
Theses

2019

Patient involvement in healthcare projects: A mixed method study on the perspectives of project staff in Western Australian (WA) public hospitals and health services

Melanie Wright

Follow this and additional works at: <https://researchonline.nd.edu.au/theses>

COMMONWEALTH OF AUSTRALIA
Copyright Regulations 1969

WARNING

The material in this communication may be subject to copyright under the Act. Any further copying or communication of this material by you may be the subject of copyright protection under the Act.

Do not remove this notice.

Publication Details

Wright, M. (2019). Patient involvement in healthcare projects: A mixed method study on the perspectives of project staff in Western Australian (WA) public hospitals and health services (Master of Philosophy (School of Nursing)). University of Notre Dame Australia. <https://researchonline.nd.edu.au/theses/228>

This dissertation/thesis is brought to you by ResearchOnline@ND. It has been accepted for inclusion in Theses by an authorized administrator of ResearchOnline@ND. For more information, please contact researchonline@nd.edu.au.



CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter seeks to provide background information into the available evidence regarding patient involvement in healthcare projects and the staff perspectives of this approach.

2.1.1 Building the search strategy

Searches were conducted in the following evidence databases: CINAHL, Cochrane Library, MEDLINE, ProQuest, Trip, and Trove. Furthermore, local, national and international websites were accessed: in WA , the Health Consumers Council (2017) and the Consumer and Community Health Research Network (2018); in New South Wales, the Agency for Clinical Innovation (2016) and the Clinical Excellence Commission (2018); in the United Kingdom the National Institute of Health Research (2016) and the National Institute for Health and Care Excellence (2017); in Canada the Health Quality Ontario (2018) and in America the Institute for Healthcare Improvement (2018) and the National Quality Forum (2018); and globally, the World Health Organisation (2013).

Searching the evidence posed many challenges and was not straightforward. Non-standardised terminology is used and there is inconsistent use of a wide variety of keywords in the literature (Barber et al., 2012). Table 1 details the initial search terms and criteria used to develop the original research proposal in 2016.

Table 1 : Search Terms

<u>Term</u>	<u>Criteria</u>
Staff perspectives	“staff perspectives” AND
Patient involvement	“patient involvement” AND
Healthcare projects	“healthcare projects”
Date ranges	1996 - 2016
Language	“English”

Table 2 details the results of the initial search completed in 2016 using the criteria set in Table 1. However, during 2017 and 2018, the researcher constantly added to the thirty-four articles initially found in 2016 (Table 2), by applying filters and alerts on various databases (SMHS Library, Trip, Trove, ResearchGate) to enable email notification of new published articles. This iterative approach was used to constantly refresh the reference material and to check for any emerging findings. For example, the most recent articles referenced in this study were published in 2018.

Table 2 : Search Results 2016

<u>Search number</u>	<u>Criteria</u>	<u>Publications</u>
1	“patient involvement”	1,280,217
2	“staff perspectives” AND “patient involvement”	112,908
3	“staff perspectives” AND “patient involvement” AND “healthcare projects”	238
<i>Studies removed as not meeting criteria:</i>		
	• <i>Patients involved in research projects not healthcare projects</i>	139
	• <i>Patients involved in clinical decision-making rather than projects</i>	26
	• <i>Patients involved in clinical outcomes measurement or reporting, rather than projects</i>	24
	• <i>Patients involved in health partnering rather than projects</i>	15
	Total number of studies remaining	34

The evidence specifically regarding staff perspectives of patient involvement in healthcare projects is minimal; therefore, literature regarding staff perspectives of patient involvement in research projects was also reviewed to ascertain any learnings or comparisons from research studies that could be applied to this study.

Most of the evidence was derived from international sources, predominantly United Kingdom (UK) based, and nationally from New South Wales in Australia. The UK based National Institute for Health Research (2016) hosts a website containing a database of published and unpublished research projects

that have or plan to actively involve members of the public in research. An evidence bibliography from this website (National Institute for Health Research, 2014a), was also reviewed, using the same search criteria as Table 1, which provided a further eight articles for review, raising the total to forty-two relevant articles.

To summarise, there is a dearth of research evidence on patient involvement in healthcare, although the bulk of the literature focuses on patient involvement in their clinical care or research projects rather than healthcare projects. While patient involvement in healthcare projects and research projects may be different, there are overlaps which means that this area of evidence was worthy of review. Thus, the following sections describe the findings from the literature review specifically based on healthcare projects and appropriate references found from searching patient involvement in research projects.

