

**Evidence Check**

# Patients' experiences in Australian hospitals

An **Evidence Check** rapid review brokered by the Sax Institute for the Australian Commission on Safety and Quality in Health Care.  
December 2015.

**This report was prepared by:**

Reema Harrison, Merrilyn Walton, Elizabeth Manias

December 2015  
© Sax Institute 2015

This work is copyright. It may be reproduced in whole or in part for study training purposes subject to the inclusions of an acknowledgement of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above requires written permission from the copyright owners.

**Enquiries regarding this report may be directed to the:**

Head  
Knowledge Exchange Program  
Sax Institute  
[www.saxinstitute.org.au](http://www.saxinstitute.org.au)  
[knowledge.exchange@saxinstitute.org.au](mailto:knowledge.exchange@saxinstitute.org.au)  
Phone: +61 2 91889500

**Suggested Citation:**

Harrison R, Walton M, Manias E. Patients' experiences in Australian hospitals: an Evidence Check rapid review brokered by the Sax Institute ([www.saxinstitute.org.au](http://www.saxinstitute.org.au)) for the Australian Commission on Safety and Quality in Health Care, 2015.

**Disclaimer:**

This **Evidence Check Review** was produced using the Evidence Check methodology in response to specific questions from the commissioning agency.

It is not necessarily a comprehensive review of all literature relating to the topic area. It was current at the time of production (but not necessarily at the time of publication). It is reproduced for general information and third parties rely upon it at their own risk.

# Patients' experiences in Australian hospitals: a rapid review of evidence

An **Evidence Check** rapid review brokered by the Sax Institute for the Australian Commission on Safety and Quality in Health Care.  
December 2015.

This report was prepared by Reema Harrison, Merrilyn Walton, Elizabeth Manias

# Contents

1	Abstract.....	1
	Background.....	1
	Method.....	1
	Results.....	1
	Conclusion.....	1
2	Introduction.....	2
	Aim.....	3
	Objectives.....	3
3	Methods.....	4
	Eligibility criteria.....	4
	Inclusion criteria.....	4
	Exclusion criteria.....	4
	Study identification.....	4
	Electronic databases.....	4
	Grey material.....	5
	Study selection and data extraction.....	5
	Data synthesis.....	5
	Data appraisal.....	5
4	Results.....	6
	Results of the search.....	6
	Figure 1: Flow diagram of selection process.....	6
	Excluded studies.....	7
	Characteristics of included studies.....	7
	Table 1: Summary of included studies (n=39).....	8
	Study quality.....	22
	Review findings.....	22
	Table 2: Research traditions that have covered the Australian patient experience qualitatively.....	23
	Table 3: Themes and subthemes.....	25

Key characteristics of positive or negative patient experiences in hospital or day procedure services in Australia.....	26
1. Reciprocal communication and information sharing.....	26
2. Interpersonal skills and professionalism.....	27
3. The care environment.....	27
4. Correct treatment and physical outcomes.....	27
5. Emotional support.....	27
6. Comfort, pain and clinical care.....	28
7. Discharge planning and processes.....	28
System- or service-related factors that contribute to positive or negative experiences.....	28
Table 4: System and service factors contributing to patients' experiences.....	29
Figure 2: Concept map of contributors to a positive patient care experience.....	30
Positive or negative experiences associated with particular patient groups.....	31
Table 5: Patient experiences in specific patient groups.....	31
5 Discussion.....	33
Implications and further research.....	33
Limitations.....	34
6 Conclusion.....	35
7 References.....	36
8 Appendices.....	42
Supplementary file 1: Database search strategy (Medline example).....	42
Supplementary file 2: Search strategy (grey material).....	43



# 1 Abstract

## Background

Patients are uniquely positioned to provide insightful comments about their care. Currently, a lack of comparable patient experience data prevents the emergence of a detailed picture of patients' experiences in Australian hospitals. This review addresses this gap by identifying factors reported in primary research as relating to positive and negative experiences of patients in Australian hospitals.

## Method

We conducted a synthesis of evidence from qualitative studies of patients' reported experiences in hospital and day procedure centres. A range of text words, synonyms and subject headings were developed and used to undertake a systematic search of seven electronic databases dating from January 1995 to July 2015 and the grey literature. Two reviewers independently screened the titles, abstracts or executive summaries and applied the inclusion criteria. Data were synthesised in a meta-narrative.

## Results

Thirty-nine publications were included; 33 articles from database searches and six from the grey literature. Quality improvement researchers produced the dominant narrative and there was a strong nursing perspective. Seven themes emerged: 'The care environment', 'Reciprocal communication and information sharing', 'Correct treatment and physical outcomes', 'Emotional support', 'Comfort, pain and clinical care', 'Interpersonal skills and professionalism', and 'Discharge planning and process'.

## Conclusion

Tangible opportunities to enhance the patient experience are apparent. Small changes to the way that the health system operates, is resourced, and the way that health professionals engage with patients could substantially improve care. Examples include inviting patients and carers to contribute to decision making and discussions about treatment options and care preferences.

## 2 Introduction

Acknowledging and utilising patients' experiences of their care is critical to providing and improving health care.<sup>1</sup> Patient experience has been identified as a core component of an optimal health system, along with improving the health of populations and reducing the per capita costs of care.<sup>2</sup> Patients are uniquely positioned to provide insightful comments about their care and healthcare management. Furthermore, they are the only common link between healthcare services and care processes by which to document the overall care experience. Patient experience data can therefore inform healthcare providers of problems in the care process, which could involve the coordination of care, the care environment or the provision of treatment.<sup>3</sup> Patients' "*direct experience of [the] care process through clinical encounters or as an observer*" (p. 2) has been associated with improved clinical effectiveness and patient safety.<sup>3</sup> For example, a good patient experience has contributed to medication adherence, appropriate use of screening services and reduced use of healthcare resources.<sup>3</sup>

Incorporation of the patient experience ensures that healthcare provision is responsive to the preferences, needs and values of each patient.<sup>4,5</sup> In Australia, the National Safety and Quality Health Service Standards require "*the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services*".<sup>6</sup> The routine integration of patient experience data into health systems assessment and evaluations is one of the first steps towards patient-centred care.<sup>7</sup> Patient experience data can be used to constantly adapt and refine services and processes to better meet patients' needs. These data can also provide insight into the extent to which patient-centred care is achieved from an individual patient's perspective.

Capturing patients' experiences is challenging.<sup>8-13</sup> Patient satisfaction surveys are often used to provide an indication of patients' experiences.<sup>14</sup> Yet, patient satisfaction surveys often contain questions that fail to portray accurately the nature of the care experience. Such surveys often ask patients about their feelings rather than about what actually happened to them during their care; thereby missing an opportunity to identify the factors that might contribute to a positive or negative care experience.<sup>15-18</sup> Patient satisfaction is a judgement of whether patients' expectations were met, which can be influenced by a range of factors. These may vary widely between different patients in an identical set of circumstances. Patients are often forgiving of healthcare providers due to providers' competing responsibilities and the high-intensity work environment.<sup>19</sup> They may therefore report high levels of satisfaction even in instances of a negative care experience and vice versa depending on their expectations and perceptions of the care process.<sup>20</sup> In addition, patient satisfaction data have not been shown to lead to improvements in care quality.<sup>21</sup> Service improvement activities are contingent upon specific data about the nature of events that identify areas for change. Such data are not captured through satisfaction ratings and can only be obtained via patient experience data.<sup>22</sup>

Patient experience surveys are used across Australia, but the content and the ways in which these surveys are administered vary between different jurisdictions, and across various types of hospitals.<sup>6,16,23,24</sup> Currently, a lack of comparable data from hospital and day procedure patients prevents a national picture of patients' experiences emerging. This review focuses only on qualitative primary research studies, as it is this type of research that facilitates freedom of patient expression of their experiences. As far as we are aware, it is the

first review to assess primary qualitative research with patients about their experiences in Australian health care.

### **Aim**

To identify primary qualitative Australian studies of patients' experiences in hospital and in day procedure services from published and grey literature.

### **Objectives**

1. To determine the key characteristics of positive and negative patient experiences in hospital or day procedure services in Australia.
2. To identify the system or service related factors that patients have identified as contributing to their positive and/or negative experiences.
3. To establish whether the positive and/or negative experiences of patients are associated with particular backgrounds or patient characteristics.

# 3 Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses – PRISMA statement – was used to guide the reporting of this rapid review.<sup>25</sup> The PRISMA statement is an evidence-based approach for reporting systematic reviews and meta-analyses.

## Eligibility criteria

### Inclusion criteria

- **Types of publication:** Publications available in English are eligible, which reported original primary data published from January 1995 when the 'Quality in Australian Health Care Study' was published in the Medical Journal of Australia, to July 2015.<sup>26</sup>
- **Types of participants:** Patients who were hospitalised overnight or as a day admission in an Australian hospital or day procedure centre. Day procedures could include, but were not limited to: surgical procedures with same-day discharge, diagnostic procedures (e.g. biopsy, endoscopy, colonoscopy), cardiology/heart procedures (e.g. stent/cardiac catheterisation), oncology/cancer interventions (e.g. radiotherapy, chemotherapy), renal dialysis, blood products/blood transfusion, in vitro fertilisation (IVF), and gynaecological procedures.
- **Types of study design:** Qualitative studies using semi-structured interviews, focus groups or other discursive methods that used narrative data.
- **Outcomes:** Patient-reported qualitative data of their hospital experience. Patient experience was defined as what actually 'happens' during the care process.<sup>1</sup>

### Exclusion criteria

Articles were excluded if they did not meet the inclusion criteria. Literature assessing patients' experiences using hypothetical vignettes or scenarios rather than actual experience was also excluded. Studies that primarily focused on patients' complaints were excluded because of their breadth and lack of sole focus on the care experience.

## Study identification

### Electronic databases

A range of text words, synonyms and subject headings were developed for the three major concepts in this review of 'patient experience', 'qualitative studies' and 'Australian hospital settings'. These phrases were used to undertake a systematic search of seven electronic databases from January 1995 to July 2015 (see [Supplementary file 1](#)). Databases searched were: MEDLINE, JSTOR, PsycINFO, CINAHL, PubMed, Informit and Joanna Briggs Database of Systematic Reviews and Implementation Reports. Hand searching of relevant journals (BMJ Quality and Safety, Health Expectations, International Journal of Quality in Health Care, Patient Experience Journal) and reference lists of published papers ensured that all relevant published material was captured. Results were merged using reference-management software (Endnote) and duplicates removed.

