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

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## CHAPTER 5: DISCUSSION

### 5.1 Introduction

Although this study involved a small sample size of project staff, it was shown to be representative of the population of project staff in WA Health. The discussions, conclusions and recommendations may be applicable to project staff working in public healthcare facilities in WA, as the contexts are all similar; however, they may be equally applicable to general project management in the private or not-for-profit healthcare sectors and indeed non-health entities.

The purpose of this study was to gather project staff perspectives around involving patients in their projects. The researcher had a guiding hypothesis that patients were not being involved in all projects for a variety of reasons, which has been supported by the data; only 70% (19) project staff stated that they had ever involved a patient in their projects. Since there is an expectation that patients are involved in healthcare projects, this figure was expected to be higher. However, the questionnaire did not specify the proportion of projects that the project staff were managing which included patient involvement, to provide a sense of the scale of projects with patient involvement e.g. if project staff were managing fifty projects but only five of these had patients involved.

On review of the comments from the questionnaire and the focus group, project staff were regarding the consumers (CAC members) as patients, rather than actual patients who had received care in the area that the project was involved with. The Participant Information Sheet ([Appx 5](#)) articulated the difference between definitions of consumers and patients for this study, however, as documented in [section 4.2.5.7](#), one staff member interpreted their own definition during the questionnaire:

*CAC (which does include some previous patients of the health service, therefore meets the definition for this research).*

Unless the individual CAC member had recently been a patient and this was known, rather than assumed, this does not meet the definition for this study. This may indicate that other respondents may not have complied with the definition and that the number of actual patients involved were less than reported.

The CAC is comprised of multiple consumers, therefore, the CAC member assigned to the project may not have had the relevant lived experience (Manafa et al., 2018) of being a patient in the ward or department that the project was involved with. Fereday (2016) describes how patients are essentially experts by experience; experience which a consumer may or may not have. There was also a high reliance noted on the CAC as a technique to gain a patient perspective during the questionnaire and the focus group. The purpose of this discussion is not to denigrate the involvement of the CAC members as they are extremely important to ensure the consumer voice is heard and valued by health service providers (Department of Health, 2018a). The focus group members discussed how important it was that project staff do not use the CAC to 'tick a box' and as an easy way out to state that they have involved consumers, and therefore not have to think about involving an actual patient.

The focus group members discussed how difficult it was to approach and recruit patients, which was also evident from the questionnaire responses. Organisations may need to review their structures and processes, as staff are reporting that the organisations are committed to patient involvement, yet there are difficulties with both patient access and patient recruitment.

The study identified age and gender issues within the project management workforce. Most respondents to the questionnaire and the focus group were female, which reflects the researchers work experience and the known female majority in the health professional workforce (Segal & Bolton, 2009). Additionally, most respondents were of mature age (over 40 years) which also reflects the researchers work experience of a maturing project workforce. Whilst from an organisational perspective this is positive, as it has been suggested that a mature workforce may have more skills, experience and potentially efficiency (Segal & Bolton, 2009), this may be a succession planning consideration that organisations will need to address in the near future.

Project staff can have multiple qualifications and use multiple project management or improvement methodologies to manage their projects. However, there were low levels of qualifications noted and low numbers of staff qualified in improvement

methodologies such as DMAIC, LEAN and Six-Sigma. Project staff are using many of the project management or improvement methodologies but without the specific training or required qualifications, suggesting a level of experiential learning. With the absence of an evaluation tool in any organisation, it is impossible to review if these methodologies were implemented appropriately and successfully, with a positive impact gained by involving patients. Organisations may consider reviewing job descriptions of project staff to stipulate certain skills or qualifications required in project management or improvement methodologies. Organisations may also consider reviewing their preferred project management or improvement methodologies to ensure that they meet organisational standards and requirements and are inclusive of patient involvement.

The questions in the questionnaire stated the main range of project and improvement methodologies that are frequently used in healthcare. PRINCE2® was the preferred project management methodology for WA Health, yet not all project staff were using this approach in their projects. Low numbers were using the PDSA methodology, although SMHS developed the first WA local Chapter of the American based Institute for Healthcare Improvement, which specifically utilises PDSA to manage its QI projects (2018). As most staff were employed in SMHS, this number would have been expected to be higher.

The following sections will discuss findings in relation to the research questions, staff perspectives, comparisons within the literature and the study limitations.

### **5.1.1 Research questions**

The questionnaire and focus group responses have provided answers to the research questions as detailed in the following sub-sections.

