayness’ in patients’ lives (Yoon, Roberts, Grau & Edvardsson, 2015), which nurses can promote through patients having a meaningful life (Edvardsson, Fetherstonhaugh & Nay, 2010). Participating in everyday tasks and activities that match patients’ needs and interests helps create meaning (Edvardsson, Varraillhon & Edvardsson, 2014). Edvardsson et al. (2010) explain the importance for dementia patients in long-term facilities to maintain their self-image and normality within the facility; a place that patients call home. Overall, these findings support McCormack and McCance’s (2006) theory of person-centred nursing, highlighting the context as influencing the success of patient-centred care.

There is a growing body of evidence of the outcomes related to patient-centred care. The strongest outcome for patient-centred care appears to be patient satisfaction (Rathert, Wyrwich & Boren, 2013), especially in the context of doctor-patient consultations (Dwamena et al., 2012; Lewin, Skea, Entwistle, Zwarenstein & Dick, 2001; McMillan et al., 2013). Further, patient-centred care appears to positively influence the quality of care for dementia patients in residential care (Sjögren, Lindkvist, Sandman, Zingmark & Edvardsson, 2013). More individualised patient-centred approaches have had an impact on outcomes like better self-care capabilities (Coulter, 2015; Rathert et al., 2013) and better adherence to treatment (Rathert et al., 2013). However, this evidence is less robust. The evidence for patient-centred care influencing health outcomes is mixed. Personalised care planning had some small effects on physical health like blood glucose levels and systolic blood pressure, as well as psychological health like depression (Coulter, 2015). In addition, patient-centred care may improve emotional well-being (Dwamena et al., 2012; McMillan et al., 2013;
Stewart et al., 2000), perceived quality of life (Sjögren et al., 2013), enhance or maintain patients abilities to undertake activities of daily living (Ekman et al., 2012; Sjögren et al., 2013) and reduce mortality and symptoms (Rathert et al., 2013). However, further evidence is required. Finally, there is a body of evidence suggesting service-level outcomes, like reduced length of stay, are related to patient-centred care (Ekman et al., 2012; McMillan et al., 2013; Olsson, Karlsson & Ekman, 2006). Overall, a variety of interventions have been tested and outcomes measured (Amati, McDonald, Majeed, Dubois & Rawaf, 2011); further research is required to establish the relationship between patient-centred care interventions and outcomes.

For nurses, improved outcomes due to patient-centred care are evident. Having a caring orientation towards nursing, being a philosophy to care where nurses consider patients’ needs and perspectives, encourage patient participation and value partnerships with patients, is reported to positively affect hospital nurses’ mental health (Drach-Zahavy, 2009). Further, patient-centred care increases hospital nurses’ satisfaction with work and care (Lehuluante, Nilsson & Edvardsson, 2012). In long-term care settings, enacting patient-centred care has been shown to decrease nurses’ stress of conscience, meaning nurses’ guilty conscience when they are unable to enact the care they want to provide, (Edvardsson, Sandman & Borell, 2014; Sjögren, Lindkvist, Sandman, Zingmark & Edvardsson, 2015), and increase nurses’ satisfaction (Edvardsson, Fetherstonhaugh, McAuliffe, Nay & Chenco, 2011).

Research aims

The aim of this study was to understand nurses’ and patients’ perceptions of, and behaviours towards, patient participation in nursing care. To achieve this, a focused ethnography was conducted that included interviews and observations of practice. Understanding potential barriers and facilitators was explored to find ways to support the practice of patient participation in hospitals. The specific research questions this research aimed to investigate include:

1. What are patients’ and nurses’ perceptions of patient participation in care?
2. What patient and nurse behaviours demonstrate patient participation in nursing care?
3. What are barriers to and facilitators of patient participation as perceived by patients and nurses?
The results may inform future strategies to promote the implementation and/or improvement of patient participation in nursing care in hospitals.

**Assumptions**

This research is underpinned by the assumption that nursing involves assessing and assisting patients to increase or maximise their independence to perform activities. This view is consistent with theories like those of ‘Virginia Henderson’s need theory’, and conceptual models like ‘Ormen’s self-care model of nursing’ and the “Roper, Logan and Tierney model of nursing’ (which evolved from Henderson’s work). In line with these views, patients have needs and may require assistance to perform activities of daily living (Williams, 2015) or self-care (Parker, Smith & ebrary, 2010). Patients have developmental needs and are capable of continuous self-care (Fitzpatrick & Whall, 2005); paternalistic environments where all care is attended for the patient is in contrast to these views. Health is the ability to function independently in activities of daily living (Fitzpatrick & Whall, 2005; Williams, 2015) and make the patient whole. However, this can be influenced by many factors like age, culture, intellectual capabilities (Parker et al., 2010), biological, psychological, sociocultural, environmental, politico-economic factors (Williams, 2015). The nurse’s role is individualising care, they adjust their methods of helping based on patients’ current needs to maintain independence (Fitzpatrick & Whall, 2005; Parker et al., 2010). Nurses discover patients’ self-care deficits and help them meet their self-care demands (Parker et al., 2010). Nurses constantly engage with patients to assess their progress on the scale of dependent to independent, and assess needs, abilities and preferences, to determine interventions to increase independence (Williams, 2015).

**Significance**

This study is significant for three reasons. First, this research will provide a better understanding of the process of patient participation, which may assist in providing clarity on how to enact it in practice and may in turn improve patient and nurse outcomes. Second, by deepening our understanding of the barriers to and facilitators of patient participation, this research will uncover strategies to enhance the practice of patient participation in practice. Third, this study may develop our conceptual understanding of patient participation. Below, each of these points are described.
Enacting patient participation

This research is firstly significant because it will enhance our understanding of the process of patient participation. In Australia, hospital standards state patients should participate in their care, however, there are no clear guidelines on how to enact patient participation. Thus, there is an abundance of health care policy written endorsing patient participation but these policies may not be consistently implemented if patient participation is not clearly defined.

This study will help to address this issue by observing patient participation in its naturalistic setting to understand how it is currently practiced. Further, interviews with patients and nurses will provide meaning for what patient participation is from the consumer and health care worker viewpoint. This could lead to more clarity around how to enact patient participation, from the perspective of patient and nurse acceptability.

In turn, new guidelines could be built that provide clearer instructions on how to enact patient participation. With clearer guidelines on the process of patient participation, tertiary education and ongoing education for nurses could inform nurses on how to involve patients more in care. Further, resources could be developed for patients to demonstrate how they can participate in care. Thus, this study may reduce the haphazard and ambiguous enactment of patient participation due to lack of definition, addressing the clear tension between policy and practice.

By understanding how to enact patient participation, patients and nurses should experience better outcomes in practice. When patients participate in their care they may enhance their own safety by identifying lapses in care (Coulter & Ellins, 2007; Longtin et al., 2010), given they witness all care (Koutantji et al., 2005). The benefits of patient participation on safety are evident, with the risk of experiencing an adverse event decreased by half when patient participation is implemented (Weingart et al., 2011). In addition, patient safety has been enhanced when patients manage their own medication (Hall et al., 2010). However, more robust evidence for the influence of patient participation on safety is needed (Berger, Flickinger, Pfoh, Martinez & Dy, 2013; Schwappach, 2010). Given the burden of adverse events and their high preventability, strategies to support patient participation in care uncovered in this study, will be significant.
Some other benefits of participation for patients are apparent. In the context of decision making in chronic disease, evidence of the benefits for patients is mounting (Longtin et al., 2010). Patient health status may be improved through patient participation with increased mobility (Arnetz, Almin, Bergstrom, Franzen & Nilsson, 2004), reduced complications (Rachmani, Levi, Slavachevski, Avin & Ravid, 2002) and reduced cardiac symptoms (Arnetz et al., 2010) associated with active participation. Further, patient participation enhances the health care experience (Hibbard & Greene, 2013; Weingart et al., 2011), and enhances patients’ feelings of certainty (Dudas et al., 2013) and commitment to care (Höglund et al., 2010).

Patient participation should improve work for nurses. With the complexity of health care systems and the pressures put on nurses, allowing patients to improve safety through participation could improve job satisfaction. With the anticipated reduced adverse events owing to patient participation, nurses could deal with less litigation, complaints and the psychological aspects of making an error, further contributing to satisfaction levels (WHO, 2005). However, these suggested outcomes of patient participation require testing. Some outcomes of encouraging patient participation in hospital care, included nurses reporting increased positive feedback from patients and family members, which in turn made nurses feel respected (Schwappach et al., 2010).

**Strategies to enhance patient participation**

This research is significant because it will uncover strategies to enhance patient participation. Researchers suggest that patient-centred care practices, inclusive of patient participation, are difficult to achieve in practice (Ekman et al., 2011), which may be influenced by nurses’ willingness to involve patients in their care (Angel, Sanne & Kirsten Norup, 2015). There is little benefit implementing more active forms of patient participation without understanding both parties’ willingness and perspectives around issues related to patient participation. Further, observations of patient participation in the setting where it occurs provides a real-world understanding of the factors that influence its implementation.

By investigating barriers and facilitators, strategies to enhance patient participation will be uncovered. Having this understanding will allow prioritisation of those strategies that support the patient and nurse’s role in patient participation, as
perceived by them. For instance, practice improvement strategies that address the barriers and foster the facilitators may be suggested for nurses.

If implemented, these strategies may in turn help achieve Australian national standards for ‘partnering with consumers’ in hospitals. Health care organisations may be able to better incorporate existing health care policy into clinical practice by knowing the barriers to and facilitators of achieving patient participation. Alternatively, this study could provide direction for those who develop organisational policies to create new strategies that build on patients’ and nurses’ strengths, thus enhancing patient participation in care.

**Contributing to conceptual clarity**

Finally, this study may assist in furthering our conceptual understanding of patient participation. Currently, the term patient participation lacks conceptual clarity (Longtin et al., 2010). The conceptualisations available are in a state of constant development (Rycroft-Malone & Bucknall, 2013). Thus, the empirical knowledge gained from this study may provide new insights into how to conceptualise patient participation or fill gaps in previous conceptualisations. Further, the knowledge gained from this study may help evaluate previous conceptualisations checking the comprehensiveness of content, logical congruence and/or legitimacy (Fawcett & Desanto-Madeya, 2013). This process of evaluation, may uncover why previous conceptualisations are ineffective, given patient participation is not optimised in practice. Feasibly, this study may lead to a new conceptualisation of patient participation to be developed, which may be beneficial for practice.

In depth study of process will assist in gaining conceptual clarity for patient participation. This thesis contributes to nursing as a discipline, because this study adds to nursing knowledge. This study will contribute to the long running debate of what is nursing by providing conceptual clarity around the process of patient participation. With this clarity, nurses can be better informed in their practice, starting with their education. Nursing is assisting patients to participate at their maximum level of function, thus nurses need to know how to enable this; and this study directly aims to provide understanding of this process.
Overview of the thesis structure

This study is a focused ethnography that aimed to investigate patient participation in nursing care. This first chapter has reported on the background of this study. Further, the aims and significance for nursing care has been discussed. The ensuing chapters are outlined in the subsequent section.

The literature relating to patient participation in nursing care is reviewed in the second chapter. This includes a review and critical appraisal of patients’ and nurses’ perceptions and behaviours related to participation in a variety of contexts, including the barriers and facilitators they perceive. A published review is presented that focuses specifically on patient participation in the medical ward context. Finally, an update considering reviews made available since this publication is presented.

In Chapter 3 an outline of the ethnographic methodology used is provided. The setting, ethical considerations and sample for this ethnography are described. Next, data collection methods used for this ethnography, including interviews and observations in the field are presented. An overview of the data analysis and methods of rigour are detailed. How the researcher entered and left the field is also described.

The findings of the study are presented in Chapter 4 and are presented in two published papers and one paper under review. Fifteen nurses and 28 patients were observed, and 40 interviews were conducted with patients and nurses. An introduction to each paper is provided and each published paper provides details of the design, sample, data collection, data analysis and ethical considerations.

In the final chapter, findings of the overall study are discussed. The findings from all published studies in Chapter 4 are considered and a conceptual synthesis is performed. A preliminary conceptual framework is then presented. Implications and recommendations for nursing are disclosed. Finally, the limitations and conclusions from the study are presented.

Summary

In summary, adverse events occur frequently in hospitals, highlighting the importance of patient safety initiatives, inclusive of patient-centred care. Patient participation has been suggested as an approach to increase patient safety and is an integral component of patient-centred care. This study aims to uncover new knowledge
about patient participation in their care. Examining this area of research may assist in understanding how it is practiced, how to enhance its practice and how to conceptually understand it. In the next chapter the literature related to patient participation in nursing care is summarised and critically examined.
Chapter 2: Literature Review

Statements of contribution to co-authored papers

One ‘Statement of contributions to co-authored papers’ is presented for the published Paper 1 presented in this chapter.

Statement of Contribution to Co-Authored Published Paper

This chapter includes a co-authored paper. The bibliographic details (if published or accepted for publication) states (if prepared or submitted for publication) of the co-authored paper, including all authors, are:


My contribution to the paper involved:

Conception and design of the research project, analysis and interpretation of the data and drafting and critical revision so as to contribute significantly to the final output.

(Signed) ___________________________ (Date) 5/2/16
Georgia Tobiano

(Countersigned) ______________________ (Date) 5/2/16
Corresponding author of paper: Professor Andrea Marshall

(Countersigned) ______________________ (Date) 3/2/16
Corresponding author of paper: Professor Tracey Bucknall

(Countersigned) ______________________ (Date) 6/2/16
Corresponding author of paper: Professor Wendy Chaboyer

(Countersigned) ______________________ (Date) 6/2/16
Supervisor: Professor Wendy Chaboyer
Introduction

In this chapter, current conceptualisations and issues associated with the term ‘patient participation’ will be examined as patient participation is the focus of this study. Next a review of patient participation in nursing care will be provided in two parts, first, studies in any hospital setting will be presented (unpublished review) and then a published review is presented, which only focuses on medical wards (Tobiano, Marshall, Bucknall & Chaboyer, 2015c). For each of these reviews the methods are described and data are extracted, appraised and described. In the first unpublished review, patient perceptions, nurse perceptions, patient and nurse behaviours, barriers and facilitators are summarised, the methodological quality assessed and critical appraisal presented. Next the published review is presented. Finally, these reviews are followed by an update of any literature reviews conducted since Paper 1 was published.

Conceptualising patient participation

There is no universally accepted term for patient participation. Various terminologies used synonymously with ‘participation’ include collaboration, involvement, partnership (Cahill, 1998; Longtin et al., 2010) and engagement (Barello, Graffigna, Vegni & Bosio, 2014). In addition, older conceptualisations associate patient participation with the activity of decision-making (Longtin et al., 2010). However, researchers have confirmed that patient participation entails more than decision-making (Eldh, Luhr & Ehnfors, 2015). This lack of clarity can be seen in the way different countries, governments, decision-makers and organisations continue to use varying terms for and definitions of patient participation in their policies and documents (Pelletier, 2014).

A clear and consistent definition of patient participation is lacking (Longtin et al., 2010). Concept analysis methodology has been used to provide meaning for this vague, yet frequently used term in nursing. Cahill’s (1996) concept analysis of ‘patient participation’ was updated by Sahlsten and team in 2008 whose findings were largely the same, although Sahlsten et al. (2008) provided more detail. As a result, patient participation in nursing has been conceptualised as having four defining attributes. First, an established relationship is required for patient participation, which includes mutual trust and respect. Second, the nurse needs to surrender power and control and empower patients as equal and responsible for self-care activities. Third, meaningful information
and knowledge-sharing is a requirement, where patients’ opinions and expectations are gained. Finally, participation is characterised by both patients and nurses being involved in intellectual and/or physical activities, which requires the nurse to support the patient to their level of willingness (Sahlsten et al., 2008). This definition has influenced research in the area (Eldh et al., 2015; Thórarinsdóttir & Kristjánsson, 2014).

Growing in popularity is the term ‘patient engagement’, which appears to be used synonymously with ‘patient participation’. This term has grown in use since 2010 and is particularly prevalent in US literature (Barello, Graffigna & Vegni, 2012). There appears to be similarities between how the term patient engagement and patient participation in nursing care are conceptualised. Like patient participation, patient engagement requires a partnership between the patient and nurses, based on strong interaction, such as information-sharing, and relational elements (Barello et al., 2012; Barello et al., 2014). This is seen as a way to engage with patients to elicit their opinions and needs (Barello et al., 2014). The term ‘engage’ is also used to describe patient involvement in what Sahlsten et al. (2008) would term ‘intellectual activities’, like planning, making choices and decisions (Barello et al., 2014).

Interestingly, patient engagement literature does not focus on nurses releasing power and control; instead these researchers place emphasis on the patient. Patient engagement researchers state patients need to be empowered by having access to information, education, support and skills, which allows them to engage with nurses (Pelletier & Stichler, 2013). This idea aligns with patient participation literature, where information-sharing is viewed as essential for patients to participate (Sahlsten et al., 2008). Patient engagement researchers’ focus on shifting the authority to the patient is an appealing viewpoint when considered within a patient-centred framework. Another defining feature of the patient engagement literature is patient activation, whereby patients are willing and able to act (Hibbard & Greene, 2013). Patients are activated when they change their behaviour to improve their own health (Hibbard & Greene, 2013; Pelletier & Stichler, 2013), a concept that aligns with Sahlsten et al.’s (2008) defining attribute ‘mutual engagement in intellectual and/or physical activities’, which requires patient activation.

There are certainly similarities between the concepts patient participation and patient engagement described in the literature. However, the researchers adopting each term do not always acknowledge each other’s work. Overall, patient participation and
patient engagement incur the same challenges; there is no clear definition and thus no clear guidelines on how to enact it (Barello et al., 2014). There is a need for empirical research to deepen understanding of what constitutes patient participation/engagement (Pelletier & Stichler, 2013). Without this, nurses are at risk of supporting patient participation in haphazard ways. In this study the term ‘patient participation’ will be adopted, due to its prevalence in the context of Australian and European research.

In Australian health policy, the terms patient and consumer participation are frequently used. One Australian health care standard is entitled “partnering with consumers”, which outlines the rights of patients and consumers to participate in many aspects of health care (Australian Commission on Safety and Quality in Health Care, 2012). Consumers are supported to participate in service planning, designing care and service measurement and evaluation (Australian Commission on Safety and Quality in Health Care, 2012). For designing care, the standard specifically outlines patients’ participation in their individual care. The requirement for nurses to ‘partner’ with patients and consumers is incorporated in seven of the ten remaining standards. The concept of partnership is closely tied to patient participation. To achieve partnerships, patients share responsibility with nurses and participate in care and decision-making (Wiggins, 2008). Nurse-patient partnerships are underpinned by communication, trust, respect and reciprocity (Wiggins, 2008). Thus, it appears that a partnership is required to promote patient participation, and vice versa, making it an appropriate choice of term for Australian health care standards.

Review of patient participation in nursing care in hospital settings

In the following section, a review of patient participation in nursing care in any hospital setting is presented. The methods that guided this review are described.

Inclusion and exclusion criteria

The search strategy was guided by population of interest, intervention of interest and outcome of interest (Polit & Beck, 2008), comparison of interest was not relevant. The population focus included studies from a variety of hospital settings, both inpatient and outpatient, and focused on adult patients and/or nurses. Studies were excluded if they focused on patients seeking hospital care for mental-health issues or if the setting was medical wards only, as this is reviewed in Paper 1 (Tobiano et al., 2015c). Further,
if health care professionals other than nurses were included and their data were unable to be separated from nurse data, these studies were excluded.

For intervention of interest, studies were included if they focused on patient participation in nursing care broadly. There are large bodies of work examining patient participation in specific nursing activities, such as handover and decision-making. As a result, reviews have been conducted in these areas. For example, for shared decision-making, reviews show that shared decision-making is achieved when the patient is knowledgeable and patient knowledge is enhanced when nurses share information (Joseph-Williams, Elwyn & Edwards, 2014; Truglio-Londrigan, Slyer, Singleton & Worrall, 2014) and build a patient-centred relationship with the patient (Truglio-Londrigan et al., 2014). Shared decision-making is described as an interaction (Joseph-Williams et al., 2014), based on negotiation (Truglio-Londrigan et al., 2014) that can be enhanced by certain patient factors, such as age and education level (Clark et al., 2009; Joseph-Williams et al., 2014). Handover at the bedside is another specific activity patients can participate in (Strople & Ottani, 2006). Yet reviews demonstrate that patient participation in handover appears to be variable (Anderson, Malone, Shanahan & Manning, 2015; Messam & Pettifer, 2009; Staggers & Blaz, 2013). A recent review demonstrated that there were benefits to patient participation in bedside handover such as patients’ ability to get information, take part in shared decision-making and clarify information, but sometimes patients did not feel involved in the process (Anderson et al., 2015). For nurses, issues around confidentiality and time are common reasons for not embracing patient participation in handover (Anderson et al., 2015; Messam & Pettifer, 2009). Specific activities like these were not the focus of this review, therefore studies related to specific nursing activities were excluded. However, these activities may form part of this review if there were findings from the studies that broadly investigated patient participation. This is in contrast to the published review presented (Tobiano et al., 2015c), as this latter review investigated patient participation in nursing care both ‘broadly’ and in ‘specific’ activities.

Finally, the outcome of interest was patients’ and/or nurses’ views and/or behaviours towards patient participation, studies were excluded if they did not investigate perceptions of behaviours. Other limiters included English language; the search was not limited by a timeframe.
The search

In August 2015 three search strategies were undertaken, with search 1 informing search 2 and 3. In the first search three databases were searched, using the same search strategy as Paper 1 (Tobiano et al., 2015c) (Sec Table 1, Page 65), except no time limit was applied. The PhD candidate had already conducted a literature search when developing her confirmation document, so she was familiar with many studies found using this strategy. However, using a structured search strategy allowed her to ensure all relevant studies were included, allowing her to update her previous search which was conducted in 2012. In addition to search strategy 1, the reference lists of studies meeting inclusion criteria were searched and included articles were searched in the database Scopus for articles citing the work since its publication. Thirty-three studies were included in this review.

Data extraction, appraisal and analysis

Data were extracted relating to author/country, setting, sample, data collection methods and main findings. Additionally, the quality of studies was appraised by the researcher and common methodological strengths and weaknesses are summarised. Finally, the main findings of studies are synthesised and described.

Findings

The findings related to patient participation in nursing care are presented in three sections, this order includes perceptions of patient participation, behaviours towards patient participation and facilitators and barriers to patient participation.

Perceptions of patient participation

Research has been conducted to understand patient and nurse perceptions of patient participation in nursing care. In this section, this body of work is summarised and the quality of studies is appraised in relation to patients and then in relation to nurses. While some research included observations, because this section focuses on perceptions, findings related to observations are not included here but are reviewed in the next section on behaviours.
Patient perceptions of patient participation

Included in this part of the review is self-reported data from 13 studies that relate to patient opinions of what patient participation in nursing care means (Table 2). Of the 13 studies included, 18 publications have arisen. In one instance it appears that two publications are from the same study (Eldh, Ehnfors & Ekman, 2006a; Eldh, Ehnfors & Ekman, 2004), whereby a sub-sample of three male patients may have been reported (Eldh et al., 2006a). However, they could be separate studies and are therefore reported separately in Table 2. Interestingly, the majority of work on patient participation with patients has been conducted in Nordic countries using interview techniques. Only three studies were found from outside Nordic countries, undertaken in Australia and the UK.

Of the 11 qualitative studies, the total number of patients in the studies was 211. Sample sizes ranged from 3–36 patients, however, some researchers that incorporated interviews and observations did not explicitly state if their entire sample underwent both methods of data collection (Henderson, 2002; Henderson, 1997; Henderson, 2003; Penney & Wellard, 2007). A total of 1,014 patients were recruited to two quantitative studies; both conducted in Sweden. Studies were largely undertaken with patients from inpatient units, while three studies were conducted with outpatients and one study included outpatients subsumed within the study. Some researchers intentionally recruited older patients (Aasen, 2015; Aasen, Kvangarsnes & Heggen, 2012b; Foss, 2011; Penney & Wellard, 2007), however, most researchers appeared to sample a range of adult patients. More males (N=731) than females (N=449) participated in the studies. Where the patient condition was reported, some patients suffered chronic conditions like end-stage renal failure, chronic heart failure and cancer (Aasen, 2015; Aasen et al., 2012b; Eldh et al., 2006a; Eldh et al., 2004; Sainio, Lauri & Eriksson, 2001), while the specific focus of two studies was patients who had recently suffered a myocardial infarction (Arnetz & Arnetz, 2009; Höglund, Winblad, Arnetz & Arnetz, 2010).
Table 2 Patient Perceptions of and Behaviours towards Patient Participation

<table>
<thead>
<tr>
<th>Author/Country</th>
<th>Setting</th>
<th>Sample</th>
<th>Data collection methods</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aasen et al. (2012, 2015)/Norway</td>
<td>Outpatient haemodialysis units for end-stage renal disease; stable, aged 70 years or older</td>
<td>11 patients with end-stage renal disease, but ‘stable’ aged 70 years or older</td>
<td>Interviews</td>
<td>Discursive practices (Aasen et al., 2012): The health-care team’s power and dominance. Struggling for shared decision-making. Themes (Aasen et al., 2015): The discourse of paternalism. The discourse of participation. The discourse of paternalism/participation.</td>
</tr>
<tr>
<td>Allen (2000)/UK</td>
<td>2 surgical wards: urology and vascular, 2 hospitals: large district general hospital and university teaching hospital</td>
<td>24 patients, age not provided</td>
<td>Interviews and observations</td>
<td>The urology ward: Patients increased their participation in the technical division of labour without changing the moral division of labour. The vascular ward: Nurses had developed egalitarian relations with patients. There was little patient participation in nursing activities.</td>
</tr>
<tr>
<td>Arnetz and Arnetz (2009)/Sweden</td>
<td>Cardiac care units</td>
<td>652 patients who recently suffered a myocardial infarction; most aged: 60–69 years</td>
<td>Questionnaires</td>
<td>86% felt it was important to be involved in discussions about treatment and care. 76% felt they should be involved in decision-making during hospitalisation, younger women significantly more than men. On admission, 64% reported giving full control for care to doctors and nurses. 1% reported actually taking part in decision-making. 30% wanted more active patient participation in hospital, older women significantly more than men.</td>
</tr>
<tr>
<td>Eldh et al.</td>
<td>Nurse-led</td>
<td>10 patients with advanced kidney disease</td>
<td>Interviews</td>
<td>Patient participation is: to be confident, to comprehend and to seek and...</td>
</tr>
<tr>
<td>(2004)/ Sweden</td>
<td>outpatient unit for heart diseases</td>
<td>chronic heart failure (NYHA class II or III)</td>
<td>Age ranged from 53-86 years</td>
<td>maintain a sense of control</td>
</tr>
<tr>
<td>Eldh et al. (2006a)/ Sweden</td>
<td>Nurse-led outpatient unit for heart failure</td>
<td>3 male patients with chronic heart failure (NYHA class II or III)</td>
<td>Ages: 53, 77, and 79 years</td>
<td>Interviews and observations</td>
</tr>
<tr>
<td>Eldh et al. (2006, 2008, 2010)/ Sweden</td>
<td>3 inpatient units (internal medicine, surgical, orthopaedic), 9 outpatient clinics (internal medicine, surgical, arthroscopy, orthopaedic, emergency department and day surgery), 1 local acute care hospital</td>
<td>362 patients with the majority suffering from symptoms or disease for 12 months or longer Most aged: 30-59 years</td>
<td>Questionnaires</td>
<td>Overarching themes (Eldh et al., 2006):</td>
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</table>
Lacking information
Facing organisation-centred rather than patient-centred care
Feeling insecure
Most frequent items for participation (Eldh et al., 2010):
Staff listen to me
To get explanations for my symptom/problem
To tell about my symptom/problem
Types of participation identified in open-ended questions (Eldh et al., 2010):
Having fruitful communication based on respect

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Participants</th>
<th>Data Collection</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foss (2011)/Norway</td>
<td>‘Several’ medical and surgical units and 1 university hospital</td>
<td>18 patients</td>
<td>Interviews</td>
<td>The construction of the hospital and carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age ranged from 80-92 years</td>
<td></td>
<td>The construction of the participating self</td>
</tr>
<tr>
<td>Frank, Asp and Dahlberg (2009b)/Sweden</td>
<td>Emergency department including different sections of the department</td>
<td>9 patients</td>
<td>Interviews</td>
<td>Categories:</td>
</tr>
<tr>
<td></td>
<td>(medical, infectious diseases, orthopaedic, surgical and ear, nose and throat)</td>
<td>Age ranged from 26-73 years</td>
<td></td>
<td>Being acknowledged</td>
</tr>
<tr>
<td></td>
<td>1 metropolitan district hospital</td>
<td></td>
<td></td>
<td>Struggling to become involved</td>
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<td></td>
<td></td>
<td></td>
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<td>Having a clear space</td>
</tr>
<tr>
<td>Henderson (1997, 2002, 2003)/Australia</td>
<td>Medical, surgical and extended care units and 4 teaching</td>
<td>32 patients (most surgical patients)</td>
<td>Interviews and observations Mean age 59</td>
<td>Facilitating category (Henderson, 97): Knowing the patient</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Influencing factors (Henderson, 2002): Attitude to self-care</td>
</tr>
<tr>
<td>Study</td>
<td>Hospitals details</td>
<td>Participants</td>
<td>Focus Group Interviews</td>
<td>Themes</td>
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<tr>
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<tr>
<td>Höglund et al. (2010)/</td>
<td>Unit details not</td>
<td>8 patients</td>
<td>Focus group</td>
<td>The meaning of patient participation, Positive outcomes, Difficult</td>
</tr>
<tr>
<td>Sweden</td>
<td>provided</td>
<td>who recently suffered a myocardial infarction</td>
<td>interviews</td>
<td>situations, Hindrances, Facilitating factors</td>
</tr>
<tr>
<td></td>
<td>3 hospitals</td>
<td>Age ranged from 40-74 years</td>
<td></td>
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</tr>
<tr>
<td>Larsson et al. (2007,</td>
<td>Somatic inpatient</td>
<td>26 patients</td>
<td>Focus group</td>
<td>Core category: Insight through consideration.</td>
</tr>
<tr>
<td>2011)/ Sweden</td>
<td>units (gynaecological ward, rehabilitation ward, heart failure ward, neurological ward), as well as discharged patients from such a setting (members of The Pensioners National Organisation)</td>
<td>Age ranged from 32-87 years</td>
<td>interviews</td>
<td></td>
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<td></td>
<td>4 hospitals</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Study</td>
<td>Unit Details</td>
<td>Observations</td>
<td>Themes:</td>
<td></td>
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<td>----------------------------</td>
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</tr>
<tr>
<td>Penney and Wellard (2007)</td>
<td>Unit details not provided</td>
<td>36 patients</td>
<td>Participation and independence</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>2 major acute hospitals in a large urban centre, 1 privately funded not-for profit, 1 government funded</td>
<td>Aged 70 or older and interviews</td>
<td>Limited opportunity for participation</td>
<td></td>
</tr>
<tr>
<td>Sainio et al. (2001)</td>
<td>Haematology and oncology units</td>
<td>34 patients with cancer</td>
<td>Views on participation in care and decision making and its preconditions</td>
<td></td>
</tr>
<tr>
<td>Finland</td>
<td>1 university hospital</td>
<td>Interviews</td>
<td>Personal experiences of participation in medical and nursing decisions</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Which factors promoted and restricted participation in decision making</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>The significance of participation to the individual patient</td>
<td></td>
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</tbody>
</table>

*Note. NYHA = New York Heart Association functional classification for heart failure.*
The findings from the 13 included studies are now summarised to provide meaning for patient participation from the patient perspective. Communication was an important element of patient participation for patients. In particular, many believed gaining information from nurses was a way they participated in their nursing care (Höglund et al., 2010; Larsson, Sahlsten, Sjöström, Lindencrona & Plos, 2007; Sainio et al., 2001). For instance, 362 Swedish hospital inpatients and recently discharged patients reported gaining information on symptoms, problems, procedures and plans was a way they participated in hospital care (Eldh, Ekman & Ehnfors, 2010). Yet, patients emphasised that the information had to be tailored to their situation (Eldh et al., 2006a; Frank et al., 2009b), based on their concerns and values and given in a respectful manner (Eldh et al., 2010; Larsson et al., 2007). When patients described ‘non-participation’, they defined it as receiving no information (Eldh et al., 2006a) making patients feel dependent on nurses (Henderson, 2003) or being giving information that was instructive without explanation (Eldh, Ekman & Ehnfors, 2006b). Further, patients did not feel they participated if their understanding of the information was not gauged (Eldh et al., 2010), resulting in a feeling of lack of control (Eldh et al., 2004).