## Grey material

Qualitative studies reported in the grey literature (e.g. reports and papers published by government departments, public or private health service providers, non-government agencies, consumer organisations, professional bodies, advocacy groups etc.) were identified by searching the websites of relevant organisations (see [Supplementary file 2](#) for a list of the organisations included). Literature identified was assessed along with the papers from the database searches.

## Study selection and data extraction

Two reviewers (SM, RH) independently screened the titles and abstracts (or executive summaries for grey literature). Copies of full articles were obtained for those that were potentially relevant. Inclusion criteria were then independently applied to the full text articles by the two reviewers. Disagreements were resolved by consensus or consultation with a third reviewer (MW or EM). The following data were extracted from eligible literature: author(s), publication year, sample, setting, design, primary focus and main findings.

## Data synthesis

Data were synthesised in a meta-narrative.<sup>27</sup> This method was selected because of its relevance to the review objectives. Using a meta-narrative allows researchers to synthesise data from a range of disciplines to identify the key storylines in each area and to build up a rich data synthesis demonstrating the commonalities and differences between findings from each study and discipline. The meta-narrative analysis was undertaken in a series of six phases: planning, search, mapping, appraisal, synthesis and recommendations. Following these phases, eligible studies were reviewed and the research traditions and academic disciplines identified by one reviewer (RH), who also explored the conceptualisation of 'patient experience' by each tradition. Two members of the research team (MW, EM) identified key elements of the research and main findings and tabulated these elements. The studies were then subjected to an appraisal process before a narrative synthesis of the findings was produced.

## Data appraisal

The fourth phase of the meta-narrative process involved an assessment using the Critical Appraisal Skills Programme's (CASP's) items for qualitative research to indicate the validity of each publication and relevance to the review questions.<sup>28</sup> Studies were assessed against 10 items and scored 'Yes', 'No', or 'Can't tell' for each item.

# 4 Results

## Results of the search

After removing duplicates, 1124 records were identified. Title and abstract screening resulted in 76 references that fulfilled the inclusion criteria and copies of the full publications were obtained. A total of 39 publications were included in the review; 33 articles were identified as eligible from the full text review and six studies were identified from the grey literature ([Figure 1](#)).

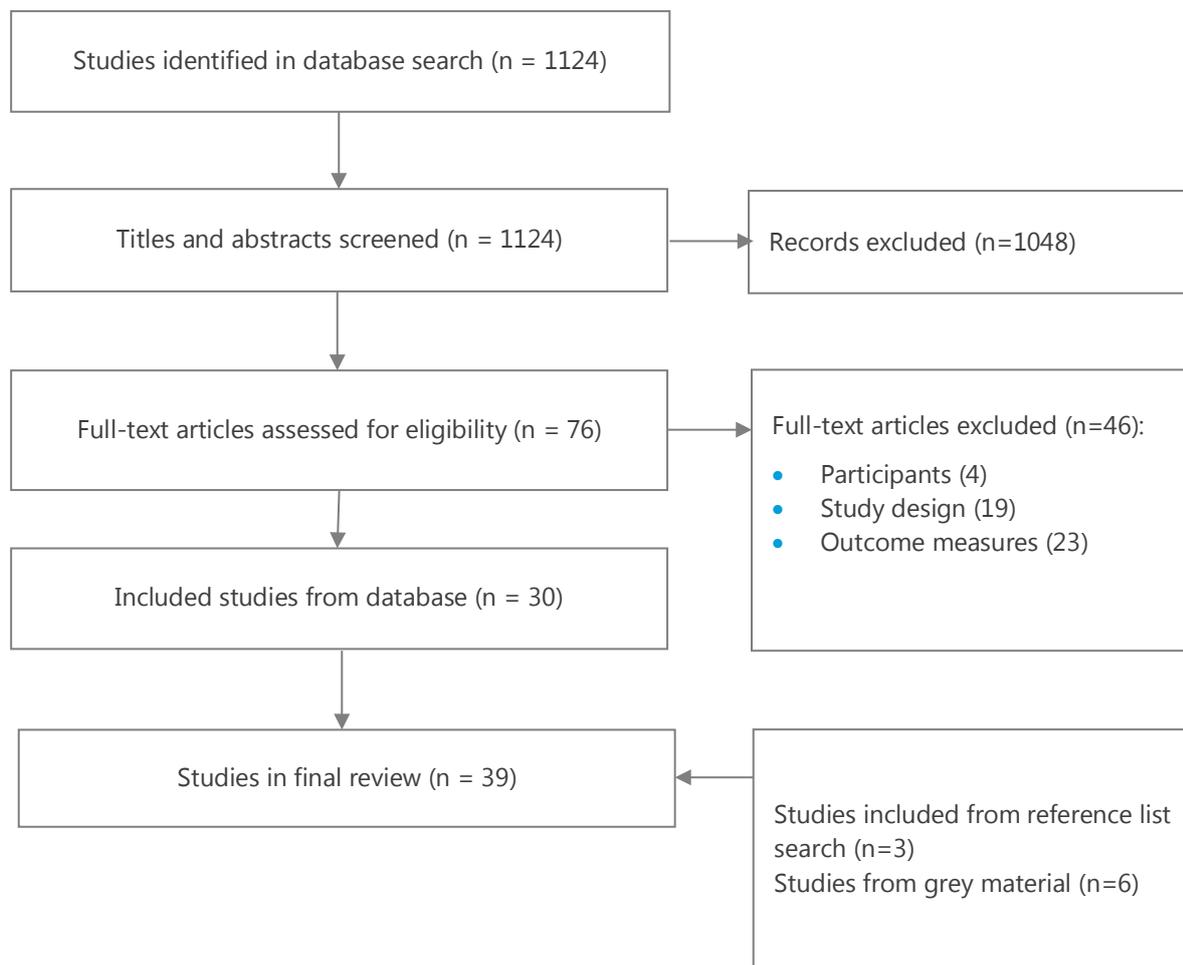


Figure 1: Flow diagram of selection process

## Excluded studies

Of the 22 papers retrieved from grey literature searching and contact made with 32 organisations, 12 were excluded; six because they did not report primary qualitative data and six because the data reported were about the needs or opinions of particular patients or patient groups about health care in general as opposed to their actual hospital experiences. A further paper was excluded due to a focus on primary care and another due to focus on patient experience data collection methods (see [Figure 1](#) for reasons for exclusion of database articles).

## Characteristics of included studies

Thirty-nine publications reported 34 unique datasets. Sample sizes ranged from one to 300 participants. Smaller sample sizes were typically used in interviews and focus group studies, and the largest studies used surveys that included open-ended items. Samples included hospital inpatients (27), hospital day case patients (4), or both hospital in- and day-patients (8). Samples were identified through the healthcare system (31), community networks (2) or were self-selected/volunteers (6). Thirty-eight studies were cross-sectional, with one taking place over a four-month period. Patient experience data were gathered using semi-structured interviews (19) surveys (3), focus groups (2), written narratives (2), or a combination of observations, interviews and/or focus groups (13). Papers focused on the following patient groups: inpatients (16), surgical patients (5), culturally and linguistically diverse patients (3), cancer patients (3), parents of child patients (2), patients with comorbidities (2), rural patients (2), adolescents (1), child patients (1), maternity (1), rehabilitation (1), brain injury (1) and chronic illness (1). See [Table 1](#) for a summary of the included publications.

Table 1: Summary of included studies (n=39)

First author	Date	Method	Analysis	Sample	Objective	Main findings	Search
Bradley, S <sup>29</sup>	2013	Ethnographic interviewing	Taxonomic	9 self-selected patients	To empirically study the process and outcomes of the implementation of nurse-to-nurse bedside handover	<p>Patients preferred bedside handovers rather than traditional closed-door office handovers</p> <p>Bedside handovers incorporate social aspects for the patient and they subsequently feel more involved in their care</p>	Database
Brough, C <sup>30</sup>	2006	Focus group and individual semi-structured interviews	Thematic	86 people from 4 non-English backgrounds recruited through formal and informal networks within each community	To determine consumer experiences on the effectiveness of language service provision, specifically interpreters, in health settings	<p>Patients were often forced to communicate via family members or to get by without assistance</p> <p>The current level and standard of language service provision appeared to compromise the effectiveness and quality of the care received</p> <p>'Inappropriate' use of interpreters of the opposite gender and the need for more access to interpreters noted</p>	Grey
De, S <sup>31</sup>	2014	Semi structured face-to-face interviews	Thematic	36 parents of 27 children < 3 months old	To describe the perspectives of parents of young infants presenting to hospital with fever	Parents of febrile infants expected reassurance and support from hospital staff but experienced a sense of relinquished control, inadequacy and guilt	Database

De Jesus, G <sup>32</sup>	1996	Semi-structured survey	Thematic	148 completed surveys of same-day surgery patients	To determine if clinical outcomes are influenced by the specific information needs and expectations of same-day surgery patients	Information delivery was a principal factor influencing clinical outcomes and patient satisfaction  Accurate and timely information provision is crucial during the pre- and post- operative periods	Database
Edwards, K <sup>19</sup>	2014	Semi-structured interviews	Thematic	1 patient, 1 family member, 8 health staff	To explore the perceptions of one patient's hospital experience, identifying what mattered to the patient and family, and whether the healthcare providers were aware of what mattered	Medication management, physical comfort and emotional security mattered most to patients  Healthcare providers were not always aware of what mattered to the patient and family during their hospital admission	Database
Ford, K <sup>33</sup>	2011	Several data collection techniques including interviews, drawings and stories	Constructivist grounded theory	10 children between the ages of 6 and 12	To study views and experiences of admission to hospital for surgery among children	Therapeutic interventions such as humour, fun and play created an enjoyable care experience, and alleviated anxiety and fear often experienced by children admitted for surgery	Database

