

## TITLE PAGE

### List of authors

*Name:* Georgia Tobiano

*Job title:* PhD Candidate

*Highest academic and professional qualification:* BN (Hons), RN

*Institution:* Centre for Health Practice Innovation, Griffith Health Institute, Griffith University, Queensland, Australia

*Phone number for corresponding author:* +61402 869 972

*Email for corresponding author:* [g.tobiano@griffith.edu.au](mailto:g.tobiano@griffith.edu.au)

*Name:* Tracey Bucknall

*Job title:* Professor<sup>1</sup> and Foundational Chair in Nursing<sup>2</sup>

*Highest academic and professional qualification:* PhD, RN

*Institution:* Centre for Quality and Patient Safety, School of Nursing and Midwifery, Deakin University, Victoria, Australia<sup>1</sup> and Alfred Health, Victoria, Australia<sup>2</sup>

*Name:* Andrea Marshall

*Job title:* Professor of Acute and Complex Care Nursing<sup>1,2</sup>

*Highest academic and professional qualification:* PhD, RN

*Institution:* Centre for Health Practice Innovation, Griffith Health Institute, Griffith University, Queensland, Australia<sup>1</sup> and the Gold Coast University Hospital, Queensland, Australia<sup>2</sup>

*Name:* Jessica Guinane

*Job title:* PhD Candidate

*Highest academic and professional qualification:* MN, RN

*Institution:* School of Nursing and Midwifery, Deakin University, Victoria, Australia

*Name:* Wendy Chaboyer

*Job title:* Professor and Director

*Highest academic and professional qualification:* PhD, RN

*Institution:* National Centre of Research Excellence in Nursing Interventions for Hospitalised Patients, Centre for Health Practice Innovation, Griffith Health Institute, Griffith University, Queensland, Australia

#### Acknowledgements

We would like to acknowledge Stephanie Newell, the patient advocate, for sharing her insight on, and providing meaning for, the created categories. We would like to thank the patient participants for sharing their time and views on participation.

#### Author contribution

Georgia Tobiano, Tracey Bucknall, Andrea Marshall, Jessica Guinane and Wendy Chaboyer contributed to study conception/design, data analysis, and manuscript drafting and critical revisions. Georgia Tobiano and Jessica Guinane contributed to data collection. Tracey Bucknall, Andrea Marshall and Wendy Chaboyer supervised the candidates.

#### Funding

This study was funded by the Australian Research Council (DP130100316).

#### Ethical approval

Ethical approval was gained from the Human Research Ethics Committees at both hospitals (CHREC-09-09-12-13, HREC/13/QGC/54) and the university (NRS/42/13/HREC).

# PATIENTS' PERCEPTIONS OF PARTICIPATION IN NURSING CARE ON MEDICAL WARDS

## Abstract

*Aims and objectives:* To explore hospitalised medical patients' perceptions of participating in nursing care, including the barriers and facilitators for this activity.

*Background:* Patient participation benefits the patient and is a core concept of patient-centred care. Patients believe in their ability to prevent errors, thus, they may play a vital role in combating adverse event rates in hospitals.

*Research methods:* This interpretive study was conducted on four medical wards, in two hospitals. Purposeful maximum variation sampling was operationalized to recruit patients that differed in areas such as age, gender and mobility status. In-depth semi-structured audiotaped interviews were undertaken and analysed using inductive content analysis.

*Results:* Twenty patients participated in the study. Four categories were uncovered in the data. First, valuing participation showed patients' willingness to participate, viewing it as a worthwhile task. Second, exchanging intelligence was a way of participating where patients' knowledge was built and shared with health professionals. Third, on the lookout was a type of participation where patients monitored their care, showing an attentive approach towards their own safety. Fourth, power imbalance was characterized by patients feeling their opportunities for participation were restricted.

*Conclusions:* Patients were motivated to participate and valued participation. Cultivating this motivation may be crucial to patient empowerment and practices of safety-monitoring, a fundamental strategy to addressing patient safety issues in hospitals. Engaging nurse-patient relationships, inclusive of knowledge sharing, is required in practice to empower patients to participate. Educating patients on the consequences of non-participation may motivate them, while nurses may benefit from training on patient-centred approaches. Future research should address ways to increase patient motivation and opportunities to participate.

*Keywords:* Consumer participation; [nurse-patient relations](#); [patient-centered care](#); patient engagement; patient involvement; patient participation; person-centred care; nursing care.

*Word count:* 4120

## INTRODUCTION

Approximately 10% of hospital patients experience an adverse event while receiving hospital care (1), causing patient distress, disability or death (2). Yet over 40% of adverse events are categorised as preventable (1). Notably, 91% of patients believe they can help prevent hospital errors (3, 4) and demonstrate responsiveness to safety education and enactment (3). Globally, patient participation, sometimes termed patient engagement or involvement (5), is increasingly recognised as a vital strategy to improve patient safety (6).

## BACKGROUND

Patient-centred and person-centred care are two terms (7) used to describe a focus on respect for patient individuality, values, perspectives, knowledge and autonomy, characterised by shared responsibility and communication (8). A patient-centred model of care is both holistic and therapeutic (8). The choice of term represents the context in which it is used (9). Ultimately, these terms are underpinned by similar values (8), and one common element is the role of patient participation in achieving patient-centred care (10).

There is no accepted definition of patient participation (11, 12). The most recent concept analysis on patient participation highlights the requirement that patients be accepted as mutual partners by nurses, with this partnership demonstrated through engagement in many aspects of their own care (13). Additionally, for patients to participate there needs to be information sharing, power sharing and an established relationship between the patient and nurse (13). Findings from a more recent integrative review support Sahlsten et al.'s (13) earlier conceptualisation of patient participation (citation masked for blinded peer review). In other work, Eldh et al. (14) created a tool attempting to increase understanding of patient participation. Its underlying framework is based on patients' experiences, and defines patient participation as having dialogue, sharing knowledge, partaking in planning and managing self-care (14). However, this framework is based largely on Swedish patients' views and

requires further testing, especially in other contexts. Ultimately, an agreed definition of patient participation, that includes the patient's voice, is still required.