2.2 Definitions of patient involvement

Harris et al. (2015) found that patient involvement is defined by some authors but the involvement can be varied, at different stages in the project and with different purposes. Patient involvement as proposed by Tritter (2009), includes 'indirect involvement', such as information gathering and seeking patient views, or 'direct involvement', where patients are involved in actual decision making. Different project management methodologies also include varying levels of patient involvement, such as voice of the patient questionnaires, telephone surveys, patient interviews and patient stories or story telling (Clinical Excellence Commission, 2018; Health Quality Ontario, 2018; Taskforce, 2008). Definitions of 'patient involvement' is inconsistent in the literature as many different terms are used, such as 'engagement' or 'participation' (Sarrami-Foroushani, Travaglia, Eikli, & Braithwaite, 2012).

Patient and public involvement in research is defined as "doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them" (National

Institute for Health Research, 2016). This suggests a level of participation and involvement that is different from day to day treatment and clinical care. In many of the healthcare research articles, the term 'patient' seems to be used less and words such as customer, community, client or consumer are being used more frequently. The Australian Commission on Safety and Quality in Health Care (ACSQHC) definition of a 'consumer and/or carer' is "members of the public who use or are potential users, of healthcare services" (2012b, p. 5). Most HSPs have their own Consumer Advisory Councils / Committees (CACs) who provide a consumer perspective on initiatives, policies and projects which impact on consumers (Department of Health, 2018a); however, a consumer or consumer representative may not have used the service which the project is aiming to improve, therefore their input may be limited and not reflect the actual patient experience. For this reason, the term consumer was not used as a definition in this study, as the researcher was interested in actual patient involvement, and their 'lived experience' (Manafó, Petermann, Mason-Lai, & Vandall-Walker, 2018). A supporting statement by Cook & Miller (2012), noted that having knowledge of a patients' direct experience is a unique source of information which is vital to service development.

The literature search was further hampered by the lack of Medical Subject Heading (MeSH) terms for patient involvement (Brett et al., 2014), and varied or inconsistent definitions of involvement (Marston & Renedo, 2013; Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). This is further complicated by an absence of clarity about what involvement actually is (Marston & Renedo, 2013), and no international standard format for reporting, describing or capturing the impact of patient involvement or the ability to track decisions made as a result of this involvement (Mockford et al., 2012; Pearson, 2012; Staniszewska, Brett, Mockford, & Barber, 2011).

A systematic review by Shippee et al. (2013), concluded that the literature surrounding the topic of patient and service user engagement (PSUE) is non-standardised and non-empirical, creating difficulties in analysis, comparison and

review of the available evidence. The authors found the terminology used in this field varied considerably and proposed a template for researchers to use including structured indexing and reporting when involving patients and service users, which also identifies the phase or stage of their involvement, which should also be reported in the research article or publication.

Due to an absence of a standard definition used in project management, and inconsistency of definitions in the literature, 'patient involvement' in this study was defined as a patient (actual service user) who participates in a healthcare project, either 'directly' (involved in decision making or in the project team) or 'indirectly' (provides viewpoint or information).

2.3 Policies / frameworks

During the literature search, it was noted that policy development in patient involvement identified international, national and state based sources, which are discussed in the following sections, that advised, suggested or directed that patients or consumers are involved in all aspects of healthcare and service design or redesign.

2.3.1 International policies / frameworks

Internationally, there are many broad based consumer engagement frameworks or patient and public involvement strategies available (Forum, 2018; K Carman et al., 2013; Kingston Hospital NHS Foundation Trust, 2013; National Institute for Health and Care Excellence, 2017; National Institute for Health Research, 2014b; Popay 2014). The World Health Organisation (2013) recognises the value of patient engagement in improving the safety and quality of healthcare, and provides tools for engaging patients in surgical safety, hand hygiene and mother and baby checks. In Canada, there is an innovative program called 'Patient Partnering' (Health Quality Ontario, 2018), which places the patient and their family at the centre of healthcare and provides tools and resources to enhance and enable patient engagement.

2.3.2 National policies / frameworks

In Australia, there are also national frameworks and strategies available for guidance on patient or consumer involvement in healthcare (Austin Health, 2013; Australian Government, 2005; Cancer Australia and Cancer Voices Australia, 2011; NHMRC, 2016). However, these documents are very broad and generalisable, and are not specific to patient involvement in healthcare projects.