Garrett, P <sup>34</sup>	2008	Language-specific focus groups	Grounded theory	49 patients and 10 carers from non-English speaking backgrounds	To better understand the experience and to identify critical factors leading to their constructions of care for non-English speaking patients	Recognition of patients' powerlessness, rights, familial roles, language ability, religious and spiritual beliefs, socioeconomic status, and gender, contributed to experiences of care and the construction of illness among non-English speaking patients	Database
Henderson, A <sup>35</sup>	2009	Observation of patient-staff interactions; patient interviews	Thematic	15 men and 24 women with a broad range of medical and surgical conditions	To identify potential threats to patient dignity and ascertain patients' perceptions about, if and how, dignity was maintained	<p>Patients' dignity and privacy were maintained during care provision</p> <p>Patients may be accepting of considerable deviations in care provision if they perceive the organisation is working in their best interests</p>	Database
Henderson, A <sup>36</sup>	2004	Semi-structured, face-to-face, and telephone interviews	Thematic	20 elective surgery, 14 males and 6 females, patients	To explore what hospitalised patients considered important for patient satisfaction to exist	<p>Several factors were identified as important to patients to make their hospital stay satisfactory, demonstrated via 16 themes</p> <p>The themes of 'medical outcomes', 'clinical outcomes', and 'professionalism and competency of staff' were the most consistently identified</p>	Database

Iedema, R <sup>37</sup>	2008a	Semi-structured interviews	Discourse analysis identifying overarching themes	23 patients involved in adverse events and incident disclosure	To explore patients' and family members' perceptions of Open Disclosure of adverse events that occurred during their health care	Health service incident disclosure rarely met needs and expectations  A combination of formal Open Disclosure, a full apology, an offer of tangible support and evidence of practice improvement has a higher chance of gaining consumer satisfaction than if one or more of these components is absent	Database
Iedema, R <sup>38</sup>	2008b	Semi-structured interviews	Discourse analysis identifying overarching themes	131 self-selected clinical staff and 23 patients and family members	To determine which aspects of Open Disclosure 'work' for patients and healthcare staff based on an evaluation of the National Open Disclosure Pilot	Patients and staff overwhelmingly supported the use of an Open Disclosure process as an information sharing strategy after an adverse event  The process was considered useful as a way to be briefed about the incident and its management in an ongoing process  Healthcare professionals must consider the patient or family perception of the severity of an event and not just the health system definition	Database

Iedema, R <sup>39</sup>	2008c	Interviews with patients and carers, complaints data, root cause analysis data, staff stories and observation	Thematic	76 patients and 109 emergency staff across 3 sites	To engage frontline staff, patients and carers in identifying the best and worst aspects of their experience, and to co-design solutions	Consistent themes identified were: gratitude for the care provided, frustration with lack of parking and discomfort in the waiting room, lack of information and communication, patients being separated from carers and being treated with a lack of respect and courtesy	Grey
Iedema, R <sup>40</sup>	2011	Semi-structured, in-depth interviews	Discourse analysis identifying overarching themes	39 patients and 80 family members who were involved in high severity healthcare incidents	To investigate patients' and family members' perceptions and experiences of disclosure of healthcare incidents and to derive principles of effective disclosure	Respondents expected better preparation for open disclosure, more two-way communication about what went wrong in their care, more follow-up support, to be consulted about the timing of a disclosure and more information about actions taken as a result of the incident	Database
Johnson, A <sup>41</sup>	2005	Semi-structured survey	Thematic	19 long stay patients with a length of stay between 14 and 30 days	To determine the perspectives of patients categorised as long-stay outliers about aspects of organisation of care and the perceived impact of their long-term hospitalisation	Long-stay patients required staff to be more family- and patient-centred when preparing for discharge  Limited or lack of involvement of participants in decision making; lack of knowledge about anticipated length of stay; and lack of early involvement of participants and their families in discharge planning were reported	Database

Lobb, E <sup>42</sup>	2011	Semi-structured face-to-face interviews	Grounded theory	Purposive sampling was used to recruit 19 patients and 21 caregivers	To describe the experience of the initial communication for patients and caregivers of being diagnosed with high-grade glioma and subsequent prognosis	Themes identified by patients and carers: (a) shock at hearing the diagnosis; (b) trying to understand and process prognostic information when still in shock; (c) the perception of hope being taken away; (d) individualising prognostic information; and (e) clinicians' lack of communication skills	Database
Manias, E <sup>43</sup>	2004	Semi-structured interviews	Framework analysis	10 chronically ill adult patients who had experienced multiple hospital admissions	To determine patients' perspectives about self-medication in the acute care setting	Participants indicated that the opportunity to self-administer medication would leave nurses with more time to attend to their other clinical duties, while providing them greater autonomy  Nurses' perception of medication management as their domain was identified as a key barrier to self-administration	Database
Markovic, M <sup>44</sup>	2004	Observations and semi-structured interviews	Thematic	10 women from different socio-economic backgrounds who had undergone a range of different surgical procedures	To explore anxiety in the context of day surgery and identify the issues pertinent to the experiences of day surgery patients	Day surgery-related anxiety was exacerbated by having to walk to the theatre and being separated from their carer	Database

Marshall, A <sup>45</sup>	2004	Semi-structured interviews	Thematic, phenomenological	10 patients (8 women and 2 men) aged 18 and over and expected to be discharged within the next 2 days	To explore patients' understanding and conceptualisation of patient-centred care	<p>Patients equated the type and quality of care they received with the staff that provided it; themes of connectedness, involvement and attentiveness were prevalent in their descriptions of what they wanted from their care</p> <p>Subthemes identified were: (1) resources (including workload and the physical environment); (2) culture; and (3) waiting</p>	Database
Montgomery, K <sup>46</sup>	2012	Semi-structured interviews	Interpretative phenomenological	10 patients undergoing aggressive inpatient cancer therapy (undergoing autologous stem-cell transplantation) and their caregivers	To gain deeper insights into patients' experiences during aggressive cancer therapy and to suggest how these insights can be applied to models of patient-centred care	<p>Patients understood that they could neither battle the cancer nor undertake the therapy on their own</p> <p>Patients were frustrated by the limited opportunities to engage in their care</p>	Database

O'Callaghan, A <sup>47</sup>	2011	Semi-structured survey	Thematic	202 patients, of working age, admitted for acute care following a moderate to severe traumatic brain injury (TBI)	To investigate the continuum of care experienced by adults and their significant others following a moderate to severe TBI	Very few participants report receiving services in line with recommendations made in clinical care guidelines  Access to services varied according to individual's healthcare funding and a lack of services were available on discharge	Database
Olver, I <sup>48</sup>	2010	Unstructured journal writing	Thematic	38 patients (22 women, 16 men)	To obtain patients' experiences of the cancer treatment pathway to enable healthcare professionals to be educated on how to improve patient care	Patients experienced a wide range of emotional reactions to their care and felt more positive when given opportunities to be involved  The treatment environment, including personnel was considered important to the care experience	Database
Peiris, W <sup>49</sup>	2012	Semi-structured interviews	Thematic	19 adults undergoing inpatient rehabilitation for neurological and musculoskeletal impairments	How do patients receiving inpatient rehabilitation experience physiotherapy and does their experience differ if they receive extra Saturday physiotherapy	Patients valued interacting with physiotherapists and other patients  The patient-therapist interaction was more important to the patient than the amount or content of their physiotherapy	Database

Penney, W <sup>50</sup>	2007	Participant observation and semi-structured interviews	Thematic	36 patients aged 70 and over and 31 nurses caring for them	To explore the participation of older people in their care in acute hospital settings and to explore their views of participation	Older people equated participation in their own care with being independent  The difficulties in communicating with health professionals and an inability to administer their own medications in inpatient settings were described as barriers to participation	Database
Piper, D <sup>51</sup>	2010	Patient and family interviews, surveys and observation	Thematic	219 patients and 378 staff across 4 sites	To engage patients, their families and staff in identifying the positive and negative aspects of their experience of two hospital departments	Aspects of the experience were consistently identified as problematic: inadequate communication between staff, patients and carers, uncomfortable waiting facilities, lack of provision of information, lack of privacy and poor communication between departments	Grey
Piper, D <sup>52</sup>	2014	Semi-structured interviews	Discourse analysis identifying overarching themes	13 participants from the '100 Patient Stories' study	To analyse rural patients' and their families' experiences of Open Disclosure and offer recommendations to improve disclosure in rural areas	Rural patients expected better preparation for disclosure, more shared dialogue about what went wrong, more follow-up support, input into when the time was right for disclosure and more information about subsequent improvement processes  A formal open disclosure meeting following an adverse event was desired  Patients reported the impact of social familiarity on the Open Disclosure process in rural areas	Database

Roden, J <sup>53</sup>	2005	Semi-structured interviews	Thematic	14 parents of ill children	To understand perceptions of parent participation in their child's care	Good communication was identified as key to effective relationships between parents and staff	Database
Schembri, S <sup>54</sup>	2013	Written patient stories	Thematic	300 self-selected patients	To provide a perspective of healthcare experience through the patients' eyes	Three themes of positive experiences were: (1) attentive and considerate service; (2) effective treatment; and (3) timely service  Three themes of negative experiences were: (1) ongoing problems; (2) service failure stories; and (3) slow and unresponsive service	Grey
Sharp, R <sup>55</sup>	2014	Semi-structured telephone interviews	Thematic	10 patients selected while they waited for Peripherally Inserted Central Catheter (PICC) insertion	To investigate the patient experience of PICC insertion, the significance of arm choice and the impact of the device on activities of daily living	Those with no previous experience of a PICC described the information given by medical staff as minimal, technical and difficult to understand, leading to a poorer care experience	Database

Stevens, J <sup>56</sup>	2001	Semi-structured interviews	Thematic	16 women aged between 26 and 42 undergoing laparoscopic sterilisation	To build theory about the day surgery experience by examining the perceptions of a group of women undergoing the same procedure: laparoscopic sterilisation	<p>Anxiety in the pre-operative period and lack of privacy in the pre- and post-operative periods were considerable concerns</p> <p>Pre-operatively this led to patients not discussing their concerns or condition with nursing staff</p> <p>Post-operatively this meant that patients were uncomfortable whilst they were experiencing pain, nausea and vomiting</p>	Database
VIC Health <sup>57</sup>	2005	Focus groups	Thematic	38 women and 5 men from the local community	To gain an understanding of the cultural aspects of childbearing that are important to Bangladeshi women and their families	<p>Adaptations to make a more culturally appropriate care environment were considered important such as a space for daily prayers and space for family gatherings if required</p> <p>The lack of availability of translators was also noted</p>	Grey
WA health <sup>58</sup>	2015	Semi-structured interviews and focus groups	None	6 patients	None provided	<p>Patients valued being treated as an individual in addition to good interpersonal skills and communication from staff</p> <p>Some experienced long waiting times, uncomfortable waiting areas, a lack of privacy and anxiety due to being left alone for long periods of time in the Emergency Department (ED)</p>	Grey