Patient participation benefits patients in many ways. When patients participate in their care, there has been evidence of increased patient satisfaction (15), safety (16, 17) and quality of care provided (17). Further, patients feel humanised and respected when engaging in their nursing care (18), viewing respect as necessary for participation to occur (19, 20). In particular, patients with chronic illnesses benefited from participation in and management of their own care (21). This has demonstrated improved attainment of treatment goals resulting in increased mobility (22) and reduced complications (23). Not surprisingly, engaging patients at the point of care is a critical strategy for enhancing patient participation (24).

Despite these benefits, patients express barriers to participating in their care. For instance, feeling knowledgeable (25, 26) or well/unwell (26, 27) can influence patients' engagement. Notably, patients express nurses as an influence on their participation, with authoritative manners hindering their participation (26, 28). Instead, patients desire participatory relationships with nurses based on shared dialogue and knowledge (20), and want a nurse who is inviting (29), respectful, listens (20, 25) and individualises care (25). Yet, other researchers suggest some patients may prefer to be more passive (30, citation masked for blinded peer review), suggesting complexity in understanding patient participation.

Ultimately, patients appear to encounter difficulties in enacting what national and international policies are advocating. Patient participation is a right of all patients (31), and is accepted as a pillar for high quality care in hospitals internationally (32). For example, Australian hospitals are governed by ten safety and quality standards, with seven of the ten standards incorporating engaging with patients as a requirement, and one standard completely dedicated to partnering with consumers (33). To promote patient participation in nursing care,

a better understanding on patients' perceptions of participation is required, including deeper understanding of the barriers and facilitators encountered. Given patients have a vested interest in preventing adverse events and when they are actively engaged in their care, they may help prevent errors (34), it is important to know how to encourage patients' participation.

## AIM

The aim of this study was to explore patients' perceptions of participating in nursing care, including the perceived barriers and facilitators for it. Understanding patient preferences provides a foundation to formulate evidence based approaches to promote patient participation in hospitals.

## METHODS

### Design

Interviews with patients were conducted for this interpretive study, as part of a larger ethnographic study that included observations and interviews with nurses. Data were collected from four medical wards, in two metropolitan hospitals that differed in location, being two states in Australia; service, being private and public; and duration of establishment. In addition to general medicine, the participating wards specialised in gerontology, immunology, neurology and respiratory medicine.

### Participants

To operationalise purposeful maximum variation sampling, data collectors liaised with nurse unit managers or their designate to discuss potential participants that differed in characteristics such as age, gender and mobility status. Inclusion criteria were aged 18 years or older, and able to provide informed consent. Medically unstable or palliative care patients were excluded.

### Data collection

The nurse unit managers granted access to the medical wards and in-services were held to inform nurses of the project. After consenting, patients took part in in-depth semi-structured interviews. The two data collectors maintained regular communication to discuss common probes and patient responses to ensure questioning was consistent. Examples of interview questions included 'Can you describe what patient participation in hospital care means to you?', 'What do you see as the advantages/disadvantages of patient participation?' and 'What things will help/hinder you to participate in your own care?' Interviews were recorded and transcribed verbatim; ranging from 15-65 minutes and were conducted in patient rooms.

#### Data analysis

Immediately after patient interviews, an initial analysis was conducted on recordings using 'contact summary forms' (35), which allowed data collectors to identify early patterns and areas requiring further investigation in subsequent interviews. Following this, formal inductive content analysis was conducted (36). Transcripts were read and re-read allowing the researchers to become immersed in the data. Open coding was then undertaken using words and sentences to describe the topic of each line. These codes were compared and contrasted, and aggregated into groups, resulting in the formation of subcategories. Finally, subcategories were abstracted to form higher order categories. The entire analysis process was iterative, with researchers constantly referring back to the raw data to substantiate emerging ideas and categories. The researchers at each site met and through the process of reflection and discussion, and returning to verbatim quotes and transcripts, agreement on categories and subcategories was reached. Data from individual hospitals were analysed separately prior to being combined. An intensive face to face workshop was held to review each sites data, identify commonalities and finalise the analysis using the same process as was undertaken in each site.

## Ethical issues

Ethics approval was gained from the participating hospitals (CHREC-09-09-12-13, HREC/13/QGC/54) and the university human research ethics committees (NRS/42/13/HREC). All participants signed consent forms and were given a plain language statement outlining the study and their role.

## Rigor

Qualitative techniques for maintaining rigor were utilised (37). Reflexivity occurred in two ways. First, the use of contact summary forms enabled reflection on interview techniques and content to enhance future interviews. Second, data collectors reflected on their own background and perceptions of the topic to consider how this influenced their approach to interviews and subsequent analysis. Involvement of many researchers and a patient advocate enhanced the credibility and dependability of analysis and findings. The patient advocate assisted the researchers to make sense of the established categories and the relationships between categories. Having varied sites and participants facilitated a more complete understanding of patient participation, including identification of divergent cases, in the medical ward setting. An audit trail of analytical decisions was maintained.

## RESULTS

Five patients from each of the four wards were interviewed, resulting in a sample of 20 patients. Just over half of the patients were female, representing a variety of age and mobility statuses (Table 1). Patients had a median length of stay of about a week when recruited and were most commonly admitted for disorders of the respiratory system including exacerbations of chronic illnesses such as asthma and chronic obstructive pulmonary disease, as well as acute chest infections. Of all the patients, 65-70% reported daily visits by, and living at home with, family or significant others. All patients suffered from a chronic condition, with 70% reporting two or more chronic conditions, the most common diseases



reported affected the ‘circulatory’, ‘endocrine, metabolic and nutritional’, and ‘respiratory’ systems. Only two patients were culturally or linguistically diverse.

Table 1 here.

Four categories of patients’ perceptions of participation were discovered (Figure 1). Patients’ age, feeling well or unwell, functional ability and experience of an adverse event appeared to affect their level of participation in all four categories. The analysis revealed older patients who were more unwell, seemed to have less desire to participate in their care. On the other hand, patients who had previously experienced an adverse event reported more active participation. Patients’ functional ability influenced the type of participation they could undertake. When comparing sites, patients admitted to the private hospital appeared to have a higher expectation of a service and experience from nurses and reported higher levels of participation by carers or family.