The Australian Commission on Safety and Quality in Health Care is a government agency that leads and coordinates national improvements in safety and quality in healthcare (ACSQHC, 2016). The importance of consumer engagement in healthcare in Australia is supported by the following documents developed by the ACSQHC: the Australian Charter of Healthcare Rights (2014); the Australian Safety and Quality Framework for Health Care (2010) and the Australian Safety and Quality Health Service Standards (2012a).

There is a specific ACSQHC national standard for consumer involvement in healthcare; Standard 2: Partnering with Consumers (2012b). Section 2.5.1 of this standard provides recommendations that “Consumers and/or carers participate in the design and redesign of health services”, (2012b, p. 23). As discussed by Lewis (2014), several key QI initiatives were implemented with patient involvement in a private hospital to comply with National Standard 2 (2012b); such as white boards installed in ward areas to display information on hospital performance and at the patient bedside to improve communication between patients and staff. However, there was no reference to the staff perspectives and experiences of recruiting and involving patients in these quality initiatives, and the value add of this approach (Lewis, 2014).

The Safety and Quality Improvement Guide (Australian Commission on Safety and Quality in Health Care, 2012b), describes positive benefits of partnering with consumers, and provides some implementation strategies, toolkits and references. The standard states that health professionals need training to deliver consumer centered care and achieve partnerships and highlights the

importance of thorough documentation when staff are involving consumers. The Australian Government Stakeholder Engagement Framework describes five levels of consumer engagement, which are to “inform, consult, involve, collaborate, or empower” (2005, p. 6). This framework provides a guide as to how consumers can be engaged in different ways in an organisation but is not a definitive decision support tool.

A discussion paper describes how patient centered care improves the patient experience, reduces adverse incidents and improves multiple key performance indicators, (Australian Commission on Safety and Quality in Health Care, 2011). The paper states that there is a link between improved employee satisfaction and retention rates when hospitals implement patient centered care. Patient involvement in design and redesign of healthcare was highly valued, and ‘Experience Based Co-Design’ which places staff and patients on an equal partnership footing, is described as a good approach. However, there are limited practical tips on implementation, and no reference as to measuring the value of patient inclusion or staff perceptions of this approach in the document.

The National Health & Medical Research Council have developed a statement on involving consumers and the community in research (NHMRC, 2016). This statement describes the various levels and stages of the research that consumers and the community can be involved in and that this involvement benefits the public, researchers, institutions and the quality and direction of the research. Many grants and funding bodies now expect consumer involvement to be documented in the research protocol and consumer involvement is now becoming a mandatory criterion in research studies.

National Standard 2 (Australian Commission on Safety and Quality in Health Care, 2012b) , states that it is best practice to involve patients (or consumers/ community members) in healthcare projects, although this is not mandatory for project managers to comply with. There is no compliance checking, auditing or reporting, except for the external accreditation process, which evaluates an

organisations overall, not specific, evidence towards meeting all national standards, including Standard 2 (The Australian Council on Healthcare Standards, 2018).

2.3.3 State policies / frameworks

Locally, WA Health Networks are involving patients in clinical pathway design and policy development to improve services and promote self-management of patients chronic conditions (Department of Health, 2017a). The purpose of the Health Consumers Council in WA is to raise awareness of and advocate for health consumers' rights and to support health consumers to be active partners in health policy, planning, review and research (Health Consumers Council, 2017). In WA, there is also an organisation dedicated to involving consumers and the community in research, who advise that at least two consumers or community members are involved in each research project, and offer several different methods to implement this approach (Consumer & Community Health Research Network, 2018). In SMHS, there is a broad policy for engaging consumers, carers and community partners (Department of Health, 2014). WA Health have a stakeholder engagement framework (Department of Health, 2005), and have recently developed a consumer, carer, community and clinician engagement framework (Department of Health, 2017b).

2.4 Staff perspectives of involving patients

There is research available which is specifically aimed at gathering patient perspectives of their involvement in the delivery of healthcare (Mende & Roseman, 2013; Pomey, Hihat, Khalifa, Lebel, & Neron, 2015; Todd & Nutbeam, 2018). The perspectives of the staff leading and managing projects where patients are involved is limited (Barber et al., 2012). This section provides an overview from the literature which specifically discusses whether the articles sourced included actual perspectives or quotes from the staff involved.