*Are project staff involving patients in WA public healthcare projects, and if so, in what ways and what types of projects?*

The questionnaire responses demonstrated that project staff involved patients in healthcare projects of short duration, but not in all projects nor all types of projects.

Patients are mostly recruited via staff and patient self-nomination with surveys being the most common form of involvement. High level involvement in committees and working groups or as decision-makers was not evident. Project staff involved patients in the more clinically based projects rather than infrastructure or Information Technology type projects.

The focus group discussions highlighted that project staff were willing to involve patients in their projects although one staff member had never involved a patient before; however, there was a heavy reliance noted on consumers from the CAC rather than involving actual patients.

*What opportunities or challenges have project staff encountered when involving patients in public healthcare projects?*

Staff described numerous opportunities (benefits) and challenges (barriers) of involving patients in their healthcare projects. The questionnaire responses suggest that the best outcome from involving patients is the insight gained into patient perspectives and needs but also that involvement can lead to increased communication and engagement with the patient population and improved services that address patients' needs or requirements. The focus group discussions also highlighted that gaining the patient perspective was an important opportunity but also discussed the potential benefits to the project in terms of improved project scoping, project outcomes, and positively impacting on staff behaviour, which was less valued in the questionnaire responses.

The largest challenge noted in both the questionnaire responses and the focus group discussions was the impact on staff time to manage the patient involvement. Both groups also highlighted difficulties with patient recruitment and staff training. Further discussions between the focus group members highlighted barriers with using different patients, setting expectations, decision making, staff anxiety, organisational risks, and resourcing.

*Are WA Health project staff receiving specific training in how to involve patients in public healthcare projects and do staff feel confident to involve the patients?*

WA Health project staff were not receiving specific training in how to involve patients in public healthcare projects, according to the questionnaire and focus group responses. Although, during the questionnaire, most staff stated that they were confident to involve patients in their projects, the small number of focus group members articulated a level of fear and anxiety with using this approach. During the focus group, staff also discussed the need for patient training in this area.

*How do project staff measure the value of patient involvement in public healthcare projects?*

Project staff were not measuring the value of patient involvement in public healthcare projects, due to a lack of a defined tool, framework or associated guidelines in any of their organisations. The questionnaire responses indicated that staff perceive this involvement can be measured and there was a genuine intent to measure and evaluate the impact of patient involvement during the focus group discussions; although, staff struggled to articulate how this could be achieved.

## **5.2 Project staff perspectives**

The findings from the quantitative and the qualitative phase demonstrate that overall involving patients in healthcare projects was perceived as positive by project staff. The project staff acknowledged that it was important and critical to involve patients, that it was deemed best practice, that patients did add value and that organisations needed the perspectives of their patients. The focus group members used positive and respectful language in terms of patient involvement such as: “they helped us; they can help you scope; patients have powerful impacts on staff; and the patients give us so much”. There was clearly an appreciation for the current level of patient involvement and the potential leverage that application of this approach can provide in future for staff and patients. Most of the project staff stated that patients want to be involved in healthcare projects; this is a positive finding as project staff may be more inclined to invite patients to join the project if they have a belief that the patient would wish to do so.

There were several challenges raised, which were mostly about staff perspectives, organisational culture and lack of organisational processes, rather than issues related to patients. This is a key finding which suggests that the difficulties with involving patients in projects is within the control and influence of staff and organisations, and therefore potential solutions may be implemented to reduce, mitigate or resolve the barriers. In the context of this study, patient related issues were not being reported because they either do not exist or they were maybe not as high a priority as other concerns. Staniszewska et al. (2011), discussed how reporting on patient involvement activities is often positively rather than negatively portrayed for fear of disengaging patients; however, in this study, patients were seemingly not the main root cause of the problems.

Project staff perceived that involving a patient in their projects will increase demands on their time and impact the overall project timeline, which was also evident in the research literature (Brett et al., 2014; Fairbrother et al., 2013; Garfield et al., 2015; Manafo et al., 2018; McKenzie et al., 2016; NHMRC, 2016; Norman, 2012; Robinson, 2014; Van Duijn et al., 2013). However, the focus group members discussed in a considered way that if a patient was to be involved, project teams should add extra time during project scoping to allow for this, so that it wouldn't be a barrier and the executive sponsor would be aware of the reason for an extended project timeline upfront. The executive sponsor was often the accountable person who approved the deadlines and timelines for the project and provided support and direction to the project team; so, it is key that they are aware of any potential disruptions or challenges and the reasons behind decisions made during project scoping.

