The University of Notre Dame Australia
ResearchOnline@ND

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

THE UNIVERSITY OF
NOTRE DAME
A U S T R A L I A

CHAPTER 4: FINDINGS

4.1 Introduction

The purpose of this study was to gain project staff perspectives regarding the involvement of patients in healthcare projects, using a mixed method approach as detailed in chapter 3. Chapter 4 provides a detailed description of the findings from each phase of the study; phase 1 quantitative; phase 2 qualitative and phase 3 data synthesis. Tables, diagrams and actual quotes from staff are included in the findings, with associated descriptions and summations provided in each section.

4.2 Phase 1 Quantitative phase – questionnaire results

4.2.1 Questionnaire response rates

One hundred project staff were emailed to request their participation in Phase 1 of this study; thirty of these staff completed the questionnaire, providing an overall response rate of 30% as shown in Table 5. Although, only sixty-nine staff out of the one hundred were able to participate (d), as other staff were on leave at the time of the questionnaire distribution (c) or they no longer worked in WA Health (b) (Table 5). This information was not known prior to survey distribution as all staff were active in the global staff address book.

Table 5 : Response Rates

Sample group (a)	No longer working in WA Health* (b)	On leave* (c)	Able to participate (d)	Responses received (e)	Overall response rate (e/a)
n =100	4	27	69	30	30%

Note. *according to out of office reply messages received via email

4.2.2 Demographics

As shown in Table 6, 40% (n=12) respondents worked in SMHS; 77% (n=23) were female, and 40 % (n=12) were aged 40-49 years.

Table 6 : Demographics

General characteristics of the study population	Number of respondents	% respondents
Q1: Please state which health authority you are currently working in by choosing one answer below	n=30	n=30
CAHS	1	3%
EMHS	6	20%
NMHS	7	24%
SMHS	12	40%
WACHS	4	13%
Total	30	100%
Q2: Please state your gender by choosing one answer below		
Male	7	23%
Female	23	77%
Total	30	100%
Q3: Please state your age by choosing one answer below		
18-29 years	6	20%
30-39 years	6	20%
40-49 years	12	40%
Over 50 years	6	20%
Total	30	100%

4.2.3 Position and experience

4.2.3.1 Position title

As shown in Table 7, 40% (n=12) respondents were Senior Project Officers which represent 14% (n=84) of the total population of Senior Project Officers employed in WA Health (Table 8).

Table 7 : Position Title

Characteristic: position title	Number of respondents	(%) respondents
Q4: Please state the title of your position by choosing one answer below	n=30	n=30
Project Director	0	0%
Project Coordinator	2	7%
Project Manager	6	20%
Senior Project Officer	12	40%
Project Officer	5	16.50%
*Other	5	16.50%
Total	30	100%

Note. *Other comments provided: Manager Program Management Office; Senior Program Management Officer; Program Management Officer; Manager; Program Manager

Further analysis of the number of responses received versus the overall population of WA Health project staff is provided in Table 8. 10% (n=30) of the total population of project staff employed in WA Health responded to the questionnaire.

Table 8 : Responses Compared to Population

Characteristic	Project / Program Director	Project / Program Coordinator	Project / Program Manager	Senior Project/ Program Officer	Project / Program Officer	Other	Total
Number of staff with this title in total population (N)	9	18	82	84	85	28	306
Number (population)	9(306)	18(306)	82(306)	84(306)	85(306)	28(306)	306(306)
(% of population)	3%	6%	27%	27%	28%	9%	100%
Respondents in this study with this title (n)	0	2	6	12	5	5	30
Number (respondents)	0(30)	2(30)	6(30)	12(30)	5(30)	5(30)	30(30)
(% of population number)	0%	11%	7%	14%	6%	18%	10%

The questionnaire was distributed to the first twenty staff from each HSP, regardless of their occupational group. Therefore, position title is random rather than specific. Despite the numerical differences identified in Table 8, there were no differences in the distribution of the two groups as demonstrated by the Chi Square calculator in Table 9. While the sample size used in this study was small, comparison of the distribution of employment titles in the sample was found to be statistically similar to the whole workforce (Table 9).