Staff perspectives are important as their experience and attitude plays a key role when implementing innovations in healthcare service delivery (Collier et al., 2016), and their real world experiences are essential to fully understand the situation (Wutzke, Benton, & Verma, 2016); which also highlights the importance of conducting this study. It is crucial for staff to regard patient involvement as an integral part of their role, rather than an additional workload or task (Fisher, 2011), as several challenges exist in normalising patient engagement (Manafa et al., 2018).

In WA Health, project completion reports were accessible from a Medical Service Improvement Program (MSIP) internal database, which had one hundred and sixteen projects listed from 2009 to 2013 (Department of Health, 2016a). This program is designed to support junior doctors to lead CSR projects in hospitals, as it was recognised that frontline clinical staff are active drivers of service improvement (Micallef & Straw, 2014). Many of the MSIP projects described voice of the patient or voice of the staff surveys, which are routinely conducted as part of the CSR improvement methodology, called DMAIC (American Society for Quality, 2016). The junior doctors described their personal satisfaction of completing the program, such as realising the results of their change management efforts, increased skills and knowledge and increased networking opportunities and relationship building; however, there was no reference as to how they managed patient involvement in their projects, or indeed if patients were actually involved (Micallef & Straw, 2014).

In New South Wales (NSW), there is a government agency who “work with clinicians, consumers and managers to design and promote better healthcare” (Agency for Clinical Innovation (ACI), 2016). The ACI provide improvement and innovation training and publish details of healthcare projects on their website. There were two hundred and sixty-two projects listed and thirty-two results retrieved when searching for patient involvement, and only six when searching for staff perspectives and patient involvement. Only a few of these project reports specifically describe staff perspectives of involving consumers;

although, these are mostly abridged comments by the authors rather than actual staff views, as discussed in the next sections.

The Roads to Recovery project involved twenty-one staff and twenty patients in surveys, interviews and process changes and the development of a mural to depict the patient's pathway to recovery. Two staff perspectives were mentioned; how team members struggled with reporting consumers' symptoms in the presence of the consumer; and an audit of care plans which suggested tensions between consumer and staff goals (Agency for Clinical Innovation (ACI), 2016).

The Tweed Opioid Treatment Program worked with twenty-seven clients, and their clinicians and case workers to define a single set of criteria to assess when clients are eligible to receive take home medications. The authors state that the project was a major lesson for staff in accepting and using the clients' own opinions and insights to develop and implement solutions, but with no specific commentary or insights provided from the staff (Agency for Clinical Innovation (ACI), 2016).

There were three other ACI projects that demonstrated a high level of consumer engagement; however, they did not detail how staff managed this engagement, or valued the engagement, which seems to be a missed opportunity. The first was a Culturally and Linguistically Diverse Engagement Strategy project where twenty women from Arabic and Chinese speaking communities were invited to an art workshop to visually express their feelings about breast screening (Agency for Clinical Innovation (ACI), 2016). The women produced powerful art works and story boards as a form of communication. There were no staff perspectives documented to articulate the challenges and opportunities faced with the participant involvement, and any cultural or language barriers that they encountered.

The second was a Transdisciplinary Approach to Brain Injury Rehabilitation project, aimed at reducing unwanted duplication of clinical assessment associated with Occupational Therapy, and included patient and family feedback, individual consultations, clinical notes audit and surveys (Agency for Clinical Innovation (ACI), 2016). The authors noted increased motivation and workplace satisfaction amongst staff but provided no description as to how staff perceived the value add of the patient involvement.

The third project was Supporting Dementia and Delirium Care with Volunteers, which was a project to train volunteers in person centered dementia care and intervention (sixty four patients) and compare outcomes with a control group (fifty three patients) (Agency for Clinical Innovation (ACI), 2016). Most staff (96%) thought that the program was worthwhile and should continue as they recognised improvements in patients' emotional care, nutrition and safety. However, there was no description of the patient and / or carer involvement and the staff perception of the value add of this approach.

The experiences and views of managers who were involved in a large scale CSR program were gathered via individual semi-structured interviews (Masso, Robert, McCarthy, & Eager, 2010). The article does contain direct quotes from the managers regarding their concerns with the program, although involving patients was not raised as an issue; sustainability of the improvements were the managers biggest concern (Masso et al., 2010).

Research staff perspectives of their experience with involvement of consumers and the community in research projects was the focus of a qualitative report in WA, containing excerpts of actual staff statements (McKenzie, Bulsara, Haines, Hanley, & Alpers 2016). The author found eight barriers, such as time and funding (McKenzie et al., 2016) and three benefits such as increased relevance and appropriate ways to disseminate findings (McKenzie et al., 2016). This report provided unique insights into the perspectives of research staff when involving consumers.