Although project staff stated that their organisations were committed to patient involvement, they were unsure if there were any associated policies and protocols. If organisations did have policies and protocols, the project staff should have been aware of their existence and their content, as they would be required to comply with them. Project staff did not provide any information during the questionnaire regarding new or innovative practices for patient recruitment and incentives. This is an area worthy of attention in organisations to maximise their patient recruitment process. The researcher concluded from the questionnaire and focus group discussions that

organisations must have robust processes to support and enable staff to be innovative and uphold the organisations values; otherwise, there may be a disconnect between the organisational commitment to patient involvement and the application of this approach.

From the questionnaire responses, most staff advised that patients with impaired cognition, aggressive behaviour or those patients with an active or unresolved formal complaint should be excluded from participating in projects. Several project staff provided additional comments stating that aggressive patients pose a safety issue and that patients who have complained may bias the project, or their complaint may be unrelated and therefore not interfere with the project. However, dealing with patients who are difficult may be overwhelming for project staff, or they may think it will affect their project team timeline or outcome. Interestingly, the focus group members stated that they used the generic patient complaints information as one source of patient input to inform their projects.

The focus group members discussed several barriers with patient involvement due to fear, anxiety, risk, frustration and bureaucracy. Mistakenly, all members of the focus group believed that any direct consultation with patients would require formal ethics committee approval which would delay the project further. In most organisations in WA Health, the executive sponsor can provide approval for project staff to speak directly with patients, if the project is not classified as a research project.

### **5.3 Comparison of findings with the literature**

The evidence related directly to healthcare project management is scarce in the available literature; therefore, comparisons had to be made with evidence found in research projects rather than healthcare projects specifically. This section has been divided into three emerging themes arising from comparison of the literature with the findings: impact on staff; impact on the project; and impacts on the organisation.

#### **5.3.1 Impact on staff**

There have been limited studies describing staff perspectives and impact on staff when involving patients (Barber et al., 2012; Thompson et al., 2014); however, this

study has partially addressed this gap by providing perspectives and quotes directly from project staff. The study design did not include measuring staff stress levels when involving patients in their projects, as per the study by Arnetz, Zhdanova and Arnetz (2016b), merely the perspectives of staff regarding the subject. Overall, staff reported in a positive manner when discussing patient involvement and no staff discussed any negative dealings with patients, only the organisational barriers and frustrations that they faced. This aligns with the literature describing how in research articles only positive statements are used with regard to patient involvement; which may be due to political correctness or fear of disengaging patients and consumers, or the patient facing difficulties may be non-existent (Staniszewska et al., 2011).

The impact on staff time was described as the most challenging in the questionnaire responses, and discussed as one of the many barriers in the focus group; the impact on staff time and effort was documented in the literature as a major challenge for staff in research projects (Brett et al., 2014; Fairbrother et al., 2013; Garfield et al., 2015; Manafo et al., 2018; McKenzie et al., 2016; NHMRC, 2016; Norman, 2012; Robinson, 2014; Van Duijn et al., 2013).

Matthews (2010), stated that confidence levels varied amongst staff and there was a general lack of confidence when involving patients. In contrast, this study discovered that most staff were confident to involve patients in their projects, although some staff disagreed, aligning with the concept that confidence levels may vary. This study also discovered that there is a significant issue with lack of staff training in patient involvement, which correlates with the evidence found in multiple literature sources (Barber et al., 2012; Harris et al., 2015; NHMRC, 2016; Pearson, 2012; Pomey et al., 2015; Raman et al., 2015). Although, it would seem from the results of this study that lack of training has not impacted negatively upon staff confidence level when involving patients in healthcare projects.

A recent report from the Australian Commission on Safety and Quality in Health Care (2018), details the impact of National Standard 2 (Australian Commission on Safety and Quality in Health Care, 2012b), which encourages consumer participation in health services. The report described how some staff were still hesitant and reticent about consumer involvement and that staff did not have the required skills or indeed

the time to involve consumers. The report includes commentary on expansion of the standards to include patients being actively involved in their healthcare, and development of a national patient reported outcome measures tool to evaluate the impact of patient and consumer involvement. The report supports the findings in this study and outlines that organisations still have much work to do to enable genuine patient involvement.

Fairbrother et al. (2013) discussed how some staff avoid involving patients due to apprehensiveness, especially if they have no prior experience. In both the questionnaire and the focus group, some staff stated that they have never involved patients in their projects, which may induce an avoidance strategy. A sense of fear and anxiety experienced by a small number of focus group members when involving patients was a feature of this study, which was not evident in the available literature. This may be since many project teams work directly for, or on the direction of, executive level staff, and they may have a heightened concern with reputation and organisational risk.