Patients also emphasised their role in information-sharing. Patients who saw themselves as knowledgeable enhanced their ability to share information with staff (Eldh et al., 2006b; Larsson et al., 2007). They described information-sharing as mutual, based on the expert knowledge that nurses and patients could exchange (Eldh et al., 2004). In particular, patients believed they could share information on their symptoms (Eldh et al., 2004; Eldh et al., 2010; Sainio et al., 2001), signs from their body (Eldh et al., 2004), concerns (Eldh et al., 2010; Larsson et al., 2007) and needs (Frank et al., 2009b). For participation to be effective patients needed their knowledge to be respected by nurses (Eldh, Ehnfors & Ekman, 2008).

It was evident that patients wanted to take some responsibility, when participating in activities like decision-making and physical self-care. Cancer patients found patient participation difficult to define; however, they affirmed that decision-making was a key feature (Sainio et al., 2001). Many Swedish patients wanted to be involved in decision-making (Arnetz & Arnetz, 2009; Eldh et al., 2008). However, patients had a range of preferences for their level of involvement in decision-making, which may depend on the type of decision (Henderson, 2002) and context (Arnetz & Arnetz, 2009; Larsson et al., 2007). Fewer patients associated patient participation with physical self-care activities
compared to decision-making. Some older patients were dissatisfied with having no role in self-care activities like medication administration, walking, toileting and showering in hospital, desiring higher levels of participation to maintain their independence (Penney & Wellard, 2007). This finding resonated with other groups of older patients (Eldh et al., 2010) and general hospital patients wanted to undertake self-care activities in hospital (Larsson et al., 2007). Although patients’ level of desire for self-care may be related to their willingness to participate, some patients preferred a passive role (Henderson, 2002).

In summary, patients perceive they participate in nursing care by sharing information, making decisions and undertaking self-care. Information-sharing may be an accepted form of participation for patients, as patients’ views appear to be in agreement, suggesting patients’ ideas around patient participation consistent. Patients’ level of involvement in decision-making and self-care activities were supported as key features of patient participation and tended to be influenced by several factors.

Overall, the majority of data pertains to Nordic countries, thus, this review of patients’ perceptions may be context-specific to Nordic patients because of the weighting of more studies from Nordic origins. In particular, the findings related to patient participation in communication and information-sharing are largely the work of Eldh and colleagues, whose work was conducted in Sweden raising questions about generalisability to other environments. The volume of Nordic research retrieved suggests that these countries may have a greater interest in the topic or may have commenced research earlier than other countries. Shields et al. (2002) describes Sweden as a country where egalitarianism is highly valued. Further, health care is well-funded to allow the provision of efficient services, with nurses providing high standards of care and having heightened responsibility for their work (Shields et al., 2002). Therefore, Sweden’s values and approach to care may provide some explanation for why research on patient participation is popular. Further research is required in other countries, to compare these findings to Nordic patients’ perceptions.

In the studies reviewed, substantially more male than female hospital patients have shared their views on patient participation. Arnetz and Arnetz (2009) discovered that females preferred a more active role in decision-making compared to men, although there were no obvious gender differences in the remaining studies. It would be important to conduct future research that represents female patients as well as males.
Quality appraisal of studies relating to patient perceptions

The quality of the studies that addressed patient perceptions will now be discussed. Researchers using interview techniques enhanced the credibility of their studies by using many strategies. For example, interviews were long in duration, as Holloway and Wheeler (2002) suggest 1.5-2.0 hour interviews as satisfactory. Two researchers did not provide any data about the length of interviews, decreasing the credibility of their studies (Foss, 2011; Penney & Wellard, 2007). Interestingly, Eldh et al. (2004) showed that only a third of the words spoken by the patients were meaningful to the phenomenon, suggesting although patient interviews were long in duration patients may go off topic. In many instances researchers incorporated more than one hospital and/or unit enhancing the variation in the perceptions they captured. Many researchers undertaking one-on-one interviews allowed patients to select where to be interviewed (Aasen et al., 2012b; Eldh et al., 2006a; Eldh et al., 2004; Foss, 2011), suggesting patients may have been comfortable, perhaps resulting in more credible accounts. This meant some patients selected interviews at home with time elapsing ranging from 1 week to 4 months post-discharge from hospital (Eldh et al., 2004; Foss, 2011; Penney & Wellard, 2007). Other researchers failed to provide details of time that elapsed after discharge (Frank et al., 2009b; Henderson, 2002). While patients may have felt more comfortable being interviewed in their homes, these interviews are at risk of recall bias because there may be issues with the accuracy or completeness of participants’ memories of hospital events.

Researchers undertaking focus group interviews conducted long discussions, enhancing credibility. Further, two researchers were always present, with one researcher being a moderator who contributed questions. It is questionable if the focus groups were large enough to benefit from group interaction (Polit & Beck, 2008), as three patients were present in some focus groups (Höglund et al., 2010; Larsson et al., 2007), which may not have generated sufficient interaction. Further, patients were grouped based on their current health care setting, meaning patients may not have had similar demographic characteristics and may not have easily expressed their views in a group setting. One group of researchers expressed their previous experience of undertaking focus interviews (Höglund et al., 2010), however, further information about the techniques used to elicit all participant opinions would have been beneficial, depending on the purpose and types of focus group.
The quality of the quantitative surveys was variable. Both surveys were pilot tested. Arnetz et al.’s (2009) survey underwent comprehensive psychometric testing, showing good reliability and validity. On the other hand, for the surveys undertaken by Eldh et al. (2006, 2008, 2010) only face validity was reported for the pilot study, with some patients misunderstanding questions in the final survey. The survey by Arnetz et al. (2009) had a better response rate (83%) than those of Eldh et al. (2006, 2008, 2010) (40%), although the latter’s work is at higher risk of non-response bias. Both studies were at risk of recall bias, as Arnetz et al.’s (2008b) surveys were returned 6–10 weeks post discharge, while Eldh et al.’s (2006, 2008, 2010) did not disclose the time that elapsed. These findings suggest that more quantitative data is required, perhaps once there is a better understanding of the specific elements of patient participation.

To sum up, in-hospital interviews conducted in a variety of settings appeared to be a frequently used data collection method for eliciting patient views on patient participation. This method allowed patients to feel at ease and provide lengthy and possibly in-depth descriptions of patient participation. Focus group interviews could have been improved by increasing the size of groups, while grouping homogenous people together. Further quantitative studies are required as only one survey showed good reliability and validity and the results are specific to MI patients (Arnetz & Arnetz, 2009).

Nurse perceptions of patient participation

Twelve studies were identified that focused on nurse perceptions of patient participation, with 17 publications arising from these studies (Table 3). Researchers investigating nurse perceptions of patient participation also tended to have conducted their research in Nordic countries (Table 3). Six studies were conducted in Nordic countries and of those studies, four were conducted in Sweden. Of the remaining studies, three were conducted in the UK, two in Australia and one in Greece.

Ten qualitative studies were conducted involving at least 154 nurses. Qualitative sample sizes ranged from 2–33 nurses. The most common data collection method was focus group interviews. Two studies used quantitative methods, with a total of 484 nurses completing questionnaires. Most researchers included a variety of inpatient hospital wards in their studies (Henderson, 1997; Henderson, 2003; Kolovos et al., 2015; Sahlsten, Larsson, Sjostrom, Lindencrona & Plos, 2007; Sahlsten, Larsson,
Lindencrona & Plos, 2005a; Sahlsten, Larsson, Plos & Lindencrona, 2005b; Sahlsten, Larsson, Sjöström & Plos, 2009; Wellard, Lillibrige, Beanland & Lewis, 2003), including rehabilitation wards subsumed within the sample in two studies. In the other instances two studies occurred in rehabilitation units (Jewel, 1994; Tutton & Ager, 2003; Tutton, 2005), two in outpatient clinics (Aasen, 2015; Aasen, Kvangarsnes & Heggen, 2012a; Eldh et al., 2006a), two appeared to be in cardiac units (Aasen, 2015; Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Höglund et al., 2010), one in ICU (Kvangarsnes, Torheim, Hole & Öhlund, 2013) and one in an emergency department (Frank, Asp & Dahlberg, 2009a). Most researchers undertook their studies in two or more hospitals. In six Nordic studies, the nurses had five or more years’ experience, suggesting clinically experienced nurses. The two Australian studies incorporated nurses with a range of experience, including novice nurses. Nurses’ ages ranged from 25–62 years.
Table 3 Nurse Perceptions of and Behaviours towards Patient Participation

<table>
<thead>
<tr>
<th>Author/Country</th>
<th>Setting</th>
<th>Sample</th>
<th>Data collection methods</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aasen et al. (2012, 2015)/Norway</td>
<td>Outpatient haemodialysis units 5 hospitals</td>
<td>10 nurses Age: 3 nurses were 30-39 years, 7 nurses were 40-50 years Experience: 6 nurses had 6-14 years’ experience, 4 nurses had 15-25 years’ experience</td>
<td>Interviews</td>
<td>Themes (Aasen et al., 2012): Nurses’ power and control Sharing power with patients Next of kin has power Themes (Aasen et al., 2015): The discourse of paternalism The discourse of participation The discourse of paternalism/participation</td>
</tr>
<tr>
<td>Allen (2000)/UK</td>
<td>2 surgical wards: urology and vascular 2 hospitals: large district general hospital and university teaching hospital</td>
<td>29 nurses Age: not provided Experience: not provided</td>
<td>Interviews and observations</td>
<td>The urology ward: Patients increased their participation in the technical division of labour without changing the moral division of labour The vascular ward: Nurses had developed egalitarian relations with patients There was little patient participation in nursing activities</td>
</tr>
<tr>
<td>Arnetz et al. (2008, 2015)/Sweden</td>
<td>12 cardiac care units 12 hospital</td>
<td>303 nurses Age: most ages 30-39 years Experience: most had more than 15 years’ experience</td>
<td>Questionnaire</td>
<td>Arnetz et al. (2008): 80% of nurses thought it was important to involve the patient Providing information (80%) and addressing patient needs (75%) were also viewed as important aspects of patient involvement Lack of time and prioritising other tasks were viewed as hindrances for patient participation by nurses 25% of all health care workers saw patient willingness as a hindrance</td>
</tr>
</tbody>
</table>
97% of health care workers agreed that an involved patient enriched their work.
30% of health care workers agreed that an involved patient took time from other patients.

Arnetz et al. (2015):
All nurses highlighted the importance of patient participation.
High level of consensus amongst nurses for providing patients with information, which was also strong for nurse behaviours.
Nurse perceptions of barriers influenced their abilities to respond to patient needs.
Discrepancy between what nurses believed and their actual behaviour in their interactions with patients.

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Eldh et al. (2006a) | Nurse-led outpatient unit for heart failure, 1 urban county hospital | 2 nurses | Interviews and observations | Patient participation as experienced by nurses:  
Main theme: getting information and security to act  
Non-participation as experienced by nurses:  
Main theme: not accepting  
Observations themes:  
Uniform procedures  
Certain information exchange |
| Frank et al., 2009a | 1 emergency department, 1 metropolitan hospital | 4 registered nurses, 4 auxiliary nurses | Interviews | Categories:  
Caregivers offer the opportunity for participation  
Patients demand participation  
Mutual participation |
| Henderson (1997) | Medical, surgical, and extended care | 33 nurses | Interviews and observations | Facilitating category (Henderson, 97):  
Knowing the patient |
<table>
<thead>
<tr>
<th>Year</th>
<th>Country</th>
<th>Setting</th>
<th>Participants</th>
<th>Age</th>
<th>Experience</th>
<th>Methods</th>
<th>Themes</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>Australia</td>
<td>4 teaching hospitals; 2 privately funded, 2 government funded</td>
<td>(SD 9.5)</td>
<td>Experience: Level 1 (novices, less than 5 years’ experience, who provide direct patient care), or level 2 (more than 5 years’ experience and deemed to be advanced clinicians with proven skills in communication, leadership and management)</td>
<td></td>
<td>Focus group interviews</td>
<td>Categories (Henderson, 2003): Nurses giving information, Nurses controlling interactions with patients, Nurses using power</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>Sweden</td>
<td>Unit details not provided</td>
<td># of nurses not provided</td>
<td>Age: ranged from 25-60 years</td>
<td>Experience: ranged from 3-32 years</td>
<td>Focus group interviews</td>
<td>Themes: The meaning of patient participation, Positive outcomes, Difficult situations, Hindrances, Facilitating factors</td>
<td></td>
</tr>
<tr>
<td>1994</td>
<td>UK</td>
<td>2 elderly care rehabilitation wards</td>
<td>4 nurses</td>
<td>Age: not provided</td>
<td>Experience: not provided</td>
<td>Focus group interviews</td>
<td>Themes: What is participation?, Promoting participation</td>
<td></td>
</tr>
<tr>
<td>2015</td>
<td>Greece</td>
<td>23 medical and surgical wards</td>
<td>181 nurses</td>
<td>Age: Mean 36.7 years (SD 7.9 years). Experience: Median 12.2 years (IQR 17.9)</td>
<td></td>
<td>Questionnaire</td>
<td>Most frequent meanings for patient participation: Receiving relevant information/providing information, Communicating symptoms, Compliance with recommended orders, Patient participation was thought to improve hospitalization,</td>
<td></td>
</tr>
</tbody>
</table>
stirneth the patient’s role and build collaborative relationships
The parameters affecting the level of patient participation to a greater
were familiarization with participation, patient encouragement,
acceptance for participation, comfortable and friendly atmosphere,
patient health status, patient physical and emotional strain during
hospitalization and communication with patients
Reasons why nurses did not encourage patient participation: low
patient knowledge, consequences for patients and nurses

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Participants</th>
<th>Methods</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kvangarsnes et al.</td>
<td>Intensive care units: 1 city</td>
<td>17 nurses</td>
<td>Focus group</td>
<td>Low level of patient power and participation</td>
</tr>
<tr>
<td></td>
<td>hospital, 1 smaller rural hospital</td>
<td></td>
<td>interviews</td>
<td>Emotional reciprocity</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Patient participation in life or death situations</td>
</tr>
<tr>
<td>Sahlsten et al.</td>
<td>Somatic inpatient units (childbirth, ear</td>
<td>31 nurses</td>
<td>Focus group</td>
<td>Categories (Sahlsten et al., 2005a):</td>
</tr>
<tr>
<td></td>
<td>nose and throat, eye, gynaecology, heart</td>
<td></td>
<td>interviews</td>
<td>Interpersonal procedure</td>
</tr>
<tr>
<td></td>
<td>failure, medical, neurology and rehabilitation</td>
<td></td>
<td></td>
<td>Therapeutic approach</td>
</tr>
<tr>
<td></td>
<td>wards)</td>
<td></td>
<td></td>
<td>Focus on resources</td>
</tr>
<tr>
<td></td>
<td>5 hospitals</td>
<td></td>
<td></td>
<td>Opportunities for influence</td>
</tr>
</tbody>
</table>

Categories for barriers to patient participation (Sahlsten et al., 2005b):
- Competence
- Influence of significant others
- Organization and work environment
Categories for facilitating strategies for patient participation (Sahlsten et al., 2009):
- Building close cooperation
<table>
<thead>
<tr>
<th>Study</th>
<th>Setting and Sample</th>
<th>Methods</th>
<th>Themes/Influencing Factors</th>
</tr>
</thead>
</table>
| Tutton and Ager (2003), Tutton (2005)/ UK | 1 ward for patients requiring slow-stream rehabilitation or having complex discharge requirements, 1 hospital | Phase 1: 9 nurses (focus groups) and 2 nurses (individual interview), Phase 2: not provided, Phase 3: 3 nurses (individual interviews x3), Phase 4: 13 nurses (individual interviews) | Getting to know the person  
Reinforcing self-care capacity  
Phase 1 themes/ influencing factors (Tutton, 2005):  
The nature of participation  
Time  
Interpersonal relationships  
Teamwork  
Environment  
Phase 3 and 4 themes (Tutton & Ager, 2003; Tutton, 2005):  
Facilitation  
Partnership  
Understanding the person  
Emotional labour |
| Wellard et al. (2003)/ Australia | A ‘variety’ of wards included in interviews. Observations occurred on cardiovascular ward, 1 acute care hospital: government funded | 20 nurses Age: not provided Experience: 6 nurses were in their first year of practice, 8 nurses had more than 1 years’ experience but no leadership responsibility and 6 nurses were team leaders or associate nurse unit managers | Interviews:  
Value of consumer participation  
Different levels of understanding of patient participation amongst staff  
Issues of control  
Observation themes:  
Division of labour  
Communication issues  
Environmental constraints |

*Note:* IQR = interquartile range. SD = standard deviation.  
*N* Nurse and doctor demographic and/or clinical characteristics were not reported separately.
The twelve studies relating to nurse perceptions of patient participation are now summarised. Mirroring patient views, nurses stated information giving was a key part of patient participation (Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Jewel, 1994; Kolovos et al., 2015; Sahlsten et al., 2005a; Wellard et al., 2003). Some Australian nurses thought patient participation was one-way where the nurse’s role was providing patients with information (Henderson, 2003; Wellard et al., 2003). Greek nurses supported this, believing giving patients information was the most important concept of patient participation (Kolovos et al., 2015). Swedish nurses identified a more engaging way of providing information, by assessing patients’ understanding of information given (Arnetz et al., 2008b; Sahlsten et al., 2005a) and basing information on patients’ needs (Arnetz & Zhdanova, 2015; Eldh et al., 2006a), perhaps enhancing patient participation, rather than simply providing information. In the context of Swedish emergency care, nurses believed participation occurred when patients were given information they understood. However, they also used information-giving as a way for the patient to understand the emergency context in an attempt to reduce patients’ demands on nurses (Frank et al., 2009a).

Mutual information-sharing was valued by European nurses (Sahlsten et al., 2007), because they believed patients could share information too. Some nurses viewed the patient as resourceful, as they knew their capabilities (Sahlsten et al., 2005a) and body (Aasen et al., 2012a) enabling them to share this information. However, outpatient dialysis nurses emphasised that not all patients were resourceful, as some patients were too old or frail to participate (Aasen et al., 2012a). The nurses emphasised the importance of building a relationship with the patient to foster frequent (Jewel, 1994; Tutton & Ager, 2003) and meaningful communication (Sahlsten et al., 2005a). In particular, a group of experienced hospital ward nurses and a group of rehabilitation nurses undertaking reflective practices, highlighted that communication was more than information-sharing, stating dialogue could be used to enable them to understand the person behind the patient (Sahlsten et al., 2005a; Tutton & Ager, 2003). However, no other nurses took this wholistic approach towards patient participation and communication. It may be that reflective practice or more experience enhanced nurses’ understanding of actions needed to engage with patients.

Another feature of patient participation identified by nurses was patients influencing their care. However, nurses had mixed views on patients’ level of influence.
For instance, some nurses supported the role patients could have in making choices and decisions around their nursing care (Höglund et al., 2010; Jewel, 1994; Sahlsten et al., 2005a). In particular, British rehabilitation nurses emphasised patient participation as constant negotiation with patients, whereby patients influenced plans and made decisions throughout the care process (Jewel, 1994). Swedish hospital nurses also gave patients high levels of influence over their care, believing patients could take responsibility for some self-care activities in hospital (Sahlsten et al., 2005a).

Yet, other nurses were more cautious about patients’ level of influence, expressing the need to keep some level of control (Kolovos et al., 2015; Kvangarsnes et al., 2013) especially Australian nurses (Henderson, 2003; Wellard et al., 2003). In terms of influencing decisions, some nurses had a paternalistic view and stated they knew best and had to make decisions for the patient (Aasen et al., 2012a; Henderson, 2003), which may have been influenced by unit cultures. Further, Greek nurses felt patients had to comply with orders which may reflect the Greek context where hierarchical structures of care are strong (Kolovos et al., 2015).

On the whole, there was a sense that nurses thought the idea of patient participation was desirable. Most verbally supported (Kolovos et al., 2015), valued (Höglund et al., 2010), were committed to (Wellard et al., 2003) and aware of its importance (Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Wellard et al., 2003). Nurses believed participation benefited the patient by improving patient commitment to recovery (Höglund et al., 2010) and hospital experience (Kolovos et al., 2015), and benefited the nurse by enriching their work (Arnetz et al., 2008b). Thus, nurses saw the significance of the notion of patient participation.

In summary, how nurses conceptualise participation is not clear. Nurses have mixed views on how information-sharing should be practiced with patients and how much patients should be allowed to influence care. Adding to the confusion, nurses appear to view patient participation as important, even though there is a lack of conceptual clarity from nurses on how it is practiced. On the whole, the geographical location the nurse was from seemed to influence their support for patient participation, which may be attributable to the differences in culture. Swedish nurses appeared more likely to facilitate patient participation, while Australian nurses were noticeably paternalistic, suggesting the need for further understanding of Australian nurses’ willingness for patient participation. Further, these Australian studies were conducted
over a decade ago (Henderson, 1997; Henderson, 2003; Wellard et al., 2003), while other countries were far more recent and the international support for patient participation has grown considerably. When comparing patients’ and nurses’ perceptions, there are similarities between their views. Both parties highlight information-sharing and patients taking some responsibility for decision-making and self-care activities as elements of patient participation. However, this understanding is dominated by the Nordic experience and thus results may not be transferrable to other settings.

**Quality appraisal of studies relating to nurse perceptions**

The twelve studies investigating nurse views of patient participation are now critiqued. The transferability of some studies is limited by the few sample details provided, including sample size and nurses’ ages and experience. Not all researchers reported years of experience, yet those researchers that have, tend to suggest that they have included quite experienced nurses, with at least five years’ experience. Thus, the findings may not apply to less experienced nurses.

Researchers who conducted individual interviews (n=5) strengthened their studies by providing clear details of the questions and probes used when interviewing nurses, allowing readers to replicate study methods. Two researchers undertook repeated interviews with the same nurses (Henderson, 2003; Tutton, 2005), enhancing the credibility of findings. Most researchers carried out interviews, triangulated their methods also conducting observations (Eldh et al., 2006b; Henderson, 2002; Henderson, 2003; Tutton, 2005), focus groups or asking participants to keep reflective diaries (Tutton, 2005).

The impact of the researcher on data could have been enhanced by more details about the researcher’s role or reflexive approach. One interviewer had insider status with 15 years’ experience in dialysis nursing (Aasen et al., 2012a). Reflexive approaches where the researcher acknowledged his/her influence on data collection may have benefited the researchers. Two interviewers described themselves as having outsider status to the areas they researched (Eldh et al., 2006a; Tutton, 2005). In particular, Tutton (2005) undertook action research and explained that she did not develop relationships with nurses on the ward, resulting in few nurses changing practice. This finding suggests her role as a research instrument may have been
enhanced by taking on a more active role with participants, and she may have benefited from reflecting throughout the study to identify this and potentially changed her approach.

Most researchers used focus groups to collect data. These six studies had lengthy interviews of 50−120 minutes, suggesting enthusiastic conversation occurred. There were some factors that may have influenced the free-flow of information in focus groups. For instance, some researchers had as few as three or four participant nurses in focus groups (Högland et al., 2010; Jewel, 1994; Sahlsten et al., 2007; Sahlsten et al., 2005a; Sahlsten et al., 2005b; Sahlsten et al., 2009; Tutton, 2005), which can limit group interaction (Morgan, 1997). In particular, Jewel’s (1994) results should be interpreted with caution, as she had intended to undertake ethnography but instead conducted a single focus group with four nurses. It is unlikely that data saturation occurred and an idiosyncratic perception of participation may have been captured. Most researchers attempted to recruit a homogenous sample by grouping nurses by similar nursing classification, experience or setting that may have enhanced conversation in the group. Most studies had two researchers present during interviews (Högland et al., 2010; Kvangarsnes et al., 2013; Sahlsten et al., 2007; Sahlsten et al., 2005a; Sahlsten et al., 2005b; Sahlsten et al., 2009; Wellard et al., 2003). Data collected in these studies may have been of a higher quality due to the second researcher’s ability to document responses and assist with probing. Most researchers provided explicit details about questions and probes used, enhancing dependability (Högland et al., 2010; Jewel, 1994; Kvangarsnes et al., 2013; Tutton, 2005).

For the two quantitative studies, confidence in the tools used was increased by the researchers demonstrating internal consistency, and content and construct validity (Arnetz, Högland, Arnetz & Winblad, 2008a; Kolovos et al., 2015). Both studies had good response rates between 65−67%, (Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Kolovos et al., 2015). Researchers were unable to provide information for non-respondents (Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Kolovos et al., 2015), who may have differed from those that responded. A strength of both studies was the researchers’ attempts to create a representative sample. Both groups gave surveys to all nurses on the participating wards, with 12−23 wards included in the studies (Arnetz et al., 2008b; Arnetz & Zhdanova, 2015; Kolovos et al., 2015). One survey was administered to doctors and nurses (Arnetz et al., 2008b); although their results were
reported separately, it is questionable whether these two clinician groups should partake in the same survey as they would likely have different approaches to patient participation. Further, Arnetz et al. (2008) used a self-reported survey to measure behaviours, while behaviour may be better measured using other data collection techniques.

To review, researchers conducting individual interviews, focus groups and questionnaires with nurses have used good strategies to enhance the quality of data collected. In future studies, researchers would benefit from collecting more demographic data from nurses, ensuring reflexive approaches and increasing the size of focus groups.

Behaviours towards patient participation

Five studies incorporating observational research of patient participation in nursing care will now be presented. No researchers undertook stand-alone observations, thus this section draws on studies previously reviewed (Table 2 and 3). Observational data of patient participation is sparse with most observational research originating in Australia (Henderson, 2002; Henderson, 2003; Penney & Wellard, 2007; Wellard et al., 2003). The remaining studies were conducted in Sweden (Eldh et al., 2006a) and the UK (Allen, 2000). It is difficult to determine how many patients and nurses have been observed, as most researchers did not explicitly provide this information. Eldh et al. (2006a) did report their sample consisted of three patients and two nurses, which may have been insufficient for data saturation. Duration of observations varied, some researchers measured 5.8–142.0 hours of observation (Eldh et al., 2006a; Henderson, 2002; Henderson, 2003; Wellard et al., 2003), while other researchers conducted 6–10 months of observation (Allen, 2000; Penney & Wellard, 2007). The majority of researchers conducted their observations on hospital wards; one research group used the outpatient setting (Eldh et al., 2006a).

Patient participation behaviours were diverse. Some patients appeared passive in observations, only sharing issues, preferences or information if prompted by nurses (Eldh et al., 2006a; Henderson, 2003). Particularly, four outpatients appeared to have an unequal relationship with nurses (Eldh et al., 2006a). On the other hand, on a urology ward, patients appeared more active, handling bodily fluids, keeping fluid balance charts, recording pain and practicing skills for discharge (Allen, 2000). However, the
researcher’s reflections suggest nurses allowed patients to undertake these tasks due to convenience and routine as opposed to a patient-centred motive (Allen, 2000).