Staff who were involved in an action research project in a renal unit, stated that due to patient involvement they had an increased awareness of the importance of patient perspectives, appreciated how patient involvement enhanced health outcomes, and patients educated staff about some myths and impacts of living with a chronic condition (Blomqvist, Theander, Mowide, & Larsson, 2010). However, the article had no descriptions of the actual direct perspectives from staff as to this inclusive research approach.

Matthews et al. (2010), involved patients in two case study projects in chronic disease management and found that project teams were less likely to make assumptions about what patients need when they involved patients; however, it was stated that the motivation and confidence of staff to involve patients and the public on an everyday basis varied. Lessons learnt were highlighted, but the actual perceptions of staff and the challenges they faced were not included in the article. Van Duijn et al. (2013) stated that staff felt positive and satisfied about patient involvement in an electronic health innovation project, but remained unsure as to the degree of involvement required to achieve patient friendly, effective outcomes. There were no direct quotes available from staff to elicit actual staff perspectives.

According to Roberts et al. (2016), there was a new era of healthcare in which the individual would be an engaged and active consumer, with an enhanced maturity and increasing technological expectations, which healthcare providers needed to embrace. This article described the patient as a person who is an equal partner in their healthcare. However, there were no indications or suggestions as to how staff can change organisational attitudes, cultures and perspectives to involving patients in healthcare projects, to ensure that organisations are ready for the challenge of this new era.

There were many documented healthcare improvement projects involving patients or consumers in the literature, but little commentary or opinion documented from actual staff quotes about the value of this involvement or the

barriers that were faced. The literature seemed to be lacking in regard to staff perspectives (positive or negative) of involving patients; this may be due to the organisations not wanting to disrupt patient involvement if negative experiences have occurred, or a lack of priority about staff experiences in this area. It may also be viewed as politically incorrect to report negative findings, as the policies and frameworks were only advising of perceived benefits of this approach. Patient involvement was usually described in a positive manner, as negative impacts may be politically difficult to report and may have disengaged patients and staff (Staniszewska et al., 2011).

2.5 Barriers to patient involvement

Many barriers to successful patient involvement were evident in the literature and can be broadly described in terms of having an unclear purpose, differing capacity of stakeholders, insufficient staff skills, irrelevant issues being discussed and the failure to review or evaluate the involvement strategy (Australian Government, 2005). Other barriers found are discussed in the following sections.

2.5.1 General recruitment

There were challenges evident with recruiting patients and the ongoing management of those patients during the project lifecycle. Mende & Roseman (2013) noted several challenges with consumer recruitment such as threshold levels for representation of the broader patient group, ability to reflect diversity of the patient cohort, unwillingness of staff to refrain from use of technical jargon, staff resistance to consumers and an unequal voice for consumers within meetings. They concluded that both staff and the consumer need preparation prior to being involved on any committees or research projects.

Brett et al. (2014), conducted a systematic review of patient and public involvement across the continuum of research, from 1995-2009, stating several other challenges such as low consumer attendance rates at meetings, conflict between research design and user ethical perspectives, and researcher

struggles with relinquishing control, causing conflict. Lord & Gale (2014), conducted semi-structured interviews with multiple stakeholders across three National Health Service Trusts, stating that there was little consensus in how to involve patients in service redesign initiatives. Stakeholders and executives regularly cited that patient centered care and patient involvement was important; however, there was an identified gap between these values and reported practice.

Finding the right people (McKenzie et al., 2016) was a major barrier to involving consumers and community members, as well as power imbalances between patients and staff (NHMRC, 2016). To achieve positive partnerships with patients, it was important to identify the right patients and recruit them to fill the right roles within the project (Mende & Roseman, 2013; Pomey et al., 2015). Recruitment of patients and hard to reach user groups into research projects can be complex and difficult, and require organisations to develop specific recruitment processes and policies (Brett et al., 2014; Garfield et al., 2015; Lord & Gale, 2014; Robinson, 2014). Patient involvement in quality committees was also very complex and required careful planning (Pomey et al., 2015).

2.5.2 Cultural challenges

There were cultural challenges noted with consumer input that organisations and staff need to be aware of to embrace a culture of positive consumer involvement. Some staff may have felt that patients were not qualified or trained in health matters enough to effectively contribute to the project or service redesign activity (Garfield et al., 2015; Lord & Gale, 2014; Robinson, 2014). Healthcare culture, although centred around the patient, has not historically valued the input of the consumer, as it is the professionals who are highly skilled and trained, whereas patients are not (Mende & Roseman, 2013).