Figure 1 here.

#### Valuing participation

The category, valuing participation, highlighted patients’ ambition for participation. Patients outlined a variety of personal preferences for participation, with an overall sense of satisfaction with participating at their desired level. In the first subcategory, patients had a variety of approaches to participating, exemplified in their expressed mannerisms ranging from an enthusiastic “go-getter” who described participation as “something I want to do” (P1), to more determined approaches to participation. Patients’ personal style and approaches appeared to influence how actively they engaged with nurses:

I think I'm a bit stubborn because I don't like to give over my control, especially the diabetes stuff because I've had it for 31 years and I think I know myself better than anyone, and also I

think too, I don't want to become complacent, and I certainly don't want to become institutionalised which is the other thing (P2)

Patients described patient participation as a worthwhile task in the second subcategory, which allowed them to achieve goals such as maintain and "settle into a routine", "feel better" and "get home early" (P3). Maintaining previous level of function was another reason patients "try to participate", given the perceived benefit was to "keep as much independence as possible" (P4). Seeing participation as worthwhile encouraged patients to participate in their care, especially undertaking physical activities like activities of daily living.

#### Exchanging intelligence

Exchanging intelligence was a form of participation where patients' knowledge was built and imparted. Seeking understanding, the first subcategory, was exemplified by patients demonstrating that "having basic knowledge" (P5) was desirable and required as patients "can't be sitting here like an idiot" (P6). Knowing what was going on was an important part of the hospital experience, making up patients' needs. Patients outlined strategies they undertook to become knowledgeable health care participants, including gaining information from a variety of sources such as nurses, doctors' rounds, family members, self-education, or reflecting on experiential knowledge. For instance, information was gained from nurses through bedside handover which "enlightens you a bit on what they're doing" (P7).

Patients used the knowledge they had pursued to share their understanding with nurses in the second subcategory. For example, one patient with chronic wounds used his knowledge of dressing products to participate: "With the nurses I can help them... with what kind of dressings work the best...you give them information and they take that into account"

(P8). Sharing understanding appeared to impact on patients' everyday activities, patients felt nurses needed the right information to ensure their care was tailored to their needs. On the whole, feeling knowledgeable heightened the exchange of intelligence and enabled patients to be partners with their nurse.

#### On the lookout

Being 'on the lookout' was a type of participation where patients monitored their care. This category describes patients participating by "keeping an eye" (P9) on their care and having an attentive approach towards their own safety. In the first two subcategories, patients monitored themselves and their physical environment. A female with multiple chronic conditions exemplified these monitoring behaviours: "...I used to do a lot more for myself but now I'm a bit shaky. I'll ring for the nurse, and get a little bit more help. Especially at night time it's dark..." (P10).

Monitoring treatment and hardwares was another subcategory, where patients ensured their safety. In terms of treatment, the majority of patients maintained their medication safety as they knew "what colour and shapes" their tablets were and they "notice(d) if something is missing (P11)". In the remaining subcategory, monitoring information, bedside handover was an example where patients were "alert" and "listening to the whole thing", which allowed them to identify if nurses "miss something or...say something that's not quite right" (P12). Although most patients listened to information exchanges like bedside handover, not all patients felt comfortable clarifying information: "That's their job, handover the bed, with the patient in it" (P13). In general, through observing patients became active participants, acting upon witnessed issues and speaking up. Most patients used 'on the lookout' behaviours at all times; part of their hospital experience was looking out for themselves and being cautious to ensure their own safety.

#### Power imbalance

The category, power imbalance, illustrates barriers patients encountered when attempting to participate. Obstacles patients outlined were congruent with a paternalistic model of health care. In the first subcategory, complying with nurses, patients described an imbalanced relationship where nurses held the power and expert knowledge, thus patients complied: “I suppose you’re... in here as a patient, aren’t you, and you’re under their care; they’ve got the responsibility of you, haven’t they? I’m always prepared to respond to any of their directions and everything like that” (P14). Further, patients wanted to be viewed as pleasant, “never growl(ing)” at nurses and instead “just say(ing) thanks...so it keeps sweet with them” (P15). A few patients saw participation as a way of reducing demands on busy nurses, and many patients were reluctant to use their nurse call bell instead they “keep quiet and just let them do it” (P16).

In the second subcategory, interpreting nurses’ approaches, patients perceived negative nurse manners, which entrenched a passive approach by the patient: “...some (nurses) I wouldn’t bother, you just know by their manner...one woman was just so bombastic” (P17). Patients made it clear that not all nurses displayed these manners and on the large their care was “very satisfactory” (P18). Overall, these perceived barriers manifested in patient disempowerment, thus minimising patients’ engagement with nurses throughout their hospital stay and diminishing patient participation.

## DISCUSSION

In this study we investigated patients’ perceptions of participation and found three out of the four categories identified in the patient data demonstrated patients’ motivation to participate, especially in knowledge exchange and monitoring. The remaining category suggests patients’ feel they have limited opportunities for participation. Overall, it appears that patients will have to feel motivated and able to participate, before they act it.

Our findings suggest that patients need to feel capable for effective patient participation to occur. In particular, it was evident that knowledge was required to build patients' self confidence in their participation capabilities. Consistent with this, other researchers have found that knowledge empowers patients (38, 39), particularly when participating in decision-making (40, 41), and is a pre-requisite for patient participation (14, 20, 25).

The findings revealed patients used various strategies to increase their knowledge for participation, including employing nurses as a supplier of information. Similarly, researchers have shown nurses to be facilitators to patient empowerment through information-sharing encounters (20, 39, 42). Our participants perceived the nursing bedside handover as one strategy to increase their knowledge of their situation, an activity which other patients have found empowering (43). Asking questions was another method used by our participants for eliciting information from nurses. Finnish researchers demonstrated that 90% of hospital patients felt encouraged to ask nurses questions and 96% were provided with adequate information (44), however, patients' comfort with asking nurses questions may depend on how challenging the question is perceived to be (45). On the contrary, others have implied when nurses do not effectively share information patient disempowerment results (28, 38) and patient participation is hindered (26, 29, 46).