Observation of nurses’ behaviours were not supportive of patient participation. For instance, nurses maintained a high level of control over care, impeding patient participation. These nurses were witnessed being task-orientated, only interacting with patients when an activity needed to be completed (Allen, 2000; Henderson, 2002; Henderson, 2003; Wellard et al., 2003). Further, when interacting with patients, these nurses controlled the communication by asking closed questions, initiating all interactions, providing no choice or decisions for patients and curbing the information they shared (Allen, 2000; Henderson, 2002; Henderson, 2003; Wellard et al., 2003). Another commonly observed nursing practice was nurses controlling plans (Eldh et al., 2006a; Wellard et al., 2003). There were divergent findings on a British vascular ward, where nurses were witnessed trying to foster relationships with patients and respecting patients’ perspectives and knowledge of condition and routines, by fostering their preferences outside of usual hospital routines (Allen, 2000). On the whole, nurses’ behaviours tend to be in contrast to nurses’ views. For instance, in Wellard et al.’s (2003) study, nurses reported valuing active patient participation, yet nurses did not display value for it, instead controlling care. Likewise, outpatient setting nurses emphasised the importance of giving patients information, yet, their information-giving practices were routine and pre-set, not allowing patients preferences to be incorporated (Eldh et al., 2006a).

Overall, there appears to be similarities across different contexts and countries with most nurses displaying behaviours that are not supportive of patient participation. The findings on the vascular ward present a disparate view from the other settings; one explanation may be that the ward’s individual philosophy towards patient participation may have fostered a more patient-centred approach. Overall, patient behaviours towards patient participation are poorly described, as most researchers tend to report nurse behaviours more thoroughly. These observational studies are dated, thus an updated observational study of patient participation in nursing care is required, especially reporting patient actions in practice.
**Quality appraisal of studies relating to patient and nurse behaviours**

In terms of critiquing the quality of observational data, a strength in all studies was the triangulation of other data collection methods with observations. However, in some cases observational and interviews findings were pooled, which may not be the richest way of presenting findings. For instance, Penney and Wellard (2007) appeared to use small sections of fieldwork to support interview findings, while Allen (2000), largely reported his observations with a few interview quotes to support. Most researchers clearly described what they intended to observe in the field, their role in the field and gave clear explanations of what they recorded as field notes. The majority of observers were nurses; however, they had no experience in the research settings in which they observed. Some researchers reflected, including documenting what they sensed after observations (Eldh et al., 2006a) and another reflected prior to commencing observations (Henderson, 2002; Henderson, 2003). However, reflexive methods undertaken throughout the study may have assisted in providing rigorous data, especially given the researchers also worked as nurses.

In summary, future research would benefit from clear descriptions of interview versus observation data, as pooling of data may hide the difference in findings. Those researchers who did report these findings separately, showed the difference between what is reported and what is actually performed. Further, reflexive approaches throughout the research process are necessary when observing practice, as the researcher are part of data collected (Polit & Beck, 2008).

**Facilitators of and barriers to patient participation**

Most researchers have gathered self-reported data from patients and nurses about patient participation and have elicited their views around barriers and facilitators on the topic. These findings will be discussed, and related to previously presented and discussed studies from Tables 2 and 3.

**Facilitators of patient participation**

There is some evidence of facilitators of successful participation in previous research investigating patients’ and nurses’ perceptions (Tables 2 and 3). Both patients and nurses identified that a good relationship between the patient and nurse facilitated patient participation. For patients, the relationship was characterised by nurses who
interacted with the patient in a positive way, encouraging the patient (Höglund et al., 2010; Sainio et al., 2001), giving time (Frank et al., 2009a; Henderson, 1997), treating the patient as an equal (Larsson et al., 2007), providing an emotional response (Tutton & Ager, 2003; Tutton, 2005), and information (Henderson, 2003; Sainio et al., 2001). In the context of emergency care, it was evident patients became frustrated when they could not develop an interactive relationship with their nurse, stating they would shout, become unpleasant or formally complain, if they were unable to engage with their nurse and obtain information (Frank et al., 2009b). These more aggressive tactics toward participation may be reflective of the emergency context but highlight the importance patients place on being able to interact with nurses. For some patients, family members were viewed as facilitators who could support patients to participate (Penney & Wellard, 2007), or participate on their behalf (Frank et al., 2009b).

Nurses acknowledged good rapport with the patient as a facilitator of patient participation. To build a relationship, nurses spoke about their relational interactions with the patient that enhanced patient participation. For example, informal chats with the patient were important, allowing patients to feel more comfortable (Henderson, 1997; Henderson, 2003; Jewel, 1994). Further, nurses emphasised the need to understand the patient, including their situation, goals and opinions (Jewel, 1994; Sahlsten et al., 2009; Tutton, 2005). Other nurses indicated that listening genuinely to the patient was integral (Frank et al., 2009a; Sahlsten et al., 2009), to allow the nurse to connect with the patient as a person and understand what is important to them and their experiences (Tutton, 2005). Using these approaches was seen to build trust and respect in the partnership (Tutton & Ager, 2003) and give patients courage to ask questions (Frank et al., 2009a).

In summary, it is favourable that patients and nurse’ viewpoints align, suggesting the nurse-patient relationship is a crucial element of patient participation. Certainly more evidence is required on facilitators of participation, given the complexity of enacting it in practice. Data from Australian nurses are especially under represented.

**Barriers to patient participation**

In this section the self-reported data from patients and nurses was reviewed for perceived barriers to patient participation (Table 2 and 3). Patients and nurses spoke about patient, nurse and environment factors as hindering patient participation. In terms
of patient factors, patients focused on their own inability to participate. For example, physical inability to participate, particularly when they were unwell, hindered patient participation (Henderson, 2002; Höglund et al., 2010; Larsson, Sahlsten, Segesten & Plos, 2011a; Sainio et al., 2001). Patients felt they lacked certainty, confidence and medical knowledge, diminishing their courage to participate (Henderson, 2003; Höglund et al., 2010; Larsson et al., 2011a). Additionally, some patients were unsure if they were allowed to participate (Henderson, 2003), feeling they would ‘confront’ authority if they participated (Aasen et al., 2012b; Sainio et al., 2001). Patients instead chose to fit in with the system (Henderson, 2003), especially older patients (Foss, 2011; Tutton, 2005). Overall many patients lacked the self-esteem to participate (Larsson et al., 2011a; Sainio et al., 2001), portraying themselves in a vulnerable light.

The patient factors highlighted by nurses differed between contexts. Nurses in the intensive care, post-operative and emergency care environment, highlighted acute illness as a barrier to patient participation (Frank et al., 2009a; Höglund et al., 2010; Kvangarsnes et al., 2013). Further, in the emergency department, nurses believed patients had to know their rights, and actively and enthusiastically express their wishes (Frank et al., 2009a). Nurses in the rehabilitation setting believed long-term conditions could also hinder patient participation (Tutton, 2005) particularly confused patients were difficult to enable (Jewel, 1994). Age was a factor in a range of settings; older patients were believed to participate to a lesser extent in decision-making (Aasen et al., 2012a; Höglund et al., 2010). In two settings where nurses displayed paternalism, patients’ lack of knowledge was highlighted as a barrier to patient participation in nursing care (Henderson, 2003; Kolovos et al., 2015).

In regards to nurse factors, patients outlined negative nurse manners that impeded their participation. Patients stated that negative experiences with nurses were unforgettable, influencing their participation in subsequent hospital visits and entrenching passivity (Henderson, 2002). For instance, when nurses were dominating and controlling, patient participation was hindered (Aasen, 2015; Aasen et al., 2012b; Henderson, 1997; Larsson et al., 2011a). Additionally, nurses were sometimes described as displaying rude behaviours (Eldh et al., 2004; Henderson, 2003), for instance, cancer patients stated snappy and arrogant nurses were particularly difficult to engage with (Sainio et al., 2001). Further, patients stated lack of acknowledgment was a hindrance. In these instances, patients felt like they were not listened to (Foss, 2011; Henderson,
2003; Larsson et al., 2011a; Penney & Wellard, 2007), not informed (Aasen et al., 2012b; Henderson, 2003; Sainio et al., 2001), ignored (Aasen et al., 2012b; Eldh et al., 2004) or dismissed (Frank et al., 2009b), all of which reduced patient participation. Overall, when patients expressed lack of confirmation by nurses, it had an impact on their confidence to participate.

Nurses were less forthcoming with nurse factors that hindered patient participation. In two studies nurses were able to recognise their own actions as controlling and impeding patient participation (Sahlsten et al., 2005b; Tutton, 2005). These nurses appeared insightful, perhaps enhanced by Tutton’s (2005) action research approach, which enhanced reflection on practice. Further, the other groups of nurses had many years of experience, perhaps influencing their recognition of the need for personal insight to acknowledge hierarchical approaches to patient participation (Sahlsten et al., 2005b).

Environmental factors have also been highlighted as a barrier to patient participation. Both patients (Foss, 2011; Höglund et al., 2010; Penney & Wellard, 2007; Sainio et al., 2001), and nurses (Arnetz et al., 2008b; Frank et al., 2009a; Henderson, 2003; Tutton, 2005; Wellard et al., 2003), thought the busy inpatient ward environment reduced time to enact patient participation. Patients highlighted that nursing turnover meant there was limited continuity of care (Eldh et al., 2004; Sainio et al., 2001), meaning patients often did not know the nurses and vice versa (Larsson et al., 2011a). For nurses, they believed they needed to work within a supportive team to encourage participation, otherwise hierarchical approaches endured (Sahlsten et al., 2005b; Tutton, 2005).

In conclusion, patients presented common barriers to participating in their care, including feelings of inability and uncertainty and nurses concern about nurses’ manners. For nurses, the patient barriers tended to relate to work setting, while nurses did not appear forthcoming with ways that nurses hindered participation. Patients and nurses identified similar environmental factors that impeded participation. Given the difference in health care systems internationally, it would be important to understand which barriers are most important to Australian patients and nurses, to uncover context-specific strategies to enhance patient participation in nursing care.
Critical appraisal of studies

In this final section, a combined critical appraisal of patient views, nurse views, patient and nurse behaviours, barriers and facilitators is presented. Overall, the arguments presented by researchers have been replicated in few other countries (other than those of Nordic origins), resulting in a context-specific understanding of patient participation. Adding to this argument, most studies are qualitative, as there are few high quality quantitative studies conducted, meaning the generalisability of findings should be interpreted with caution; also suggesting context specific findings. Some patients and nurses see patient participation as one-way information sharing (from nurse to patient), while others see it as two-way. The very notion that one-way communication is seen as participation is juxtaposition, as receiving information is a passive action. Further, patients’ and nurses’ views on activities like decision-making and self-care vary among studies, suggesting there are no conclusive findings. There was a tendency for Nordic patients and nurses to have more similarities in terms of what patient participation was perceived to be, however findings from other countries emphasised disparate views.

Furthermore, the omission of observations in many studies affects authors’ arguments. While perceptions are varied, observations would add important insights related to actual behaviours. For instance, Nordic researchers paint patient participation in a positive light, yet their limited observations do not align with their claims of what patient participation is. Further, most observational research shows patient participation is infrequent, possibly highlights the ambiguity around this activity. If nurses are to practice it, they need to know how to practice it, which is not evident in many studies that sought participants’ perceptions. Without really understanding how patient participation is practiced, nurses will continue to find challenges promoting patient participation.

Patient participation in nursing care on medical wards: An integrative review

(Paper 1)

A review was conducted in August 2013 to critique and synthesise the literature relating to patient participation in nursing care on medical wards. Studies included in the integrative review differ from studies discussed in the previous review in this chapter in two ways. First, only research conducted on medical wards was included, which provided a context-specific understanding of patient participation. Second, research investigating both patient participation in specific activities and more broadly were included. Eight studies met inclusion criteria. The review revealed that patients were often passive in their nursing care, which may be due to challenging factors uncovered in the review. Information-sharing was found to be a way for patients to participate and enhanced patient participation.

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Further evidence regarding patient participation

Following the acceptance for publication of the integrative review in February 2015 (Tobiano et al., 2015c), another team of researchers have synthesised literature relating to patient participation in the context of nursing care. In this newer review, accepted in April 2015, the researchers aimed to uncover the challenges to patient participation in nursing care (Angel et al., 2015). The researchers identified four barriers that resonate with findings from our integrative review. First was the nurse-patient relationship; the researchers found that nurses tended to show dominance in these relationships that hindered participation (Angel et al., 2015). Although our review did not directly discuss nurse-patient relationships, the challenges uncovered in our review, including the nurse’s approach, suggest productive relationships may have been hard to achieve (Tobiano et al., 2015c). Second, information-sharing and knowledge-sharing were seen as formative to patient participation and required shared time between patients and nurses (Angel et al., 2015). Similarly, our review showed information-sharing as a promoter of patient participation, while shared time was more difficult to attain (Tobiano et al., 2015c). Next, patient factors like severe illness and age were viewed as barriers (Angel et al., 2015), that confirm the challenges identified in our review. Finally, nurses’ attitude towards patient participation was highlighted, with nurses seen as gate-keepers who sometimes exerted power and did not invite patients to participate (Angel et al., 2015). These findings were like our integrative review, where nurses often did not acknowledge patients (Tobiano et al., 2015c). The consistency between reviews demonstrates the large range of barriers to patient participation.

Just prior to the submission of our integrative review, another review was published relating to patient participation. However, the researchers did not specifically focus on patient participation in nursing (Thórarinsdóttir & Kristjánsson, 2014). The researchers only included patients’ perceptions in their review and combined studies relating to patient participation, patient-centeredness, partnership and shared decision-making, in the context of a variety of health-care professionals. The researchers created a conceptual framework for patient participation, viewing patient participation as passing through three phases. In Phase 1, the ‘human connection phase’, patients required an inviting atmosphere, genuine interest and attention from nurses and needed to feel respected as equal human beings (Thórarinsdóttir & Kristjánsson, 2014). These findings are similar to the facilitators found in our integrative review, as patients needed
inviting and supportive nurses, who engaged in genuine dialogue and respected patients as people (Tobiano et al., 2015c). In phase 2, the phase of information processing, patients seek and receive appropriate information, and have ongoing dialogue where they further develop their understanding and confidence (Thórarinsdóttir & Kristjánsson, 2014). This phase is a prerequisite for shared decision-making. Like our integrative review, information-sharing was an important feature of patient participation making patients feel informed and included and able to contribute to decisions (Tobiano et al., 2015c). In the final phase, the action phase, patients have confidence and accept responsibility (Thórarinsdóttir & Kristjánsson, 2014). As a result, they may take part in shared decision-making, monitor and control symptoms, perform self-care or comply with regimes (Thórarinsdóttir & Kristjánsson, 2014). Even though similar patient participation activities were identified in our integrative review, we found patients were passively participating in activities and adhering to nurse instructions (Tobiano et al., 2015c). There are certainly similarities between the reviews that suggest Thórarinsdóttir and Kristjánsson (2014) have created a framework that is useful. However, neglecting nurses’ views puts it at risk of missing important factors.

Although not a review, Eldh et al.’s (2015) tool provides a representation of and way of measuring patient preferences for participation that was published online around the same time our review was submitted. Like Thórarinsdóttir and Kristjánsson (2014), Eldh et al. (2015) focused on patient perceptions only. The researchers reviewed all of their own previous qualitative and quantitative work with patients, to create the tool. Their patient participation tool has four dimensions that make up patient participation. The first dimension, ‘having dialogue with health-care staff’, entails nurses setting up conditions to enable mutual communication where the patient is seen as resourceful; sharing knowledge, preferences, and their needs and senses, are listened to, and acted on by nurses (Eldh et al., 2015). The patient and nurse sharing their knowledge of symptoms and issues in the second dimension ‘sharing knowledge’, with the nurse explaining the purpose, process or consequence of procedures (Eldh et al., 2015). Both dimension one and two are similar to the facilitators in our integrative review, where mutual information-sharing, and the facilitating nature of dialogue enhance patient participation (Tobiano et al., 2015c). For the third dimension, ‘partaking in planning’, the patient needs to know what is planned, is respected as someone who can make decisions with nurses and phrase reasonable goals (Eldh et al., 2015). While our
integrative review did not directly identify planning, our findings suggested patients should be more involved in this way due to the mismatch in expectations between patients and nurses (Tobiano et al., 2015c). In the final dimension, patients may perform self-care, manage self-care or show knowledge of symptom management (Eldh et al., 2015), activities identified in our study but not often enacted (Tobiano et al., 2015c).

In summary, these papers extend knowledge of patient participation. Only two reviews focus on the context of nursing care (Angel et al., 2015; Tobiano et al., 2015c), emphasising the barriers patients and nurses face when enacting patient participation in nursing care. Other researchers focused on patient perceptions only and included studies relating to patient participation with several health care professionals. Across the studies the nature of dialogue, information-sharing and examples of activities patients can participate in are common findings. Our review had many strengths in that it included both patients’ and nurses’ views and behaviours, we uncovered barriers and facilitators and we were able to show actual enactment of the types of participation suggested in other reviews.

Summary

In this chapter the relevant literature relating to patients’ and nurses’ perceptions and behaviours around patient participation has been summarised and critically reviewed. Although research is emerging, patient participation remains an elusive concept, with differences found around its meaning. Overall, patients’ and nurses’ perceptions largely come from Nordic countries, like Sweden, affecting the transferability of these findings. As a result, an understanding of Australian patients’ and nurses’ willingness is a gap in the literature that will be addressed in this study. Importantly, this study will contribute necessary observational research as there is a paucity of observational data available and what is available is largely dated. Notably, nurses’ perceptions and behaviours appear to conflict, suggesting observational data, analysed and reported separately from interview data, is important when investigating the topic of patient participation. There is more agreement about facilitating and hindering factors in the literature. However, understanding which of these factors are important in the Australian hospital context is unknown but would provide understanding of how to promote it. This study will address these issues by providing a better understanding of what patient participation is perceived to be, how it is enacted and the barriers and facilitators to it.
In the following chapter, an overview of the paradigm and methodology to address the research questions will be presented. Key strategies for this methodology will be discussed, including the researcher as an instrument and entering and leaving the field. Subsequently, the ethical considerations, setting and sample are described. Next, the methods of data collection and analysis consistent with the methodology will be presented. Finally, how rigour was maintained is detailed.
Chapter 3: Methods

Introduction

In the previous chapter, the literature on patient participation in nursing care was reviewed. In this chapter the research paradigm, and methodology that address the study aim and research questions are described. A description of the ‘researcher as an instrument’ that is an integral principle of the methodology, is included. Then, the field settings and sample are discussed, detailing the way in which the researcher gained entry to the field. Following this, ethics requirements for the study are addressed. Next, the data collection and analysis methods are described, including when and how the researcher exited the field. Finally, the way in which rigor was maintained will be presented.

The constructivism paradigm

The constructivist paradigm is the ontological and epistemological foundation for this study. To elaborate, the constructivist paradigm supports a relativist ontology, whereby multiple social constructions of reality exist. These are intangible mental constructions that are only true for groups or individual people at the time elicited, making them tentative (Guba & Lincoln, 1989). It may be that people within a setting/group hold similar views about the nature of reality of these may differ (Appleton & King, 1997). Thus, through the constructivist lens, patient participation is an entity that exists only through the various meanings attributed to it by patients and nurses. To gain this constructed reality, I described patients’ and nurses’ multiple, mentally-constructed realities of patient participation within their local context (Guba & Lincoln, 2001; Lincoln & Guba, 1985). Reality was represented by producing the most informed construction possible, inclusive of divergent constructions of reality, that could be agreed upon at that time (Guba & Lincoln, 1989).

In terms of epistemology, the researcher takes a subjectivist and transactional approach to produce knowledge (Appleton & King, 1997). In other words, the findings in the study were created by the interaction and relationship between the researcher and participant (Guba & Lincoln, 1989). Therefore, I maximised my knowledge of patient participation by interacting with and observing the patients and nurses in the study. The
ontological and epistemological underpinnings of this study cannot be separated, without interacting with participants; I could not obtain in-depth interpretations or convincingly describe the entity that is patient participation.

**Focused ethnography**

This study was a focused ethnography; a description of this methodology is provided. The product of ethnographic methodology is a rich and trustworthy story about the phenomenon of interest (Fetterman, 2010). The phenomenon of interest for this study was patient participation. To tell an ethnographic story, the researcher needs to understand and describe peoples’ culture (Hammersley & Atkinson, 1983). Culture is a key concept of ethnography that traditionally relates to people’s behaviours (Fetterman, 2010), especially understanding their daily practices and mundane activities (Liberati et al., 2015). Understanding people’s culture also requires an understanding of their perspectives (Fetterman, 2010; Hammersley & Atkinson, 1983; Spradley, 1980). Importantly, ethnographic methodology demands wholism; these behaviours and perspectives need to be understood within the context of where they occur (Roberts, 2009), including understanding of the influences of things like structures, functions, symbols and rituals (Fetterman, 2010). In this study the culture of patient participation was examined by understanding the perspectives, behaviours and context related to it.

Ethnography is a suitable constructivist approach for gathering knowledge about what exists in the world. Consistent with the constructivist paradigm, ethnographers’ ontological beliefs support that truth is ‘in the eye of the beholder’ (Angrosino, 2008, p. 36). Further, ethnographers gain their knowledge and understanding of the culture by interacting with people and observing their everyday lives, consistent with a constructivist view on epistemology (Hammersley & Atkinson, 1983). Constructivist methodology is hermeneutic and dialectic, whereby the researcher employs hermeneutics by executing interpretive skills to understand patient participation, and is dialectic by seeking divergent thinking (Appleton & King, 1997). This is consistent with ethnography, because the researcher interprets the culture and includes many peoples’ views on the phenomenon of interest. Therefore, by utilising ethnographic methodology, many perspectives of reality are able to be accessed, combined and interpreted; both participants’ and the researcher’s perspectives of behaviour, while in the places where they occur. Angrosino’s (2007) philosophical view on ethnography aligns with my own, and supports a constructivist approach:
We cannot realistically strive to achieve a universally accepted, objective, value-neutral ‘truth’, we should strive to blend our voices, in full recognition of the situations whence they emanate, in order to establish a kind of mosaic view that approaches but never quite achieves absolute truth. (Angrosino, 2007, p. 96)

As seen in the quote above, there are two distinct perspectives that those undertaking ethnographic methods strive to grasp, the *etic* and *emic*. The *emic* perspective is that of the patient and nurse in the field. They use their own language to give insider knowledge of their experiences of the meaning they attribute to the phenomenon of interest (Spradley, 1979); in this case patient participation. This helps to understand why people do what they do. The *etic*, is the researcher’s understanding of witnessed behaviours within the context, the researcher adopts a cultural lens that allows him/her to focus and understand the people’s environment (Fetterman, 2010). The *etic* is an external perspective of reality that helps complete the picture of what is going on in the setting. Together these sources of knowledge, insider and outsider, provide a true but conditional story.

Field work is the essence of ethnography (Brewer, 2000). Ethnographers conduct interviews and observation in the field, and ethnography used in this setting allows the researcher to explore patients’ and nurses’ usual patterns of participation, within the setting in which they occur (Fetterman, 2010; Hammersley & Atkinson, 1983). Field observations provide an *etic* viewpoint of patient participation (Brewer, 2000), while in-depth interviews and quick questions in the field allow participants the opportunity to provide their *emic* meanings to the researcher’s observations of practice (Fetterman, 2010; Spradley, 1979).

Ethnography is accepted as a suitable methodology to understanding health care activities, especially nursing activities (Thomson, 2011). Nursing ethnographies can help understand societal issues (Cruz & Higginbottom, 2013), beliefs and practices (Savage, 2000) and the knowledge found can contribute to improving practice (Holloway & Wheeler, 2002). Researchers investigating patient-centred care benefit from being guided by ethnographic principles, as they can be in close proximity to the context where patient-centred care practices occur, enabling them to see contradictions between nurses’ verbal commitment to patient-centred care and their actions, and contradictions between policy and practice (Liberati et al., 2015).

This study is a focused ethnography, or micro ethnography; a modified form of ethnography (Fetterman, 2010). Focused ethnography emerged to meet the needs of
health care research, where traditional ethnographies are not always feasible (Cruz & Higginbottom, 2013). Traditional ethnography has its roots in anthropology, whereby researchers aimed to understand people in strange, exotic or sometimes rural settings, demanding prolonged fieldwork and the researcher to become a member of the setting (Lambert, Glacken & McCarron, 2011). Instead, focused ethnography acknowledges that researchers are sometimes in familiar environments, and thus can undertake smaller-scaled projects in their everyday settings (Savage, 2000). This applied methodology, is able to be used when the researcher has a clearly defined issue to focus on (Cruz & Higginbottom, 2013). Having this focus means the project can be shorter in duration, as intensive data collection can concentrate on actions and interactions related to the topic of interest (Cruz & Higginbottom, 2013; Knoblauch, 2005; Thomson, 2011), thus the lens in the field is narrowed. Further, this contemporary form of ethnography allows multiple settings to be investigated, allowing the researcher to discover similarities and differences between settings in relation to the topic (Savage, 2000). Despite the differences between traditional and focused ethnography, both methodologies use the same methods of data collection and are underpinned by the same values.

This study was part of a funded three-phased project. Phase 1 of the funded study was to involve interviews only at two sites. This PhD undertook Phase 1 but extended it at one site to be a focused ethnography. A focused ethnography was not feasible to perform at Site 2 due to funding and location. Site 2 interviews contributed to the focused ethnography, enhancing confirmability and transferability of findings.

**The researcher as an instrument**

In this section, an account of the ‘researcher as an instrument’ is provided. As an ethnographic researcher I am an instrument that facilitated the entire ethnography (Angrosino, 2008). I, the ethnographer was reflexive to ensure that I was a high quality instrument in the field. The research assistant (RA) hired to collect interviews at the Site 2 did not undergo the same reflexive processes. Ethnographers are connected to data they collect, because they shape the context and participant behaviours (Hammersley & Atkinson, 1983). Thus, no matter how unobtrusive I tried to be in the field, my presence had the potential to make people reactive (Angrosino, 2008; Angrosino, 2007). Thus, I used a number of techniques to try and minimise obtrusiveness and maintain
participants’ natural behaviours. These strategies included both rejecting and embracing my nursing experience and role.

One strategy was being honest with participants about my roles. This study was my first ethnography. I am a novice researcher, having undertaken a prior study using case study methodology, which included observations and interviews. In addition to my research role, I am a nurse with 7 years of experience in acute care nursing. I work part-time in a surgical ward at Site 1, but have no association with the wards included in this study. Being a nurse and a researcher can be viewed as both a benefit and a challenge in ethnography (Gelling, 2014). When recruiting participants I disclosed my status as a nurse and researcher, but emphasised that my current role was to research patient participation; I was not performing nursing care. In addition, I stressed to nurses that the project was not being conducted by the hospital; it was for the purpose of a PhD. Audits occurred frequently on the hospital wards, I wanted to reassure nurses that I was not judging clinical practice. Despite these explanations, a small portion of nurses refused to participate, based on their discomfort with my nurse status.

Taking a passive participation role in the field meant I was present in the field where patient participation occurred, but mainly spectated (Spradley, 1980). To adopt this passive role, I practiced contrasting actions to my regular behaviours when nursing patients. For instance, I shadowed nurses silently while providing personal space, answered participants’ questions but did not initiate them, I did not initiate or terminate nursing activities or interactions and I avoided direct eye contact when patients and nurses were interacting (Gobo, 2008). Further, I chose to wear similar outfits to student nurses. This allowed me to blend in while following nurses, but still allowed my own distinct identity. Adopting this role was in contrast to my nursing role, where I direct patient care and am identified as a nurse by my nursing uniform.

Despite attempting to minimise my nursing characteristics, at times my role as a nurse may have influenced nurses’ practice. For instance, when nurses encountered problems with clinical patient care, I sensed nurses’ discomfort with my presence. In all clinical tasks, I was careful to provide nurses with adequate space and sometimes undertook small actions to make them feel supported and at ease. In one example, a patient’s nasogastric tube was blocked, which resulted in water being spilt over the patient. I assisted the nurse by passing paper towels to him; the nurse expressed gratefulness and appeared calmer. There was role conflict in a small number of cases
where nurses sought confirmation that they were providing nursing care correctly. Depending on the simplicity of the query, I confirmed their query or directed them to a senior nurse on the ward.

On the other hand, there were benefits to being a nurse and I used my nursing skills and experience to enhance my researcher role (Colbourne & Sque, 2004). For instance, nurses generally have skills in building beneficial relationships (Oliffe, 2005). Building these relationships allows research participants to feel valued and encourages their engagement in the research process (Leslie & McAllister, 2002). One strategy I used to build relationships was having informal talks with patients and nurses in the field, when the two parties were not interacting, which appeared to put them at ease and built rapport. I commonly asked nurses about their nursing careers, which resulted in enthusiastic conversations, and allowed me to disclose small portions of information about my nursing role in response to their questions. Being a nurse I had the skills to build an empathetic, yet professionally distant, relationship with participants (Leslie & McAllister, 2002).

Embracing my various roles as a nurse, PhD student and researcher may have enhanced participants’ comfort with my presence. After a while, nurses invited me to sit next to them when typing patient notes, asked me to join them during meal breaks, and encouraged me to ‘be part of the team’. I debriefed with my supervisors, pondering whether my student status increased nurses’ willingness to participate and their acceptance of me. Being a teaching hospital, nurses are generally used to having a student nurse shadow them, possibly reducing outsider status (Gobo, 2008). Or perhaps my role as an insider and outsider enhanced nurses’ acceptance of my presence. Knowledge of my insider status as a nurse in the institution may have enhanced participants’ willingness to take part in research (Leslie & McAllister, 2002), while being an outsider, in terms of having no affiliations with the ward, only holding temporary membership with the group (Angrosino, 2007), could have enhanced nurses comfort in speaking with me and disclosing issues they are not comfortable sharing with ward members (Leslie & McAllister, 2002). Patients appeared especially comfortable with my presence. Disclosing my role as a nurse may have enhanced this, as nurses are typically viewed as trustworthy by patients, and patients are used to interacting and disclosing information with nurses (Leslie & McAllister, 2002).
One issue I was wary of was nurses trying to please me and force data to complete the study. Most noticeably, on shifts where nurses were less time-pressured they expressed worry that I may be ‘bored’ and ‘not seeing enough’. In these instances I was careful to interpret their behaviours as routine, in case nurses were trying to look ‘busy’ and please me. Nurses were repeatedly reassured that I was there to observe usual behaviour.