Radiologists Raman, Horton and Fishman (2015) planned to lead a project to improve their services but realised that despite their medical knowledge, they had no expertise in patient experience improvement, nor understanding of what

patient needs were from a service perspective. They consulted experts in people and customer service from other industries and business, to educate staff and engage with patients to provide input and improve their services. They implemented a patient experience advisory service and are yet to publish outcome results; however, this was an example of staff having insight into their limitations whilst attempting to change the culture of the organisation. Organisations may not appreciate the skills required to successfully involve patients in projects. Not all organisations had adequate policies, processes and protocols in place to support staff with patient involvement (Brett et al., 2014; Garfield et al., 2015; Lord & Gale, 2014; McKenzie et al., 2016; NHMRC, 2016; Robinson, 2014). Ford & Bowness (2012) described how organisations needed a deeper focus in order to successfully involve patients and reduce barriers, as some staff remained unclear as to why patient involvement was useful and important.

2.5.3 Training / skills

Lack of staff training, skills and knowledge features heavily in the literature as significant barriers to optimising and managing patient involvement (Barber et al., 2012; Harris et al., 2015; NHMRC, 2016; Pearson, 2012; Pomey et al., 2015; Raman et al., 2015). Matthews et al. (2010), involved patients in two case study projects in chronic disease management and found the motivation and confidence of staff varied. Staff may also avoid involving patients due to apprehensiveness, especially if they have no prior experience (Fairbrother et al., 2013). In a mixed methods Delphi study, the authors discussed the lack of knowledge regarding the effects of public involvement on the researchers, and the perceived threat to their professional skill and knowledge (Barber et al., 2012).

Another barrier found was that patients also require training prior to their involvement to ensure that all parties are aware of their roles and responsibilities, and to increase their confidence (Barber et al., 2012; Consumer & Community Health Research Network, 2018; Fairbrother et al., 2013; Todd &

Nutbeam, 2018). Todd & Nutbeam (2018) interviewed twenty consumer volunteers in Sydney about their perspectives of being involved in research projects, and although the sample size was noted as small, they concluded that investment in education for consumers about research would change the way that research is conducted and shift the way researchers interact and draw on the experiences of consumers.

2.5.4. Time, cost and workload

The cost of patient involvement was also cited as a significant barrier, not only the daily rate paid to the patient, but the cost of increased staff time and effort to organise and manage the patient (Brett et al., 2014; Fairbrother et al., 2013; Garfield et al., 2015; Manafo et al., 2018; NHMRC, 2016; Norman, 2012; Robinson, 2014; Van Duijn et al., 2013). Time, effort and funding were the major key barriers to consumer and community involvement in research projects (McKenzie et al., 2016). Staff also need time to adjust to receiving and responding to patient input, as an equal partner in the project, as staff may not be used to this (Fairbrother et al., 2013). This increased workload and time imposition may lead to a form of negative stress for staff (Arnetz, Zhdanova, & Arnetz, 2016a).

2.5.5 Tokenism

Tokenistic involvement was an issue when involving patients or consumers (NHMRC, 2016), and was frequently cited in many articles. Patients may be involved for externally influenced reasons, such as compliance with standards, local policy, project approvals, or 'ticking a box mentality', rather than a genuine desire to gain valuable patient perspectives (Garfield et al., 2015; Robinson, 2014). This tokenistic approach may place staff and patients in an uncomfortable situation, rather than in a partnership, and may have some impact on negative staff perspectives of patient involvement (Brett et al., 2014). A systematic review by Shippee et al. (2013), suggested that current approaches are more tokenistic, rather than real patient and service user integration. Garfield et al. (2015) described how involving lay persons in data

collection in research projects can reduce tokenism but advised to proceed with caution as there was a potential to professionalise lay people (Garfield et al., 2015). Robinson (2014) discussed how researchers may want to tick a box to state that they have involved a consumer, primarily as this is a stipulation of a grant or funding body, but have no meaningful involvement plan. Patients may also think that their involvement is a token gesture, so their involvement has to be carefully managed to avoid any misperceptions (Robinson, 2014).