Other sources that enhanced patient knowledge were family members and personal experience. Researchers affirm the role of family members as a supplier of information, sometimes being the conduit between nurse and patient (47). In addition, patients' using their experiential knowledge when participating, is characteristic of patients with chronic illnesses (39). The sources of information we discovered may be indicative of our sample, given the majority of patients were visited daily by family or significant others, suggesting patients were well-supported, and the entire sample had at least one chronic condition, which may be why patients held experiential knowledge. Nethertheless, our findings show gaining

information as a facilitator to patients participating in their care, as well as revealing some channels patients used to gain this information.

Our patients not only sought information, but comprehended it, using it as knowledge (48) to participate with nurses. Other patients have spoken of interpreting information as vital to participating and maintaining a sense of control in the health care environment (49), characteristic of empowered patients (50). In turn, nurses would need to legitimise patients' shared knowledge to achieve effective participation (25, 51) and patient-centred care (8). Although there is evidence that gaining knowledge heightens patient participation (52), information does not always result in engaged patients, as some patients gain a sense of security and assume passivity from being informed (53).

Our study revealed patients' perceived they were actively monitoring their own safety; motivated by expectations of better outcomes by participating in this way. Other researchers have described patients' monitoring behaviours (34), in activities such bedside handover (18), medication administration (30, 54, 55) and identification of symptoms (42, 49), however, monitoring is not widely performed by all patients. According to Schwappach and Wernli (56), when patients perceive they receive safe care, they are less attentive in ensuring their own safety.

In our study, part of the sample expressed the confidence to speak up based on what they monitored. This resonates with Schwappach and Wernli's (56) findings, where chemotherapy patients voiced eagerness for intercepting errors, particularly using communication strategies. However, speaking up can be challenging for patients. Patients' thoughts on the seriousness of the outcome, ability to monitor and the manner of nurses can influence patients' courage to speak up (57). Further, feeling monitoring safety is a taboo activity can cause patients to conceal their concerns from nurses (56). Schwappach and

Wernli (58) further support the difficulty patients have speaking up, reporting patients may value the positive outcome expected from preventing errors more than actually participating in error prevention. Nevertheless, our findings suggest that heightening patient awareness of the consequences of non-participation in safety is instrumental to heightening patients' value for participation, which may reduce adverse events and limit patient harm.

For some patients, the value of participation was more than foreseeing a positive outcome; some patients had objectives they wanted to achieve and participation was a way to achieve these goals. Other patients have identified being confident in their own goals as a key feature of participation (49). The major goals identified by patients in this study included maintaining previous level of function and independence and hastening recovery. According to Höglund et al. (29), getting better was identified by patients as a means of participating in their care in order to increase their commitment to recovery. Older patients have shown value for the goal of maintained level of function, with sustaining independence and self-care abilities seen as an important feature of patient participation (59).

Our findings indicate that social impacts influenced patients' perceptions of participation. For instance, patients held set ideas about how to behave as a patient, characterised by being compliant and easy. Viewing patients' role in participation as being obedient and accepting of nurses' instructions appears to be widely reported (30, 60). Some suggest patients' fear being labelled as difficult by participating (61, 62), instead taking on the good and passive patient role in order to receive sound nursing care (63, 64). For other patients, they attempt to address their own needs first, before disturbing nurses (65). On the contrary, some patients' motives for compliance stem from their assumptions that participation is the nurse's duty and their role is to receive a service (66), which was particularly evident in our sample of patients in private hospital.

Another social influence evident in the data was the role of power. Our patients believed nurses held expert power, which entrenched a passive approach to participation. This is congruent with Soleimani's (60) findings, whereby patients believed nurses knew better, thus patients adhered to nurse instructions. In our study, another power issue identified by patients was nurses exerting authoritative mannerisms. Complementing our findings, researchers have identified dominant nurse manners as a barrier to patient participation (5, 26), with examples of nurse manners including lack of respect for patient knowledge (25, 53), lack of information (53, 67, 68) and being belittled (51, 69). These nurse mannerisms are evident during episodes of patient vulnerability (38) and have been linked with increased patient passivity towards participation (60, 63, 70). These social influences uncovered are barriers to patient participation, highlighting the important role nurses play in the success of patient participation.

Some of the influencing factors we found to inhibit or facilitate participation have been shown to impact patient participation in other studies. In terms of generation, our older patients tended to prefer a passive approach to patient participation, which is supported in the safety (4, 27) and decision-making literature (62, 71). Older generations appear to be more trusting of health care professionals, lacking the self-confidence to participate (72), thus hindering patient participation (73). Low levels of participation when patients are unwell is well-supported by previous researchers (26, 27, 42). Conversely, our patients who had past negative experiences of health care emphasized participating more actively in their care. Other researchers have found the link between previous adverse events and higher levels of concern for safety (74) and more proactive patient involvement in some activities (67, 75).

Less reported is the effect of functional ability. Our findings revealed that some patients had physical limitations which influenced their ability and willingness for participation. Being physically dependent on care affects the nurse-patient relationship, as



patients have to accept nurses' assistance in tasks they are unable to independently perform (76-78). This dependence is associated with loss of control and powerlessness (79), and patients commonly participate by communicating their needs to nurses (76, 77, 79). Maintaining patients' decisional autonomy and effective nurse-patient dialogue in these instances is necessary for patient-centred care to occur (80).

Overall, these findings resonate with behaviour change theories, which can be used to help understand how patients construct their approach towards participation. For example, given the way patients spoke about their motivation and ability to participate, the theory of planned behaviour (TPB) may be useful in understanding patients' intentions to undertake participation in nursing care.

The TPB consists of three levels of concepts that are used to sequentially predict behaviour. We accessed patients' constructed beliefs; these belief concepts make up the first level of TPB. These beliefs directly influence and provide understanding for the second level of concepts or predictors; attitudes, subjective norms and perceived behavioural control (81). Attitudes reflect a person's positive or negative appraisal of the outcome of the behaviour (81), and was reflected in the way patients' viewed the outcome of participating as beneficial and advantageous, heightening patients' willingness to engage. Subjective norms illustrate an individual's perceived support for the behaviour from important individuals and groups (81), which were evident in the social pressure patients felt to not engage in participation, which may have been influenced by perceived nurses' manners.