Watson, J <sup>59</sup>	2002	Semi-structured interviews	Thematic	12 Indigenous women	To explore issues and experiences that existed for Indigenous women during and after their birthing experiences in an acute care setting	Inadequate communication and lack of understanding of cultural and spiritual traditions by healthcare professionals were issues even for those reporting a positive experience generally	Database
Williams, A <sup>60</sup>	2004a	Semi-structured interviews	Thematic	12 patients within 14 days of being discharged home after an acute illness episode	To investigate perceptions of quality of care by patients experiencing comorbidities who required an acute hospital stay	<p>Patients experienced poor continuity of care for comorbidities</p> <p>Discharge planning did not consider comorbidities</p> <p>The management of the acute problem took precedence</p> <p>As frequent hospital patients they perceived that they got 'a bad deal'</p>	Database

Williams, A <sup>61</sup>	2004b	Semi-structured interviews, observation, document analysis of as nursing care plans and patient notes	Grounded theory	40 patients who were, or who recently had been, hospitalised  32 nurses	To explore and describe, from the perspective of hospitalised patients, the perceived therapeutic effect of interpersonal interactions that were experienced during hospitalisation	Emotional comfort was identified as therapeutic in enhancing patient's recovery  Factors influencing emotional comfort are: level of security; level of knowing; and level of perceived personal value  These factors were influenced by the interpersonal interactions that patients experienced	Database
Williams, A <sup>62</sup>	2005	Semi-structured interviews and observation	Thematic	40 patients who were, or who recently had been, hospitalised  32 nurses	To investigate the impact of the hospital environment on patients' experiences of personal control and the influence on health status	All of the patients in the study experienced feelings of reduced personal control that negatively affected their care experience	Database
Williams, A <sup>63</sup>	2006	Semi-structured interviews and observation	Thematic	40 patients who were, or who recently had been, hospitalised  32 nurses	To explain the perceived therapeutic effects of interpersonal interactions experienced by patients during hospitalisation	Patients' degree of emotional comfort was important for a positive care experience  The interpersonal skills of the healthcare staff influenced the emotional comfort of patients	Database

Williams, A <sup>64</sup>	2008	Semi-structured interviews and observation	Thematic	56 patients who were, or who recently had been, hospitalised	To further develop the theory of optimising personal control to facilitate emotional comfort, in relation to therapeutic and non-therapeutic aspects of the hospital environment	Patients' experience of feeling secure, their level of knowing and their level of personal value in terms of aspects of the hospital environment either contributed to feelings of reduced personal control or facilitated patients' ability to optimise their personal control and emotional comfort	Database
Zeit, K <sup>65</sup>	2011	Focus groups  Co-operative inquiry approach  5 workshops over 4 months with facilitators	Thematic	4 volunteers 70 years or older who had either been patients at the hospital or cared for an older person, 4 clinicians, 3 facilitators	To identify the care issues experienced by older people in the acute setting that could be improved through a collaborative approach to action	Aspects of a negative experience included unsuitable food, lack of involvement and chaotic discharge processes  Participants identified the opportunity to work together with health providers as key to a positive experience	Database
Zugai, J <sup>66</sup>	2013	Semi-structured interview	Thematic	8 adolescent recovered-anorexic patients	To establish how nurses ensure weight gain and a positive inpatient experience for the treatment of adolescents with anorexia nervosa by considering consumer perspectives	Patients' motivation to adhere to care was derived from strong relationships with nurses and they valued nurses who created a comfortable and productive environment	Database

## Study quality

Assessment of the studies using the CASP suggested that all studies used qualitative methods appropriately, used appropriate research designs and 22 of the articles described rigorous analytic processes. However, the appraisal also revealed areas of weakness. The recruitment strategies relied on the healthcare services to invite their patients in four studies. The purposive selection process may have introduced bias; patients with better experiences or an ongoing relationship with the healthcare service may have been selected. In addition, a sample size of fewer than 10 was used in seven studies and 15 studies were conducted at a single hospital/day centre site, resulting in limited applicability of findings across settings. Information about the recruitment process was insufficient to make a judgement about its quality in five studies. Despite the use of strategies to provide a rigorous analysis, most studies (27) did not describe the researcher-participant relationship and consider how this relationship may have shaped the data. Ten studies did not report receipt of ethical approval to conduct the work and in one study it was unclear whether ethical approval had been granted.

Five of the six articles retrieved from the grey literature were assessed using the CASP appraisal questions.<sup>30,39,52,54,57</sup> The patient stories identified on the Western Australia Health website were not appraised because they were simply transcripts and did not provide any detail regarding aims, data collection methods or analysis.<sup>58</sup> Similar findings were identified in the five appraised articles as in the articles retrieved from the database searches. The aims were clearly stated with appropriate study designs and use of qualitative methods. None of the articles provided details of ethical approval for the work undertaken or adequate consideration of the relationship between researcher and participant in terms of the potential impact on the resulting data. Only one of the articles provided sufficient detail to determine the level of rigour in the analytic process. No papers were excluded following the appraisal.

## Review findings

A meta-narrative is “*the unfolding ‘storyline’ of research in a particular scientific tradition*”.<sup>27</sup> The 12 meta-narratives that contributed to the review are shown in [Table 2](#); each had a particular conceptualisation of ‘patient experience’. Quality improvement researchers produced the dominant narrative (18 of the 39 studies). The nursing perspective was strong; 13 of the quality improvement studies came from nursing, with the discipline producing or contributing to 19 studies overall. Public health and health services researchers also had a key role in producing the literature; contributing to six studies across several health-related research traditions including paediatric health, cancer care, and ethnicity and health. Notably, only two studies were grounded in the medical discipline.

The conceptualisation of patient experience varied but often included patients’ perspectives of clinical processes, the engagement of patients in care and the notion of patient-centredness. None of the studies provided an explicit theoretical basis. Health professionals mostly conducted this work; the unifying principle was therefore the desire to make an improvement to practice rather than establish a theoretical principle. The literature was pragmatic and often focused on patients’ experiences in a particular healthcare setting rather than producing more widely applicable evidence. Seven overarching themes relating to characteristics of positive and negative care experiences emerged (see [Table 3](#)).

**Table 2: Research traditions that have covered the Australian patient experience qualitatively**

<b>Research tradition</b>	<b>Academic discipline</b>	<b>Definition and scope</b>	<b>Conceptualisation of patient experience</b>	<b>No. of studies</b>
1. Quality Improvement	Multi-disciplinary: <ul style="list-style-type: none"> <li>• Nursing (13)</li> <li>• Public health (2)</li> <li>• Management (2)</li> <li>• Medicine (1)</li> </ul>	The analysis of a system's or organisation's performance and identification of systematic strategies to improve it	Satisfaction with clinical outcomes; a way of assessing patient-centredness; feedback on expectations; consumer participation	18
2. Communication studies	Interdisciplinary: Social sciences, nursing, and midwifery	The study of communication, including interpersonal and mass media	Patient engagement via ongoing, interactive communication between patients, carers and professionals before during and after a care experience	5
3. Paediatric health	Multi-disciplinary: <ul style="list-style-type: none"> <li>• Nursing/midwifery (2)</li> <li>• Public health (1)</li> </ul>	The study of the medical care of infants, children and adolescents from birth up to 18 years of age	Carer participation; active involvement; satisfaction with medical management of care	3
4. Ethnicity and health	Health services research	The study of health and healthcare delivery for ethnically diverse consumers	Patient-based perspective of the care environment and processes	3
5. Rural health	Nursing	The study of health and healthcare delivery in rural environments	A patient-centred approach; stories of needs and expectations	2
6. Cancer care	Public health	The study of health and healthcare delivery for those with cancer	Insight to apply to treatment policies and staff education	2
7. Palliative care	Medicine	The study of health and healthcare delivery for consumers with terminal health care issues	Understand and identify patient needs	1

8. Women's health	Sociology	The study of health and healthcare delivery for women	Patients' ideas, perspectives and interpretations of processes and the environment	1
9. Community health	Health services research	The study and of the health characteristics of biological communities, generally geographically based	Consumer preferences and evaluations of care processes	1
10. Rehabilitation	Allied health	Studies that aim to enhance and restore functional ability and/or quality of life to those with physical impairments or disabilities	Perceptions and attitudes about the amount of care received	1
11. Indigenous health	Nursing	The study of health and healthcare delivery for Indigenous consumers	Identifying sociocultural needs, with a focus on communication	1
12. Adolescent health	Nursing	The study of health and healthcare delivery for adolescent consumers	Consumer contribution for therapeutic alliance	1

Findings, in relation to the review questions, were organised into themes. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. The full list of themes and related subthemes are shown in [Table 3](#).

**Table 3: Themes and subthemes**

<b>Theme</b>	<b>Description</b>	<b>Subthemes</b>
1. Reciprocal communication and information sharing	Effective or ineffective communication between patients, carer and staff or between staff members	<ul style="list-style-type: none"> <li>• Facilitating patient/and or family engagement</li> <li>• Negotiated patient autonomy</li> <li>• Setting expectations</li> <li>• Denying patient and family involvement</li> <li>• Gaps in information provision</li> <li>• Unclear information</li> <li>• Openness</li> </ul>
2. Interpersonal skills and professionalism	The level of friendliness, professionalism and competence of staff	<ul style="list-style-type: none"> <li>• The social environment</li> <li>• Connected staff</li> <li>• Absence of empathy</li> <li>• Cultural competence</li> </ul>
3. The care environment	The availability, cleanliness and experience of the hospital surroundings and equipment	<ul style="list-style-type: none"> <li>• Resource deficiency</li> <li>• Attentiveness to the physical environment</li> </ul>
4. Correct treatment and physical outcomes	Problems in the treatment process and whether the treatment led to the desired outcome	<ul style="list-style-type: none"> <li>• Holistic care</li> </ul>
5. Emotional support	The level of emotional and psychological support provided by the healthcare team	<ul style="list-style-type: none"> <li>• Emotional security</li> </ul>
6. Comfort, pain and clinical care	Ongoing day-to-day patient care beyond the main treatment	<ul style="list-style-type: none"> <li>• Responsive, compassionate care</li> </ul>
7. Discharge planning and process	The organisation and implementation of the discharge process	<ul style="list-style-type: none"> <li>• Chaos and confusion</li> </ul>

## Key characteristics of positive or negative patient experiences in hospital or day procedure services in Australia

Patients often reported being happy or satisfied with their care, but only 15 papers explicitly identified specific features of a positive patient experience. A further four papers identified patient preferences and needs that, if addressed, may contribute to a positive experience. Factors identified in relation to positive experiences were generally related to communication and the interpersonal skills of staff. Twenty-nine papers identified factors leading to a negative patient experience.