As a researcher, my knowledge, experience, views and ideas inevitably shaped the research (Angrosino, 2007). I had insider status being a nurse, which was advantageous as I already had knowledge of some behaviours and contextual elements. It was important that I used this knowledge and experience to give meaning to data collected (Gelling, 2014). I reflected prior to starting field work, documenting things like my values and beliefs related to patient participation within the institution and my own perceived behaviours and personality when conducting nursing care (Appendix B). I tried to remain aware of making assumptions based on my prior nursing knowledge and opinions, which could have led to missing, or taking for granted, tacit knowledge in the field (Fetterman, 2010; Spradley, 1980). Acknowledging my preconceptions, allowed me to switch off from what is ‘normal’ practice and notice everything occurring in the field (Gobo, 2008). Yet my outsider status on the ward also enhanced my astuteness to new knowledge and subtle differences in practice (Thomson, 2011). Having experience in nursing was advantageous as I had developed skills in observation, documentation, analytics and had a good memory, which enhanced my ability to undertake a researcher role (Oliffe, 2005).

For logistical reasons, a RA conducted interviews at the second site. Even though the Site 2 RA did not undergo the same reflexive processes, I used my reflexive approach (i.e. researcher as instrument) in guiding her. For instance, the RA’s reflective processes were enhanced by undertaking initial analysis under my guidance, which heightened her understanding of the findings and allowed her to probe further for in-depth understanding in subsequent interviews. I engaged with her frequently while she was collecting interviews. I interpreted her initial analysis documents and helped to shape her approach to future interview to ensure she was also a high quality instrument. By reflecting, I was able to share my understanding of the topic with her and any preconceptions that I had brought, helping her to be aware of her own (especially if these were evident in her initial analysis). Having a RA also enhanced my reflexivity;
discussions with her fostered dialogue, making me reflect on whether Site 2 preliminary findings were complimentary or divergent to those at Site 1 and helped me to gain understanding of the situation (Cohen & Crabtree, 2006). I had to use my reflexive approach towards Site 2 data (interview transcripts). This data collected as Site 2 required my input and interpretation, and I put my perspective onto data. I built an understanding of how Site 2 data supported or refuted Site 1 findings.

Field setting

This field setting for this focused ethnography was Gold Coast University Hospital (Site 1). Cabrini Hospital (Site 2) was where interviews were conducted. Descriptions of these sites are now outlined. Site 1 opened in 2013, after being relocated from an older facility. The Gold Coast University Hospital has 750 overnight beds; however, around 500 were opened at the time of data collection. This institution provides care to South-East Queensland, Australia, with a population of 520,000 and is a referral facility for the far north coast of New South Wales. The hospital provides a range of services including cardiac surgery, emergency care, intensive care, operating theatres, neuroscience, mental health, maternity and paediatrics, and is a government funded facility.

Interview data were also collected at Cabrini Hospital (Site 2), in order to capture both similarities and differences between states and the public and private sector. By trianguating settings, the Site 1 findings on patient participation could be tested in another setting. Site 2 is a 508-bed private hospital in metropolitan Melbourne, Victoria. Melbourne has a population of over 4 million and over 35 metropolitan hospitals. Cabrini Hospital provides coronary care, oncology, emergency care, intensive care, maternity and paediatrics. It is Victoria’s largest private hospital, which opened in 1958 and has continued to expand in physical size since that date (The University of Melbourne, 2008). Interviews were conducted at Site 2 by a RA, to provide another viewpoint on the topic to compare and contrast to the Site 1. Observations were not conducted at this site due to feasibility. These two sites differ in many aspects such as location, duration of establishment and type of service, providing rich and diverse perspectives on and expanding our understanding of patient participation.

Data collection was undertaken in four medical wards, two at each site. All four medical wards provided general medical care. At Site 1, the two medical wards
primarily admitted patients with respiratory conditions and immunology disorders, while Site 2 catered for neurology and gerontology. At Site 1 the respiratory ward had 24 beds and immunology had 22 beds. Medical wards were purposefully chosen for pragmatic reasons, as patients admitted to medical wards commonly present with chronic conditions and may use hospital services more frequently. Thus, these types of patients may be more active in their care (National Health Priority Action Council, 2006), providing more opportunities to understand patient participation. Further, in this ethnography a distinct focus on medical ward practices of patient participation was desired. There are distinct cultural differences between settings like rehabilitation, intensive care and emergency units, which may result in distinct cultures in relation to patient participation. By focusing on medical wards only, a more specific understanding of this setting and participants was generated.

**Entering the field**

Interviews were conducted at both sites but only observations were carried out at Site 1, therefore this section on entering the field reflects Site 1 only. Several gatekeepers were approached to gain entry to the field. First, approval from the Director of Nursing (DON) for the medical division had to be gained. It was easy to arrange an appointment to meet with her as I had worked within the institution and could gather contact details and was guided by the principal supervisor who had undertaken this process. Both the principal supervisor and I met with the DON who was given a broad overview of the study and was supportive, providing contact details for the Nurse Unit Managers (NUMs) for the participating wards.

Next, I gained approval from the NUMs. This process was more difficult due to their busy schedules. Once I had met with the NUMs, a broad overview of the project was provided and the NUMs were supportive of the project. I used bargaining principles to gain entry, outlining the benefits of the research for the ward and assuring dissemination of findings to the ward once complete (Thomson, 2011). A common query from the NUMs was about how the study would have an impact on their staff and their work. Both NUMs stated they would not be able to facilitate the project at a practical level, but wanted to be kept updated on its progress. Both NUMs designated their clinical facilitators as the ‘gate keeper’ that I would need to liaise with on a regular basis. In Australia, clinical facilitators are located on each ward and are responsible for delivering clinical training to meet nurses’ learning and developmental needs, providing
support and supervision to promote clinical care outcomes, and supporting staff to adopt new practices.

I met with the clinical facilitators and gave more in-depth descriptions of the logistics of the project and how they may assist with the flow of the project. Both clinical facilitators were supportive of the research and I maintained close contact with them throughout the project. Building a relationship with the clinical facilitators was advantageous, as they assisted in arranging information sessions for nurses to hear about the project and encouraged nurses to attend these sessions. The clinical facilitators organised introductions to the field and its members. Feasibly, the trust the members of the field placed on clinical facilitators may have been extended to me through association (Fetterman, 2010).

Ethics

The Human Research Ethics Committees (HREC) at Site 1 and 2 and the university were another type of gatekeeper (Thomson, 2011), thus ethical requirements were addressed and are explained in this section. Ethics approval was gained from Gold Coast University Hospital, Cabrini Hospital and Griffith University HREC to proceed with the project. Throughout the study nurses and patients were treated in an ethical manner. The nurses and patients had the right to consent freely and without coercion and were made aware that they could withdraw from the study at any time with no consequence. All participants received an information sheet (Appendix C, D, E, F) accompanied by a verbal explanation of the study, its risks and benefits, with time set aside for participants’ questions. All participants signed consent forms (Appendix G, H, I, J). Identity of participants was protected through use of codes, with the codes stored in a separate location from raw data. All raw data are stored in a locked filing cabinet at Griffith University or Cabrini Hospital, dependent on where it was collected, and on password-protected computers. Data will be destroyed after seven years (National Health and Medical Research Council, 2012). Raw data will be destroyed by shredding hard copies and clearing computer files and digital recordings.

Sample

For this study, both patients and nurses were sampled. Participants were recruited for observations at Site 1 only. Of the sample that was observed at Site 1, a portion of were interviewed. Interviews were undertaken at Site 2. All patient and nurse
participants at Site 1 and 2 had to meet explicit selection criteria. To be included, patients had to be adults, who were able to provide informed consent and were excluded if they were unstable or palliative. In regards to selecting nurses, the nurses had to be providing direct care for the recruited patients. Agency nurses or pool nurses that were not contracted to the ward were not selected. Similar recruitment processes were undertaken at both sites for interviews. The sampling procedure is outlined below describing observations followed by interviews. First, the sampling procedure for recruiting nurses for observations is provided. At Site 1, the clinical facilitator on the wards arranged information sessions for nurses. Nurses were offered to attend information sessions, and if they attended I gave written and verbal explanations of the project and the opportunity to ask questions. All nurses that agreed to take part signed consent forms during the information sessions, even though they were offered the opportunity to return the forms after considering their participation. Thus, nurses were largely recruited using convenience methods. Undertaking the recruitment process days prior to observations enabled the researcher to plan visits to the ward, based on when recruited nurses were working.

Recruiting patients for observations occurred on the day of observation. When a nurse participant was working, the clinical facilitator or their designate was approached to ask if any of the nurse’s patients were eligible participants. At least two of the nurse’s patients had to be eligible and willing to participate on the day for the nurse to be observed. If there were not enough patients I left the ward and returned on another day. While most patients were recruited via this convenience method, purposive sampling was undertaken also. In some cases more patients were able and willing to participate than required and in these cases patients that differed from previously observed participants were selected to reflect variation in the sample. On each day of observations new patients and nurses were observed, thus nurses and patients were only observed once.

For interviews, similar approaches were carried out at both sites. When sampling for interviews, maximum variation sampling was employed (Polit & Beck, 2008). At Site 1, participants had already been observed and their demographic and clinical information had been collected, allowing for the selection of a sample to interview that varied. At Site 1, participants who differed in level of participation observed were also able to be selected. At Site 2, the NUM or their designate, assisted in selecting a sample
that had maximum variation. At both sites, participants were purposefully chosen to reflect people who differed in terms of age and gender. Also, nurses who differed in clinical experience and patients who differed in clinical condition were selected. These purposefully selected participants gave in-depth accounts of the phenomena, meaning not all participants observed had to undergo interviews (Gobo, 2008; Thomson, 2011).

**Fieldwork**

A focused ethnography was conducted at Site 1 only. Interviews were conducted at a second site to capture similarities and differences between states and public and private sectors. Conducting observations and extending the focused ethnography to the second site was not deemed feasible because it would be beyond the scope of this PhD in terms of time, financial resources and ability to contribute to new nursing knowledge in a reasonable volume of work. Fieldwork on the two wards at Site 1 occurred at different times. During November-December 2013 fieldwork occurred on the immunology ward until no new behaviours were observed. Fieldwork on the respiratory ward occurred from January to February in 2014, until data saturation occurred.

The methods of data collection included observations at Site 1 and interviews at Site 1 and 2. Field observations occurred first to capture participant behaviours towards patient participation. If interviews had occurred first, participants may have perceived a preferred behaviour, thus showing a lack of candour and potentially biasing observations (Polit & Beck, 2008). Further, ethnographic interviews come logically after observations (Angrosino, 2008). Once the observer has witnessed and documented meaningful patterns of behaviour in the field, they need to discover the meanings of these behaviours (Angrosino, 2008). Thus, observational findings were used to prompt participants in interviews to explain their behaviour, which helped ground or disconfirm the *etic* perspective.

**Observations**

Observations occurred over four months at Site 1. My observations began ‘wide’, in order to observe as much as could be seen and sensed in the field (Edvardssson & Street, 2007), trying to take no behaviour or sense for granted (Angrosino, 2007; Spradley, 1980). As observations proceeded the focus narrowed in line with focused ethnography, searching for patterns of behaviours and unique experiences related to patient participation that occurred predictably (Angrosino, 2007). Although the focus
narrowed, these typical patterns observed were placed within context, noting artefacts, places, times and things perceived through my senses that gave a wholistic picture of the observed behaviours (Angrosino, 2007; Gobo, 2008). At least four hours of observations with each nurse were conducted, as this short and intensive period of observation is an effective way of conducting fieldwork (Fetterman, 2010). Observations continued and narrowed until saturation occurred (Angrosino, 2008).

I took on a non-participant role, being present in the field but only spectating and shadowing the nurse (Fetterman, 2010). Shadowing the nurse allowed me to keep up with them and see all events occurring in their everyday occupation. When observing, I undertook time-sampling (Hammersley & Atkinson, 1983). I entered the field at varying times of the day, on either the day shift or afternoon shift, and week, on either weekdays or weekends, to increase the chance of observing different activities that may relate to patient participation. Day shifts and afternoon shifts were selected for observation as patient participation is likely to be minimal at night when most patients will be sleeping. By undertaking time-sampling and shadowing nurses, I gained access to a variety of contexts, even moving beyond the ward to accompany patients and nurses to other areas of the hospital. I got firsthand experience of nurse-patient interactions and activities (Liberati et al., 2015) at a variety of times and with a variety of patients and nurses. Further, patient participation was viewed during a number of events such as handover and medication rounds. Ultimately, shadowing nurses allowed me to sample different contexts and understand nurse-patient interactions within these contexts.

Producing a descriptive product of field experiences was achieved through written field notes and digital recordings. Short field notes were written immediately after observing in a notepad in a discreet manner while on the ward. Digital recordings were another means of documenting observed behaviours. Whenever the nurse observed took a break or on completion of observations, digital recordings of field notes were undertaken maximising the speed and accuracy of recording findings. These two sources were used to guide the writing of formal field notes, which occurred promptly after leaving the field (Fetterman, 2010).

I documented my final field notes in a systematic manner (Appendix K). Field notes were organised into tables that were written chronologically. Each table was divided into two columns: the left column provided details of the date, time and context of the interaction; the right column was used to document actions, interactions, verbatim
quotes, physical objects and things sensed. I was careful to code my field notes; verbatim quotes were in italics to ensure patient and nurse quotes were explicit due to the different words they used (Spradley, 1979). During my time in the field and immediately after leaving the field, I wrote personal thoughts and reflections. These reflections raised queries in the field that required further investigation, helped make my ideas explicit of what was occurring in the field, and helped guide future interviews (Thomson, 2011). These reflections were always underlined to differentiate them from observations of practice.

**Interviews**

Interviews occurred after observations at Site 1. Reflection on Site 1 fieldwork findings allowed interview questions and probes to be customised to enhance understanding of the phenomenon of patient participation. Interviews at Site 2 occurred around the same time as Site 1 interviews. These interviews were conducted by a RA, who was part of the research team. The research team comprised of three supervisors, the RA and me. Two supervisors and I were located at Site 1, while one supervisor and the RA were located at Site 2. The RA and I met in person prior to interviews and then maintained frequent contact to discuss questioning techniques. We had consistency in training, with practice interviews and meetings with supervisors; however I had more extensive knowledge of the topic and had undertaken reflexive practices.

Patient interviews occurred in the days following observations at Site 1, to ensure patients were still hospitalised. Patients at both sites were made comfortable by choosing the location of interviews, usually in their rooms. Nurse interviews occurred throughout the data collection process at Site 1 at a time and place that was convenient for nursing staff. It was often challenging for nurses to find time to be interviewed. Weekends or evening shifts were often more successful for interviews as nurses appeared less busy. Every attempt was made to interview nurses soon after patient encounters at the Site 1 to enhance recall. Nurses at both sites usually selected a quiet and private room like a meeting room for interviews to occur.

Interviews were semi-structured, with extra probes added guided by findings from fieldwork at Site 1. The interview guides used at both sites is available in Appendix L and M. As can be seen, some specific questions around patient participation in safety were added. This study was part of a larger project on patient safety and these data were
required to fulfil the grant requirements. Further, as seen in chapter 1, the link between patient-centred care and safety is growing and understanding the patient’s role in safety is an important part of understanding patient participation. The wording of questions was sometimes adapted during interviews at both sites to match participants’ natural language and aid understanding (Spradley, 1979). The interviews began with a preamble (Appendix L and M), reminding participants of the focus of the interview. Interviews began with general questions, such as ‘How was your day?’ easing interviewees into the process. A digital recorder was used to capture all interviews.

There were techniques the RA and I used and discussed to enhance the depth of interviews. The RA and I tried to approach interviews like a stranger (Spradley, 1979), to encourage participants to give an exhaustive account of patient participation; however, the semi-structured framework helped create a demeanour of informed ignorance. Further, we attempted to maintain balance between listening to participants rich responses to the questions and keeping the focus on patient participation (Spradley, 1979). Anytime a patient or nurse abbreviated or assumed the RA or I knew what they were talking about, clarification was sought (Spradley, 1979). This was important as both the RA and I were nurses and I experienced participants who assumed I understood them and did not require in-depth explanations.

**Data analysis**

Data analysis included deductive and inductive analysis of field notes and inductive analysis of interviews. Details are provided of the steps taken. I led data analysis, meaning I independently coded Site 1 interview and observation data. However, my findings were regularly reviewed by my supervisory team, who questioned and/or confirmed findings. Site 2 data underwent preliminary analysis by researchers at that site, with my assistance. I presented my established categories at a 1 day face-to-face meet-up. I led a comparison of site 1 and 2 findings, and ultimately led the development of final categories and subcategories. I obtained all raw data from Site 2 and organised all data into categories. Analysis of Site 1 data occurred concurrently with its collection throughout the entire study (Fetterman, 2010). While in the field, data were reviewed in an iterative manner, looking for patterns and testing impressions of patient participation in successive observations and interviews (Fetterman, 2010). These methods of analysis were embedded and made known by journaling thoughts about what was going on that continued until crystallisation of ideas occurred.
Interviews

For analysis of interviews, there was a team of researchers, including two supervisors and myself on the Gold Coast and one supervisor and the RA in Melbourne. The team of researchers was divided into two groups due to their geographical location, being Site 1 and 2. The two groups of researchers undertook similar analytic processes at both sites. The RA and I conducted initial analysis immediately after the interviews were conducted, using an adaptation of Miles et al. (2014) contact summary forms (Appendix N and O). This involved listening to the interview recording and summarising the information gathered, including responses that seemed important or interesting, and gaps in the interviews that allowed these areas to be investigated in more depth in successive interviews (Miles et al., 2014). This process also allowed the RA and I to reflect on our interviewing techniques, allowing modification in future interviews to ensure the most in-depth responses were gained. Further, initial analysis allowed preliminary categorisation of data. The RA and I kept in close contact, discussing our initial findings and common probes used. Having initial analysis forms sent to me via email, allowed me to ensure the RA was collecting sufficient data and provided early understanding of emerging patterns at the second site.

Formal qualitative content analysis (Elo & Kyngäs, 2008) was used to analyse transcribed interview data. As per Elo and Kyngäs (2008), content analysis comprised of three phases; the preparation phase, organising phase and reporting phase. Researchers at both sites undertook inductive qualitative content analysis separately but both used a similar analytic process. I lead Site 1 analysis of 20 patient and nurse interviews and Site 2 researchers analysed 20 patient and nurse interviews from Site 2 to a preliminary subcategory level, to allow comparison with Site 1 findings. The first phase of inductive content analysis was preparation (Elo & Kyngäs, 2008). Interviews were transcribed by an outside party and checked against original audio for consistency. Checking transcripts against audio allowed me to hear interviews again, becoming immersed in them. I then read the transcripts in their entirety many times. This allowed me to get a sense of the whole, highlighting sections that stood out, and spurring thoughts and ideas that were documented as analytic memos.

In the next phase, data were organised (Elo & Kyngäs, 2008). In the case of Site 1, QSR International’s NVivo 10 software was used to assist with data management in this phase. The units of analysis were whole interview transcripts, which were uploaded
into the software. Nurse and patient data were analysed separately, allowing similarities and differences between their perspectives to be identified. I undertook line-by-line coding, giving headings or sentences that described the content of the line. However, I was not restricted by the formality of each line. If I judged more than one line of the transcript were required to capture the meaning of the content, a few lines were coded together under one heading or sentence. A log with descriptions of the meaning of each code was created. I took the headings and sentences coded to data and began trying to group similar codes together; trying to reduce the number of codes, grouping them into subcategories. Tables and flow charts were created to visualise the process of grouping similar terms that belonged together. These codes were grouped together into subcategories if they showed similar events, and subcategories that belonged together were developed into categories. This entire process was iterative; I constantly referred back to the transcripts to ensure the analysis was trustworthy and representative of participant views. I had frequent team meetings with supervisors throughout all phases of data analysis, to question and interpret my findings as a group.

Once the groups of researchers at Sites 1 and 2 had completed analysis, they met for a two-day face-to-face meeting. Analysis from Site 2 was less refined, thus Site 2 data continued to be interrogated and the analytic process continued among the team under my leadership. I discussed categories and subcategories formulated at Site 1, which were compared and contrasted to Site 2 findings. The researchers worked together to ensure the categories and subcategories I had created had labels that explained the similarities at both sites, as well as capturing the divergence between sites. The researchers constantly returned to raw data to assist in this component of analysis. Each category was mutually exclusive and represented data at both sites; diagrams and flow charts were used to assist the process, with some examples shown in Appendix P.

Preliminary findings from both sites were compared and subcategories and categories re-examined and their label refined. In the final phase of analysis, the reporting phase, I gave the categories descriptions and reported a condensed and broad description of the phenomenon of patient participation from the patient and nurse perspective (Elo & Kyngäs, 2008; Fetterman, 2010). Tables and participant quotes were used to connect raw data and the analytic process to the final findings, and descriptions
of the analysis process were provided (Elo et al., 2014), as seen in the published papers, (Tobiano, Bucknall, Marshall, Guinane & Chaboyer, 2015a; Tobiano et al., 2015b).

In the final step of analysis, I undertook a secondary analysis of the findings of patients’ and nurses’ views. Researchers can re-use self-collected data to investigate additional research questions to those posed in the primary research (Heaton, 2008). I undertook a supplementary analysis, whereby a more in-depth analysis of emergent issues or aspects of data not addressed in the primary research was undertaken (Heaton, 2008). The aim of this reanalysis was to identify the similarities and differences between patient and nurse views. Formal, inductive content analysis was undertaken (Elo & Kyngäs, 2008). In the preparation phase I returned to raw data and combined QSR International’s NVivo 10 Software files of patient and nurse views. I read and reread the transcripts many times. In the organisation phase each transcript was treated as a unit of analysis. Data were coded line-by-line, and subcategories and categories were built using the codes, reflecting the similarities and differences in patient and nurse views. In the reporting phase, categories were given descriptions, which are reported in Chapter 4.

**Observations**

Although preliminary analysis of observation data occurred concurrently with collection, formal content analysis of observation data occurred after interview analysis, to determine the difference between what participants said and did. In the preparation phase (Elo & Kyngäs, 2008) I read the field notes in their entirety many times, noting thoughts about data as memos. Data appeared mundane to me, mirroring everyday practices. For this reason I decided to test an existing conceptualisation of patient participation in this new context, to try and uncover patient participation activities within the field notes. This idea was supported by the supervisory team. Thus deductive content analysis was used to guide the process (Elo & Kyngäs, 2008), with data not fitting into deductive categories being analysed inductively. The preparation phase outlined above was relevant to both the deductive and inductive analysis approach.

In the organisation phase, Eldh et al.’s (2015) conceptualisation of patient participation was used as a categorisation matrix to code data against. Their conceptualisation has four dimensions. These dimensions and items that link to these dimensions are presented in Table 4. Descriptions for these dimensions have been
PATIENT PARTICIPATION IN NURSING CARE

previously described in Chapter 2. QSR International's NVivo 10 software was used to assist with data management and analysis and these dimensions and items were made into nodes within the program to code data against.

Table 4 Patient Participation Categorisation Matrix

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having dialogue with</td>
<td>1. There are conditions for mutual communication</td>
</tr>
<tr>
<td>health-care staff</td>
<td>2. My knowledge and preferences are respected</td>
</tr>
<tr>
<td></td>
<td>3. Health-care staff listen to me</td>
</tr>
<tr>
<td>Sharing knowledge</td>
<td>1. I get explanations for my symptoms/issues</td>
</tr>
<tr>
<td></td>
<td>2. I can tell about my symptoms/issues</td>
</tr>
<tr>
<td></td>
<td>3. Health-care staff explain the procedures to be performed/</td>
</tr>
<tr>
<td></td>
<td>that are performed</td>
</tr>
<tr>
<td>Partaking in planning</td>
<td>1. Knowing what is planned for me</td>
</tr>
<tr>
<td></td>
<td>2. Taking part in planning of care and treatment</td>
</tr>
<tr>
<td></td>
<td>3. Phrasing personal goals</td>
</tr>
<tr>
<td>Managing self-care</td>
<td>1. Performing some care myself</td>
</tr>
<tr>
<td></td>
<td>2. Managing self-care</td>
</tr>
<tr>
<td></td>
<td>3. Knowing how to manage symptoms</td>
</tr>
</tbody>
</table>

Note. Adapted from “The development and initial validation of a clinical tool for patients' preferences on patient participation – the 4Ps,” by A. C. Eldh, and K. Luhr, M. Ehnfors, 2015, Health Expectations, 18, p. 2527.

The field notes were prepared into ‘encounters’, enabling sections of field notes to be coded to the categorisation matrix, which was part of the preparation phase. An encounter was defined by the presence of a nurse and patient within physical proximity to interact. In the organisation phase, I reviewed each encounters for content and coded them to the categorisation matrix, to uncover the frequency of Eldh et al.’s (2015) dimensions and items of participation in data. The matrix was structured, meaning only data that fit the categorisation matrix were included (Elo & Kyngäs, 2008). Overall, the deductive analysis provided an account of the types of participation activities occurring in the field.

However, not all data fitted this matrix; cultural and contextual factors were not captured by deductive content analysis. Data were also analysed using the principles of inductive content analysis to provide meaning for the participation activities uncovered. Elo and Kyngäs’ (2008) steps for inductive content analysis were followed as previously described for the interview analysis. In the preparation phase, the units of analysis were entire field notes. These field notes were uploaded into QSR
International's NVivo 10 Software and read and re-read many times, allowing me to get a picture of what was going on. In the organising phase, data were openly coded, by applying codes to each line of data that provided detail of the content of it. These codes were then grouped into subcategories, based on which codes fit together, drawing flow charts assisted with this step. Once subcategories were developed, they were grouped under higher order categories based on where they belonged. The process was iterative and the supervisory team reviewed developing subcategories and categories to confirm findings.

In the reporting phase, the inductive and deductive analysis process was described for readers. Further, the findings were presented under their inductive and deductive titles, with descriptions of their meaning and supporting quotes, allowing the reader to understand how the categories were conceived, evident in the published paper (Tobiano, Marshall, Bucknall & Chaboyer, 2016).

Exiting the field

After 28 patients and 15 nurses were observed at Site 1 and interviews with 20 patients and 20 nurses had been conducted at Site 1 and 2 consistent patterns of perceptions and behaviours were identified, with no new ideas emerging (Fetterman, 2010). As stated by others, there is no one way of reaching data saturation (Bowen, 2008; Kerr, Nixon & Wild, 2010). However, it is important to make the steps for achieving data saturation transparent (Bowen, 2008). One important step for achieving data saturation in this study was the use of initial analysis forms. This allowed me to ensure that both the RA and I were capturing content on all questions required to understand all viewpoints on the topic. For observations, reflections provided more insight into the data saturation process, by reflecting on field notes and reflecting during and after field work, I began to see common patterns, allowing me to focus in on these. The point where data saturation was confirmed was by holding a face-to-face meeting. This meeting was intended to discuss the findings and determine as a group if saturation had occurred. For this meeting I had analysed interview categories formally and identified that each category was complete, which I had discussed with my supervisory team prior to this day. I presented the developed categories to the group. Site 2 subcategories were then explored and mapped to my developed categories as a way to
test my categories and achieve data saturation (Bowen, 2008). Through group discussion it was evident that Site 2 findings confirmed my developed categories, while providing divergent opinions within categories. Analytic comments during my early analysis of observation data highlighted my feelings of repetitiveness of what was being observed in the field was discussed at this meeting and in subsequent supervisory meetings. On this date it was decided that no further data would be collected as the findings were sufficiently saturated. Therefore, analysis at that point confirmed there was sufficient data to describe the phenomenon of patient participation convincingly and no new information was being obtained (that is data saturation) (Kerr et al., 2010) and write an ethnographic story (Fetterman, 2010), thus it was time to leave the field. I approached The NUM and clinical facilitator on each ward at Site 1 to inform them that the project was complete. They were thanked for their participation and assured that they would hear the final findings. Contact details were provided in case further information was required.

Rigor

The framework designed by Lincoln and Guba (1985) for assessing trustworthiness was used to maintain rigor. The criteria that need to be met to create a trustworthy study include credibility, transferability, dependability and confirmability. Several strategies were used to address these criteria. Data triangulation occurred by collecting and analysing data in more than one way, which produces a more credible, dependable and confirmable construction of the phenomenon of patient participation within the field (Krefting, 1991). For instance, triangulation occurred by using both interviews and observations. Second, sources of data were triangulated through involving a variety of patients and nurses, from several settings, who were observed at differing times and contexts; providing a complete picture of patient participation. Using two hospital sites was also a way of triangulating sources, as the Site 2 interviews helped to understand and confirm the ethnography conducted at Site 1. Third, triangulation of researchers occurred during data analysis. Although I led analysis, multiple researchers were involved in checking categorisations and discussing divergent opinions (Elo et al., 2014), enhancing dependability of findings. Having two groups of researchers independently analyse data and then meet acted as a strong cross-verification process, as the convergence of findings at two sites was strong. Further, a
patient advocate was employed during the analysis process to review and interpret the established categories from interview data. This provided the research team with another perspective on the emerging findings and allowed a consumer to provide meaning for the established categories.