The final concept, patients' perceived behavioural control, describes one's belief in the extent to which the behaviour is under their control, as well as the perceived ease or difficulty of performing a behaviour, thus, comprising of two factors, controllability and self-efficacy (82). Consistent with the TPB, knowledge was one factor that increased patients'

self-efficacy, increasing the ease of participation. That is, their understanding increased their belief in their ability to participate and ultimately, their perceived behavioural control.

Patients' sense of controllability, another factor that influences perceived behavioural control, was less clear and would require further investigation.

Together these second level concepts (i.e. predictors) reflect intention, being the third and final concept to impact behaviour (81). Schwappach and Wernli (58) confirm the use of theory of planned behaviour when investigating patient engagement in safety. In fact, the findings in our study resonate with many patients' views on engaging in safety behaviours, with knowledge beliefs, attitudes and role approval from health care professionals being key factors in the success of patients' participation in safety activities (83). Other researchers investigating patient participation may benefit from using similar concepts.

## LIMITATIONS

The study has certain strengths and limitations. This interpretive study was conducted with attention to maintaining the rigor of qualitative research. The repetitiveness of patterns in the data demonstrates a consensus of patient views on the topic. However, the data are self-reported, which may not reflect patients' actual practice of participation, nevertheless, it did demonstrate patients' beliefs, with TPB suggesting beliefs influence action. Because patients have reported their perceived beliefs and practices, it would be important to consider patient complexities such as capability and preference before involving patients in their care (84).

## CONCLUSION

Data from four medical wards, in two hospitals in two Australian states, with 20 patients provides four categories relating to the value for, ways of and factors influencing participation. The findings provide a better understanding of patients' perceived role, which may be useful in promoting patient participation. In particular, enhanced knowledge appears

to facilitate patient participation in nursing care. This analysis demonstrated that patients were motivated to participate, evident in the positive outcomes and goals patients perceived for participation in nursing care. Cultivating this motivation and encouraging patients' monitoring behaviours may be crucial to increasing patient empowerment and patients' involvement in safety, a fundamental strategy to addressing patient safety issues in hospitals. Patients felt their opportunities for participation were restricted, due to a sense of power imbalance. Now that the influence of this barrier has been confirmed, strategies to overcome this barrier are required so that core concepts of patient participation and patient-centred care are to be achieved.

### Recommendations

A number of recommendations can be made based on the findings and are summarised in Table 2. In practice, patients will need to be activated, meaning they need the knowledge, motivation and confidence to participate (85); required qualities highlighted in our study. To activate patients, they need to feel empowered and engaged (86), which nurses can achieve through sharing knowledge and power (13, 87). Knowledge transfer in practice should be seen as a two-way process to attain patient empowerment. Engaging patients in goal setting may be another way to nurture patients' motivation for participation. Further, nurses should foster patients' confidence for acting as an added safety net. Finally for practice, creating ward environments that embrace patient-centred care may also assist in activating patients (86).

For education, if patients understand the benefits and risks of participation and non-participation, they may feel more persuaded to participate, given the advantages of participation. Having nurses engage patients in a patient-centred way, inclusive of building a relationship, sharing knowledge and power, is a pre-requisite to achieving patient participation (88), thus, nurses may benefit from training in patient-centred and interpersonal

skills to enhance their readiness to engage. Future research investigating ways of motivating patients' participation and conquering barriers related to nurses' approaches would be beneficial. Researchers may benefit from using behavioural theory concepts, such as those used in the TPB, when investigating patient motivation for and ability to participate. To conclude, practice, education and research approaches could be utilised to enhance patient participation.

Table 2 here.

## REFERENCE LIST

1. de Vries EN, Ramrattan MA, Smorenburg SM, Gouma DJ, Boermeester MA. The incidence and nature of in-hospital adverse events: a systematic review. *Qual Saf Health Care* 2008; 17: 216-23.
2. Brady A, Redmond R, Curtis E, Fleming S, Keenan P, Malone A, et al. Adverse events in health care: a literature review. *J Nurs Manag* 2009; 17: 155-64.
3. Schwappach DLB, Frank O, Koppenberg J, Müller B, Wasserfallen J. Patients' and healthcare workers' perceptions of a patient safety advisory. *Int J Qual Health Care* 2011; 23: 713-20.
4. Waterman AD, Gallagher TH, Garbutt J, Waterman BM, Fraser V, Burroughs TE. Brief report: hospitalized patients' attitudes about and participation in error prevention. *J Gen Intern Med* 2006; 21: 367-70.
5. Kovacs Burns K, Bellows M, Eigenseher C, Gallivan J. 'Practical' resources to support patient and family engagement in healthcare decisions: a scoping review. *BMC Health Serv Res* 2014; 14: 175-90.
6. Koutantji M, Davis R, Vincent C, Coulter A. The patient's role in patient safety: engaging patients, their representatives, and health professionals. *Clinical Risk* 2005; 11: 99-104.
7. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs* 2011; 10: 248-51.
8. Hughes JC, Bamford C, May C. Types of centredness in health care: themes and concepts. *Medicine, Health Care and Philosophy* 2008; 11: 455-63.
9. Morgan S, Yoder LH. A concept analysis of person-centered care. *J Holist Nurs* 2012; 30: 6-15.
10. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *J Adv Nurs* 2013; 69: 4-15.
11. Barello S, Graffigna G, Vegni E, Bosio AC. The challenges of conceptualizing patient engagement in health care: a lexicographic literature review. *Journal of Participatory Medicine* 2014; 6: e9.
12. Gallivan J, Kovacs Burns K, Bellows M, Eigenseher C. The many faces of patient engagement. *Journal of Participatory Medicine* 2012; 4: e32.
13. Sahlsten MJM, Larsson IE, Sjöström B, Plos KAE. An analysis of the concept of patient participation. *Nursing Forum* 2008; 43: 2-11.
14. Eldh AC, Luhr K, Ehnfors M. The development and initial validation of a clinical tool for patients' preferences on patient participation – the 4Ps. *Health Expect* 2014: e1-14.
15. Poochikian-Sarkissian S, Sidani S, Ferguson-Pare M, Doran D. Examining the relationship between patient-centred care and outcomes. *Canadian Journal of Neuroscience Nursing* 2010; 32: 14-21.
16. Schwappach DLB, Frank O, Buschmann U, Babst R. Effects of an educational patient safety campaign on patients' safety behaviours and adverse events. *J Eval Clin Pract* 2013; 19: 285-91.
17. Weingart SN, Zhu J, Chiappetta L, Stuver SO, Schneider EC, Epstein AM, et al. Hospitalized patients' participation and its impact on quality of care and patient safety. *Int J Qual Health Care* 2011; 23: 269-77.
18. McMurray A, Chaboyer W, Wallis M, Johnson J, Gehrke T. Patients' perspectives of bedside nursing handover. *Collegian* 2011; 18: 19-26.
19. Eldh AC, Ekman I, Ehnfors M. A comparison of the concept of patient participation and patients' descriptions as related to healthcare definitions. *International Journal of Nursing Terminologies and Classifications* 2010; 21: 21-32.