### 1. Reciprocal communication and information sharing

The most substantial factor associated with both a positive and a negative patient experience was the existence and degree of effective communication between staff and patients. Seven subthemes emerged under 'Reciprocal communication and information sharing'. The first subtheme was 'Facilitating patient and/or family engagement'. Parents expressed a sense of partnership and involvement with medical teams when they were provided with a clear management plan, timely updates and given the opportunity to ask questions and discuss treatment options.<sup>31</sup>

Conversely, the subtheme 'Denying patient and family involvement' described negative care experiences (identified in nine studies) in which healthcare providers did not allow patients and/or their family members to engage in the care process.<sup>19,31,34,45-47,50,53</sup> For example, parents of child inpatients often felt disempowered due to being excluded from decision-making associated with the medical management of their child.<sup>31</sup> 'Gaps in information provision' described patients in seven studies who expressed dissatisfaction with the information they received pre-, during and post-hospitalisation.<sup>31,44,48,52,55,56,59</sup> For example, inadequate information during the consent process was identified as leading to negative care experiences as patients did not understand the procedure.<sup>55</sup> Lack of contact and communications with obstetricians/surgeons prior to an operation and a lack of debriefing from them after the operation also marked poor care.<sup>44</sup> 'Unclear information' was a subtheme in six studies.<sup>32,41,44,48,50,59</sup> Long-stay patients expressed a lack of knowledge about the expected duration of their stay; this issue links with inadequate patient involvement in care.<sup>41</sup> Indigenous women reported not understanding the information provided by nurses about their maternity care and not having the opportunity to ask questions.<sup>59</sup> They identified a need for nurses to recognise and adapt to varying levels of English language use in these communities.

'Openness' described a lack of openness among healthcare staff. Three studies of incident disclosure highlighted patient distress when they were not listened to, a feeling that staff were hiding mistakes made in their care and patients feeling as though they were not being included in an open discussion about problems occurring in their care.<sup>37,38,40</sup> Particular concerns in the open disclosure process were inadequate patient preparation, inappropriate approaches to disclosing adverse events, and a lack of follow-up support and communication.<sup>40</sup>

'Negotiated patient autonomy' relates to the experiences of patients with chronic conditions. The opportunity to negotiate with staff about the arrangements for managing their medications, including self-administration of medications if requested, was favoured.<sup>43</sup> In the subtheme 'Setting expectations', patients reported emotional comfort in the relief of anxiety when provided with clear information about what to expect from the overall treatment process prior to their procedure.<sup>56,59</sup>

## 2. Interpersonal skills and professionalism

'Interpersonal skills and professionalism' was a second important theme, with four sub-themes. Lack of 'Interpersonal skills and professionalism' among health professionals were key characteristics of negative experiences, generally highlighted by vulnerable patient groups. 'The social environment' described the importance of friendly nursing staff and a welcoming care setting. Positive and enjoyable care experiences were enhanced by friendly interactions with nurses in five studies.<sup>35,49,58,59,66</sup> 'Connected staff' were described in a further subtheme where two studies identified the value of attentive and considerate staff members who responded to them in a timely way and were available when needed.<sup>45,54</sup> In relation to the subtheme 'Absence of empathy', parents of paediatric patients described feeling distressed and angry when health professionals were not able to empathise with the stress and worry they faced about their child's care, and did not provide adequate emotional support to them as a result.<sup>33,53</sup> 'Cultural competence' was highlighted in the negative care experiences of culturally and linguistically diverse patients (CALD) and Indigenous patients due to staff who were neglectful, lacked caring qualities, lacked understanding of their perspective or were perceived as racist.<sup>34,59</sup>

## 3. The care environment

Two subthemes emerged in relation to 'The care environment.' The first subtheme, 'Resource deficiency,' was evident in four studies.<sup>19,45,52,65</sup> Patients identified a lack of, or faulty equipment, bad, insufficient or unsuitable food and the lack of a clean and comfortable bed as contributing to negative experiences.<sup>19,45,52</sup> Where equipment was available, negative experiences were noted if staff lacked the necessary training and skills to use it. Lack of transportation resources were blamed for delays in the transfer of patients to larger hospitals when needed.<sup>52</sup> The second subtheme was 'Attentiveness to the physical environment'. Older patients' dignity was compromised when nurses did not ensure that curtains were drawn, patients were not suitably clothed when being escorted to the bathroom and when patients' beds and surrounding areas were not kept clean.<sup>35</sup>

## 4. Correct treatment and physical outcomes

Negative care experiences associated with 'Correct treatment and physical outcomes' were only discussed in relation to patients with comorbidities. The only subtheme was 'Holistic care.' Patients described staff who only addressed their acute condition and failed to attend to their broader set of clinical needs.<sup>50</sup> This lack of attentiveness to broader needs meant that being cared for in hospital was often less comfortable than staying at home.

## 5. Emotional support

The subtheme of 'Emotional security' was identified in relation to both positive and negative experiences. Three studies identified feeling safe and secure as critical contributors to a positive experience for children and for adults.<sup>19,33,61,63</sup> Good communication with healthcare staff, combined with a trusting and close relationship, were important determinants of feeling secure in the care environment. Studies exploring emotion focused on anxiety. Child and adult patients described feelings of anxiety that were not recognised or alleviated by healthcare staff prior to or immediately after their treatment, causing them distress.<sup>33,44</sup> Emotions were often discussed in relation to the outcomes of having a positive or negative care experience rather than as an aspect of the experience itself.

## 6. Comfort, pain and clinical care

'Responsive, compassionate care' was the only subtheme and described the lack of awareness among health professionals, and particularly nursing staff, of patients' day-to-day needs. These needs included the provision of analgesia, the need to plan meals around individual patients' health requirements and planning for interpreters throughout the care process to ensure patients' concerns are known and met.<sup>34,43</sup>

## 7. Discharge planning and processes

Inadequacies in 'Discharge planning and processes' were identified in the negative experiences of patients in three studies.<sup>47,50,65</sup> 'Chaos and confusion' in the discharge process was a common problem, with repetition, duplication and conflicting information often identified.<sup>65</sup> Patients who were not consulted in the planning of their discharge said the process was poor. In one study, poor planning resulted in patients being re-admitted within 24 hours of their discharge and hospitalised for a further week.<sup>50</sup> Patients described a lack of follow-up care after discharge and a general lack of support from health professionals beyond their immediate procedure.<sup>47</sup>

### **System- or service-related factors that contribute to positive or negative experiences.**

Patients' experiences were predominantly influenced by the attitudes and behaviours of healthcare staff, which manifested as inviting opportunities for engagement, being respectful and being friendly. Nonetheless, six system- and service-related factors were identified as important and often lacking, contributing to negative experiences. These were: staff resources, equipment and transport resources, a process to ensure coordination of the care between services, interpreters/translation services, pre- and post-admission information and an adequate discharge process. The types of system and service factors that influenced positive and negative experiences are shown in [Table 4](#).

**Table 4: System and service factors contributing to patients' experiences**

<b>System or service factor</b>	<b>Examples of factors resulting in positive care experiences</b>	<b>Examples of factors resulting in negative care experiences</b>
Staff resources	<ul style="list-style-type: none"> <li>• Sufficient staff numbers</li> <li>• Appropriate skill mix of staff</li> <li>• Well-trained staff</li> </ul>	<ul style="list-style-type: none"> <li>• Qualified staff not available</li> <li>• Staff are not trained in use of necessary equipment</li> <li>• Inappropriate staff skill mix</li> <li>• Lack of staff</li> </ul>
Equipment and transport resources	<ul style="list-style-type: none"> <li>• Suitable equipment</li> <li>• Working equipment</li> <li>• Clean equipment</li> <li>• Appropriate transport available to take patient to hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of equipment</li> <li>• Lack of suitable transport</li> <li>• Lack of available transport to hospital</li> </ul>
Coordination of care processes	<ul style="list-style-type: none"> <li>• Policy to ensure that staff involved in a patient's care communicate with each other</li> <li>• Accurate documentation processes to maintain patient records that are accessible to all involved in their care</li> </ul>	<ul style="list-style-type: none"> <li>• Different methods for recording patient information</li> <li>• Different storage locations for patient information in each specialty</li> </ul>
Translation services	<ul style="list-style-type: none"> <li>• Available interpreter</li> <li>• Interpreters in a range of languages</li> <li>• Interpreters for all types of clinical situations</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of interpreter</li> <li>• Bilingual staff not required to use their other language</li> </ul>
Pre- and post-admission information services	<ul style="list-style-type: none"> <li>• Consistent pre-admission policy implemented in every area</li> <li>• Central contact point that is available to patients pre- and post-admission</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of written information for patients pre- or post-admission</li> <li>• No point of contact for the patient pre- or post-admission</li> </ul>
Discharge processes	<ul style="list-style-type: none"> <li>• Consistent discharge planning policy that is implemented</li> <li>• Follow up service for discharged patients</li> <li>• Discharge process that includes the patient or carer</li> </ul>	<ul style="list-style-type: none"> <li>• Different processes used by different team members</li> <li>• No follow up process for discharged patients</li> <li>• Lack of a clear policy around discharge</li> </ul>

Based on the emerging themes, the key features of a positive care experience are depicted in [Figure 2](#).