The data obtained was in-depth, contributing to the trustworthiness of the study. Interviews and observations employed in the study were in-depth methods for data collection and are internally consistent methods that produced a rich description of the phenomenon of patient participation (Krefting, 1991; Lincoln & Guba, 1985). Ethnographic interview techniques specifically enhanced the richness of knowledge of patient participation through repeating and reframing questions to participants and utilising observations to add interview questions (Krefting, 1991). This study is not intended for generalisation, however, the field, contexts, times and participants have been thoroughly described. The in-depth descriptions provided for this study increase transferability, by allowing readers to judge the similarity of the context to their own, to decide if the study is appropriate to transfer to their setting (Lincoln & Guba, 1985).

In addition to being in-depth, the study was time-intensive. Observations and interviews were intensive, enabling the discovery of reoccurring patterns and divergent cases of patient participation (Krefting, 1991). Importantly, I exited the field when no new patterns were emerging and credible accounts of nurses and patients different constructions of patient participation were obtained, instilling confidence in readers that adequate time was spent in the field (Krefting, 1991).

Further improving the credibility of the study were attempts to maintain the quality of data. Accuracy of findings was enhanced by using a digital recorder for field notes and interviews, with promptly written formal field notes written to elaborate. In addition, the quality of findings was heightened by the quality of the researcher as an instrument (Krefting, 1991), I used many strategies to enhance the quality of data collected. For example, the interview guide was pilot-tested on four nurses, allowing questions to be modified for ease of understanding, providing initial insights into the topic and allowing reflection on interview techniques. Furthermore, frequent meetings with supervisors, who were part of the research team, during all phases of the study, enabled me to reflect on my data collection techniques to improve forthcoming interviews and observations.
One of the most important strategies used was reflexivity, essential for ethnography due to the researcher’s effect on data (Hammersley & Atkinson, 1983). Throughout the entire study, I undertook self-reflection (Darawsheh, 2014), noting feelings, actions, biases, assumptions, values and interpretations (Brewer, 2000; Hammersley & Atkinson, 1983). This allowed me to remain aware of my subjective role throughout data collection and analysis (Darawsheh, 2014). Being reflexive meant I understood why I chose my approach to the study, my position on the topic, my motivations, clarity of roles, how I got to the findings and my influence on the participants allowing me to alter my actions (Darawsheh, 2014) (Appendix B). These items were sometimes discussed in meetings with supervisors. Making these explicit helped understand how these thoughts shaped the emerging findings, ultimately enhancing the study’s credibility and confirmability (Krefting, 1991; Lincoln & Guba, 1985). The final approach to conducting a rigorous study was maintaining an audit trail that addressed the rigor criteria of dependability and confirmability. The records outlined in Table 5 were kept and are available for external perusal to ensure readers can see the rationale for choices made throughout the study.
### Table 5 Outline of Records for Audit Trail

<table>
<thead>
<tr>
<th>Record type</th>
<th>Records available for audit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Records of process</td>
<td>Summaries of meetings with supervisors</td>
</tr>
<tr>
<td></td>
<td>Concept maps</td>
</tr>
<tr>
<td></td>
<td>Notes with methodological ideas</td>
</tr>
<tr>
<td>Records relating to intentions and dispositions</td>
<td>Proposals</td>
</tr>
<tr>
<td></td>
<td>HREC applications</td>
</tr>
<tr>
<td></td>
<td>Confirmation documents</td>
</tr>
<tr>
<td></td>
<td>Reflexive notes</td>
</tr>
<tr>
<td>Instrument development</td>
<td>Interview question guides</td>
</tr>
<tr>
<td></td>
<td>Information sheets</td>
</tr>
<tr>
<td></td>
<td>Consent forms</td>
</tr>
<tr>
<td>Raw data</td>
<td>Field notes</td>
</tr>
<tr>
<td></td>
<td>Interview transcripts</td>
</tr>
<tr>
<td></td>
<td>Digital recordings</td>
</tr>
<tr>
<td>Records of data reduction</td>
<td>Evidence of each stage of data analysis</td>
</tr>
<tr>
<td>Data reconstruction and synthesis products</td>
<td>Iterations of drafts</td>
</tr>
<tr>
<td></td>
<td>Final analytic themes</td>
</tr>
<tr>
<td></td>
<td>Published papers</td>
</tr>
<tr>
<td></td>
<td>Final thesis</td>
</tr>
</tbody>
</table>


### Summary

To conclude, this study was a focused ethnography, grounded in the constructivist paradigm. Gate-keeper requirements were met to allow entry to the field and gain ethical clearance for the project. The ethnography, inclusive of interviews and observations, was conducted at one site, while interviews were conducted at a second site to deepen understanding of patient participation. Both patients and nurses were sampled for this project. Data collection continued until data saturation occurred and then the fields were exited. Participant interviews were transcribed verbatim and analysed using inductive content analysis, while fieldwork was analysed using the principles of inductive and deductive analysis. To minimise obtrusiveness in the field, my nursing qualities were either embraced or rejected to minimise obtrusiveness in the field, enhancing the authenticity of data collected. Other rigorous techniques were undertaken to maintain the trustworthiness of data. The findings that emerged from observations and interviews are presented in the next chapter.
Chapter 4: Findings

Statement of contribution to co-authored published paper

Three ‘statement of contribution to co-authored published paper’ for the published papers presented in this chapter are provided.

Statement of Contribution to Co-Authored Published Paper

This chapter includes a co-authored paper. The bibliographic details (if published or accepted for publication)/status (if prepared or submitted for publication) of the co-authored paper, including all authors, are:


My contribution to the paper involved:

Conception and design of the research project, analysis and interpretation of the data and drafting and critical revision so as to contribute significantly to the final output.

(Signed) __________________ (Date) 5/2/16
Georgie Tobiano

(Coauthor) __________________ (Date) 5/2/16
Corresponding author of paper: Professor Andrea Marshall

(Coauthor) __________________ (Date) 5/2/16
Corresponding author of paper: Professor Tracey Bucknall

(Coauthor) __________________ (Date) 5/7/16
Corresponding author of paper: Professor Wendy Chaboyer

(Supervisor) __________________ (Date) 5/7/16
Supervisor: Professor Wendy Chaboyer
Statement of Contribution to Co-Authored Published Paper

This chapter includes a co-authored paper. The bibliographic details (if published or accepted for publication) or status (if prepared or submitted for publication) of the co-authored paper, including all authors, are:


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(Signed) ___________________________  (Date) 5/2/16
Georgie Tobiano

(Countersigned) ___________________________  (Date) 3/2/16
Corresponding author of paper: Professor Tracey Bucknall

(Countersigned) ___________________________  (Date) 6/2/16
Corresponding author of paper: Professor Andrea Marshall

(Countersigned) ___________________________  (Date) 6/4/2016
Corresponding author of paper: Jessica Quinane

(Countersigned) ___________________________  (Date) 6/4/2016
Corresponding author of paper: Professor Wendy Chaboyer

(Supervisor: Professor Wendy Chaboyer)
Statement of Contribution to Co-Authored Published Paper

This chapter includes a co-authored paper. The bibliographic details (if published or accepted for publication/status (if prepared or submitted for publication) of the co-authored paper, including all authors, are:


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(Signed) __________________________ (Date) 5/2/16
Georgina Tobiano

(Co-signs): __________________________ (Date) 3/2/16
Corresponding author of paper: Professor Tracey Bucknall

(Co-signs): __________________________ (Date) 5/2/16
Corresponding author of paper: Professor Andrea Marshall

(Co-signs): __________________________ (Date) 6/4/16
Corresponding author of paper: Jessica Guinane

(Co-signs): __________________________ (Date) 2/2/16
Corresponding author of paper: Professor Wendy Chaboyer

(Co-signs): __________________________ (Date) 2/2/16
Supervisor: Professor Wendy Chaboyer
Introduction

The findings of this research are presented in this chapter in three papers, which have all been published, as well as unpublished findings comparing patient and nurse perceptions. First, observations of practices of patient participation are presented in Paper 2. Patients’ perceptions of participation are then provided in Paper 3. The final paper shows nurses’ views of patient participation (Paper 4). Finally, the findings from Paper 3 and 4 are reanalysed to compare and contrast patient and nurse views. These papers address the study aims by investigating both perceptions and behaviours relating to participation, as well as uncovering their barriers and facilitators.

Activities patients and nurses undertake to promote patient participation (Paper 2)

Citation: Tobiano, G., Marshall, A., Bucknall, T., Chaboyer, W. (2016). Activities patients and nurses undertake to promote patient participation. *Journal of Nursing Scholarship, 48*(4), 362-370. doi: 10.1111/jnu.12219. This paper presents the findings from observations of 28 nurse-patient dyads in one setting. The deductive findings show that patients participated most frequently by having dialogue with nursing staff and sharing knowledge. Patient participation in planning and self-care was viewed less frequently. The inductive findings indicate that nurses exerted control over nursing care, which may have been a barrier, influencing the frequency of patient participation witnessed.

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Patients’ perceptions of participation in nursing care on medical wards (Paper 3)

Citation: Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., Chaboyer, W. (2015b). Patients’ perceptions of participation in nursing care on medical wards. Scandinavian Journal of Caring Sciences, 30(2), 260-270. doi:10.1111/scs.12237. This paper presents the results of twenty patients’ perceptions of patient participation, including barriers and facilitators. Patients from four wards in two hospitals, one private and one public, in two states, took part in semi-structured interviews. The results demonstrate patients valued participation, and especially wanted to participate in knowledge exchanges and monitoring their own safety. Knowledge exchanges acted as a facilitator to patient participation. However, a sense of power imbalance was a barrier that made it difficult for them to participate.

In order to comply with copyright the article has been removed.
Nurses’ views of patient participation in nursing care (Paper 4)

Citation: Tobiano, G., Bucknall, T., Marshall, A., Guinane, J., Chaboyer, W. (2015a). Nurses’ perceptions of patient participation in nursing care. *Journal of Advanced Nursing. 71*(12), 2741-2752. doi: 10.1111/jan.12740. The aim of this paper was to discover nurses’ views, including what helps and hinders patient participation. Twenty semi-structured interviews were conducted with nurses from four wards at two hospitals in two states. Nurses reported acknowledging patients as rightful partners in their care. Yet, nurses thought they had to restrict patient participation because of rules and perceptions of safety. Nurses explained they had a central role in enabling patient participation and believed patients with certain characteristics were difficult to enable. Thus, nurses saw themselves as facilitators of patient participation, while patients were viewed as a barrier to patient participation. Nurses realised that patient participation as patients taking part in clinical communication or activities like activities of daily living.

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PATIENT PARTICIPATION IN NURSING CARE

G. Tobiano et al.

The Journal of Advanced Nursing (JAN) is an international, peer-reviewed, scientific journal. JAN contributes to the advancement of evidence-based nursing, midwifery, and health care by disseminating high-quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management, or policy. JAN publishes research reviews, original research reports, and methodological and theoretical papers.

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- Positive publishing experience: rapid, double blind peer review with constructive feedback.
- Rapid online publication: six week average time from final manuscript arriving in production to online publication.
- Online Open: the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency’s preferred archive (e.g., PubMed).
Comparison on patient and nurse views

In published Paper 2, observations of patient and nurses have been compared and contrasted. However, patient and nurse views were published separately. In this section of the results they are compared and contrasted. Table 6 provides an overview of the categories and subcategories that emerged from this comparison.

Table 6 Findings from comparison of patient and nurse views

<table>
<thead>
<tr>
<th>Categories</th>
<th>Subcategories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborating for patient safety</td>
<td>- Assuring medication safety</td>
</tr>
<tr>
<td></td>
<td>- Keeping patients safe in the environment</td>
</tr>
<tr>
<td></td>
<td>- Contributing to quality communication</td>
</tr>
<tr>
<td>Working together towards independence</td>
<td>- Striving for independence and hospital discharge</td>
</tr>
<tr>
<td></td>
<td>- Assessing current level of independence</td>
</tr>
<tr>
<td></td>
<td>- Participating to the limit</td>
</tr>
<tr>
<td>Factors determining patient participation</td>
<td>- Relying on nurses to determine patient participation</td>
</tr>
<tr>
<td></td>
<td>- Acknowledging patients’ wishes</td>
</tr>
<tr>
<td></td>
<td>- Nurse determining factors</td>
</tr>
<tr>
<td></td>
<td>- Patient determining factors</td>
</tr>
</tbody>
</table>

Collaborating for patient safety

A common idea amongst patients and nurses was that patients could contribute to care by helping nurses keep the patient safe. Both patients and nurses stated patients had a strong role in making sure the right medications were given, as both emphasised that patients knew their usual medication routine and could watch and cross-check medications given. Nurses highlighted the importance of open dialogue when administering medications, and wanted patients to ask questions about medications given. Nurses did affirm the importance of having more control than patients, especially when patients physically administered medication. That is nurses needed to overlook patients’ self-medication practices to ensure they were safely and correctly administering and educate them if they were not. Patients and nurses stated they each respectively had a role in keeping the environment safe for mobilisation. One item in
the environment, the nurse call bell, was emphasised as essential by both parties for patients to maintain safety. Patients stated they needed to keep the nurse call bell close, especially patients with limited mobility, as they knew nurses could help ensure their safety in the environment. Nurse views complimented patient views. Nurses wanted patients to use their nurse call bell to call for help and did not want patients to worry about ‘bothering’ nurses. Nurses had an important role to help keep patients safe in their environment. Another similarity in patient and nurse perceptions was the patient’s role in ensuring up-to-date and quality information. Patients and nurses believed patients knew information about upcoming plans and activities that had been undertaken, especially in terms of doctors’ plans, when nurses missed rounds. Bedside handover was suggested as an activity patients could monitor and listen to for errors, especially related to ‘treatments’. Overall both had a role in safety, but the nurse had a stronger role as nurses need to be present to assist and nurses stated this more strongly than patients. The patient is a supplementary role in terms of safety, to compliment nurse practice and the two needed to work together to make it happen.

**Working together towards independence**

A strong category that emerged was that patients and nurses were working together to get patients to their maximum level of independence, particularly related to physical independence in activities of daily living. There was a common desire: patients and nurses wanted patients to be independent. Patients saw patient participation as a way to get better and get home quicker. Similarly, nurses wanted patients to be independent for discharge and tried to motivate patients to be independent and autonomous, they saw the benefits of physical participation to keep patients’ current level of independence. A difference was patients linked participation to being helpful; they were assisting the nurse by participating. Both parties had a role in assessing patients’ current level of independence. Patients stated they knew their current capabilities, limits, symptoms and had some knowledge of vital signs. They expressed they could inform nurses of their current capabilities and symptoms. Nurses stated patients could tell them about issues with their body, how they were currently feeling, ultimately nurses wanted open dialogue to gain an understanding of patients’ current capability, but also were assessing patients’ capabilities for returning home. Interestingly, both parties highlighted the benefits of previous experience with the same nurses during previous hospitalisation, if nurses knew their patient they had a better
understanding of their progress and capabilities, while patients’ knowledge of routine assisted them in working with nurses for independence. However, assessing independence was not only physical, patients and nurses acknowledged that patients required understanding. Most notably, nurses recognised that patients needed to understand activities that had occurred in hospital, to ensure they could continue to manage at home. For instance, medication changes or patients’ ability to self-medicate were educational opportunities. Patients emphasised the importance of knowledge, and constantly obtained knowledge in hospital and from other sources to ensure they knew what was going on with their health care. As a result of assessment, patients participated to their limit. For patients they participated in activities of daily living and pressure area care as much as they could, but knew their capabilities and ensured they did not do too much. Some patients were less independent, such as unwell patients or patients with many physical limitations. These patients felt helpless and a loss of control, and relied on nurses to achieve higher levels of independence. This finding resonated with nurse views. Nurses adjusted care based on patient ability; nurses either assisted dependent or sick patients or collaborated with independent patients to encourage their independence.

Factors determining patient participation

Although patients were willing to contribute to their care and participate, many diverse factors impacted how patient participation was determined. Although some patients were willing to participate and wanted some control, many patients spoke about nurses as having greater knowledge so patients were passive allowing nurses to control care. Even patients who were confident in their abilities at least checked with nurses before participating. Patients wanted a good rapport with nurses and were mindful of being nice to nurses as they determined participation. On the other hand, nurses acknowledged that the patient knew best. Patients had experimental knowledge that was valued by nurses and were viewed as assertiveness and had wishes, rights and preferences, which allowed them to determine participation. Nurses’ ability to determine was influenced by external factors and internal factors. Both patients and nurses agreed that the nurse’s approach determined patient participation. Patients required a nurse with an inviting manner that openly communicated and built rapport to participate. Likewise, nurses acknowledged the need for rapport and open communication to engage with patients and used tactics like humour and social dialogue to encourage patient participation. However, nurses felt more influenced by external
contextual pressures, like rules, time and discharge pressures, which determined how much they could encourage patient participation. Both patients and nurses agreed that patient factors influenced patient participation including patient capability, illness and age. Patient and nurse views on patient factors did differ, patients highlighted that having experienced an adverse event encouraged patient participation in safety. On the other hand, nurses emphasised the ‘approach’ of the patient diminished patient participation, being how willing patients were to participate, as some patients may feel down or may expect hand maiden service.

Summary

This chapter presented the findings from interviews and observations with patients and nurses related to patient participation. The observations of practice showed that dialogue and information-sharing most commonly occurred between patients and nurses in practice. Yet, nurses’ control over care was a barrier in practice that impeded enactment of patient participation in many ways. This finding appeared consistent with patient interviews, where patients described a power imbalance as hindering their participation, despite their value and motivation for being involved in their care. In nurse interviews, nurses too described value for patients as partners, and thought their role was facilitating patient participation. Both patients and nurses had knowledge of ways patients could participate in care, with both highlighting sharing information as a way to participate, which was also shown to be a facilitator to patient participation. Nurses and patients described patient characteristics as hindering participation, while risk perceptions varied between patients and nurses. When patient and nurse views are compared, it is evident that both parties see patient participation as patients contributing to safety and maximizing patient function. However, there are contrasting views on who should determine patient participation, which is influenced by many factors. These findings will be further considered in the following chapter that provides a conceptual synthesis of my findings with other sources. This is followed by discussion of the limitations, recommendations and conclusions of the study.
Chapter 5: Discussion

Introduction

This study has increased the understanding of patient participation in nursing care in the Australian hospital context. A review of the relevant literature revealed limited evidence to date of the meaning of patient participation in nursing care. Further, observational evidence was dated and showed nurses’ challenges in encouraging patient participation in care. The findings of this study revealed patient and nurse perceptions of patient participation, as well as their dyadic interactions related to patient participation. A synthesis of the findings is presented in relation to previous studies and conceptual understandings. A preliminary conceptual framework patient participation is provided. Additionally, the limitations are discussed. Finally, the recommendations and conclusions arising from the study are presented.

Summary of findings

This ethnographic study used both interviews and observations to address the research questions. Patients and nurses were observed undertaking their everyday activities and practices to uncover the meaning of patient participation. In addition, patients and nurses partook in semi-structured interviews that provided an understanding of their perceptions of patient participation, including the barriers and facilitators.

The findings from observations demonstrated patient participation was most frequently enacted through dialogue and knowledge-sharing, while patient participation in planning and self-care was less evident. Nurses were witnessed controlling nursing care and this was a barrier to patient participation.

The findings of patient interviews showed patients were motivated to take part in their care. Patients especially wanted to be part of the knowledge-exchange process and monitor their own care. Yet, the main barrier to their participation was a sense of disempowerment, influenced by the nurse’s manner. Findings from nurse interviews showed nurses valued the idea of patients being partners in their care. But nurses described participation as a balancing act, between fully engaging the patient, and managing risks and certain patient characteristics. Nurses recognised they had an
important role in facilitating patient participation and described how patients could participate physically in activities and verbally in clinical communication.

Conceptual synthesis

In this chapter a synthesis of the evidence from this study and how it contributes to current evidence related to patient participation is presented. Sahlsten et al.’s (2008) concept analysis is used as a template to allow synthesis of a variety of sources. The researchers listed four defining attributes for patient participation including, an established relationship, shared information and knowledge, active mutual engagement in intellectual and/or physical activities and surrendering of some power and control by the nurse (Sahlsten et al., 2008). The researchers also presented antecedents and consequences that are considered, in relation to other sources of evidence. By considering evidence from this PhD and other sources, in relation to this concept analysis, theory construction may progress.

Other sources synthesised include findings from this current study and other empirical primary sources. Further, others’ conceptualisations in the form of reviews and tools published since the beginning of this PhD will be integrated, which include: Angel et al.’s (2015) literature review relating to challenges in achieving patient participation in nursing; Eldh et al.’s (2015) tool for measuring patient preferences for patient participation; Thórarinsdóttir and Kristjánsson (2014) framework analysis of patient perceptions of patient participation; and our integrative review investigating patient and nurse perceptions and behaviours around patient participation in nursing care on medical wards (Tobiano et al., 2015c). Synthesis of these various sources will show how they support or refute the findings of my study, as well as Sahlsten et al.’s (2008) concept analysis of patient participation.

Discussing the findings from this study in relation to the previous evidence described will be beneficial for many reasons. For instance, it will be shown how this study’s findings fill gaps and provide new insights. Further, this study included both patients and nurses, which may add new dimensions to the understanding of the enactment of patient participation, as capturing and comparing both viewpoints has not always been considered (Eldh et al., 2015; Thórarinsdóttir & Kristjánsson, 2014). Finally, the investigation of barriers and facilitators in the current study and integrative
An established relationship

According to Sahlsten et al. (2008), an established and existing relationship between the patient and nurse is a defining attribute of patient participation. To be authentic, the relationship needs to be based on values including respect, mutuality and trust (Sahlsten et al., 2008), concepts that overlap with conceptualisations of partnership (Wiggins, 2008). My study showed that respect and mutuality was a facilitator to patient participation. A new insight discovered was the importance of using relational tactics to create a climate where patients felt comfortable to participate. Based on my findings, it can be argued that trust and an established relationship should be viewed as possible consequences of patient participation, rather than defining attributes only.

Based on our findings, nurses demonstrated respect for patients’ clinical needs and preferences, evident in the category ‘having dialogue with health-care staff’, that was consistent with the nurse interview category ‘acknowledging patients as partners’. Using these tactics to demonstrate respect helped patient participation. Other nurses recognise showing respect towards patients’ needs as a strategy to enhance patient participation (Sahlsten et al., 2009). Nurses’ acknowledgment of patients’ needs and choices, like analgesia and basic care, appeared to be problem-based needs because they assisted patients with their acute illness and hospital stay. Researchers have shown addressing problem-based needs like analgesic requirements (Koskenniemi, Leino-Kilpi & Suhonen, 2013) and basic care needs (Marshall, Kitson & Zeitz, 2012) satisfies patients and makes them feel respected in hospital.

By respecting patient preferences, nurses were able to individualise care. For instance, the category ‘having dialogue with health-care staff’ showed nurses addressed patient medication preferences by adjusting times to meet patient routines. Understanding patient preferences has been highlighted as a facilitator to patient participation (Chaboyer et al., 2016). Further, researchers have shown patients feel respected if their wishes are met in terms of timing of medication administration (Koskenniemi et al., 2013). For nurses, by providing flexibility around medication time and incorporating patients’ preferences, they think they individualise care and enact patient-centred care (Bolster & Manias, 2010).
The study showed respect for patients as an important element of enabling participation, supported by others’ conceptualisations. The importance of respecting patient individuality, including their needs and preferences, is emphasised in Thórarinsdóttir and Kristjánsson’s (2014) conceptual model and Eldh et al.’s (2015) conceptual tool. Notably, Thórarinsdóttir and Kristjánsson (2014) feature respect and individualising care as phase 1 of patient participation, integral for enacting patient participation. Sahlsten et al. (2008) presents an alternate viewpoint and lists individualising care as an antecedent of patient participation, while respect forms part of ‘an established relationship’. My findings, with support from many researchers, show the importance of both respect and individualising care as key enablers of patient participation.

Creating a climate where patients felt comfortable was demonstrated as an enhancer of patient participation in my findings. For instance, in the interview category ‘enabling participation’, nurses spoke about their relational approaches like humour, introductions and informal talking to build rapport and encourage patient participation. This was supported by observations of practice, as ‘having dialogue with health-care staff’ was frequently enacted. These relational tactics are used by other nurses to ease and enhance communication with patients (Bundgaard, Nielsen, Delmar & Sørensen, 2012; Chan, Jones, Fung & Wu, 2012). Moreover, patients have stated they require the nurse to create a comfortable atmosphere to be able to participate, that is enhanced by the nurse relating to them (Larsson et al., 2007). In my observations, relational dialogue was often initiated by nurses, demonstrating nurses’ willingness to build rapport and create an accommodating atmosphere.

The enabling effect of creating comfortable climates on patient participation resonates with other reviews and tools relating to patient participation (Angel et al., 2015; Eldh et al., 2015; Thórarinsdóttir & Kristjánsson, 2014). Thórarinsdóttir and Kristjánsson (2014) highlighted nurses’ creation of an inviting atmosphere as phase 1 of patient participation, showing it facilitates enactment of patient participation. Likewise, Sahlsten et al. (2008) underscore creating a climate for participation as an antecedent. Therefore, my findings on an obliging atmosphere for participation are well supported, showing this strategy is required to enhance patient participation.

In my study, mutuality was shown to promote patient participation. Mutuality was evident in the interview categories like ‘exchanging intelligence’ and ‘acknowledging
patients are partners’ where the knowledge patients could contribute was valued. Observations corroborated interviews as mutual communication was frequently witnessed in categories like ‘having dialogue with health-care staff’ and ‘knowledge-sharing’. Other patients have expressed increased feelings of mutuality when knowledge is shared (Larsson et al., 2011a). It seems that hospital patients feel reciprocity when nurses provide knowledge based on medical expertise and in return patients articulate their feelings and experiential knowledge (Marshall et al., 2012). Note that nurses in my study often initiated interactions with patients, thus the mutuality of nurses-patient communication appeared dependent on the nurse.

The importance of mutuality for encouraging patient participation is highlighted in previous patient participation syntheses (Angel et al., 2015; Eldh et al., 2015; Sahlsten et al., 2008). In our integrative review, mutuality in communication exchanges was shown to enhance participation, especially when genuine and non-clinical dialogue was used (Tobiano et al., 2015c). Interestingly, Thórarinsdóttir and Kristjánsson (2014) and Sahlsten et al. (2008) focused on the need for equality between patient and nurse. For partnerships to be mutual, interactions between the patient and nurse do not have to be equal but both parties need to be acting towards a common goal (Henson & Moloney, 1997). Difficulty achieving equality may be attributable to nurses’ medical knowledge, skill and power to determine how to involve the patient (Ashworth, Longmate & Morrison, 1992). Thus, Thórarinsdóttir and Kristjánsson (2014) and Sahlsten et al. (2008) may present an unrealistic idea for patient participation but the authors do suggest equality as ‘ideal’.

My findings demonstrated that an ‘established’ relationship is not required for patient participation; instead nurses should display respect, mutuality and build rapport that may develop nurse-patient relationships. This is in contrast to Sahlsten et al.’s (2008) concept analysis and Thórarinsdóttir and Kristjánsson (2014) review, where an established relationship is listed as a requirement. Established nurse-patient relationships may be unrealistic in modern health care where hospital length of stay is short and nurses face staffing issues such as skill mix and lack of continuity as well as work intensification including complex care demands and high workloads (McMurray, 2014). Like our study, Angel et al.’s (2015) review emphasises that actions within the nurse-patient relationship are vital, rather than the level of establishment achieved in the relationship. Patients have substantiated this finding, perceiving that nurses who show
mutuality (Larsson et al., 2011a), build rapport and make the patient feel comfortable (Jonsdottir, Litchfield & Pharris, 2004) and are respectful (Chaboyer et al., 2016; Ferguson, 2013) help build the nurse-patient relationship. Overall, nurses’ tactics described in my study optimise every opportunity with patients to having meaningful encounters that enhanced patient participation and could develop the nurse-patient relationship.

Like relationship-building, trust between patients and nurses could be developed by nurses using tactics identified in my study. Sahlsten et al.’s (2008) identify the need for the trust in the nurse-patient relationship in their defining attribute. In the category ‘power imbalance’ we found that some patients trusted nurses implicitly and were submissive when approaching their care. Other patients have expressed their trust for nurses’ competence, making them compliant and passive participants (Arnetz & Zhdanova, 2015; Dyrstad, Laugaland & Storm, 2015; Rathert et al., 2011; Scott, Dawson & Jones, 2012). Patients’ sense of hierarchy is reminiscent of paternalism, where plans and care are decided by the health care professional due to their knowledge (Pelto-Piri, Engström & Engström, 2013). Because nurses’ strategies in my study enhanced patient participation, these approaches may decrease patients’ paternalistic views of trust. Researchers have found when nurses are approachable, patients trust the nurse and want to participate rather than being passive recipients of care (Ferguson, 2013). These findings highlight that without nurses taking deliberate actions to have respectful and mutual dialogue and creating an enticing atmosphere for participation, patients may be recipients of paternalism.

In summary, meaningful and relational tactics like showing respect and mutuality and creating a climate for participation are ways of enhancing patient participation. Interestingly, nurses’ tactics to enhance patient participation are consistent with patient-centred care principles. As highlighted in Chapter 1 (see page 19), respect, rapport and reciprocity are requirements for patient-centred care. This strengthens the link between patient participation being an aspect of patient-centred care. My study showed an established relationship and trust could be viewed as outcomes of nurses’ meaningful and relational tactics. How established or trusting the relationship is could be viewed on a continuum, dependent on the strategies nurses undertake.

Shared information and knowledge
The next defining attribute of patient participation focuses on sharing information and knowledge between patients and nurses (Sahlsten et al., 2008). Sahlsten et al. (2008) emphasised that patients share their opinions, expectations and experiences and nurses provide individually-adapted information and knowledge (Sahlsten et al., 2008). In this section how my findings confirm those of Sahlsten et al. (2008) are demonstrated. However, my findings provide further insight into how and what types of information-sharing enhances patient participation. Importantly, we describe information-sharing as not only a way to enact patient participation but a facilitator of patient participation.