Focus group members discussed how staff behavior and attitude can change in a positive way because of patients being involved, which aligns with the findings in the available literature (Consumers Health Forum of Australia, 2015; Locock et al., 2014; Pizzo et al., 2014). Focus group members also discussed, in line with the evidence, how staff need to understand and gain the patients perspectives and not assume what patients need (Locock et al., 2014; Matthews et al., 2010; Tsianakas et al., 2012).

### **5.3.2 Impact on the project**

Focus group members discussed how involving patients assisted to drive change in their projects that they would not have been able to do without their perspectives, which echoes findings in the literature (Crawford et al., 2002; Garfield et al., 2015; McKenzie et al., 2016). Staff advised that when patients had been involved in their projects, their stories and insights had a powerful impact on the project team. One project changed the way that an organisation booked clinic appointments for patients, as they did not align with radiology and pathology appointments or reporting

requirements. By listening to the patients, the project team were able to re-design the flow so that patients completed blood tests first, then x-rays and then had their clinic appointments scheduled last, when test results would be available. The project team was not aware that appointments were being booked in such an unstructured way before.

Staff discussed how involving patients improved project outcomes which is also consistent with the literature findings (Fereday, 2016; National Institute for Health Research, 2014b). However, the issue of sustainability of project outcomes when patients are involved was the only factor that did not arise during the focus group discussions, although it featured in the literature (Pizzo et al., 2014). 54% (14) of the questionnaire respondents agreed that involving patients does lead to improved project sustainability.

Impact to the project timeline was a barrier noted in this study, consistent with the findings in a qualitative research paper discussing researcher perspectives on consumer and community involvement in research (McKenzie et al., 2016). The focus group participants discussed the time it takes to 'manage' the patient interface with travel arrangements, financial payments and contacting the patients; this is articulated well in the research article with a quote from staff stating "it's something I do on top of everything else", (McKenzie et al., 2016, p. 6). However, this was less of an issue in the questionnaire responses.

### **5.3.3 Impact on the organisation**

This study identified issues with staff having differing definitions for patient involvement intertwined with consumer involvement; this is consistent with findings in the literature that described an absence of standards and inconsistency in definitions (Brett et al., 2014; Marston & Renedo, 2013; Mockford et al., 2012; Shippee et al., 2013). This lack of clarity has an impact on the organisation as policies should clarify the differences between consumer and patient involvement and when either or neither is required. There seemed to be a level of confusion amongst project staff related to the organisational expectations and intent in these matters, which may be mitigated by clear guidelines.

This study has highlighted that although organisations are subject to accreditation processes around involving consumers as per National Standard 2, (Australian Commission on Safety and Quality in Health Care, 2012b), project staff were not implementing this standard as not all projects involved patients and there was a clear lack of reporting, policies and protocols in this area, which is a topic of concern noted in many of the research articles (Brett et al., 2014; Ford & Bowness, 2012; Garfield et al., 2015; Lord & Gale, 2014; McKenzie et al., 2016; NHMRC, 2016; Robinson, 2014). Project staff also stated in the questionnaire and the focus group that patient involvement is not just about compliance with policy or accreditation nor should it be used just to purely 'tick a box'.

During the focus group, members discussed that there is this 'tick box mentality' and tokenistic practices in organisations to state that patients or consumers have been involved in the project, without evidence of true partnership or the level of involvement achieved, which is heavily reflected in the literature (Garfield et al., 2015; NHMRC, 2016; Robinson, 2014; Shippee et al., 2013). Patients and consumers may be consulted or informed, but they may not be involved in decision making or change. According to the questionnaire responses, patient input was mostly gained through surveys, which is classified as a low level of involvement and influencing, namely 'consulting' (Department of Health, 2016b). The level of patient involvement is important for organisations to note and report on, so that this can be increased and improved upon. If organisational values are to genuinely involve patients and consumers at higher levels of involvement, to empower patients with the outcome being patients and consumers being able to set objectives, policies and strategic directions (Department of Health, 2016b), then the organisation needs to understand what levels of involvement are actually occurring in their healthcare projects.

Mende and Rosman (2013) discussed barriers with staff resistance to patient involvement, patient recruitment and ensuring patient representativeness which surfaced in the study findings; however, the issue of staff resistance was dissimilar in this study, as WA Health project staff did not seem resistant or reluctant to involve patients, more hesitant (unsure) how to involve them in their projects. Low patient attendance at meetings was also discussed as a barrier in this study and stated by

Brett et al. (2014), as it's often difficult to gain patient commitment. Conflict between patients and staff was raised as an issue in the literature (Brett et al., 2014), however, this did not surface as an issue in the findings of this study.