Health care services are **designed and resourced adequately** to enable health professionals to provide a positive care experience

Health care **professionals' attitudes and interpersonal skills** provide the atmosphere for a positive care experience

Health care professionals and service enables the patient to **have a positive care experience**

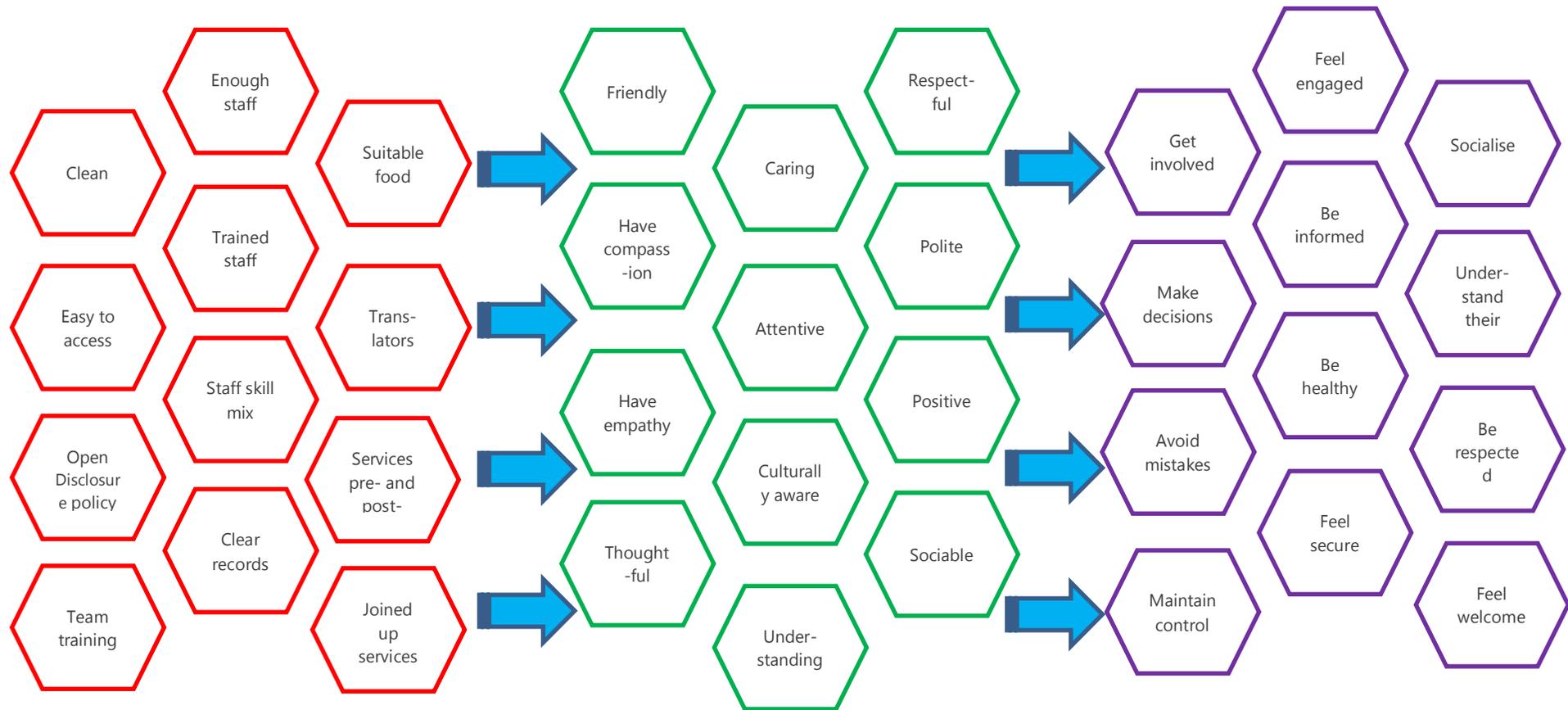


Figure 2: Concept map of contributors to a positive patient care experience

## Positive or negative experiences associated with particular patient groups.

Particular aspects of a positive patient care experience were important to the following patient groups: a) culturally and linguistically diverse patients (CALD); b) child patients; c) parents of child patients; d) Indigenous patients; e) cancer patients; f) those with comorbidities; g) those with chronic conditions; and h) rural patients. Key findings relating to each of these patient groups are shown in [Table 5](#).

**Table 5: Patient experiences in specific patient groups**

Patient group	No. of studies	Key issues affecting patients' experiences
CALD patients <sup>30,34,57</sup>	3	<ul style="list-style-type: none"> <li>• Lack of cultural sensitivity among healthcare staff e.g. same sex wards, lack of consideration for modesty when bathing</li> <li>• Lack of involvement or consideration of religious figures important to the patient</li> <li>• Provisions needed to support cultural and religious beliefs e.g. accommodating family gatherings and prayers</li> <li>• Not being able to directly communicate with health professionals means patients not being informed about or involved in decisions and feeling ignored or poorly treated</li> <li>• Over-reliance on family as interpreters and reluctance of bilingual staff to use the patients' native language – presence of professional interpreter key to positive experiences</li> <li>• Active engagement of patients by staff despite language barriers highly valued</li> </ul>
Child patients <sup>33</sup>	1	<ul style="list-style-type: none"> <li>• Children left alone and cared for in adult wards as stressful</li> <li>• Being placed in clinical areas such as the ED was difficult</li> <li>• Social and emotional support in the healthcare environment particularly important. Provision of nursing support at the time of surgery, and health professionals who engage with children and make the experience fun contribute to enjoyable care</li> </ul>
Parents of child patients <sup>31,53</sup>	2	<ul style="list-style-type: none"> <li>• Parental empowerment as a determinant of a positive or negative experience. Empowerment facilitated by attentiveness of healthcare team, engaging parents as partners in the care process, and validating the importance of parents' roles</li> <li>• Negative experiences associated with relinquishing parental control to the healthcare team, a serious atmosphere in assessment resulting in feelings of fear, a lack of information about the procedure or a lack of empathy and feeling dismissed</li> <li>• Parents have a more positive care experience if they understand the level of involvement expected</li> </ul>
Indigenous patients <sup>59</sup>	1	<ul style="list-style-type: none"> <li>• Miscommunication and a lack of cultural and spiritual understanding among health professionals</li> <li>• Lack of preparation about what to expect from hospital and challenges of</li> </ul>

		<p>having to leave close communities to give birth</p> <ul style="list-style-type: none"> <li>• The provision of hospital self-care accommodation valued as a way to feel safe when outside of the community</li> <li>• Lack of communication and information provision in hospital led to feelings of loneliness</li> <li>• Lack of clear communication with Indigenous women who speak little English threatens safety of care</li> <li>• Those that had a positive experience were proactive in asking questions and seeking information</li> </ul>
Cancer patients <sup>42,46,48</sup>	3	<ul style="list-style-type: none"> <li>• The communication of diagnosis and prognosis as important</li> <li>• Lack of compassionate and empathetic communication</li> <li>• Limited opportunities to participate in the treatment process frustrating</li> <li>• Carers being allowed to address a patient's non-medical needs while in hospital as important</li> </ul>
Patients with comorbidities <sup>50,61</sup>	2	<ul style="list-style-type: none"> <li>• Health professionals overly focus on the acute problem and a lack of consideration for patients' other health issues</li> <li>• Changes to regular medications, lack of provision of necessary medications and lack of opportunity to self-administer</li> <li>• Feeling overlooked, treated with a lack of respect and support due to the regularity of hospital visits</li> <li>• Negative experiences of coordination of care due to seeing a different specialist for each health concern</li> <li>• Lack of holistic care exacerbated by the use of cover specialists unfamiliar with the patient's case. A good handover important</li> <li>• Nurses that provided comfort created a positive experience</li> </ul>
Patients with chronic conditions <sup>43</sup>	1	<ul style="list-style-type: none"> <li>• The opportunity to self-administer medications important; enabling patients to remain engaged and in control of their care</li> <li>• Self-administration perceived to save nurses a substantial amount of time that could be directed at other clinical activities</li> <li>• Some patients do not wish to self-administer medications in hospital; engaging with patients to identify their preferences is necessary to provide a good care experience</li> <li>• Timing of meals important for patients with diabetes to maintain the routines they are used to at home</li> </ul>
Rural patients <sup>29,52</sup>	2	<ul style="list-style-type: none"> <li>• Lack of resources and experienced clinicians in smaller rural hospitals results in delayed diagnosis, transfer and treatment</li> <li>• Lack of equipment and lack of adequate training among staff</li> <li>• Lack of communication and coordination between rural and larger hospitals creates challenges in the coordination of care</li> <li>• Patients and clinicians often know each other in the local community, inhibiting open disclosure</li> </ul>

# 5 Discussion

The review provides evidence of key characteristics of a positive or negative patient care experience among inpatients and day-procedure patients in Australian hospitals. Patients' sense of communication between with healthcare staff pre-, during and post-admission; interpersonal relationships with staff; the hospital environment; engagement in their care and discharge planning were all important. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. For example, where having opportunities to engage in care led to a positive care experience, healthcare staff who denied patient engagement created a poor care experience.

Our findings reflect those of other reviews of qualitative studies of patients' experiences of hospital internationally (which often focused on a specialised clinical setting or specific patient group).<sup>67-73</sup> Patient-professional communication, opportunities for patient/carer involvement and the attitudes and behaviour of health professionals were the most important features determining a positive or negative care experience in the Australian literature and in international literature reviews. For example, one international review reported a synthesis of 11 studies of patients' experiences of patient-doctor relationships in the UK, US, Canada and Sweden, finding that positive care experiences were associated with doctors who listened well, explained issues clearly and provided opportunities for patients to be involved in discussions and decision-making about their care.<sup>72</sup>

The extent to which experiences were positive or negative depended on staff attending to patients' cultural and language needs, the quality of the care environment and the coordination of care and discharge.<sup>67-73</sup> A synthesis of 10 qualitative studies from the UK, Ireland, Australia and Canada explored experiences of the discharge process from critical care environments to general wards.<sup>67</sup> Similar to the Australian studies, the need to be supported through feelings of stress and anxiety in the discharge process was important, along with a need for information about their clinical progress and discharge.<sup>67</sup> Specific features of the Australian healthcare environment, such as rural and Indigenous populations have not however been considered in the international qualitative literature.