In my study, patients stated ‘exchanging intelligence’ was a way they participated that helped them feel knowledgeable, in turn enhancing their participation. This resonates with my observations where patients were frequently witnessed being involved in knowledge-sharing. Like previous research, having knowledge enhanced patient participation because patients felt able to communicate with nurses (Henderson, 2003; Latimer, Chaboyer & Gillespie, 2013; Soleimani, Rafii & Seyedfatemi, 2010). One way patients perceived that they built their knowledge was by seeking information from nurses, a finding consistent with others’ research (Aasen et al., 2012b; Sainio et al., 2001; Soleimani et al., 2010). Thus, gaining knowledge may enhance patients’ sense of empowerment to participate in many nursing activities (Nygårdh, Ahlström, Wikby & Malm, 2012).

For nurses, analysis of interviews showed ‘informing patients’ was a way of ‘enabling participation’. This is supported in other studies, for example Arnetz et al. (2008b), found 90% of health care workers agreed that providing clear information to patients enhanced patient participation. Nurses perceive they have a central role in informing patients (Höglund et al., 2010; Kolovos et al., 2015) for the purpose of motivating, facilitating and building patients’ clinical competence to participate (Schoot, Proot, Meulen & Witte, 2005). On the whole, nurses support informing patients as a way of encouraging patient participation.

In my observations, the content of communication exchanged frequently related to clinical information, such vital signs and patient capabilities, seen in categories like ‘sharing knowledge’. Both patients and nurses were witnessed contributing to these exchanges, perhaps enhanced by patients’ chronic illness status. In the interview category ‘exchanging intelligence’, patients spoke about using their experienced-based
knowledge that can include awareness of body and symptoms and knowing what works best for themselves (Fox, 2005), to be able to communicate with nurses. Researchers suggest that patients’ experiential knowledge empowers them to share and receive factual information and heightens their confidence to participate (Schoot et al., 2005; Soleimani et al., 2010). Both patients and nurses’ ability to contribute clinical information, may demonstrate membership, as both parties have a shared stock of knowledge (Ashworth et al., 1992). Perhaps patients’ expert knowledge lessened the language difference between patients and nurses in my study, known to enhance nurse-patient communication (Fleischer, Berg, Zimmermann, Wüste & Behrens, 2009). My findings highlight the opportunity for nurses to facilitate self-management through dialogue (Thorne, 2006), and the valuable contribution chronically ill patients can make by sharing their expertise.

When we observed knowledge-sharing, it occurred while nurses completed other tasks. The success of observed communication practices like ‘sharing knowledge’ may be because this was achieved while still attending tasks and not taking extra time. Similarly, other nurses have used every opportunity to communicate with patients (Chan, Jones & Wong, 2013; Hemsley, Balandin & Worrall, 2012), viewing communication with patients while undertaking tasks having little influence on time (Chan et al., 2012). Further, some nurses acknowledge that this practice can save time in the long run (Chan et al., 2013). Thus, communication may have been frequently accomplished due to ease and nurses being time-driven.

My study confirms that information-sharing is an enhancer of patient participation. Confirming Sahlsten et al.’s (2008) view, my study demonstrated that information-sharing should be a key feature of patient participation. My findings are consistent with other reviews that have shown information-sharing as a way of participating (Eldh et al., 2015) and a facilitator to participation (Angel et al., 2015; Thórarinsdóttir & Kristjánsson, 2014; Tobiano et al., 2015c). My study emphasises the importance of sharing information about clinical topics as it enables patient participation in nursing care.

To review, both patients and nurses value the roles both parties can play in information transactions. The success of communication exchanges in hospital may be related to content, time, content and patient condition. My study shows shared
information and knowledge is essential to patient participation and should be viewed as a facilitator of patient participation.

**Active mutual engagement in intellectual and/or physical activities**

Active mutual engagement in intellectual and/or physical activities is the next defining attribute of patient participation (Sahlsten et al., 2008). For this attribute to be achieved, nurses encourage and invite patients to take part in all aspects of the caring process (Sahlsten et al., 2008). However, the patient’s willingness needs to be taken into account and this is influenced by many factors (Sahlsten et al., 2008). Based on my findings, issues included risk and time that may have impacted on patients’ active mutual engagement in activities. Three activities where data were found to support these issues include bedside handover, activities of daily living and medication administration. In addition, my study supports Sahlsten et al.’s (2008) view that patient willingness affects engagement in activities.

Active and mutual engagement in activities like bedside handover and medication administration was not consistently witnessed in my study. Risk may be one reason why active and mutual engagement was not achieved, as nurses expressed concerns over involving patients in these types of activities in the category ‘managing risk’. Researchers have shown nurses’ worry about confidentiality of information making them view bedside handovers as risky (Messam & Pettifer, 2009). In addition, previous research shows that nurses perceive active patient participation in medication choices and physical medication administration can be unsafe (Lever, O'Reilly & Pryor, 2008; Soleimani et al., 2010). My finding around enactment of medication choices, conflicts with the nurses’ views. In the interview category ‘acknowledging patients as partners’, nurses disclosed their acceptance for patient actively making choices.

Active mutual engagement in handover and medication administration may also be influenced by time. There was consistency in my observations and interviews in relation to time pressures. Like my findings, others nurses find patient involvement in bedside handovers as taxing on their time (Jeffs et al., 2013; Liu, Manias & Gerditz, 2012). In my study, we observed that nurses completing medication administration for patients, rather than facilitating it, in the category ‘maintaining control of work’. It has been suggested that physical participation in activities is perceived as more time intensive and thus avoided by nurses due to time efficiency (Thorne, Hislop, Stajduhar...
& Oglov, 2009). As identified by Soleimani et al. (2010), when the context was not busy, nurses were more likely to encourage patients to physically participate in activities.

These findings are in contrast to patients’ views, as the categories ‘on the lookout’ and ‘valuing participation’, confirmed that patients wanted to actively participate and decrease risks. My findings show patients believed they could make handover less risky by being attentive during handover. This is consistent with previous research, where patients listened to the information exchange during handover and expressed a desire to clarify information that may be incorrect (McMurray, Chaboyer, Wallis, Johnson & Gehrke, 2011). Further, patients in my study wanted to maintain some control over their care. This verifies previous research showing that patients saw participation as a way to maintain control (Eldh et al., 2004; Schoot et al., 2005), and being part of the administration of medication allowed them to achieve this and maintain independence (Penney & Wellard, 2007).

On the other hand, active mutual engagement in activities like daily living and other elements of medication administration were witnessed, possibly because it mitigated risks to the patient. In my study, patients and nurses communicated about patients’ current capabilities prior to promoting patients’ physical participation in activities of daily living, seen in categories like ‘managing risk’ and ‘on the lookout’. Researchers have shown the importance of mutual assessments and information exchanges to understand chronically ill patients’ current condition (Bendixen, Ejlersen Wæhrens, Wilcke & Sørensen, 2014) and to determine the level of activity the patient can undertake (Lomborg & Kirkevold, 2008).

Active and mutual engagement in patient participation in activities of daily living may also mitigate risk of loss of function and independence. This finding is supported in patient and nurse interview categories like ‘enabling participation’ and ‘participation’, and was observed in ‘having dialogue with health-care staff’. Low in-hospital mobility is associated with functional decline at discharge (Zisberg, Shadmi, Gur-Yaish, Tonkikh & Sinoff, 2015) and other negative patient outcomes (Kleinpell, Fletcher & Jennings, 2008) that appeared to be a driver for participation in my study. Nurses emphasised the importance of their role in identifying patients at risk of functional decline and tailoring interventions to encourage their participation (Hoogerduijn, Grobbee & Schuurmans, 2014). For medication administration, communication was observed more than physical
participation, supported in interviews where patients were ‘on the lookout’ for medication issues, while nurses respected patients’ medication knowledge by ‘acknowledging patients as partners’. Researchers have shown nurses value patients’ role in cross-checking medications (Schwappach et al., 2010) and patients have been shown to examine medications and speak up (Schwappach & Wernli, 2010a). Patients who actively participate in safety activities will help achieve the core values of safe, effective, patient-centred, efficient and equitable care as described by the Institute of Medicine (2001).

My study provides evidence of the impact of patient willingness of active and mutual engagement. This was visible in patient and nurse interviews, as nurses described patient factors as ‘hindering participation’, while patient factors were found to influence all categories in the patient interviews. Patients and nurses in my study identified many patient factors as hampering patients’ willingness to participate such as age, clinical wellness and attitude. In previous research age has been seen to both enhance (Eldh et al., 2010; Florin, Ehrenberg & Ehnfors, 2008; Weingart et al., 2011) and impede (Chaboyer et al., 2016; Henderson, 2002) patient participation. Thus, older patients’ preference for participation truly ranges (Dyrstad et al., 2015). Clinical wellness is another concept that is viewed by many to affect patient participation. The acuity of the illness (Arnetz et al., 2008b; Höglund et al., 2010), duration of illness (Eldh et al., 2010; Soleimani et al., 2010) and type of illness (Latimer et al., 2013) can all influence patient participation. Patient attitudes is another concept that has been suggested to influence willingness. Some patients lack the will and self-determination to participate (Arnetz et al., 2008b; Henderson, 2002; Nordgren & Fridlund, 2001), while others valued self-determination and taking responsibility (Schoot et al., 2005). Interestingly, Drach-Zahavy and Shilman (2015) have suggested that patients’ personalities may even influence their willingness to participate.

Overall, my findings highlight the importance of nurses assessing risk, time and patient factors to tailor active and mutual patient participation accordingly. Other researchers have identified patient participation requires a responsive nurse who assesses each patient’s willingness and capability to understand how they can participate at that time and in which activities (Eldh et al., 2006a; Jewel, 1994; Ross, Tod & Clarke, 2015; Sahlsten et al., 2005a; Tutton, 2005). On the contrary, when nurses have made assumptions about patients, due to factors like age, it hinders patient
participation (Aasen et al., 2012a). This was highlighted in our integrative review, where nurses’ failure to assess and know their patient, meant they assumed patient willingness to participate, which was often wrong (Tobiano et al., 2015c). Bos-Touwen et al.’s (2015) work highlights the importance of nurses assessing patients’ potential for self-management, as patients who are unmotivated, motivated or have limited capacity all required a different approach to encourage them to participate. To determine patient willingness and ability to participate, researchers suggest nurses could use care planning as a set time to involve patients and assess their desired participation level (Jewel, 1994). In my study, patients were rarely ‘partaking in planning’, presenting an opportunity to enhance this practice and tailor participation in care to patient willingness. When patients are in a position where they are unable or unwilling to participate, researchers have suggested that family members are keen to be encouraged to partner with nurses, to participate in the patient’s care process (Mitchell & Chaboyer, 2010). However, like patient participation, family-centred care nursing requires consideration of many factors such as family members’ willingness to participate in care (Shields et al., 2006).

When comparing my findings with other reviews published since this study was commenced, my work confirms and provides further insight. In the nurse interview category, ‘realising participation’, nurses stated patients could participate physically in activities and could contribute clinical information, with both requiring mental abilities. Other reviews have defined the ‘defining attribute’ (Sahlsten et al., 2008), ‘action phase’ (Thórarinsdóttir & Kristjánsson, 2014) or ‘enactment’ (Tobiano et al., 2015c) of patient participation as including both mental and physical activities. My study provided new knowledge as it shows the factors affecting patients’ ability to mentally and physically engage in nursing care. In my study, patient factors were highlighted as influencing patients’ active and mutual engagement. These findings are consistent with many reviews of patient participation, where researchers have identified patient willingness and factors as affecting patient participation (Angel et al., 2015; Thórarinsdóttir & Kristjánsson, 2014; Tobiano et al., 2015c).

To summarise, my findings have deepened the understanding of patients’ mutual and active engagement in nursing care. It has been shown how risk, time and patient factors need to be assessed and acknowledged. Based on these assessments nurses can
Surrendering some power or control by the nurse

The final defining attribute of the concept of patient participation is nurses surrendering some power and control (Sahlsten et al., 2008). For this defining attribute to be met, nurses need to show commitment to patient participation by reducing their control over care. This can be done by giving patients some responsibility for care, for example, Sahlsten et al. (2008) suggest nurses need to both empower and facilitate patients to participate in order to demonstrate that they are ‘surrendering some power and control’ (Sahlsten et al., 2008). It was evident in my study that nurses undertook a controlling approach rather than an empowering and facilitating approach. This was especially visible in observations of practice where nurses’ control affected the success of patient participation. Based on my findings, we provide explanations of why nurses may have adopted this approach. For instance, we determined nurses may rationalise their controlling approach over patient participation based on their time and risk perceptions. Although these factors have been addressed in the previous section and shown to limit mutual and active engagement, we provide further descriptions to show reasons why these perceptions can heighten control. Further, task-orientated nursing and lack of insight may influence nurses’ controlling approach. Finally, the impact of nurses’ approach on patients is demonstrated.

The way nurses perceived time showed their control and power over patient participation. My interview category ‘managing risk’ showed nurses prioritised other tasks over patient participation due to perceived time pressures, supported by my observations. Consistent with my findings, nurses have internal normative ideas of how much they can accomplish in a shift (Chan et al., 2012; Thorne et al., 2009), choosing to neglect encouraging patient participation so that time structures are maintained (Arnetz et al., 2008b; Sahlsten et al., 2005a; Soleimani et al., 2010; Tutton, 2005). The view that patient participation is time intensive is a common myth (Frampton et al., 2008). Researchers have demonstrated that nurses used time as an excuse to not involve patients in their care; even when nurses were not busy they did not engage with patients, instead controlling care (Henderson, 2003). Recently, Queensland legislation changed, mandating safer nurse-patient ratios in public hospitals of one nurse to four patients.
Because my observations were conducted prior to this legislation it is unknown whether the larger patient loads at the time contributed to nurses’ perceptions of time and controlling approaches.

Nurses’ perceptions of time and, in turn, controlling behaviours, may also be attributable to organisational culture. Inductive analysis of observation data yielded the sub-category ‘facing pressures’, where pressures led nurses to focus on activities other than patient participation. Like other settings, completing tasks is often more valued at an organisational level than patient-centred activities (Chan et al., 2013; Jones, 2001). For instance, observations showed patient transfers were not always carried out in a patient-centred manner. Consistent with other findings, the organisational culture valued quick discharges to allow new patients to be admitted (Larsson, Sahlsten, Segesten & Plos, 2011c; Roch, Dubois & Clarke, 2014). Hospitals are often ruled by an organisation of bed allocation that enforces regulation by nurses and routine practice (Rankin, 2015). Researchers have shown that a strong organisational commitment to patient participation is essential to its success (Chaboyer et al., 2016). Overall, internal time perceptions and the organisational culture may contribute to nurses’ controlling approach.

We observed task-oriented nursing that further illustrated nurses’ controlling approach towards care. Task-orientation is an approach that allows repetitive and habitual tasks to be performed that is perceived to be easier and quicker to accomplish (Chan et al., 2013). Prior studies have shown nurses follow set routines and tasks rather than individualising care because it enhanced nurses’ sense of control and reduced their feelings of time pressure (Dalgaard & Delmar, 2008; Jones, 2001; Waterworth, 2003). Unfortunately, task-orientated approaches have been shown to have negative effects on patient-centred care principles. In previous research, task-orientated approaches reduced purposeful interactions with patients (Roch et al., 2014) and caused nurses to deny patient needs (Rankin, 2015). In my interviews nurses expressed acknowledgement for some patient-centred values like these, yet they had difficulty promoting them in practice. Consistent with Ross et al.’s (2015) findings, nurses value for patient-centred concepts was not enough to encourage patient-centred behaviour, as nurses tended to maintain rigid ward routines. Thus, my findings display the tension between task-orientated approaches and patient-centred care, highlighting the need for nurses to surrender some control and take a more flexible approach to care.
The link between risk perceptions and adopting a controlling approach to care was made clear in my study. Nurses perceived their role as identifying and ‘managing’ risk, possibly intensifying their control over care. Likewise, other nurses viewed their role as safeguarding patients (Bu & Jezewski, 2007) by recognising and acting on potential risks, including both those in relation to the patient’s condition and those arising from hospital processes (Choi, Cheung & Pang, 2014). Similar to our observations, Choi et al.’s (2014) fieldwork revealed nurses’ approach to safety was paternalistic; although they advocated by safeguarding patients, patients had little role in their own safety. It has been demonstrated that when nurses focus on risk assessments, it decreases their engagement with patients (Boase, Mason, Sutton & Cohn, 2012). Similarly, Thorne (2006) highlights the danger of missing opportunities for patient participation, speculating that many view patient safety as dependent on health care professionals’ expertise and authority, rather than incorporating the patient in safety. Conceivably, the patient safety movement may have created a culture of increased risk perception, where nurses have a desire to control care to avoid risk. Overall, my findings highlight nurses’ overemphasising their role in safety may influence patient participation in care and safety.

Nurses’ sense of professionalism and rule orientation may also contribute to their controlling approach. Nurses in my study described a balancing act between doing what they feel is best for the patient, evident in ‘managing risk’, and doing what patients states they want and need, as seen in the category ‘acknowledging patients as partners’. This represents a moral dilemma between autonomy and beneficence. Based on previous findings, when nurses advocate for patients they consider both respecting patient as humans and their rights, while considering their professional duties (Vaartio, Leino-Kilpi, Salanterä & Suominen, 2006). Contributing to this conflict of professionalism is documents like the ‘Code of Professional Conduct for Nurses in Australia’ that outlines nurses’ role as practicing in a safe manner, in accordance with standards and the law (Nursing and Midwifery Board of Australia, 2008). Based on my findings, it appears that professional duties and conduct were highly valued, as nurses in my study stressed the importance of following the rules. Nurses’ rule orientation may be influenced by the organisation. McMurray (2014) pointed out that organisational pressures create hospital environments of extreme efficiency and control that undermines nurses’ ability to provide genuine care. Sometimes termed ‘audit culture’,
nurses working in these environment may feel an overwhelming need to defend their care, with no ability to present diverse views or diverge from the rules (McMurray, 2014).

To summarise, nurses’ control may stem from their belief that they are regulated to do what benefits the patient, even though there is an opportunity for patients to contribute to providing best care. Nurses’ tendency to maintain control of care may be habitual as the controlling approaches observed appear embedded in Australian nurse practice. Over a decade ago, Australian researchers investigating patient participation in hospitals, noted similar issues were evident in practice (Henderson, 2002; Henderson, 1997; Henderson, 2003; Penney & Wellard, 2007; Wellard et al., 2003). For instance, nurses were task-orientated, maintaining routine plans rather than incorporating patient views (Henderson, 2003; Wellard et al., 2003), despite showing value for the idea of patient participation (Wellard et al., 2003). Observations in Australian hospitals have supported this as nurses maintained control by limiting interactions with patients and only approaching patients when tasks were due (Henderson, 2003; Wellard et al., 2003). Task-orientated approaches to practice appear deep-rooted in Australian nursing history, as nurses have been expected to complete as many tasks as possible otherwise they were punished (Shields, 2013). Further, nurses have identified rules and busyness as organisational hindrances to patient participation (Henderson, 2003; Wellard et al., 2003) that patients tended to support (Penney & Wellard, 2007). The similarities between these findings and the current study suggest that nurses in Australian hospitals struggle to surrender power and control.

It is possible that nurses in my study lack insight into their controlling approach towards patient participation. In my study, nurses acknowledged their role in ‘enabling participation’, a category found in nurse interview data. This is congruent with reports of other nurses’ views, whereby informing the patient (Kolovos et al., 2015) and verbally encouraging the patient (Sahlsten et al., 2009), are seen as a ways nurses can enhance patient participation. Yet, these facilitating approaches were not achieved in practice observed in the category ‘maintaining control of work’, showing incongruence between nurses’ perceptions and behaviours. Researchers suggest nurses are sometimes not aware of their controlling approach to patient participation (Tutton, 2005). This finding supports Poochikian-Sarkissian, Sidani, Ferguson-Pare and Doran (2010), who found nurses perceived that they had encouraged a medium-high extent of patient
participation, a perspective not held by patients who stated nurses encouraged their participation only to a limited extent. Sahlsten et al. (2005b) asserts nurses are required to take deliberate actions to engage patients in care; it is not an inherent practice. The incongruence between nurse perceptions and behaviours in my study suggests that nurses assume they encourage participation, or, on the other hand, perceptions and contextual factors limit their actual encouragement of participation in practice.

When nurses do not release control, it can be viewed in the approach they take towards the patient. In my findings, nurses’ controlling manners influenced patients’ confidence to engage, evident in the interview category ‘power imbalance’. Researchers have demonstrated that the nurse’s manner is a central reason for patient disempowerment (Aasen et al., 2012b; Nygårdh et al., 2012) that can make patients passive recipients of care (Nordgren & Fridlund, 2001; Sainio et al., 2001) rather than actively participating. Other patients have highlighted certain manners that make them feel disempowered such as being unsupported, belittled or ignored (Larsson, Sahlsten, Segesten & Plos, 2011b) and a dominating approach (Aasen et al., 2012b). Hospital patients have identified that nurses need to engage them in a way that facilitates their participation (Höglund et al., 2010) that can be achieved through opportunities, invitations and approval from nurses to increase their motivation and power to act (Frank et al., 2009a; Schwappach, 2010; Schwappach & Wernli, 2010b). Overall, nurses are individuals, with power and discretion with regards to how much they involve the patient, and they can digress from the institution’s ethos of patient-centred care (Chaboyer et al., 2016). My findings highlight how patients can perceive nurses as in control and that this entrenches a passive approach in patients.

My findings show nurses’ power and control over participation as a strong influence on the success of patient participation. Many syntheses of previous literature have highlighted the importance of nurses’ manner and control as influencing patient participation (Angel et al., 2015; Sahlsten et al., 2008; Tobiano et al., 2015c). The common theme amongst these published papers is they all focused on patient participation in the context of nursing care, perhaps providing reason for why this influencing factor was identified as important. Interestingly, Eldh et al. (2015) and Thórarinsdóttir and Kristjánsson (2014) did not highlight the need for health care professionals to relinquish control, yet their work does not specifically focus on patient
participation with nurses. Thus, my work highlights the importance of a controlling approach as an influencing factor in the context of nursing.

In summary, the influence of nurses’ control and power on the success of patient participation is evident. When nurses overestimate time and risk, undertake task-orientated nursing, or lack insight into their approach, they may adopt a controlling approach to care. The incongruence between nurses’ perceived approach to patient participation and enactment highlights control as an area that may require addressing in practice. The way nurses in my study exerted power and control hindered opportunities for patients to participate.

**A preliminary conceptual understanding of patient participation**

Conceptual synthesis of my findings, Sahlsten et al.’s (2008) concept analysis, other reviews and tools and empirical evidence support the development of a conceptual framework for patient participation. This conceptual framework builds on previous concept analyses (Cahill, 1996; Sahlsten et al., 2008), as well as the new insights gained from the preceding conceptual synthesis in this chapter, providing insights and relationships between those proposed concepts. This conceptual framework contains six concepts and five propositional statements and is represented schematically in Figure 1. It is important to note, that this conceptual framework presents a preliminary conceptual framework for patient participation based on the theoretical and empirical evidence (Walker & Avant, 1988). Many contextual factors may affect this conceptual framework; some may include the organisation’s and ward’s support for patient-centred care, internal and external policy and resources. If the patient is unable to participate, family member participation could be sought. We propose ‘nursing’ activities implies that nurses own them, instead we prefer the term ‘care activities’ for this conceptual framework suggesting that patients and nurses may share the activity.
Figure 1. Preliminary conceptual framework of patient participation in nursing care.

Concept definitions

**Meaningful interactions**: An approach where nurses use encounters with patients to engage in interplay that is respectful, mutual, and relational.

**Clinical communication**: Shared dialogue between patients and nurses about clinical topics like symptoms, capabilities or usual regimes.

**Tailoring**: An approach where the nurse assesses risk, time, patients factors like patient condition, abilities and willingness, and patient needs and preferences, to adapt care activities for each patient and their situation.

**Nurse’s approach**: The nurse’s way of undertaking care activities, inclusive of the manner the nurse displays towards the patient.

**Patient participation in care activities**: Involvement of patients in care activities, which can range from intellectual to intellectual and physical activity.

Figure 1 shows preliminary relationships between concepts, which are described in the following propositions:
Propositions

1. Undertaking meaningful interactions provides a foundation to tailor patient participation in care activities.

2. Clinical communication exchanges are fundamental to tailor patient participation in care activities.

3. The extent to which nurses tailor opportunities for patient participation to each individual patient’s situation determines nurses’ approach to patients.

4. Nurses’ approach towards patients influences the extent to which patients participate in care activities.

The four proposition statements are briefly described. In the first proposition, engaging in meaningful interactions is a precursor to tailoring patient participation. Undertaking meaningful interactions is essential to deciding how to tailor patient participation and in turn enact patient participation in care activities. In meaningful interactions, nurses discover patient needs and preferences that can be used to tailor care. Further, nurses create an atmosphere where patients feel comfortable to participate, enhancing their likelihood of patient participation in care activities.

Proposition two shows clinical communication as a precursor to patient participation. Nurses and patients who engage in effective two-way clinical communication, enhance nurses’ understanding of topics like patients’ current capability and wellness, which can be used when tailoring patient participation. Nurse-patient information-sharing enhances patient participation in care activities, as they feel knowledgeable to participate.

In the third proposition, nurses tailor opportunities for patient participation to the patient’s situation that determines how they approach patient participation. When nurses determine the situation is too risky, time pressured or the patient is not fit to participate they take on a controlling approach. When the nurse views the situation as mitigating risk, time efficient and the patient is capable, clinically well enough and willing, the nurse takes on a facilitating approach.

In proposition four, the nurses’ approach determines the extent to which patients participate in care activities. Nurses who adopt a controlling approach limit patient
participation in the care activity. On the other hand nurses who assume a facilitating approach encourage patients to take part in care activities.

Nurses’ approaches will influence meaningful interactions and clinical communication with patients. The feedback loop represents this, as well as the need for nurses to constantly cycle through the conceptual framework each time they approach a patient for a care activity to determine the appropriate level of participation for that patient in that activity.

**Limitations of the study**

There are several limitations that may have affected the study. First, patients’ degree of illness may have influenced both their viewpoints and behaviour in relation to patient participation. Most patients in my study stated that they felt clinically ‘well’. It may be that patients who feel more ‘unwell’ hold different views. However, patients’ and nurses’ interviews provided insight into the role patients have in patient participation when unwell. Second, this study was qualitative, therefore the findings are strongly influenced by the context in which the study was conducted and may not be broadly applicable. However, this study aimed for understanding of the phenomenon of interest and the detailed descriptions that have emerged from this research allows readers to judge applicability of the findings to their own setting. The conduct of the study within two hospital settings, one private and one public, each in different states in Australia further enhanced understanding of patient participation and may enhance transferability of findings, particularly in the Australian health-care context. Third, observations were not conducted at both sites. Understanding of patients’ and nurses’ behaviours in relation to patient participation may have been enhanced with data collection in both hospitals. However, in-depth and time-intensive observations were conducted at Site 1, with confirmation by Site 2 data, which generated sufficient new knowledge and allowed a conceptual framework for patient participation to be developed. Fourth, a deductive framework was used to analyse observational data, which may have tied down the findings, however, data were also analysed inductively to ensure data not fitting the categorisation matrix was captured. Finally, data were interpreted by a researcher who is also a nurse. Interpreting data is how meaning was made in this study, in line with the constructivist paradigm. Being a nurse may heighten the risk of preconceptions influencing interpretation of data. However, being a nurse also gave insider knowledge, enhancing understanding of data. Further, the reflexive
approaches undertaken enhanced the credibility of data collected and interpreted. The RA involved did not take the same degree of reflexive approach towards data collection, meaning she may have influenced data collection, or missed opportunities, however, use of initial analysis forms strengthened my ability to monitor her outputs and guide her with probes. Overall, rigorous approaches have been carried out to strengthen the study limitations as much as possible.

**Recommendations**

Although advocated in Australian hospitals, it is evident that nurses in this study had difficulty practicing patient participation. The key barriers and enablers identified in this study are considered in relation to the Theoretical Domains Framework and recommendations formulated (Michie et al., 2005). The Theoretical Domains Framework combines many overlapping psychological theories (Michie et al., 2005), providing a succinct and validated list of 14 domains to guide behaviour change interventions (Cane, O’Connor & Michie, 2012), that can be used to develop strategies intended to enhance the enactment of patient participation by nurses. Of the 14 domains within the Theoretical Domains Framework there were four that most closely linked with the barriers to and enablers of patient participation identified in my study. These included ‘social influence’, ‘beliefs about consequences’, ‘social and professional role and identity’ and ‘environmental context and resources’ (Figure 2). Based on an understanding of what helps and hinders nurses to enact patient participation, recommendations can be developed that incorporate behaviour change strategies. In addition to these recommendations, suggestions for future research will be presented. All recommendations proposed can be used in staff development and/or student education. For all of the recommendations suggested below to be successful, clear hospital guidelines may be required outlining how to enact patient participation, perhaps based on the conceptual framework developed (Figure 1).
Social influences

Social influences are interpersonal processes that cause people to change thoughts, feelings or behaviours (Cane et al., 2012). Researchers have shown for change approaches to be successful, there needs to be a culture of receptivity for patient-centred care, rather than task-orientated care, which was found in my study. Many have affirmed that all levels of people, including the macro (hospital level), meso (ward level) and micro (colleague level), need to embrace a philosophy of patient-centred care for changes to practice to occur (Chaboyer et al., 2016; Jackson & Thurgate, 2011; Luxford, Safran & Delbanco, 2011). Thus, social influences are at the centre of Figure 2, because the actions and support others show for patient participation will influence the success of other recommendations suggested for the remaining domains. Addressing

Figure 2. Theoretical domains influencing nurse perceptions and behaviours towards patient participation.
social influences may address the barrier of nurses’ controlling approach, perhaps reducing task-orientated nurses and risk perceptions.