2.6 The value of patient involvement

The value of patient involvement is multi-faceted and may be perceived differently by staff, patients, consumer / community groups and the organisation. Value is difficult to define and evaluate; mostly due to inconsistent reporting and terminology and is sometimes referred to as success measures, positive outcomes, benefits or opportunities. The success of patient involvement has also been described mainly in terms of the collaborative relationship that is formed between patients and professionals, rather than merely outcomes or improved performance indicators (Marston & Renedo, 2013). The complexities and differences within each project make it difficult to generalise the impact of patient involvement, or predict where the greatest impact will be (Popay 2014).

2.6.1 Staff and patient benefits

There were multiple benefits evident for staff when patients were involved in projects or research. Face to face encounters with patients can be transformative, inspiring and revelatory to staff, which can ultimately effect positive change and improvements (Locock et al., 2014). Staff can better understand patient perspectives when patients are involved, and listen to their patients rather than tell them what to do (Locock et al., 2014; Tsianakas et al., 2012). Staff can make assumptions about what patients want or need, but by involving patients in the project, the outcome is more likely to meet the patients' needs and improve their care (Matthews et al., 2010). Involving patients can be fulfilling and induce a positive stress response in staff (Arnetz et al., 2016a), and increase staff enthusiasm for the change effort (Pizzo, Doyle, Matthews, &

Barlow, 2014). Consumer input may assist to change professionals attitudes towards consumer involvement (Consumers Health Forum of Australia, 2015).

Patients offer their unique voice to service development as they are experts by experience (Fereday, 2016, p. 5). Fairbrother et al (2013), conducted a feasibility trial to investigate self-telemonitoring of blood pressure by patients. The researchers noted three main benefits of involving patients in this research: patient communication issues were resolved; practical technology use was enhanced; and set up of the trial and research study was more patient focused. Patients also added extra credibility to their qualitative research component as several factors would have been overlooked had they not been involved. Mullins, Abdulhalim & Lavalee (2012), stated that success hinges on patients being interested, emotionally involved and understanding of their role.

Consumers, carers and members of the community may feel a greater sense of ownership of health service design, delivery and evaluation when they are engaged to participate (Department of Health, 2017b). Consumer input can improve existing services, assist to create new services, and improve communication and consumer information (Consumers Health Forum of Australia, 2015). The unique perspectives and relevance that consumers and the community members bring to research projects are key benefits along with the ability to foster long-term beneficial relationships (McKenzie et al., 2016).

Gillard et al. (2012), completed a mixed method cohort study of one hundred and twenty new users of adult Mental Health services, aimed at critical reflection on patient and public involvement. Participants completed qualitative and quantitative interviews on commencement at the service and nine months later. The article described how team members who were not from research backgrounds i.e. consumers, challenged academic conventions, which led to complex findings that would have otherwise been missed. This led to re-evaluation of the data as another layer of interpretation was revealed by

patients. The authors stated that a limitation of this study was its retrospectivity, however future prospective studies were encouraged.

2.6.3 Project / organisational outcomes

Patient involvement may lead to improved health outcomes, or non-health outcomes, such as co-designed healthcare leaflets which improve communication with the general patient population (Ansari & Andersson, 2011; Marston & Renedo, 2013). Patients add positive new perspectives, especially with communication and improvements to study design (Garfield et al., 2015). Although patient and public involvement requires careful planning, time and effort it can positively influence the development of research questions and outcomes (National Institute for Health Research, 2014b). Interestingly, Pizzo, Doyle, Matthews and Barlow (2014) stated that an increase in patient involvement in decisions leads to project sustainability.

Patient involvement in quality improvement projects utilising the PDSA methodology provided unique perspectives from patients that staff had not thought about and assisted them to deliver better project outcomes; such as a patient physical health plan for mentally unwell patients that met the needs of the patient (Fereday, 2016). Involving consumers and the community in research may enable better ways to disseminate findings and gain wider community support (McKenzie et al., 2016) and may also improve organisational culture (Consumers Health Forum of Australia, 2015). Organisations may see increased efficiency with an associated reduction in costs when consumers are engaged (Department of Health, 2017b).

Crawford et al. (2002) conducted a systematic review of papers involving patients in the planning and development of healthcare, which scanned the literature from 1966 to 2000. Only forty-two of the three hundred and thirty-seven studies sourced specifically described the effects of patient involvement. Interestingly, two large-scale decisions regarding hospital closures were overturned when patients were involved, and the hospitals remained open. The

authors found minimal evidence supporting the tangible effects of patient involvement in the planning and delivery of health care, except for some qualitative research and case study evidence ; concluding that there needs to be a better evidence base of the effects of patient involvement (Crawford et al., 2002).