Table 9 : Population Distribution

	Project / Program Director	Project / Program Coordinator	Project / Program Manager	Senior Project/ Program Officer	Project / Program Officer	Other	Total
Not in study	9	16	76	72	80	23	276
Included in study	0	2	6	12	5	5	30
Total population	9	18	82	84	85	28	306

Chi-square calculation on population distribution

Test	Result
Chi-square	7.026
degrees of freedom	5
p-value	0.21871383
Yates' chi-square	4.301
Yates' p – value	0.50694178

4.2.3.2 Experience

As shown in Table 10, 50% (n=15) respondents have worked for between 1 and 5 years in healthcare projects.

Table 10 : Experience

Characteristic: experience	Number of respondents	(%) respondents
Q5: Please state how long you have worked in healthcare projects by choosing one answer below	n=30	n=30
Less than 1 year	1	3%
1-5 years	15	50%
6-10 years	11	37%
11 years or more	3	10%
Total	30	100%

4.2.4 Qualifications and skills

Project staff could have a multitude of various project management and / or improvement qualifications and may be skilled in using an adjunct improvement methodology in their projects such as LEAN.

4.2.4.1 Qualifications

As shown in Table 11, 49% (n=14) were PRINCE2® certified at Foundation or Practitioner level. Some respondents stated that they had qualifications in improvement methodologies: 24 % (n=7) for both DMAIC and LEAN, with only 7% (n=2) completing a Six-Sigma course. Low response rates were received for completion of university level studies and none had completed a master's in project management. 17% (n=5) had no qualifications.

Table 11 : Qualifications
(multiple response)

Characteristic: qualifications	Responses n=29	% of total (=58)	% respondents n=29
Q6: What project related qualifications do you have? Please choose all relevant answers below			
DMAIC	7	12%	24%
Fundamentals of Project Management	10	17%	34%
Post Graduate Certificate in Project Management	1	2%	3%
Post Graduate Diploma in Project Management	1	2%	3%
Masters in Project Management	0	0%	0%
PRINCE2® Foundation	8	14%	28%
PRINCE2® Practitioner	6	10%	21%
Project Management Professional	1	2%	3%
LEAN	7	12%	24%
Six-Sigma	2	3%	7%
None	5	9%	17%
*Other	10	17%	34%
Total	58	100%	

*Other – comments provided:
- *Project management within MBA and LEAN as part of Emerging Leaders (this is a senior staff development program offered by WA Health)*
- *MBA (Master Business Administration)*
- *Diploma of Project Management*
- *Diploma of Project Management (TAFE qualification) and additional unit within master's level*
- *Diploma of Management (not project specific)*
- *Cert IV Project Management*
- *Agile*
- *Short 2-day course many years ago*
- *Lean Six Sigma Green Belt*
- *Attended a number of project management, CSR, LEAN, Six sigma and DoH courses*

4.2.4.2 Skills

As shown in Table 12, 52 % (n=15) used Clinical Service Redesign and 10% (n=3) use none of the methodologies listed in the questionnaire.

Table 12 : Skills
(multiple response)

Characteristic: skills	Responses n=29	% of total (=67)	% respondents n=29
Q7: Which project or improvement methodologies do you use to manage your projects? Please choose all that apply			
Clinical Service Redesign	15	22%	52%
LEAN	14	21%	48%
Six Sigma	8	12%	28%
Plan-Do-Study-Act (PDSA)	9	13.5%	31%
PRINCE 2®	11	16.5%	38%
PMBOK	5	7.5%	17%
None	3	4.5%	10%
*Other	2	3%	7%
Total responses	67	100%	

Other comments: Depends on the project; For Project management (governance and project control) we use a tailored PRINCE2 approach. In conjunction with this we use Quality Improvement methods such as lean six sigma, PDSA

4.2.5 Staff perspectives

As shown in Figure 5, 70% (n=151 of 216) of respondents agreed with the value-based statements overall; noting that all statements were positively worded, meaning that agreement indicated a positive attitude. Ninety-six percent (n=26) respondents agreed that patients add value to healthcare projects, that it is best practice to involve patients in healthcare projects and that patient involvement should be representative of the patient population.