At the micro level, colleagues need to demonstrate behaviours that support patient participation to influence each other. Role-modelling is an effective way to show patient-centred behaviours (Wolff, 2015). Key members of the team, ideally senior staff, should demonstrate appropriate patient participation as they are influential. Role-modelling may be especially beneficial for changing nurses’ approach to risk, allowing less experienced nurses to observe autonomous practice and reflect (Cruess, Cruess & Steinert, 2008). These senior nurse role-models will need to be clinically competent in patient participation, have teaching skills and personal qualities that include enthusiasm for teaching and practice (Cruess et al., 2008). Part of the role-model’s job would be to facilitate reflection sessions where staff reflect on the behaviours the role model has performed (Cruess et al., 2008), allowing understanding of the senior nurse’s thought processes, such as how they assessed risk and tailored care. Understanding risk management thought processes could enhance autonomous nursing actions. Nurses need to feel confident that their nursing knowledge and expertise allows them to make sound clinical judgements, allowing them to embrace patient involvement that may at times feel in conflict to rules and safety.

At the meso and macro level, social approval for patient participation needs to be made explicit. At the meso level, NUMs could show their support for patient-centred practices and encourage its uptake, by discussing and promoting patient-centred care during performance appraisals and in ward meetings. Macro level decision-makers could increase communication and marketing to show the culture of patient participation and patient-centred care they want to create. Organisational commitment to patient participation in care could also be demonstrated in strategic and organisational planning (Australian Commission on Safety and Quality in Health Care, 2015b). Importantly leaders at the meso and macro levels need to enact their expressed commitment to patient-centred care by ‘walking the talk’ (Australian Commission on Safety and Quality in Health Care, 2015b). Leaders could do this by walking around wards enacting patient-centred principles with patients and family by asking them their preferences and needs (Australian Commission on Safety and Quality in Health Care, 2015b). Role-modelling may be another appropriate approach that has been discussed in more depth previously.
**Beliefs about consequences**

‘Beliefs about consequences’ relates to nurses’ acceptance of the truth of outcomes of behaviour, in a given situation (Cane et al., 2012). In my research, nurses’ negative beliefs about the consequences of patient participation were a barrier to patient participation. This barrier was linked to negative perceptions of patient participation increasing time and risk. Interventions that help change and debunk nurses’ beliefs about time and risk are suggested. Tackling nurses’ beliefs may be a logical next step because if nurses hold strong beliefs about patient participation other behavioural intervention may not be successful.

Persuasive approaches may change nurses’ views of consequences, allowing them to think of safety more wholistically. For example, storytelling is a way for nurses to understand and appreciate patient participation (Wolff, 2015) and has a lasting impact on health-care workers patient-centred skills (Towle et al., 2010). Patients and/or nurses could share their positive stories of patient participation, providing real life examples of how patient participation reduced patient risk and enhanced safety. Additionally, coaching nurses on risk management could increase team effectiveness. Coaching motivates staff, consults staff to discuss current approaches and plan new approaches and educates staff to ensure proper use of resources and effort for patient participation (Hackman & Wageman, 2014).

Further, learning sessions about the pros and cons of patient participation on risk and time could persuade nurses, reshaping their personal construction of risk and time. For example, nurses could be informed of the benefits of involving patients, such as improved medication safety. On the other hand, nurses could be informed of how they put the patient at risk of missing patient-centred opportunities by not participating, threatening patients’ individuality and autonomy (Currie, Harvey, West, McKenna & Keeney, 2005). For time beliefs, myth-busting may be required as the belief that patient-centred care increases time is a common myth (Frampton et al., 2008). Demonstration of behaviours in the form of video or role play could be used to show nurses how to enhance patient participation in their standard consultations, displaying the minimal extra time required. Informing nurses of the pros of patient-centred care, like increased job satisfaction (Lehuluante et al., 2012), could also be a motivator for change.
Another approach to improving nurses’ views of the outcomes of patient participation could be problem-based learning (Shreeve, 2008; Wolff, 2015). Nurses could be presented with cases where a problem related to risk or time is present. In groups, nurses could consider how to address the problem, reflecting on the consequences of their suggested approaches. A facilitator guiding the process would be useful to question nurses’ approaches and ensure they consider risk and time in a way that fosters patient participation and is safe. Problem-based learning may enhance nurses’ skills in tailoring care and group work may promote group uptake of the practice, addressing ‘social influences’ (Shreeve, 2008).

**Social/professional role and identity**

The domain of ‘social/professional role and identity’ is defined as the coherent set of behaviours displayed by individuals in their work setting (Cane et al., 2012). In my study, nurses’ tendency to take a controlling approach towards patient participation appeared set in their professional role, creating a barrier to patient participation. On the other hand, ideas about the nurse’s role in exchanging clinical information and undertaking meaningful encounters were more accepted practices and highlight an aspect of nursing practice that should be supported and further developed. In order to enhance enactment of patient participation, interventions to address nurses’ beliefs about their pivotal role in patient participation is recommended.

First, nurses may benefit from practising their role in patient participation. Dramatisation is an approach that allows people to act out their role in a safe environment, which increases nurses’ relational skills and confidence to enact practices (Arveklev, Susanna, Helena, Linda & Bruce, 2015). For instance, drama students, nursing students or other nurses could play the role of patients, and nurses would act out their role undertaking patient participation with them. The audience or facilitator of the drama session could help to highlight areas for improvement in the scene, to encourage the nurse acting to demonstrate all parts of the nurse’s role in patient participation (Figure 1).

Reflection on experiences of patient participation may facilitate nurses to consider their role in patient participation, by gaining insight into their current approach (Shreeve, 2008). This has been successful in other research relating to patient participation (Tutton, 2005). Undertaking reflection in a group setting could have a
positive impact on ‘social influences’. For reflection exercises, a member of the group could describe a previous experience of patient participation and all members of the group internally examine what they think and feel about the situation. Critical analysis of the nurse’s role in the experience from different perspectives, including a patient-centred perspective, should be encouraged. These methods can provide nurses with new understandings of their role (Tashiro, Shimpuku, Naruse, Maftuhah & Matsutani, 2013), help realise controlling mindsets (Irwin-Whitney, 2014) and encourage nurses to respond differently in the future (Devenny & Duffy, 2014).

In general practice, nurses’ role could include set clinical encounters with an explicit plan for how to engage patients. In particular, communication patterns that are well-established and routine are more successful for patient participation (Chaboyer et al., 2016). For instance, bedside handovers, hourly rounding and patient care boards are potential encounters for patient participation in clinical communication (Chaboyer et al., 2016). These set encounters will encourage clinical communication and meaningful encounters between patients and nurses. However, nurses need to correctly enact facilitating approaches for these to be successful, by pausing and inviting the patient (Chaboyer et al., 2016).

Finally, nurses could work together to develop facilitating approaches towards patient participation, which may take advantage of positive ‘social influences’. Nurses in wards could collectively identify approaches and ward initiatives that facilitate patient participation. For example, SOAR (strengths, opportunities, aspirations, results) could be used to their planning process (Stavros, Cooperrider & Kelley, 2003). Using SOAR shifts the focus to appreciate inquiry, where change is viewed as a social and creative process (Bushe, 2013). The steps involved include nurses visualising their strengths, building on their opportunities, openly collaborating and identifying a shared aspiration and measuring their results (Stavros et al., 2003). These plans to engage frontline staff in transformative initiatives are similar to ‘Transforming Care at the Bedside’ initiatives, which allow nurses to take ownership and engage in leading the changes required (Burston, Chaboyer, Wallis & Stanfield, 2011). Further, nurses could design lists of acceptable and unacceptable approaches to patient participation, establishing patterns of social behaviour that are expected in the environment. This strategy may help put into effect nurses’ role in patient participation, as per current national standards for safety and quality in health care.
Environmental contexts and resources

Cane et al. (2012) defines “environmental contexts and resources’ as any conditions in a person’s situation or environment that affect their ‘skills, abilities, independence, social competence, and adaptive behaviour’” (p. 14). In this study, it was evident nurses’ viewed time as an environmental factor that hindered their ability to enact patient participation. In addition to the previously mentioned recommendations to address beliefs about the consequences of time, strategies to restructure the organisational and environmental context will be presented, as they may assist in addressing time concerns.

To change the organisational context nurses could create mission statements and philosophies of care for the ward that embrace environments of patient-centred practices, rather than paternalistic models of care that focus on time. Utilising nursing staff to create these philosophies may affect ‘social influences’ as nurses would work together to be part of the restructure. Previous researchers have demonstrated the importance of norms on individual wards influencing nurses’ behaviours towards patient participation (Chaboyer et al., 2016).

In terms of nurses’ perceptions of time and workload, assessments of resources and the physical environment may be required. Initiatives such as ‘The Productive Ward’ could be used to ensure the ward environment is set up in the most efficient way possible, so that nurses can easily obtain the resources they require, which increases direct patient care time (Burston et al., 2011). For instance, ‘managing self-care’ was an activity where patient participation was low. Wards could invest in equipment that encourages patients’ self-management practices, perhaps making kits that are easily obtainable for certain chronic conditions. For example, insulin pens, blood glucose measurement machines and documents could be bundled together and administered to patients on arrival and kept in patients’ rooms. Further, medication trolleys may allow nurses to organise medication administration at the bedside, rather than the treatment room; allowing both parties to witness tablet administration and participate. Having time efficient mechanisms like these suggestions may encourage nurses to facilitate patient participation.

To assist time barriers, hospital administrators may need to be accountable for service provision of patient participation, while governments could help ease workload.
Services need to be organised in a way that encourages patient participation, by having appropriate staffing, and money for resources and training to allow patient participation to be enacted. Top-down initiatives like the ‘Studer Group’, where leaders are responsible for creating sustainable outcomes, including creating a service that is patient-centred may be required (Burston et al., 2011). The legislation of nurse-patient ratios in Queensland may also be a policy initiative that addresses time in the future (Australian College of Nursing, 2015, December).

**Research**

The findings from this study could be used to inform and frame future research. The qualitative methods used have aided understanding of patient participation through the rich data collected. Future qualitative studies could help understand the phenomenon more by exploring similarities and differences in other contexts such as different patient populations, inclusive of patients of differing clinical wellness, and different health care settings. More observational studies would be beneficial to expand knowledge of patients’ and nurses’ behaviours that demonstrate patient participation.

Quantitative studies could be designed, based on qualitative findings, producing more generalisable results. For example, the findings from my study relating to patient participation in bedside handover were used to create a discrete choice experiment survey, to compare and weight patients’ and nurses’ preferences for patient participation in handover with a large sample (Spinks, Chaboyer, Bucknall, Tobiano & Whitty, 2015).

A further research direction is to evaluate and refine the preliminary conceptual framework of patient participation developed from this study. Conceptual frameworks are constantly redeveloped as new evidence emerges (Rycroft-Malone & Bucknall, 2013). Other researchers could evaluate the legitimacy of the conceptual framework by testing its utility for guiding nursing practice, education and/or research (Fawcett & Desanto-Madeya, 2013). The current study was conducted in two settings; no statements of generalisation were made. Testing the framework in other contexts with different populations will contribute to the development of the conceptualisation, perhaps demonstrating its applicability to a wider context. Additionally, certain parts of the conceptual framework could be the focus of future research, for instance, further understanding of nurses’ tailoring behaviours may be an important area to investigate.
Researchers may also attempt to generate grand or mid-range theories from the conceptual framework. Researchers could test propositions listed in this study to build more concrete concepts and propositions, which may assist in the development of theory (Fawcett & Desanto-Madeya, 2013).

In recognition of the need to change nurses’ approaches towards patient participation, it is suggested that behaviour change research projects be undertaken. To successfully change nurses’ approach to patient participation, behaviour change interventions should be underpinned by behavioural theory (Cane et al., 2012; Lipworth, Taylor & Braithwaite, 2013). An extensive range of theories can be used to implement knowledge into practice (Rycroft-Malone & Bucknall, 2013). The Theoretical Domains Framework is one useful tool for health care professionals and researchers wanting to change behaviour, as it integrates and simplifies a range of behavioural theories (Michie et al., 2005). It is suggested that researchers use frameworks like these to identify the specific barriers to and facilitators of patient participation for that particular context, allowing interventions to be designed that may be successful (Michie, Stralen & West, 2011). Using this approach may allow researchers to identify barriers and facilitators at any levels of the patient participation conceptual framework proposed. Considering the conceptual framework can help to develop behavioural interventions that are appropriate for patient participation (Rycroft-Malone & Bucknall, 2013).

Conclusion

This study was driven by the current state of health care that advocates and values patient-centred approach to care, which may improve the quality and safety of health care provided. This focused ethnography enhanced understanding of patient and nurse perceptions and behaviours related to patient participation, ultimately capturing the culture being “the way things are done around here” (Davies et al., 2000, p. 112). My study contributes to nursing knowledge as it shows that patients and nurses value participation and have some understanding of ways patients can participate in their care. However, these perspectives are not enacted consistently in practice as nurses have a strong influence on the success of patient participation. Second, knowledge of the barriers and facilitators influencing patient participation has been made explicit. Key barriers and facilitators have been considered in relation to behavioural theory suggesting strategies that address social influences, nurses’ perceptions of
consequences, nurses’ professional role and the environment may enhance future practice suggested. Finally, a contribution of this study is a preliminary conceptual framework, which showed clinical communication and meaningful interactions as foundational, while tailoring and nurses’ approach determine to what extent patients participate in care activities. This framework and descriptions provided has the potential to benefit nurses, improving their understanding of patient participation and perhaps their approach towards patient participation in practice. To conclude, if nurses are of the mindset that they share ownership of patient participation with patients, they need to rise to the task by encouraging patients to participate in what is rightfully their own care.
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## Appendix A: Frequency of Adverse Events in Australia

<table>
<thead>
<tr>
<th>Author/year/year data collected/state</th>
<th>Year data collected/state</th>
<th>Methods</th>
<th>Total sample/contextual details</th>
<th>Adverse event frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adams 09</td>
<td>2004-2005 SA</td>
<td>Cross-sectional, population-based self-reported survey</td>
<td>3522 Adults reflecting on prior hospitalisation</td>
<td>4.2</td>
</tr>
<tr>
<td>Ehsani 06/2003-2004 VIC</td>
<td>2003-2004 VIC</td>
<td>Analysis of hospital dataset</td>
<td>979834 All admissions to 45 ‘larger’ hospitals</td>
<td>6.9</td>
</tr>
<tr>
<td>Ehsani 07/2003-2004 VIC</td>
<td>2003-2004 VIC</td>
<td>Analysis of hospital dataset</td>
<td>16766 Cardiac disease patients only</td>
<td>36.9</td>
</tr>
<tr>
<td>Evans 06/2001 SA</td>
<td>2001 SA</td>
<td>Cross-sectional, population-based self-reported survey</td>
<td>1137 Adults hospitalised in last 5 years, ≥ 40 years</td>
<td>7.0</td>
</tr>
<tr>
<td>Gillman 06/2004 WA</td>
<td>2004 WA</td>
<td>Prospective observational study</td>
<td>290 AEs during ED to ICU transfers</td>
<td>22.7</td>
</tr>
<tr>
<td>Hauck 12/2005-2006 VIC</td>
<td>2005-2006 VIC</td>
<td>Analysis of hospital dataset</td>
<td>131561 Surgical patients only</td>
<td>16.9-17.8c</td>
</tr>
<tr>
<td>Jackson 06/2000-2001 VIC</td>
<td>2000-2001 VIC</td>
<td>Analysis of hospital dataset</td>
<td>1,650,000 All hospital admissions</td>
<td>8.0</td>
</tr>
<tr>
<td>Kable 02/1992 NSW, SA</td>
<td>1992 NSW, SA</td>
<td>Retrospective medical record review</td>
<td>5432 Retrospective medical record</td>
<td>21.9</td>
</tr>
<tr>
<td>Kable 08/-</td>
<td>-</td>
<td>Retrospective medical record review</td>
<td>1177 Surgical patients only</td>
<td>23.1</td>
</tr>
<tr>
<td>NSW</td>
<td>NSW</td>
<td>review</td>
<td>Surgical patients only with highly preventable ops</td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>----------------</td>
<td>------------------------------------</td>
<td>------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>McLaughlin 07/2006</td>
<td>WA</td>
<td>Prospective observational study</td>
<td>156 patients, 72 hours post ICU to ward transfer</td>
<td></td>
</tr>
<tr>
<td>Moje 06/2000-2001</td>
<td>VIC</td>
<td>Analysis of hospital dataset</td>
<td>177533 patients, Elective surgery patients only</td>
<td></td>
</tr>
<tr>
<td>Rigby 99/1992</td>
<td>NSW, SA</td>
<td>Retrospective medical record review</td>
<td>14179 patients, All admissions to 28 randomly selected hospitals</td>
<td></td>
</tr>
<tr>
<td>Wilson 95%/1992</td>
<td>NSW, SA</td>
<td>Retrospective medical record review</td>
<td>14179 patients, All admissions to 28 randomly selected hospitals</td>
<td></td>
</tr>
</tbody>
</table>

AE= adverse event. HP= highly preventable. PP= probably preventable.

a The authors used the term permanent “physical harm” rather than permanent disability, thus interpret the results with caution. b Authors were unable to determine the extent to which adverse events contribute to death. The authors presented individual mortality rates for the 10 diagnostic groups that scored highest in terms of incidence of adverse events. The range of mortality rates for these diagnostic groups is presented.

c16.9% of adverse events occurred for emergency surgery patients, 17.3% of adverse events occurred for elective surgery patients. d Same dataset as Wilson et al. (1995) “The Quality in Australian Health Care Study” used for analysis. e Conservative measure of costs, only included 22% of adverse event categories.

f Same dataset as Wilson et al. (1995) “The Quality in Australian Health Care Study” used for analysis. However, different analytic methods undertaken, Harvard Medical Study methods utilised (Brennan et al., 1991).

8 The Quality in Australian Health Care Study.
Appendix B: Examples of Reflective Notes

Examples of reflective notes recorded prior to fieldwork

Reflecting on my own nursing behaviour: I believe I act in a professional manner when I am nursing, but I also try to focus on being personable with patients. I believe sometimes I may across as having a timid manner, although I am confident in my abilities and knowledge. My nursing behaviours may benefit my observations as I am not an obtrusive person, so other nurses may feel more comfortable conducting everyday behaviours around me and being followed by me.

Reflecting on the phenomenon under study: Reflecting on my own nursing practice, I believe I am encouraging of patient participation in my own practice. Verbally I can think of many way I get patients to participate, by keeping my patients informed of everything I am doing and encouraging their input and feedback when I discuss nursing duties and plans. I like to encourage surgical patients’ independence as these activities allow patients to regain their independence after surgery and can result in safer outcomes. I think that patient participation does not have a definitive end and start point I try to constantly weave patient participation into my practice. For example, while doing nursing cares I am discussing plans with the patient.

Examples of reflective notes recorded during fieldwork

Reflections immediately after observation nurse D2: D2 had a lot of comments like “I’m very anal”. She always ensured patients allergies were recorded and red strikers were on the medication charts, at one point she exclaimed “I love rules!”…She told me how she disliked the BSL forms; she stated there is some confusion around them at the moment for the section that relates to sliding scale…D2 thinks that the sliding scale needs to be addressed daily as it depends on what blood sugars the patient has, plus most nurses find it confusing. D2 states she has addressed this issue further and ‘taken it right to the top’. The feedback she has received is that the form will be reviewed. She seemed very passionate about the safety scrum …which I agree with it. I think that her approach and the way she checked things enhanced patient safety, for example the way she told the patient the bed
was up high, she always asked the patient what medications they were normally on…This makes me think that she is someone who is quite proactive in her approach to nursing, perhaps driven by safety and rules.

I think that D2 had a great bedside manner. Every time she came into the patient’s room she was very positive…She would greet the patient every time she came into their room and every time she left the room she would acknowledge them and say “thank you” or “farewell” or “I’ll be back soon”. She constantly spoke with the patients, but she somehow did more than just telling them what she was doing. She had a way of including the patients, which would generate more than a yes/no answer, it would generate conversational answers…D2 had a great rapport with the patients- the patients wanted to talk to her and tell her about things happening at home- D2.1 (patient) was telling D2 about her grandchildren. I witnessed a lot of verbal communication from D2 with the patients…

D2 did something different to other nurses- she gave one of her patients a fluid balance chart to fill, I find this quite novel. I would like to see if that is a usual practice for her or anyone else on the ward, as it seemed like at times D2 was trying to please me a little bit- which is something to be aware of…I will debrief with my supervisors about this issue…Everyone on the ward has been very kind and received me well. They offered for me to sit down when I was not conducting observations…

Questions I want to ask D2 when I interview her:

You stated that you like rules, how does this influence your encouragement of patient participation?

I noticed the way you communicate with patients, could you tell me a little bit about your methods of communicating with patients. How does your way of communicating influence patient participation?

I noticed you gave a patient a fluid balance chart to fill out, is this a common practice? Tell me your thoughts on this type of practice? …
Appendix C: Patient Information Sheet, Gold Coast Hospital

Plain Language Statement: Patient Information Sheet; Phase 1

Dear Participant,

We are conducting a study looking at patients’ and nurses’ participation in safety activities. The term “participation” is used to describe both physical and verbal forms of patient involvement in hospital care, one way to involve patients are “safety activities” which are tasks/situations that help to prevent error or reduce the risk of patient harm during hospitalisation. Patient participation in safety activities has been shown to improve patient safety, quality of care and can improve patient and nurse satisfaction, however, we have little understanding of patients’ and nurses’ preference for patient participation.

This study has two components. The chart below outlines each component and your involvement:

<table>
<thead>
<tr>
<th>Component</th>
<th>What data is gathered?</th>
<th>What do I need to do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation</td>
<td>4-6 hours of observation of your everyday activities while in hospital. Some demographic information such as age, gender, diagnosis will be required.</td>
<td>Continue your usual activities</td>
</tr>
<tr>
<td>Interview</td>
<td>The day after observations, you may be asked to undergo an interview where you will be asked a series of questions by a researcher. Questions will include: Can you describe what patient participation in hospital care means to you? What things will help you to participate in your care? What hinders your participation in care?</td>
<td>30–60 minute interview with one of our researchers</td>
</tr>
</tbody>
</table>

It is not anticipated that there will be any benefits or risks to you personally as a result of participating in this research. However, we hope the views of patients and nursing staff coming out of this research will be used by health care providers to assist with the design of models for patients to participate in their own care in hospital.

When the research project is completed, a copy of the final report will be available on request. Participants will not be able to gain their individual results because the information will be de-identified. Results of the project will be published in Australian and international academic journals, and presented at conferences and seminars. The project findings will also be reported back to the Queensland Health and Griffith University ethics committees, as well as the executive committee of this organisation. We will also provide the ward with written feedback. Your details will be kept confidential and you will not be identified in any publication or report arising from this research project.
We can be contacted if you have any queries about the study, and you have the right to withdraw your participation from this study at any time. We would like to take this opportunity to thank you for your time and support for this study.

In the event that you have any further queries in relation to any aspect of this study or any other matter related to the study or should you wish to speak to someone during the conduct of the study please contact the HREC Administrator, Gold Coast Hospital and Health Service Ethics Committee by phone: (07) 5687 3879 or email: GCHEthics@health.qld.gov.au OR contact Gold Coast Hospital and Health Service Patient Liaison Service by phone: (07) 5687 2048 or email: GCPLS@health.qld.gov.au.

The conduct of this research involves the collection, access and/or use of your identified personal information. If you consent, you will sign a consent form and we will you a study number. We will keep a code book with names and study numbers so that during data collection we ensure we collect data on only the patients who consent. After data collection is completed we will destroy the code book. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/privacy-plan.

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Mr Rick Williams, Research Ethics and Integrity, Bray Centre (N54) 0.15, Office for Research, Nathan campus, Griffith University, QLD 4111. Phone (07) 3735 4375 or email: rick.williams@griffith.edu.au. Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

Professor Wendy Chaboyer- Director for the National Centre of Research Excellence in Nursing (NCREN), Griffith University, Gold Coast Campus, Parklands Drive, Southport Qld, 4222. Ph: 55528518 Email: w.chaboyer@griffith.edu.au

Dr Jennifer Whitty- Senior Lecturer of Health Economics, Centre for Applied Health Economics, School of Medicine, Griffith University, Logan Campus, University Drive Meadowbrook QLD, 4131. Ph: (07) 338 21486 Email: j.whitty@griffith.edu.au

Professor Tracey Bucknall- Professor, School of Nursing and Midwifery, Deakin University, 221 Burwood Hwy, Burwood VIC, 3125. Phone: 03 924 46529 Email: tracey.bucknall@deakin.edu.au

Professor Andrea Marshall- Professor of Acute and Complex Care Nursing, School of Nursing and Midwifery, Griffith University, Gold Coast Campus, Parklands Drive, Southport Qld, 4222. Ph: 5552 8847 Email: a.marshall@griffith.edu.au

Ms Georgia Tobiano- PhD student, School of Nursing and Midwifery, Griffith University, Gold Coast Campus, Parklands Drive, Southport QLD, 4222. Ph: 55528518 Email: georgia.tobiano@griffithuni.edu.au
Appendix D: Nurse Information Sheet, Gold Coast Hospital

Plain Language Statement: Nurse Information Sheet; Phase 1

Dear Participant,

We are conducting a study looking at patients’ and nurses’ participation in safety activities. The term “participation” is used to describe both physical and verbal forms of patient involvement in hospital care, one way to involve patients are “safety activities” which are tasks/situations that help to prevent error or reduce the risk of patient harm during hospitalisation. Patient participation in safety activities has been shown to improve patient safety, quality of care and can improve patient and nurse satisfaction, however, we have little understanding of patients’ and nurses’ preference for patient participation.

This study is an ethnography and has two components. The chart below outlines each component and your involvement:

<table>
<thead>
<tr>
<th>Component</th>
<th>What data is gathered?</th>
<th>What do I need to do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation</td>
<td>4–6 hours of observation of your everyday activities while working in hospital. Some demographic information such as age, gender, years of experience will be required.</td>
<td>Continue your usual activities</td>
</tr>
<tr>
<td>Interview</td>
<td>In the days after observations (at a convenient time) you may be asked to undergo an interview where you will be asked a series of questions by a researcher. Questions will include: Can you describe what patient participation in hospital care means to you?; What do you see as the advantages of patient participation?; What do you see as the disadvantages of patient participation?</td>
<td>30–60 minute interview with one of our researchers</td>
</tr>
</tbody>
</table>

It is not anticipated that there will be any benefits or risks to you personally as a result of participating in this research. However, we hope the views of patients and nursing staff coming out of this research will be used by health care providers to assist with the design of models for patients to participate in their own care in hospital.

When the research project is completed, a copy of the final report will be available on request. Participants will not be able to gain their individual results because the information will be de-identified. Results of the project will be published in Australian and international academic journals, and presented at conferences and seminars. The project findings will also be reported back to the Queensland Health and Griffith University ethics committees, as well as the executive committee of this organisation. We will also provide your ward with written feedback. Your details will be kept confidential and you will not be identified in any publication or report arising from this research project.
We can be contacted if you have any queries about the study, and you have the right to withdraw your participation from this study at any time. We would like to take this opportunity to thank you for your time and support for this study.

In the event that you have any further queries in relation to any aspect of this study or any other matter related to the study or should you wish to speak to someone during the conduct of the study please contact the HREC Administrator, Gold Coast Hospital and Health Service Ethics Committee. Phone (07) 5687 3879 or email: GCEthics@health.qld.gov.au.

The conduct of this research involves the collection, access and/or use of your identified personal information. If you consent, you will sign a consent form and we will you a study number. We will keep a code book with names and study numbers so that during data collection we ensure we collect data on only the nurses who consent. After data collection is completed we will destroy the code book. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/privacy-plan.

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Mr Rick Williams, Research Ethics and Integrity, Bray Centre (N54) 0.15, Office for Research, Nathan campus, Griffith University, QLD 4111. Phone (07) 3735 4375 or email: rick.williams@griffith.edu.au. Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

Professor Wendy Chaboyer- Director for the National Centre of Research Excellence in Nursing (NCREN), Griffith University, Gold Coast Campus, Parklands Drive, Southport Qld, 4222. Ph: 55528518 Email: w.chaboyer@griffith.edu.au

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Professor Tracey Bucknall- Professor, School of Nursing and Midwifery, Deakin University, 221 Burwood Hwy, Burwood VIC, 3125. Phone: 03 924 46529 Email: tracey.bucknall@deakin.edu.au

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Ms Georgia Tobiano- PhD student, School of Nursing and Midwifery, Griffith University, Gold Coast Campus, Parklands Drive, Southport QLD, 4222. Ph: 55528518 Email: georgia.tobiano@griffithuni.edu.au
Appendix E: Patient Information Sheet, Cabrini Hospital

Plain Language Statement: Patient Information Sheet; Phase 1
Dear Participant

We are conducting a study looking at patients’ and nurses’ participation in safety activities. The term “participation” is used to describe both physical and verbal forms of patient involvement in hospital care, one way to involve patients are “safety activities” which are tasks/situations that help to prevent error or reduce the risk of patient harm during hospitalisation. Patient participation in safety activities has been shown to improve patient safety, quality of care and can improve patient and nurse satisfaction, however, we have little understanding of patients’ and nurses’ preference for patient participation.

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<th>What do I need to do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview</td>
<td>You will be asked to undergo an interview where you will be asked a series of questions by a researcher. Questions will include: Can you describe what patient participation in hospital care means to you? What things will help you to participate in your care? What hinders your participation in care?</td>
<td>30–60 minute interview with one of our researchers</td>
</tr>
</tbody>
</table>

It is not anticipated that there will be any benefits or risks to you personally as a result of participating in this research. However, we hope the views of patients and nursing staff coming out of this research will be used by health care providers to assist with the design of models for patients to participate in their own care in hospital.