20. Larsson IE, Sahlsten MJM, Sjöström B, Lindencrona CSC, Plos KAE. Patient participation in nursing care from a patient perspective: a grounded theory study. *Scand J Caring Sci* 2007; 21: 313-20.
21. Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. *Mayo Clin Proc* 2010; 85: 53-62.
22. Arnetz JE, Almin I, Bergstrom K, Franzen Y, Nilsson H. Active patient involvement in the establishment of physical therapy goals: effects on treatment outcome and quality of care. *Advances in Physiotherapy* 2004; 6: 50-69.
23. Rachmani R, Levi Z, Slavachevski I, Avin M, Ravid M. Teaching patients to monitor their risk factors retards the progression of vascular complications in high-risk patients with type 2 diabetes mellitus—a randomized prospective study. *Diabet Med* 2002; 19: 385-92.
24. Luxford K, Safran DG, Delbanco T. Promoting patient-centred care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care* 2011; 23: 510-5.
25. Eldh AC, Ekman I, Ehnfors M. Conditions for patient participation and non-participation in health care. *Nurs Ethics* 2006; 13: 503-14.
26. Larsson IE, Sahlsten MJM, Segesten K, Plos KAE. Patients' perceptions of barriers for participation in nursing care. *Scand J Caring Sci* 2011; 25: 575-82.
27. Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? *Health Expect* 2007; 10: 259-67.
28. Aasen EM, Kvangarsnes M, Heggen K. Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scand J Caring Sci* 2012; 26: 61-9.
29. Höglund AT, Winblad U, Arnetz B, Arnetz JE. Patient participation during hospitalization for myocardial infarction: perceptions among patients and personnel. *Scand J Caring Sci* 2010; 24: 482-9.
30. Rathert C, Huddleston N, Pak Y. Acute care patients discuss the patient role in patient safety. *Health Care Manage Rev* 2011; 36: 134-44.
31. World Health Organisation. *Declaration of Alma-Ata*. 1978, [http://www.who.int/publications/almaata\\_declaration\\_en.pdf](http://www.who.int/publications/almaata_declaration_en.pdf). (Last accessed March 12, 2014)
32. International Alliance of Patients' Organizations. *Patient-centred healthcare indicators review*. 2012, [www.patientsorganizations.org/indicatorsreview](http://www.patientsorganizations.org/indicatorsreview). (Last accessed September 27, 2014)
33. Australian Commission on Safety and Quality in Health Care (ACSQHC). *Patient-centred care: improving quality and safety through partnerships with patients and consumers*. 2011, ACSQHC, Sydney, Australia
34. Peat M, Entwistle V, Hall J, Birks Y, Golder S. Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *J Health Serv Res Policy* 2010; 15: 17-25.
35. Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook*. 2014, SAGE, Thousand Oaks, CA.
36. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; 24: 105-12.
37. Lincoln YS, Guba EG. *Naturalistic Inquiry*. 1985, Sage, Newbury Park, CA.
38. Fiveash B, Nay R. Being active supports client control over health care. *Contemp Nurse* 2004; 17: 192-204.

39. Schoot T, Proot I, Meulen Rt, Witte L. Recognition of client values as a basis for tailored care: the view of Dutch expert patients and family caregivers. *Scand J Caring Sci* 2005; 19: 169-76.
40. Nygårdh A, Malm D, Wikby K, Ahlström G. The experience of empowerment in the patient-staff encounter: the patient's perspective. *J Clin Nurs* 2012; 21: 897 - 904.
41. Rise MB, Solbjør M, Lara MC, Westerlund H, Grimstad H, Steinsbekk A. Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expect* 2013; 16: 266-76.
42. Sainio C, Lauri S, Eriksson E. Cancer patients' views and experiences of participation in care and decision making. *Nurs Ethics* 2001; 8: 97-113.
43. Jeffs L, Beswick S, Acott A, Simpson E, Cardoso R, Campbell H, et al. Patients' views on bedside nursing handover: creating a space to connect. *J Nurs Care Qual* 2014; 29: 149-54.
44. Sahlström M, Partanen P, Turunen H. Safety as experienced by patients themselves: a Finnish survey of the most recent period of care. *Res Nurs Health* 2014; 37: 194-203.
45. Davis RE, Koutantji M, Vincent CA. How willing are patients to question healthcare staff on issues related to the quality and safety of their healthcare? An exploratory study. *Qual Saf Health Care* 2008; 17: 90-6.
46. Eldh AC, Ehnfors M, Ekman I. Considering patient non-participation in health care. *Health Expect* 2008; 11: 263-71.
47. Tobiano G, Chaboyer W, McMurray A. Family members' perceptions of the nursing bedside handover. *J Clin Nurs* 2013; 22: 192-200.
48. Chaboyer W, Blake S. Information sharing, knowledge transfer and patient safety. *Nurs Crit Care* 2008; 13: 121-3.
49. Eldh AC, Ehnfors M, Ekman I. The phenomena of participation and non-participation in health care-experiences of patients attending a nurse-led clinic for chronic heart failure. *Eur J Cardiovasc Nurs* 2004; 3: 239-46.
50. St John W, Keleher H. *Community Nursing Practice: Theory, Skills and Issues*. 2007, Allen & Unwin, Crows Nest, NSW.
51. Larsson IE, Sahlsten MJM, Segesten K, Plos KAE. Patients' perceptions of nurses' behaviour that influence patient participation in nursing care: a critical incident study. *Nursing Research and Practice* 2011; 2011: 1-8.
52. Eldh A, Ehnfors M, Ekman I. The meaning of patient participation for patients and nurses at a nurse-led clinic for chronic heart failure. *Eur J Cardiovasc Nurs* 2006; 5: 45.
53. Tariq Saleem JA, Carlström E, Ekman I, Jarneborn A, Olsson L. Experiences of person-centred care - patients' perceptions: qualitative study. *BMC Nursing* 2014; 13.
54. Bolster D, Manias E. Person-centred interactions between nurses and patients during medication activities in an acute hospital setting: qualitative observation and interview study. *Int J Nurs Stud* 2010; 47: 154-65.
55. Schwappach D. "Against the silence": development and first results of a patient survey to assess experiences of safety-related events in hospital. *BMC Health Serv Res* 2008; 8: 59-67.
56. Schwappach D, Wernli M. Am I (un)safe here? Chemotherapy patients' perspectives towards engaging in their safety. *Qual Saf Health Care* 2010; 19: e9.
57. Entwistle VA, McCaughan D, Watt IS, Birks Y, Hall J, Peat M, et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Qual Saf Health Care* 2010; 19: 1-7.
58. Schwappach D, Wernli M. Predictors of chemotherapy patients' intentions to engage in medical error prevention. *Oncologist* 2010; 15: 903-12.