## Implications and further research

Tangible opportunities to enhance the patient experience are apparent from the review findings. Small changes to the way that the health system operates, is resourced, and the way that health professionals engage with patients could substantially improve care. Based on the reviewed studies, several actions pre-, during and post-admission are likely to enhance patients' experiences. For example, prior to hospital admission, healthcare organisations and staff should consider routinely speaking with patients and their carers about what will happen before, during and after their hospital admission. During hospitalisation, patients' stay experiences are likely to be enhanced by healthcare organisations and staff that are welcoming and friendly, and that invite patients and carers to contribute to decision making and discussions about their treatment options and care preferences. Upon leaving hospital, healthcare staff should engage with patients and their carers to ensure patients are ready to be discharged and provide clear information about what will happen during this process.

Data about patients' experiences in Australian hospitals are sparse and more work is needed to address some significant gaps. Studies of the following groups are currently required: rural, Indigenous, child, parent, mental health, family and carers of adults and patients with chronic conditions. While these groups have been included in patient experience studies, reliance on structured survey methods has restricted the degree to which their nuanced experiences have been captured. Larger multi-site studies with qualitative components would be valuable in addressing this goal.

## Limitations

The review had limitations in terms of the review methods and of the limitations of the included studies. Most of the studies in the meta-narrative were grounded in the quality improvement paradigm and presented from a nursing perspective.<sup>27</sup> Having a dominant narrative shaped the evidence and led to a focus on aspects of care that are often provided by nursing staff as opposed to the broader healthcare system. Literature from healthcare management, medicine and allied health professional perspectives would be valuable to develop this evidence base further.

There is extensive debate around the distinction between patient experience and satisfaction in existing literature, but these concepts were not delineated by authors in the included studies.<sup>20</sup> Studies often conceptualised patient experience as the processes and feelings that patients experienced in the care process, but there was a heavy focus on whether patients' expectations were met, which links to the concept of patient satisfaction rather than experience.<sup>20,74</sup> This conceptualisation is perhaps in part influenced by the Medical Subject Heading (MeSH) term of 'Patient satisfaction' which is often used for patient experience studies due to the absence of a 'Patient experience' subject heading.

The lack of weight currently given to patient experience research is evident from the small pockets of work identified; generally conducted by individuals and small groups with an interest in this area rather than as part of significant research programs. This gap is also evident in the opportunistic and generally small sample sizes, gathered from single sites in most of the studies. These disparate pieces of work with varied aims and focus contribute to a patchy knowledge base about patients' experiences in Australian hospitals.

## 6 Conclusion

Patients' sense of communication between with healthcare staff pre-, during and post-admission; interpersonal relationships with staff; the hospital environment; engagement in their care and discharge planning were all central to a positive or negative care experience. Rather than distinct characteristics of a positive care experience and a negative care experience, a continuum emerged. Thus, where a good experience was associated with receiving good communication, a bad experience may result from a lack of communication. Tangible opportunities to enhance the patient experience are apparent from the review findings. Small changes to the way that the health system operates and is resourced, and the way that health professionals engage with patients could substantially improve care.

# 7 References

1. Health Foundation. Measuring patient experience: evidence scan. London: Health Foundation 2013.
2. Institute for Healthcare Improvement 2015. IHI Triple Aim Initiative. [www.ihl.org/engage/initiatives/tripleaim/pages/default.aspx](http://www.ihl.org/engage/initiatives/tripleaim/pages/default.aspx) [Retrieved 25 August 2015]
3. Doyle C, Lennox L, Bell DA systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013; 3(1):e001570.
4. Clinical Excellence Commission, 2015. Partnering with patients. [www.cec.health.nsw.gov.au/programs/partnering-with-patients#overview](http://www.cec.health.nsw.gov.au/programs/partnering-with-patients#overview) [Retrieved 29 June 2015]
5. Gerteis M. Through the patient's eyes: understanding and promoting patient-centered care. San Francisco: Jossey-Bass 1993.
6. Australian Commission on Safety and Quality in Health Care. Review of patient experience and satisfaction surveys conducted within public and private hospitals in Australia. Sydney: Australian Commission on Safety and Quality in Health Care 2012.
7. Luxford K, Sutton S. How does patient experience fit into the overall healthcare picture? *Patient Experience Journal*. 2014; 1(1):20–7.
8. Australian Commission on Safety and Quality in Health Care, 2010. Australian Safety and Quality Framework for Health Care. [www.safetyandquality.gov.au/wp-content/uploads/2012/01/32296-Australian-SandQ-Framework1.pdf](http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/32296-Australian-SandQ-Framework1.pdf) [Retrieved 16 April 2014]
9. Agency for Healthcare Research Quality, 2011. The CAHPS Program. <https://www.cahps.ahrq.gov/about-cahps/cahps-program/index.html> [Retrieved 18 July 2013]
10. Department of Health. Creating a Patient-Led NHS: Delivering the NHS Improvement Plan. London: Department of Health 2005.
11. Department of Health. Equity and Excellence: Liberating the NHS. London: The Stationery Office 2010.
12. Ward J, Armitage G. Can patients report patient safety incidents in a hospital setting? A systematic review. *BMJ Quality and Safety*. 2012; 21:685–99.
13. Godlee F. Partnering with patients. *British Medical Journal* 2013; 346: f3153.
14. Aiken LH, Sermeus W, Van den Heede K, Sloane DM, Busse R, McKee M, et al. Patient safety, satisfaction, and quality of hospital care: cross sectional surveys of nurses and patients in 12 countries in Europe and the United States. *British Medical Journal*. 2012; 344:e1717.

15. Department of Health. NHS Patient Experience Framework. London: Department of Health 2012.
16. Bureau of Health, 2014. NSW Patient Survey Program. [www.bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](http://www.bhi.nsw.gov.au/nsw_patient_survey_program) [Retrieved 22 May 2014]
17. Victoria Patient Satisfaction Monitor, 2014. The Victorian Patient Satisfaction Monitor Hospital Information Site. [www.vpsm.com.au](http://www.vpsm.com.au) [Retrieved 22 May 2014]
18. Luxford K. The forgotten tenet: client focus and quality improvement in health care. *Building Quality in Health Care*. 2010; 4(2):10–2.
19. Edwards KJ, Duff J, Walker K. What really matters? A multi-view perspective of one patient's hospital experience. *Contemporary Nurse*. 2014; 49(1):122–36.
20. Devkaran S. Patient experience is not patient satisfaction: Understanding the fundamental differences. [www.isqua.org/docs/default-source/education-/isqua-webinar-november-2014-subashnie-devkaran.pdf?sfvrsn=0](http://www.isqua.org/docs/default-source/education-/isqua-webinar-november-2014-subashnie-devkaran.pdf?sfvrsn=0) [Retrieved 23 July 2015]
21. Sitzia J, Wood N. Patient satisfaction: a review of issues and concepts. *Social Science and Medicine*. 1997; 45(12):1829–43.
22. Berwick DM. Disseminating Innovations in Health Care. *Journal of the American Medical Association*. 2003; 289(15):1969–75.
23. South Australia Health. Measuring Consumer Experience: Annual Report. SA Health 2005.
24. Queensland Health. Small hospitals patient experience survey 2014. Queensland Government 2015.
25. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of Internal Medicine*. 2009; 151(4):264–9.
26. Wilson RM, Runciman WB, Gibberd RW, Harrison BT, Newby L, Hamilton JD. The quality in Australian health care study. *Medical Journal of Australia*. 1995; 163(9):458–71.
27. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O, Peacock R. Storylines of research in diffusion of innovation: a meta-narrative approach to systematic review. *Social Science and Medicine*. 2005; 61(2):417–30.
28. Critical Skills Appraisal Programme (CASP) 2006. CASP Checklists. [www.casp-uk.net/#!/casp-tools-checklists/c18f8](http://www.casp-uk.net/#!/casp-tools-checklists/c18f8) [Retrieved 26 June 2015]
29. Bradley S, Mott S. Adopting a patient-centred approach: An investigation into the introduction of bedside handover to three rural hospitals. *Journal of Clinical Nursing*. 2014; 23(13–14):1927–36.
30. Brough C. Language services in Victoria's Health System: Perspectives of culturally and linguistically diverse consumers. Centre for Culture Ethnicity and Health, Victoria 2006.

31. De S, Tong A, Isaacs D, Craig JC. Parental perspectives on evaluation and management of fever in young infants: An interview study. *Archives of Disease in Childhood*. 2014; 99(8):717–23.
32. De Jesus G, Abbotts S, Collins B, Burvill A. Same day surgery: results of a patient satisfaction survey. *Journal of Quality in Clinical Practice*. 1996; 16(3):165–73.
33. Ford K. 'I didn't really like it, but it sounded exciting': admission to hospital for surgery from the perspectives of children. *Journal of Child Health Care*. 2011; 15(4):250–60.
34. Garrett PW, Dickson HG, Whelan AK, Roberto F. What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study. *Ethnicity and Health*. 2008; 13(5):479–96.
35. Henderson A, Van Eps MA, Pearson K, James C, Henderson P, Osborne Y. Maintenance of patients' dignity during hospitalization: comparison of staff-patient observations and patient feedback through interviews. *International Journal of Nursing Practice*. 2009; 15(4):227–30.
36. Henderson A, Caplan G, Daniel A. Patient satisfaction: the Australian patient perspective. *Australian Health Review*. 2004; 27(1):73–83.
37. Iedema R, Sorensen R, Manias E, Tuckett A, Piper, D, Mallock N, et al. Patients' and family members' experiences of open disclosure following adverse events. *International Journal for Quality in Health Care*. 2008; 20(6):421–32.
38. Iedema RA, Mallock NA, Sorensen RJ, Manias E, Tuckett AG, Williams AF, et al. The National Open Disclosure Pilot: evaluation of a policy implementation initiative. *Medical Journal of Australia*. 2008; 188(7):397.
39. Iedema R, Merrick E, Piper D, Walsh, J. Emergency Department Co-Design Stage 1 Evaluation – Report to Health Services Performance Improvement Branch, NSW Health. Sydney: Centre for Health Communication, University of Technology Sydney 2008c.
40. Iedema R, Allen S, Britton K, Piper D, Baker A, Grbich C, et al. Patients' and family members' views on how clinicians enact and how they should enact incident disclosure: the "100 patient stories" qualitative study. *British Medical Journal*. 2011; 343:d4423.
41. Johnson A, Gaughwin B, Moore N, Crane R. Long-stay views from the hospital bed: patient perspectives of organisation of care and impact of hospitalisation. *Australian Health Review*. 2005;29(2):235–40.
42. Lobb EA, Halkett GKB, Nowak AK. Patient and caregiver perceptions of communication of prognosis in high grade glioma. *Journal of Neuro-Oncology*. 2011; 104(1):315–22.
43. Manias E, Beanland C, Riley R, Baker L. Self-administration of medication in hospital: patients' perspectives. *Journal of Advanced Nursing*. 2004; 46(2):194–203.