2.6.4 Measuring the value

There was no agreed mechanism for measuring the value of the consumer contribution (Consumers Health Forum of Australia, 2015). Mockford et al. (2012), conducted a systematic review from 1997-2009, also concluding that there was no evidence base to understand the full impact of involving service users, no reliable measurement tool and no evidence of related costs. A further systematic review by Shippee et al. (2013), suggested that current approaches demonstrated limited evidence on tangible benefits. A systematic review proposal by Harris et al. (2015), focused on patient and public involvement in diabetic research, stating that there was evidence of the positive impact of patient and public involvement in this research; however, the evidence to justify the value of involvement was weak. Pearson (2012), also highlighted the mixed success achieved with consumer participation in the health system and that there was an evidence gap in the economic and health benefits of consumer participation.

Barber et al. (2012), conducted a mixed method study including a Delphi panel, including one hundred and twenty-four participants and fourteen interviews with UK and international researchers. The results indicated that it was feasible, appropriate and important to evaluate the impact of public involvement in research. The value of public involvement was endorsed by participants. However, the limitations of the study were a lack of international panelists; researchers had a bias towards public involvement, and they had used a simplistic approach to develop measurable impact issues. However, this article confirms some belief that involvement can and should be measured and goes some way to provide measurement criteria.

Littlechild and Staley (2015) discussed the balance between the right of patients to be involved outweighing any measurable value, as it was a moral or ethical obligation to involve them in any aspect of healthcare. They questioned if the value can be measured and compared, as all projects have different contexts, purposes and outcomes. More evidence is required, from the staff who manage patient involvement, as to date this has been insufficiently detailed and the evidence was weak (Brett et al., 2014; Littlechild & Staley, 2015). Measuring the value of patient involvement from a cost effectiveness approach is difficult, as often the benefits are intangible or beyond economic value, and this remains to be evidenced (Ansari & Andersson, 2011).

Before a project involving patients was agreed, staff requested evidence (Barber et al., 2012) or known cost effectiveness of this approach, to convince them that the effort was a worthwhile venture (Marston & Renedo, 2013). However, due to a lack of standardised tools and reports the evidence was difficult to quantify, to use as leverage or a supporting argument, linking back to use of the ethical or moral viewpoint only. Patient involvement in healthcare projects may be a fundamental human right (Public Involvement Impact Assessment Framework, 2013), negating the need to measure the value of the impact (Popay 2014). Gillard et al. (2012) stated that the impact of involving patients and the public in research projects was hard to evaluate, and that knowledge of co-production in health services research remains largely unexplored. Public involvement was emerging as a new science where evaluation is critical as the science surrounding patient engagement was weak (Miller, Patton, Dobrow, Marshall, & Whitney, 2018).

2.7 Summary

It was evident that there was a plethora of research regarding the involvement of patients in healthcare; however, the articles were mostly concerned with a clinical intervention, research or clinical outcome, rather than process, patient flow or environment redesign projects. The literature points to the concept of patient involvement in design and redesign as being well regarded and agreed

by researchers, staff and executives, however the execution from best principles to practice was difficult and complex. Many of the articles provided limited information about how and when patients were involved and what the impact of this involvement was, which limits learning in this area (Staniszewska et al., 2017).

There has been limited research on the perspectives and experiences of staff managing patient involvement, and the effect that this involvement has on staff (Barber et al., 2012; Thompson, Bissell, Cooper, Armitage, & Barber, 2014). An improved understanding of staff perspectives may enhance patient involvement and assist to remove any barriers caused by negative perceptions and previous experiences (Arnetz, Höglund, Arnetz, & Winblad, 2008). Although there was some evidence of the positive impact of patient involvement, there was limited literature on the value of patient involvement (Harris et al., 2015; Van Duijn et al., 2013).

There were many policies and frameworks guiding and encouraging staff to involve patients, without an associated training package or organisational process to assist with recruitment issues and general patient management. The literature described a 'tokenistic' approach to document or report that a patient had been involved, without the required infrastructure or organisational drive to promote a genuine commitment to it.

There was a gap in the evidence regarding staff perceptions in this subject, the rate of patient involvement and the documented value of patient involvement which this study aims to provide. This study provides information and thoughts directly from staff, who may or may not have involved patients in their healthcare projects, to inform and enrich this poorly understood aspect of patient involvement.