When the research project is completed, a copy of the final report will be available on request. Participants will not be able to gain their individual results because the information will be de-identified. Results of the project will be published in Australian and international academic journals, and presented at conferences and seminars. The project findings will also be reported back to the Queensland Health, Griffith and Deakin Universities and Cabrini Hospital ethics committees, as well as the executive committee of Cabrini Hospital. We will also provide the ward with written feedback. Your details will be kept confidential and you will not be identified in any publication or report arising from this research project.

We can be contacted if you have any queries about the study, and you have the right to withdraw your participation from this study at any time. We would like to take this opportunity to thank you for your time and support for this study.

The conduct of this research involves the collection, access and/or use of your identified personal information. If you consent, you will sign a consent form and we will you a study number. We will keep a code book with names and study numbers so that during data collection we ensure we collect data on only the patients who consent. After data collection is completed we will destroy the code book. The information collected is confidential and
will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/privacy-plan.

Griffith and Deakin Universities conduct research in accordance with the National Statement on Ethical Conduct in Human Research. If you have any concerns or complaints about the ethical conduct of the research project they should contact the Manager of Research Governance (Anne Spence) in the Cabrini Institute, ph. 9508 1375 or email, aspence@cabrini.com.au. Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

Professor Wendy Chaboyer- Director for the National Centre of Research Excellence in Nursing (NCREN), Griffith University, Gold Coast Campus, Parklands Drive, Southport Qld, 4222. Ph: 55528518 Email: w.chaboyer@griffith.edu.au

Professor Tracey Bucknall- Professor, School of Nursing and Midwifery, Deakin University, 221 Burwood Hwy, Burwood VIC, 3125. Phone: 03 924 46529 Email: tracey.bucknall@deakin.edu.au
Appendix F: Nurse Information Sheet, Cabrini Hospital

Patients’ and Nurses’ Preference for Patient Participation in Safety Activities

Plain Language Statement: Nurse Information Sheet; Phase 1

Dear Participant,

We are conducting a study looking at patients’ and nurses’ participation in safety activities. The term “participation” is used to describe both physical and verbal forms of patient involvement in hospital care, one way to involve patients are “safety activities” which are tasks/situations that help to prevent error or reduce the risk of patient harm during hospitalisation. Patient participation in safety activities has been shown to improve patient safety, quality of care and can improve patient and nurse satisfaction, however, we have little understanding of patients’ and nurses’ preference for patient participation.

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<th>What do I need to do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview</td>
<td>You will be asked to undergo an interview where you will be asked a series of questions by a researcher. Questions will include: Can you describe what patient participation in hospital care means to you?; What do you see as the advantages of patient participation?; What do you see as the disadvantages of patient participation?</td>
<td>30–60 minute interview with one of our researchers</td>
</tr>
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It is not anticipated that there will be any benefits or risks to you personally as a result of participating in this research. However, we hope the views of patients and nursing staff coming out of this research will be used by health care providers to assist with the design of models for patients to participate in their own care in hospital.

When the research project is completed, a copy of the final report will be available on request. Participants will not be able to gain their individual results because the information will be de-identified. Results of the project will be published in Australian and international academic journals, and presented at conferences and seminars. The project findings will also be reported back to the Queensland Health and Griffith and Deakin Universities and Cabrini ethics committees, as well as the executive committee of Cabrini Hospital. We will also provide your ward with written feedback if requested. Your details will be kept confidential and you will not be identified in any publication or report arising from this research project.

We can be contacted if you have any queries about the study, and you have the right to withdraw your participation from this study at any time. We would like to take this opportunity to thank you for your time and support for this study.

The conduct of this research involves the collection, access and/or use of your identified personal information. If you consent, you will sign a consent form and we will give you a study number. We will keep a code book with names and study numbers so that during data collection we ensure we collect data on only the nurses who consent. After data collection is completed we will destroy the code book. The information collected is confidential and
will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. Griffith and Deakin Universities conduct research in accordance with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the ethical conduct of the research project they should contact: Manager of Research Governance (Anne Spence) in the Cabrini Institute, ph. 9508 1375 or email, aspence@cabrini.com.au. Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

**Professor Wendy Chaboyer**- Director for the National Centre of Research Excellence in Nursing (NCREN), Griffith University, Gold Coast Campus, Parklands Drive, Southport Qld, 4222. Ph: 55528518 Email: w.chaboyer@griffith.edu.au

**Professor Tracey Bucknall**- Professor, School of Nursing and Midwifery, Deakin University, 221 Burwood Hwy, Burwood VIC, 3125. Phone: 03 924 46529 Email: tracey.bucknall@deakin.edu.au
**Appendix G: Patient Consent Form, Gold Coast Hospital**

GOLD COAST HOSPITAL AND HEALTH SERVICE & GRIFFITH UNIVERSITY
PATIENT CONSENT FORM FOR RESEARCH STUDIES; PHASE 1

<table>
<thead>
<tr>
<th><strong>Project Title</strong></th>
<th>Patients’ and Nurses’ Preference for Patient Participation in Safety Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chief Investigator</strong></td>
<td>Professor Wendy Chaboyer RN, BN, MN (Research), PhD</td>
</tr>
</tbody>
</table>
| **Principal Investigators** | Doctor Jennifer Whitty BPharm(Hons), GC ClinPharm, GDipClinPhar, PhD.  
Professor Tracey Bucknall RN, ICU Cert, BN, PostGradDipNursing, PhD.  
Professor Andrea Marshall RN, IC Cert, BN, MN, Grad Cert Ed Studies (Higher Ed), PhD.  
Ms Georgia Tobiano RN, BN (Hons). |
| **Address** | Griffith University  
National Centre of Research Excellence in Nursing (NCREN)  
Gold Coast Campus, Parklands Drive, Southport QLD 4222 |
| **Phone Number** | 55528518 |

1. You are invited to participate in the research project titled “Patients’ and Nurses’ Preference for Patient Participation in Safety Activities”. The term “safety activity”, refers to any task/situation where a patient can be involved, which helps prevent error or reduce the risk of patient harm during hospitalisation. This research project will form part of a PhD thesis being undertaken by Ms Georgia Tobiano who is a student within the School of Nursing and Midwifery at Griffith University.

2. Background to the study
   The aim of this study is to gain a better understanding of the patients’ and nurses’ perceptions of and behaviours towards patient participation. The data will be collected over the next 24 hours and will involve the following:
   a) Observations of your everyday activities and collection of demographic information
   b) Interviews 30-60 minutes with a subgroup of nurses (about your perceptions of patient participation)

3. Data management
   It is anticipated the data gathered from the two methods described above will allow us to better understand patients’ and nurses’ preferences for participation activities. It is hoped this research will result in the implementation of clinical practices to further enhance patient participation in hospitals.
   The information we will collect from you will remain confidential. During the data collection and data entry periods all data will be de-identified and stored in a locked filing cabinet, in a locked office, within a locked building in the School of Nursing and Midwifery, Griffith University. Data entered into computer files will be stored in secure computers and password protected. At the completion of the required information storage period, all information will be destroyed. We do not anticipate there are likely to
be any risks to you as a result of you participating in this project. Your privacy and
wishes are paramount and you are able to withdraw your consent at any time.

4. I acknowledge that I have read the above statement that explains the purpose, the
method of data collection and the possible risks of the investigation, and the statement
has been explained to me to my satisfaction. Before signing this document I have been
given the opportunity to ask questions relating to any possible physical and
psychological harm I might suffer as a result of my participation, and I have received
satisfactory answers. I have also been informed that I may not receive any benefits from
participating in this study.

5. I acknowledge I have been provided with a written Patient Information Sheet outlining
the purpose, risks, benefits and anticipated outcomes of this study.

6. My decision whether or not to participate will not prejudice my future relations with the
Gold Coast Hospital and Health Service or my healthcare providers. If I decide to
participate, I am free to withdraw my consent and to discontinue participation at any
time without prejudice.

7. I acknowledge I am able to choose to participate in phase one of the study
(observation), but may not be offered to participate in phase two of the study
(interview). If I am required to participate in interviews they will be recorded.

8. I agree that research data gathered from the results of this study may be published
provided my name is not used.

9. I have fully explained to the participant the nature and purpose of the study and the procedures to be employed as described
above and such risks as are involved in their performance, and I have provided the
participant with a copy of a written Participant Information Sheet.

10. In the event that you have any further queries in relation to any aspect of this study or
any other matter related to the study or should you wish to speak to someone during the
conduct of the study please contact the HREC Administrator, Gold Coast Hospital and
Health Service Ethics Committee by phone: (07) 5687 3879 or
e-mail: GCHEEthics@health.qld.gov.au OR contact Gold Coast Health Patient Liaison
Service by phone: (07) 5687 2048 or email: GCPLS@health.qld.gov.au.

11. This study has also been approved by the Griffith University Human Research Ethics
Committee. In the event that you have any complaint about the way you have been
treated during the study, or a query that the investigators have not been able to satisfy,
you may contact the Manager, Mr Rick Williams, Research Ethics and Integrity, Bray
Centre (N54) 0.15, Office for Research, Nathan campus, Griffith University, QLD
4111. Phone (07) 3735 4375. Email: rick.williams@griffith.edu.au
Appendix H: Nurse Consent Form, Gold Coast Hospital

GOLD COAST HOSPITAL AND HEALTH SERVICE & GRIFFITH UNIVERSITY
NURSE CONSENT FORM FOR RESEARCH STUDIES; PHASE 1

<table>
<thead>
<tr>
<th>Project Title</th>
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</tr>
</thead>
<tbody>
<tr>
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Professor Tracey Bucknall RN, ICU Cert, BN, PostGradDipNursing, PhD.  
Professor Andrea Marshall RN, IC Cert, BN, MN, Grad Cert Ed Studies (Higher Ed), PhD.  
Ms Georgia Tobiano RN, BN (Hons). |
| Address | Griffith University  
National Centre of Research Excellence in Nursing (NCREN)  
Gold Coast Campus, Parklands Drive, Southport QLD 4222 |
| Phone Number | 55528518 |

1. You are invited to participate in the research project titled “Patients’ and Nurses’ Preference for Patient Participation in Safety Activities”. The term “safety activity”, refers to any task/situation where a patient can be involved, which helps prevent error or reduce the risk of patient harm during hospitalisation. This research project will form part of a PhD thesis being undertaken by Ms Georgia Tobiano who is a student within the School of Nursing and Midwifery at Griffith University.

2. Background to the study
   The aim of this study is to gain a better understanding of the patients’ and nurses’ perceptions of and behaviours towards patient participation. The data will be collected over the next 2-3 weeks and will involve the following:
   a) Observations of your everyday nursing activities and collection of demographic information
   b) Interviews 30-60 minutes with a subgroup of nurses (about your perceptions of patient participation)

   You will be asked to participate in a, but may not be asked to participate in b.

3. Data management
   It is anticipated the data gathered from the two methods described above will allow us to better understand patients’ and nurses’ preferences for participation activities. It is hoped this research will result in the implementation of clinical practices to further enhance patient participation in hospitals.
   The information we will collect from you will remain confidential. During the data collection and data entry periods all data will be stored in a locked filing cabinet, in a locked office, within a locked building in the School of Nursing and Midwifery, Griffith University. Data entered into computer files will be de-identified and stored in secure computers and password protected. At the completion of the required information storage period, all information will be destroyed. We do not anticipate
that there are likely to be any risks to you as a result of you participating in this project. Your privacy and wishes are paramount and you are able to withdraw your consent at any time.

4. I acknowledge that I have read the above statement that explains the purpose, the method of data collection and the possible risks of the investigation, and the statement has been explained to me to my satisfaction. Before signing this document I have been given the opportunity to ask questions relating to any possible physical and psychological harm I might suffer as a result of my participation, and I have received satisfactory answers. I have also been informed that I may not receive any benefits from participating in this study.

5. I acknowledge I have been provided with a written Nurse Information Sheet outlining the purpose, risks, benefits and anticipated outcomes of this study.

6. My decision whether or not to participate will not prejudice my future relations with the Gold Coast Hospital and Health Service. If I decide to participate, I am free to withdraw my consent and to discontinue participation at any time without prejudice.

7. I acknowledge I am able to choose to participate in phase one of the study (observation), but may not be asked to participate in phase two of the study (interview). If I am asked to participate in interviews they will be recorded.

8. I agree that research data gathered from the results of this study may be published provided my name is not used.

9. I have fully explained to the participant the nature and purpose of the study and the procedures to be employed as described above and such risks as are involved in their performance, and I have provided the participant with a copy of a written Participant Information Sheet.

10. In the event that you have any further queries in relation to any aspect of this study or any other matter related to the study or should you wish to speak to someone during the conduct of the study please contact the HREC Administrator, Gold Coast Hospital and Health Service Ethics Committee by phone: (07) 5687 3879 or email: GCHEthics@health.qld.gov.au. This study has also been approved by the Griffith University Human Research Ethics Committee. In the event that you have any complaint about the way you have been treated during the study, or a query that the investigators have not been able to satisfy, you may contact the Manager, Mr Rick Williams, Research Ethics and Integrity, Bray Centre (N54) 0.15, Office for Research, Nathan campus, Griffith University, QLD 4111. Phone (07) 3735 4375. Email: rick.williams@griffith.edu.au
Appendix I: Patient Consent Form, Cabrini Hospital

GOLD COAST HOSPITAL AND HEALTH SERVICE & GRIFFITH UNIVERSITY / 
CABRINI HOSPITAL MALVERN & DEAKIN UNIVERSITY

PATIENT CONSENT FORM FOR RESEARCH STUDIES; PHASE 1

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Professor Andrea Marshall RN, IC Cert, BN, MN, Grad Cert Ed Studies (Higher Ed), PhD. 
Ms Georgia Tobiano RN, BN (Hons). |
| Address | Griffith University 
National Centre of Research Excellence in Nursing (NCREN) 
Gold Coast Campus, Parklands Drive, Southport QLD 4222 |
| Phone Number | (07) 5552 8518 |

1. You are invited to participate in the research project titled “Patients’ and Nurses’ Preference for Patient Participation in Safety Activities”. The term “safety activity”, refers to any task/situation where a patient can be involved, which helps prevent error or reduce the risk of patient harm during hospitalisation. This research project will form part of a PhD thesis being undertaken by Ms Georgia Tobiano who is a student within the School of Nursing and Midwifery at Griffith University.

2. Background to the study
The aim of this study is to gain a better understanding of the patients’ and nurses’ perceptions of and behaviours towards patient participation. The data collection will involve a 30-60 minute interview with you about your perceptions of participation in safety activities.

3. Data management
It is anticipated the data will allow us to better understand patients’ and nurses’ preferences for participation activities. It is hoped this research will result in the implementation of clinical practices to further enhance patient participation in hospitals.

The information we will collect from you will remain confidential. During the data collection and data entry periods all data will be de-identified and stored in a locked filing cabinet, in a locked office, within the Cabrini Institute. Data entered into computer files will be stored in secure computers and password protected. At the completion of the required information storage period, all information will be destroyed. We do not anticipate there are likely to be any risks to you as a result of you participating in this project. Your privacy and wishes are paramount and you are able to withdraw your consent at any time.

4. I acknowledge that I have read the above statement that explains the purpose, the method of data collection and the possible risks of the investigation, and the
statement has been explained to me to my satisfaction. Before signing this
document I have been given the opportunity to ask questions relating to any
possible physical and psychological harm I might suffer as a result of my
participation, and I have received satisfactory answers. I have also been informed
that I may not receive any benefits from participating in this study.

5. I acknowledge I have been provided with a written Patient Information Sheet
outlining the purpose, risks, benefits and anticipated outcomes of this study.

6. My decision whether or not to participate will not prejudice my future relations with
staff at Cabrini Hospital Malvern. If I decide to participate, I am free to withdraw
my consent and to discontinue participation at any time without prejudice.

7. I acknowledge that if I participate in the interview, it will be voice recorded.

8. I agree that research data gathered from the results of this study may be published
provided my name is not used.

9. I have fully explained to the participant
........................................................................ the nature and purpose of the study
and the procedures to be employed as described above and such risks as are
involved in their performance, and I have provided the participant with a copy of a
written Participant Information Sheet.


10. Approval to undertake this research project has been given by the Human Research
Ethics Committee of Cabrini Hospital. If you have any concerns or complaints
about the ethical conduct of the research project they should contact: Manager of
Research Governance (Anne Spence) in the Cabrini Institute, ph. 9508 1375 or
email, aspence@cabrini.com.au. Any complaint made will be treated in confidence,
investigated fully and the participant informed of the outcome.

11. In the event that you have any further queries in relation to any aspect of this study
or any other matter related to the study or should you wish to speak to someone
during the conduct of the study please contact Professor Tracey Bucknall by phone:
+61 3 92446529 (Deakin) or +61 3 90765391 (Alfred) or email:
tracey.bucknall@deakin.edu.au
Appendix J: Nurse Consent Form, Cabrini Hospital

GOLD COAST HOSPITAL AND HEALTH SERVICE & GRIFFITH UNIVERSITY / CABRINI HOSPITAL MALVERN & DEAKIN UNIVERSITY

NURSE CONSENT FORM FOR RESEARCH STUDIES; PHASE 1

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Professor Andrea Marshall RN, IC Cert, BN, MN, Grad Cert Ed Studies (Higher Ed), PhD.  
Ms Georgia Tobiano RN, BN (Hons). |
| **Address** | Griffith University  
National Centre of Research Excellence in Nursing (NCREN)  
Gold Coast Campus, Parklands Drive, Southport QLD 4222 |
| **Phone Number** | (07) 55528518 |

1. You are invited to participate in the research project titled “Patients’ and Nurses’ Preference for Patient Participation in Safety Activities”. The term “safety activity”, refers to any task/situation where a patient can be involved, which helps prevent error or reduce the risk of patient harm during hospitalisation. This research project will form part of a PhD thesis being undertaken by Ms Georgia Tobiano who is a student within the School of Nursing and Midwifery at Griffith University.

2. Background to the study
The aim of this study is to gain a better understanding of the patients’ and nurses’ perceptions of and behaviours towards patient participation. The data will be collected over the next 2-3 weeks and will involve the following:
 a) Interviews 30-60 minutes with a group of nurses (about your perceptions of patient participation).

3. Data management
It is anticipated the data gathered from the methods described above will allow us to better understand patients’ and nurses’ preferences for participation activities. It is hoped this research will result in the implementation of clinical practices to further enhance patient participation in hospitals.

The information we will collect from you will remain confidential. During the data collection and data entry periods all data will be stored in a locked filing cabinet, in a locked office, within the Cabrini Institute. Data entered into computer files will be de-identified and stored in secure computers and password protected. At the completion of the required information storage period, all information will be destroyed. We do not anticipate there are likely to be any risks to you as a result of you participating in this project. Your privacy and wishes are paramount and you are able to withdraw your consent at any time.

4. I acknowledge that I have read the above statement that explains the purpose, the
method of data collection and the possible risks of the investigation, and the statement has been explained to me to my satisfaction. Before signing this document I have been given the opportunity to ask questions relating to any possible physical and psychological harm I might suffer as a result of my participation, and I have received satisfactory answers. I have also been informed that I may not receive any benefits from participating in this study.

5. I acknowledge I have been provided with a written Nurse Information Sheet outlining the purpose, risks, benefits and anticipated outcomes of this study.

6. My decision whether or not to participate will not prejudice my future relations with staff at Cabrini Hospital Malvern. If I decide to participate, I am free to withdraw my consent and to discontinue participation at any time without prejudice.

7. I acknowledge that if I participate in interviews they will be recorded.

8. I agree that research data gathered from the results of this study may be published provided my name is not used.

..................................................  ..................................................
Date                              Signature of Participant

..................................................  ..................................................
Date                              Signature of Witness

9. I have fully explained to the participant the nature and purpose of the study and the procedures to be employed as described above and such risks as are involved in their performance, and I have provided the participant with a copy of a written Participant Information Sheet.

..................................................
Date                              Signature of Principal Investigator/Research Assistant

10. Approval to undertake this research project has been given by the Human Research Ethics Committee of Cabrini Hospital. If you have any concerns or complaints about the ethical conduct of the research project they should contact: Manager of Research Governance (Anne Spence) in the Cabrini Institute, ph. 9508 1375 or email, aspence@cabrini.com.au. Any complaint made will be treated in confidence, investigated fully and the participant informed of the outcome.

11. In the event that you have any further queries in relation to any aspect of this study or any other matter related to the study or should you wish to speak to someone during the conduct of the study please contact Professor Tracey Bucknall by phone: +61 3 92446529 (Deakin) or +61 3 90765391 (Alfred) or email: tracey.bucknall@deakin.edu.au
### Appendix K: Examples of Field Notes

D5= nurse, D5.1=patient 1, SN=student nurse

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>0730</td>
<td>Start observing. It is time for D5.1 medication as per time grid. D5 stands at patient bedside, SN stands at end of bed.</td>
<td>As D5 moves into the room, D5.1 informs D5 that her hands are still shaking. D5 moves to the side of the bed and asks D5.1 to hold her hands out. D5: <em>it is less than last night</em>. D5 informs D5.1 that it is probably the high dose of prednisone that causes the shaking. D5 states she will ask the doctors about the shaking, but encourages the patient <em>you tell the doctor if I’m not here.</em> D5 converses with the patient but educates at the same time. D5 informs D5.1 that D5 needs to get in touch with the dietician because <em>your blood sugars are high...it’s probably the resource.</em> D5.1 states that she likes the resources. It seems like D5 is letting the patient know the issues or tasks she would like to address on this shift. They converse for a while about washing the TED stockings, the air-conditioning and the patient’s pyjamas: D5 asks D5.1 about her TED stockings and asks when they were last washed and changed. D5 tells the patient that she needs 2 pairs and need to alternate between the two every two days and wash them every two days. The questions D5 asks elicit conversational responses from the patient, not yes/no answers.</td>
</tr>
<tr>
<td>0735</td>
<td>D5 and SN move to the patient’s bedside drawers to get 0800 medication out.</td>
<td>Today, I am at the Eastern end of the ward in the 2 rooms closest to the balcony. There is a lot of clutter in the hallways but I know that yesterday the filters in the negative pressure rooms had to be changed, which resulted in many patients having to be moved to different rooms. D5 lets SN get the medication out, D5 supervises the patient as she gets puts the tablets in the cup. As they take one tablet out D5 asks D5.1 <em>are you usually on blood thinners?</em> D5.1 states that she is not usually on blood thinners. D5 and SN move to separate sides of the bed and SN gives the oral medication in a medicine cup to D5.1. After D5.1 has taken her oral medication, D5 talks to D5.1 and tells her that we need to give sliding scale insulin. D5 tells D5.1 that her blood sugars have been high. D5 wants to check D5.1 BSL again but D5.1 informs D5 that she has already commenced her breakfast and has had a juice. D5 states that she will not do a BSL. D5 asks the patient if she is normally on insulin at home. D5.1 states she is <em>only on metformin at home and diet controlled.</em> D5 asks D5.1 if her bowels have moved, D5.1 states no they have not. D5 and SN go to leave the room, as they leave the room D5 tells the patient that they are going to get the insulin checked and will be back with the lactulose.</td>
</tr>
<tr>
<td>Sometimes when SN was placing tablets in medication cup, D5 was talking to the student and educating her on the purpose of the tablets, but it was always loud enough for the patient to hear. D5 calls the patient darl at one point during this encounter.</td>
<td></td>
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<tr>
<td>---</td>
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<tr>
<td>D5 returns to D5.1 room. D5 stands at the end of the bed. SN is in the doorway. D5.1 in bed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D5 asks the patient if she is going to shower today. D5.1 states that she will shower soon. D5 states she will get the patient a pad, towels and a gown. Nurses seem to coordinate/encourage shower time. Even for independent patients in single rooms with their own ensuites.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix L: Patient Interview Guide

Preamble

Before we commence the interview, I would like to give you some background on what I want to talk to you about today. I want to understand your experiences of participating in your own care; this can include any physical or verbal form of participation you take part in while in hospital. At some point in the interview I may lead the conversation towards your participation in safety activities. There has been a move to involve patients more in their care, with the implementation of safety activities such as bedside handover or taking part in pressure area care. Involving patients in these types of safety activities have been shown to improve safety and quality in health care.

Questions

1. Can you tell me what participating in your own care means to you?
2. What are some examples of how you participate in your care?
3. When you participate in your care what are you hoping to achieve?
4. Can you think of any further role you would like to take in your own care?
5. Safety activity:
   a. What role do you think you could have in participating in activities related to ensuring your own safety while in hospital?
   b. Have you experienced the opportunity to play a role in safety activities while in hospital?
   c. (If participant explicitly states they don't think they should/could have a role in safety), can you tell me why you think you can't/shouldn't play a role in safety activities while in hospital?
6. Bedside handover:
a. What role do you think you could have in participating in bedside handover while in hospital?

b. Have you experienced the opportunity to play a role in bedside handover while in hospital?

c. (If participant explicitly states they don't think they should/could have a role in bedside handover), can you tell me why you think you can't/shouldn’t play a role in bedside handover while in hospital?

7. Pressure area care:

   a. What role do you think you could have in participating in pressure area care while in hospital?

   b. Have you experienced the opportunity to play a role in pressure area care while in hospital?

   c. (If participant explicitly states they don't think they should/could have a role in pressure area care), can you tell me why you think you can't/shouldn’t play a role in pressure area care while in hospital?

8. What things would help you to participate in your care?

9. What hinders your participation in care?
Appendix M: Nurse Interview Guide

Preamble

Before we commence the interview, I would like to give you some background on what I want to talk to you about today. I want to understand your experiences of patients participating in their care; this can include any physical or verbal form of participation that you and your patients take part in. At some point in the interview I may lead the conversation towards patient participation in safety activities. There has been a move to involve patients more in their care, with the implementation of safety activities such as bedside handover or patients taking part in their pressure area care. Involving patients in these types of safety activities have been shown to improve safety and quality in health care.

Questions

1. Can you describe what patient participation in patient care means to you?
2. What are some examples of how patients currently participate in their hospital care?
3. What are some examples of patient participation that you get patients to undertake?
4. How do you go about encouraging these forms of patient participation?
5. Safety activities:
   a. What role do you think patients could have in participating in activities related to ensuring their own safety while in hospital?
   b. Have you experienced any examples of patients participating in safety activities while in hospital?
   c. (If participant explicitly states they don't think patients should/could have a role in safety), can you tell me why you think patients can't/shouldn’t play a role in safety activities while in hospital?
6. Bedside handover:
   a. What role do you think patients could have in participating in bedside handover while in hospital?
   b. Have you experienced any examples of patients participating in bedside handover while in hospital?
c. (If participant explicitly states they don't think patients should/could have a role in bedside handover), can you tell me why you think patients can't/shouldn’t play a role in bedside handover while in hospital?

7. Pressure area care:
   a. What role do you think patients could have in participating in pressure area care while in hospital?
   b. Have you experienced any examples of patients participating in pressure area care while in hospital?
   c. (If participant explicitly states they don't think patients should/could have a role in pressure area care), can you tell me why you think patients can't/shouldn’t play a role in pressure area care while in hospital?

8. What factors help you to undertake patient participation at work?
9. What barriers to patient participation do you experience in the workplace?
10. What do you see as the advantages of patients participating in their own care?
11. What do you see as the disadvantages of patients participating in their own care?
12. Can you think of any further role you would like to take in patient participation?
Appendix N: Patient Contact Summary Forms

<table>
<thead>
<tr>
<th>Contact type:</th>
<th>Site:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant:</td>
<td>Contact date:</td>
</tr>
<tr>
<td>Written by:</td>
<td>Today’s date:</td>
</tr>
</tbody>
</table>

1. What were the main issues or themes that struck you in this contact?

2. Summarise the information you got (or failed to get) on each target question you had for the contact.

| Patients’ participation – what it means and examples | - |
| What patient is trying to achieve by participating in care | - |
| Further role patient desires in patient participation | - |
| Patients’ role in safety | - |
| Patients role in bedside handover | - |
| Patients role in pressure ulcer prevention | - |
| What helps patient participation | - |
| What hinders patient participation | - |

3. Anything else that struck you as salient, interesting, illuminating or important in this contact?

4. What new (or remaining) target questions do you have in considering the next contact with this site?
Appendix O: Nurse Contact Summary Form

<table>
<thead>
<tr>
<th>Contact type: Interview</th>
<th>Site:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant:</td>
<td>Contact date:</td>
</tr>
<tr>
<td>Written by:</td>
<td>Today’s date:</td>
</tr>
</tbody>
</table>

1. What were the main issues or themes that struck you in this contact?

2. Summarise the information you got (or failed to get) on each target question you had for the contact.

<table>
<thead>
<tr>
<th>Patient participation – what it means and examples</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>How nurses encourage patient participation</td>
<td></td>
</tr>
<tr>
<td>What nurse is trying to achieve by encouraging patient participation</td>
<td></td>
</tr>
<tr>
<td>Patients’ role in safety</td>
<td></td>
</tr>
<tr>
<td>Patients role in bedside handover</td>
<td></td>
</tr>
<tr>
<td>Patients role in pressure ulcer prevention</td>
<td></td>
</tr>
<tr>
<td>What helps patient participation</td>
<td></td>
</tr>
<tr>
<td>What hinders patient participation</td>
<td></td>
</tr>
<tr>
<td>Advantages to patient participation</td>
<td></td>
</tr>
<tr>
<td>Disadvantages to patient participation</td>
<td></td>
</tr>
<tr>
<td>Further role desired for patient participation</td>
<td></td>
</tr>
</tbody>
</table>

3. Anything else that struck you as salient, interesting, illuminating or important in this contact?

4. What new (or remaining) target questions do you have in considering the next contact with this site?
Appendix P: Examples of Interview Analysis Process