Only 26% (n=7) respondents had received specific training in how to involve patients in healthcare projects, yet 66% (n=18) were confident to involve them. Only 30% (n=8) respondents agreed that their health authority has a good system to recruit patients yet 78% (n=21) agree that their organisation is committed to patient involvement.
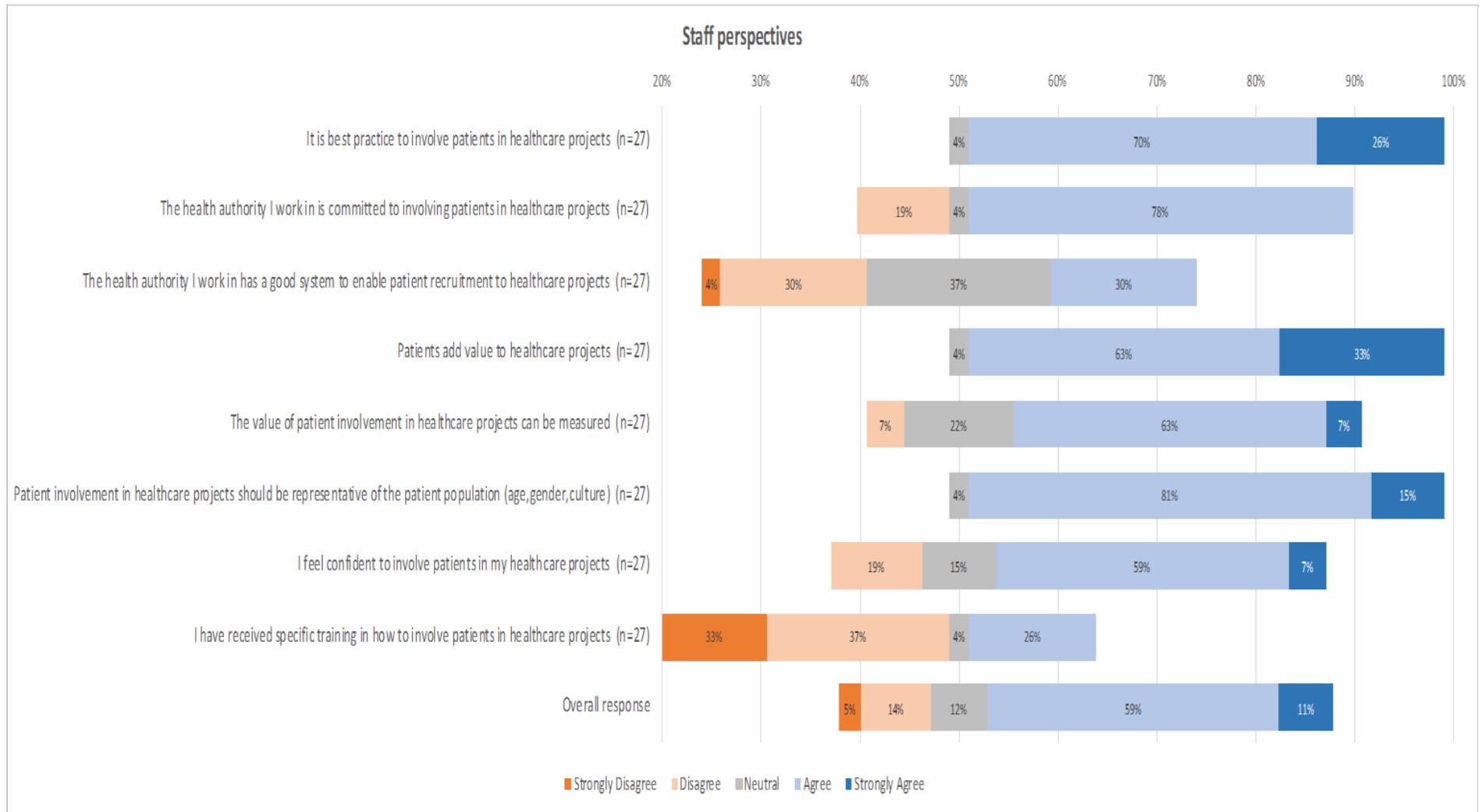
Figure 5. Staff perspectives

4.2.6 Patient involvement

4.2.6.1 Patient involvement

Table 13 shows that 70% (n=19) respondents had involved patients in their projects at some point in their career; however, 30% (n=8) had not involved patients.