59. Penney W, Wellard SJ. Hearing what older consumers say about participation in their care. *Int J Nurs Pract* 2007; 13: 61-8.
60. Soleimani M, Rafii F, Seyedfatemi N. Participation of patients with chronic illness in nursing care: an Iranian perspective. *Nurs Health Sci* 2010; 12: 345-51.
61. Huby G, Stewart J, Tierney A, Rogers W. Planning older people's discharge from acute hospital care: linking risk management and patient participation in decision-making. *Health, Risk & Society* 2004; 6: 115-32.
62. Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014; 94: 291-309.
63. Henderson S. Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *J Clin Nurs* 2003; 12: 501-8.
64. Shattell M. Nurse bait: strategies hospitalized patients use to entice nurses within the context of the interpersonal relationship. *Issues Ment Health Nurs* 2005; 26: 205-23.
65. Hallström I, Elander G. Needs During Hospitalization: definitions and descriptions made by patients. *Nurs Ethics* 2001; 8: 409-18.
66. Barrere CC. Discourse analysis of nurse-patient communication in a hospital setting: implications for staff development. *J Nurses Staff Dev* 2007; 23: 114-22.
67. Latimer S, Chaboyer W, Gillespie B. Patient participation in pressure injury prevention: giving patient's a voice. *Scand J Caring Sci* 2013; 28: 648-56.
68. Wellard S, Lillibridge J, Beanland C, Lewis M. Consumer participation in acute care settings: an Australian experience. *Int J Nurs Pract* 2003; 9: 255-60.
69. Iedema R, Allen S, Britton K, Gallagher TH. What do patients and relatives know about problems and failures in care? *BMJ Quality and Safety* 2011; 21: 198-205.
70. Casey D. Findings from non-participant observational data concerning health promoting nursing practice in the acute hospital setting focusing on generalist nurses. *J Clin Nurs* 2007; 16: 580-92.
71. Florin J, Ehrenberg A, Ehnfors M. Patient participation in clinical decision-making in nursing: a comparative study of nurses' and patients' perceptions. *J Clin Nurs* 2006; 15: 1498-508.
72. Foss C. Elders and patient participation revisited - a discourse analytic approach to older persons' reflections on patient participation. *J Clin Nurs* 2011; 20: 2014-22.
73. Scott J, Dawson P, Jones D. Do older patients' perceptions of safety highlight barriers that could make their care safer during organisational care transfers? *BMJ Quality & Safety Online* 2011; 21: 112-7.
74. Schwappach DLB, Frank O, Hochreutener M. 'New perspectives on well-known issues': patients' experiences and perceptions of safety in Swiss hospitals. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen (German Journal for Quality in Health Care)* 2011; 105: 542-8. [In English].
75. Davis RE, Anderson O, Vincent C, Miles K, Sevdalis N. Predictors of hospitalized patients' intentions to prevent healthcare harm: a cross sectional survey. *Int J Nurs Stud* 2012; 49: 407-15.
76. Strandberg G, Norberg A, Jansson L. An exemplar of a positive perspective of being dependent on care. *Sch Inq Nurs Pract* 2000; 14: 327-46.
77. Strandberg G, Norberg A, Jansson L. Being overwhelmed by the feeling of having a home and family. One aspect of the meaning of being dependent on care: a study of one patient and two of his nurses. *J Adv Nurs* 2001; 35: 717-27.
78. Tutton EMM. Patient participation on a ward for frail older people. *J Adv Nurs* 2005; 50: 143-52.