44. Markovic M, Bandyopadhyay M, Manderson L, Allotey P, Murray S, Vu T. Day Surgery in Australia Qualitative Research Report. *Journal of Sociology*. 2004; 40(1):74–84.
45. Marshall A, Kitson A, Zeitz K. Patients' views of patient-centred care: A phenomenological case study in one surgical unit. *Journal of Advanced Nursing*. 2004; 68(12):2664–73.
46. Montgomery K, Little M. Enriching Patient-Centered Care in Serious Illness: A focus on patients' experiences of agency. *The Milbank Quarterly*. 2011; 89(3):381–98.
47. O'Callaghan AM, McAllister L, Wilson L. Experiences of care reported by adults with traumatic brain injury. *International Journal of Speech and Language Pathology*. 2010; 12(2):107–23.
48. Olver IN, Elliott JA, Long L, McKinnon M, Rumsby G. The impact of receiving treatment for cancer at a large metropolitan teaching hospital as recorded by patients using unstructured journals. *Journal of Cancer Education: the official journal of the American Association for Cancer Education*. 2012; 27(4):625–30.
49. Peiris CL, Taylor NF, Shields N. Patients value patient-therapist interactions more than the amount or content of therapy during inpatient rehabilitation: a qualitative study. *Journal of Physiotherapy*. 2012; 58(4):261–8.
50. Penney W, Wellard SJ. Hearing what older consumers say about participation in their care. *International Journal of Nursing Practice*. 2007; 13(1):61–8.
51. Piper D, Iedema R, Merrick E, Perrott B. Experience-based Co-Design Program 2 Stage 1 Evaluation Report – Final Report to Health Services Performance Improvement Branch, NSW Health. Sydney: Centre for Health Communication, University of Technology Sydney 2010.
52. Piper D, Iedema R, Bower K. Rural patients' experiences of the open disclosure of adverse events. *Australian Journal of Rural Health*. 2014; 22(4):197–203.
53. Roden J. The involvement of parents and nurses in the care of acutely-ill children in a non-specialist paediatric setting. *Journal of Child Health Care*. 2005; 9(3):222–40.
54. Schembri S. Through the patient's eyes: Strategic insight derived from patient narratives. ANZAM Conference Tasmania 4–6 December 2013.
55. Sharp R, Grech C, Fielder A, Mikocka-Walus A, Cummings M, Esterman A. The patient experience of a peripherally inserted central catheter (PICC): A qualitative descriptive study. *Contemporary Nurse*. 2014; 48(1):26–35.
56. Stevens J, van de Mortel T, Leighton D. Generating theory from the client's experience of same day laparoscopic sterilisation. *School of Health and Human Sciences Papers*. 2001; 1.
57. Victoria Health. Consumer participation and culturally and linguistically diverse communities. Centre for Culture Ethnicity and Health, Victoria 2005.

58. WA Health, 2015. Patient Stories Bank. [ww2.health.wa.gov.au/Corporate/Articles/N\\_R/Patient-stories/Patient-stories-bank](http://ww2.health.wa.gov.au/Corporate/Articles/N_R/Patient-stories/Patient-stories-bank) [Retrieved 23 July 2015]
59. Watson J, Hodson K, Johnson R, Kemp K. The maternity experiences of indigenous women admitted to an acute care setting. *Australian Journal of Rural Health*. 2002; 10(3):154–60.
60. Williams AM, Irurita VF. Therapeutic and non-therapeutic interpersonal interactions: the patient's perspective. *Journal of Clinical Nursing*. 2004; 13(7):806–15.
61. Williams A. Patients with comorbidities: perceptions of acute care services. *Journal of Advanced Nursing*. 2004; 46(1):13–22.
62. Williams AM, Irurita VF. Enhancing the therapeutic potential of hospital environments by increasing the personal control and emotional comfort of hospitalized patients. *Applied Nursing Research*. 2005; 18(1):22–8.
63. Williams AM, Irurita VF. Emotional comfort: the patient's perspective of a therapeutic context. *International Journal of Nursing Studies*. 2006; 43(4):405–15.
64. Williams AM, Dawson S, Kristjanson LJ. Exploring the relationship between personal control and the hospital environment. *Journal of Clinical Nursing*. 2008; 17(12):1601–9.
65. Zeitz K, Kitson A, Gibb H, Bagley E, Chester M, Davy C, et al. Working together to improve the care of older people: a new framework for collaboration. *Journal of Advanced Nursing*. 2011; 67(1):43–55.
66. Zugai J, Stein-Parbury J, Roche M. Effective nursing care of adolescents with anorexia nervosa: A consumer perspective. *Journal of Clinical Nursing*. 2013; 22(13–14): 2020–9.
67. Bench S, Day T. The user experience of critical care discharge: A meta-synthesis of qualitative research. *International Journal of Nursing Studies*. 2010; 47(4):487–99.
68. Bridges J, Flatley M, Meyer J. Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*. 2010; 47(1):89–107.
69. Gordon J, Sheppard LA, Anaf S. The patient experience in the emergency department: A systematic synthesis of qualitative research. *International Emergency Nursing*. 2010;18(2):80–8.
70. Munn Z, Jordan Z. The patient experience of high technology medical imaging: a systematic review of the qualitative evidence. *Radiography*. 2011; 17(4): 323–31.
71. Nairn S, Whotton E, Marshal C, Roberts M, Swann G. The patient experience in emergency departments: a review of the literature. *Accident and Emergency Nursing* 2004; 12(3):159–65.

72. Ridd M, Shaw A, Lewis G, Salisbury C. The patient–doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *British Journal of General Practice*. 2009; 59(561): e116–e133.
73. Waibel S, Henao D, Aller MB, Vargas I, Vázquez ML. What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies. *International Journal for Quality in Health Care*. 2012; 24(1):39–48.
74. Cleary PD. Satisfaction may not suffice! A commentary on 'A patient's perspective'. *International Journal of Technology Assessment in Health Care*. 1998; 14(1):35–7.

# 8 Appendices

## Supplementary file 1: Database search strategy (Medline example)

1. ((Patient\* adj2 (perspective\* or opinion\* or experience\* or perception\* or view\*)) or health care consumer\*).mp.
2. (consumer\* adj2 (perspective\* or opinion\* or experience\* or perception\* or view\*)).mp.
3. (client\* adj2 (perspective\* or opinion\* or experience\* or perception\* or view\*)).mp.
4. patient participation/
5. patient preference/
6. patient satisfaction/
7. patient\* involve\*.mp.
8. patient\* report\*.mp.
9. exp Professional-Patient Relations/
10. Hospital patient relations/
11. or/1-10
12. inpatients/
13. patients.mp and (exp hospitals/ or exp hospital departments/ or exp hospitalisation/)
14. (Acute adj (service\* or care or setting\*)).mp.
15. tertiary care/ or secondary care/
16. or/12-15
17. 11 and 16
18. day procedure\*.mp.
19. (same day adj3 procedure\*).mp.
20. Ambulatory Surgical Procedures/
21. Elective surgical procedures/
22. Ambulatory care/ and (exp Hospitals/ or exp Hospital departments/)
23. surgicenters/ or surgicentre\*.mp. or surgicenter\*.mp.
24. day surger\*.mp.
25. or/18-24
26. 11 and 25
27. 17 or 26
28. limit 27 to (abstracts and english language and yr="1995 -Current")
29. limit 28 to (case reports or comment or editorial or letter or news)
30. 28 not 29
31. exp Australia/ or Australia\*.mp. or Australi\*.in.
32. 30 and 31.

## Supplementary file 2: Search strategy (grey material)

The following organisations working in the field of patient experience were contacted and their websites searched to identify relevant work. The number of articles retrieved from each is listed:

1. Patient Opinion Australia – 1
2. Australian Commission for Safety and Quality in Health Care – 2
3. Clinical Excellence Commission – 1
4. Agency for Clinical Innovation – 3
5. Consumers' Health Forum of Australia – 5
6. State and territory health departments:
  - a. NSW Health – 0 – survey based
  - b. Queensland Health – 0 – survey based
  - c. Western Australia DoH – 1
  - d. South Australia Health – 0 – survey
  - e. ACT Health – 0 – survey based
  - f. Northern Territory Health – 0
  - g. Victorian Health – 0 – survey based
  - h. Tasmania Health – 0 – no data from patients
7. Federal Department of Health – 0 – all survey work
8. State and territory consumer associations (CHF site used in most):
  - a. Health Consumers NSW – 0
  - b. Health Consumers Queensland – 0
  - c. ACT Health Consumers Association – 0
  - d. Health Consumers Council – 0 – Patient Opinion used
  - e. Health Consumers Alliance of South Australia – 0
  - f. Health Issues Centre – 0 – journal on Informat
9. Centre for Ethnicity and Health – 2
10. National Association of County and City Health Officials (NACCHO) – 0
11. Centre for Health Communication and Participation (Latrobe) – 1
12. Health Consumers of Rural and Remote Australia – 1
13. Professional organisations:
  - a. Royal Australian College of General Practitioners – 0 – survey based
  - b. Royal Australian College of Physicians – 0
  - c. Royal Australian College of Surgeons – 0
  - d. Australian and New Zealand College of Anaesthetists – 0 – survey based
  - e. Allied Health Professions Australia – 0
14. Australian Institute for Patient and Family Centred Care (AIPFCC) – 2
15. CHOICE (previously Australian Consumers Association) – 0 – survey based
16. Combined Pensioners and Superannuants Association.