Organisations did not have a tool, mechanism or evidence to measure the value of patient involvement which is consistent with the literature findings (Consumers Health Forum of Australia, 2015; Gillard et al., 2012; Harris et al., 2015; Mockford et al., 2012; Pearson, 2012; Shippee et al., 2013; Van Duijn et al., 2013). There was also a notable gap between the intent of staff to involve patients, the value they perceived and reported practice of how many patients were involved, as described by Lord & Gale (2014). In this study, staff intent to involve patients in their projects was high, however, this was not translating to their practice.

#### **5.4 Limitations**

There are several limitations in this study. Firstly, this study was restricted to project staff working in public healthcare services in WA and does not include the private or not-for-profit sector staff. Restricting the research area to staff working in public health services provides focused perspectives for patient involvement in public healthcare projects in WA Health. These findings may or may not relate to private organisations due to the different contexts and environments staff are working in, the different funding models and differing policies.

The study targeted people whose key role was to undertake project management duties, rather than any staff member who had been involved in a project. As WA Health does not maintain a register of people involved in project work, subjects invited to participate in this study were identified by their position title only. The findings may not be transferable to ward based staff leading healthcare projects or private contractors and consultancy firms who are specifically employed to manage a project in WA Health.

The population of project staff fluctuated, often due to the employment contracts being fixed term, reflecting the duration of the project. This also had an impact on sample sizing and response rates. The responses to the questionnaire were lower

than anticipated (30%); however, a response was received from each HSP in WA Health. The study was approved for sampling and questionnaire distribution on one day, to one hundred staff only, which limited further opportunities to re-distribute the questionnaire based on low response rates. A reminder email was included in the research proposal, but to those staff already sent the initial email request, which did encourage a few more staff to complete the questionnaire. As a local comparison, the EMHS Staff Engagement Survey (East Metropolitan Health Service, 2017) received a 30% response rate to an email survey which is congruent with email response rates documented in the literature (Fincham, 2008). Future studies may require staff to be nominated in advance by their organisation rather than random sampling techniques; however, this would need to be carefully planned and managed to avoid organisational bias. A limitation of this study was the low response rates to both the questionnaire and the focus group; however, the information received is valuable and provides some data to inform the existing evidence base.

The sampling method used was convenience sampling, which can have a risk of bias if the sample is atypical of the population (Polit & Tatano Beck, 2014); although, the stratified sampling with the individual HSP lists may have negated this affect (O'Leary, 2014) and the further population analysis demonstrated generalisability. However, decisions were made on who was available, with the specialised knowledge and willingness to answer the questionnaire and participate in the focus group, as described by Liamputtong (2013). The response sample size was below one hundred participants, which may lead to insufficient power to claim statistical significance (Pallant, 2013). Due to knowledge of this limitation, the researcher has used the term 'association' rather than significance.

The questionnaire did not review the impact of patient involvement on specific projects, merely if staff had ever involved a patient.

The focus group was limited to one health authority only, due to the vast geographical nature of WA; however, the health authority comprises five hospitals with representative services to those of the WA Health system; including rural, general, specialist and tertiary hospitals, with a proportionate casemix of planned and unplanned adult and paediatric patients, general and mental health services.

Staff working in remote areas may have differing perspectives and experiences from those of their metropolitan based colleagues, due to the contextual challenges of the environment and the barriers that patients may face in travelling to regular project meetings, due to their distance away from the healthcare setting. There was no minimum number set on focus group participants as it is the rich narrative from their discussions that is required rather than number of participants.

Although perspectives of patients or consumer groups are extremely important, this study focused on the perspectives of staff, as this was the noted gap in the literature. There was a plethora of research articles describing patient perspectives in experiences of their healthcare and involvement in research, however very limited evidence was found in the healthcare project setting. It would be an interesting project to compare the patient perspectives to the findings of staff perspectives in this study, as described by Pomey et al. (2015).

## **5.5 Summary**

This chapter has discussed the findings regarding staff perspectives, offered comparisons with the literature and stated the study limitations. The findings from this study demonstrate that while many project staff recognised the value of patient involvement in their projects, a range of personal and organisational factors limited this from routinely happening. This study contributes new knowledge to a limited evidence base, particularly in the field of healthcare project management, and actual staff perspectives into patient involvement. The concluding chapter will discuss the conclusions and recommendations arising from this study.