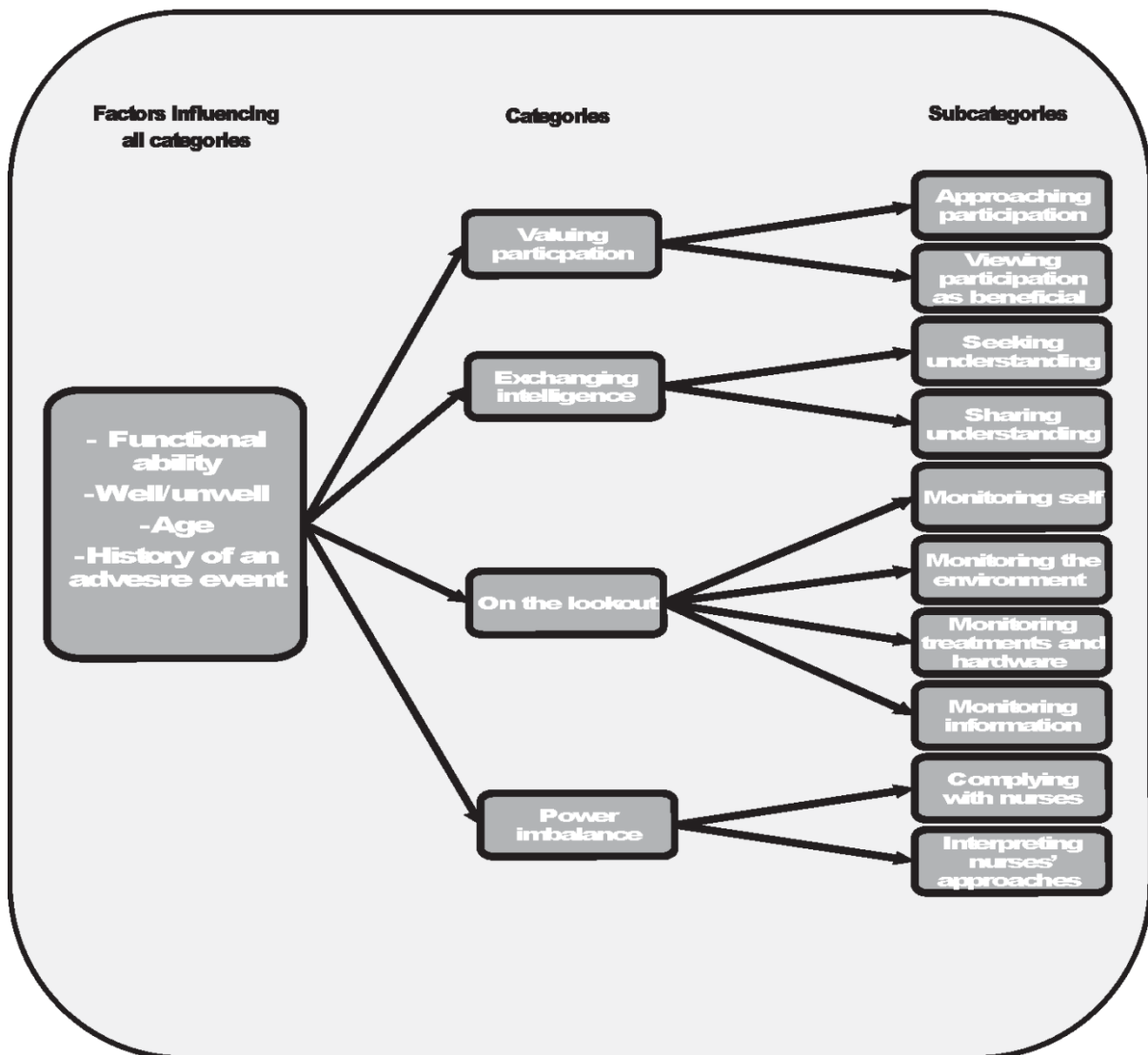
79. Strandberg G, Norberg A, Jansson L. Meaning of dependency on care as narrated by 10 patients. *Res Theory Nurs Pract* 2003; 17: 65-84.
80. Lepage A, Gzil F, Cammelli M, Lefevre C, Pachoud B, Ville I. Person-centredness: conceptual and historical perspectives. *Disabil Rehabil* 2007; 29: 1555-65.
81. Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process* 1991; 50: 179-211.
82. Ajzen I. Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior. *Journal of Applied Social Psychology* 2002; 32: 665-83.
83. Vaismoradi M, Jordan S, Kangasniemi M. Patient participation in patient safety and nursing input – a systematic review. *J Clin Nurs* 2014.
84. Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol* 2012; 65: 1041-51.
85. Mayer DK. How do we encourage patient engagement? *Clin J Oncol Nurs* 2014; 18: 487-8.
86. Pelletier LR, Stichler JF. Action brief: patient engagement and activation: a health reform imperative and improvement opportunity for nursing. *Nurs Outlook* 2013; 61: 51-4.
87. Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: polysemy or cacophony? *Patient Educ Couns* 2007; 66: 13-20.
88. McCormack B, McCance TV. Development of a framework for person-centred nursing. *J Adv Nurs* 2006; 56: 472-9.

## TABLES AND FIGURES

Table 1 Demographic data of participants

Patient	Hospital	Gender	Age	Hospital admissions last 6 months	Required assistance mobilising	Required mobility aids	Previous experience of adverse event
P1	Public	F	32	1	No	No	No
P2	Private	F	43	2	No	Yes	No
P3	Public	M	80	3	No	Yes	No
P4	Public	F	52	3	No	No	Yes
P5	Public	M	30	1	No	No	Yes
P6	Public	M	66	2	Yes	Yes	No
P7	Private	F	87	1	No	No	No
P8	Public	M	40	3	No	Yes	Yes
P9	Private	M	47	2	Yes	Yes	Yes
P10	Private	F	78	3	Yes	Yes	No
P11	Private	F	35	4	Yes	Yes	No
P12	Public	F	31	2	No	No	No
P13	Public	M	54	1	Yes	Yes	No
P14	Private	M	78	1	No	No	No
P15	Private	F	84	3	Yes	Yes	Yes
P16	Public	F	80	2	No	Yes	Yes
P17	Private	F	86	1	Yes	Yes	Yes
P18	Private	F	92	2	No	No	No
P19	Public	F	60	7	No	No	No
P20	Private	M	89	1	Yes	Yes	No

Figure 1 Patients' perceptions of participation in nursing care



(EPS hardcopy available).

Table 2 Recommendations for nurses

<b>Practice recommendations</b>	<b>Education recommendations</b>
<ul style="list-style-type: none"><li>- Facilitate patient knowledge</li><li>- Undertake two-way knowledge transfers</li><li>- Help motivate patients to participate in care</li><li>- Undertake goal setting with patients</li><li>- Encourage patients to monitor practice</li></ul>	<ul style="list-style-type: none"><li>- Enhance own understanding of patient-centred care practices</li><li>- Enhance own interpersonal skills</li><li>- Educate patients about the consequences of non-participation</li></ul>