Table 13 : Patient Involvement

Characteristic: involved patients	Number of respondents (n=27)	(%) respondents
Q9: Have you ever involved patients in your projects? Please choose one answer below		
Yes	19	70%
No	8	30%
Total	27	100%

4.2.6.2 Number of patients involved

Table 14 shows that 50% (n=9) respondents included small numbers of patients (1-5) in their healthcare projects in the last 12 months.

Table 14 : Number of Patients Involved

Characteristic: number involved	Number of respondents (n=18)	(%) total responses (n=18)
Q10: How many patients have you involved in your healthcare projects in the last 12 months? Please choose one answer below		
1-5 patients	9	50%
6-10 patients	4	22%
11-20 patients	0	0%
Over 20 patients	5	28%
Total responses	18	100%

4.2.6.3 Project duration with patient involvement

Table 15 shows 47% (n=9) respondents involved patients in projects of short

duration i.e.1-6 months.

Table 15 : Duration of Patient Involvement
(multiple response)

Characteristic: duration of involvement	Number of responses (n=19)	% total responses (n=20)	% respondents (n=19)
Q11: What is the average length of the healthcare projects that you have involved patients in? Please choose all that apply			
Less than 1 month	3	15%	16%
1-6 months	9	45%	47%
7-12 months	2	10%	11%
More than 12 months	3	15%	16%
*Other	3	15%	16%
Total	20	100%	

*Other – comments received: too various and intermittent to average; on a as needed basis at different points in time; Only involved patients in Voice of Patient (VOP) surveys

4.2.6.4 Project type with patient involvement

Table 16 shows 74% (n=14) respondents involved patients in CSR projects;

whereas, less respondents involved patients in infrastructure projects, such as

building redesign projects and new builds.

Table 16 : Types of Projects
(multiple response)

Characteristic: types of projects	Number of responses (n=19)	% total responses (n=48)	% respondents (n=19)
Q12: Please select from the list below any types of healthcare projects that you have involved patients in. Please choose all that apply			
New building	4	8%	21%
Building redesign	3	6%	16%
Patient flow redesign	8	17%	42%
Quality Improvement	7	15%	37%
Clinical Service Redesign	14	29%	74%
Clinical Pathways	9	19%	47%
Information Technology	0	0%	0%
*Other	3	6%	16%
Total	48	100%	

*Other comments received: Provision, environment and location of services; Only involved patients in Voice of Patient (VOP) surveys / Policy; Furniture, Fixtures and Equipment (FF&E)

4.2.7 Patient perspectives, recruitment and incentives

4.2.7.1 Patient perspectives

Table 17 shows that 79% (n=15) respondents gained patient perspectives via surveys.

Table 17 : Patient Perspectives
(multiple response)

Characteristic: patient perspectives	Number of responses (n=19)	% total responses (n=68)	% respondents (n=19)
Q13: Please select from the list below any techniques that you have used to gain patient perspectives or input in your healthcare projects. Please choose all that apply			
Patient surveys	15	22%	79%
Patient focus groups	7	10.5%	37%
Patient interviews/stories	9	13.5%	47%
Patient as a project team member	5	7%	26%
Observation of the patient journey	10	15%	53%
Observation of patient interaction with staff	3	4%	16%
Patient experience tracker	1	1.5%	5%
CAC input	11	16%	58%
Marketing i.e. inviting comments through media	0	0%	0%
Case studies	5	7.5%	26%
*Other	2	3%	11%
Total	68	100%	

Other comments received: Consumer Advocacy Group; Patients included in workshop participants with staff

4.2.7.2 Patient recruitment

Table 18 shows that 58 % (n=11) of patient recruitment to healthcare projects occurred via either staff nomination or patient self-nomination.

Table 18 : Recruitment
(multiple response)

Characteristic: patient recruitment	Number of responses (n=19)	% total responses (n=36)	% respondents (n=19)
Q14: How do you recruit patients to your healthcare projects? Please choose any relevant answers below			
Staff nomination	11	30.5%	58%
Patient self-nomination	11	30.5%	58%
Internal database of interested patients	6	17%	32%
Social media	0	0%	0%
Newspaper adverts	1	3%	5%
Bedside cards	0	0%	0%
*Other	7	19%	37%
Total	36	100%	

*Other comments received : ask patients if they would participate in a survey; voice of patient – ask patients if they would like to participate; surveyed patients are recruited from the floor; Community Advisory Council (CAC); CAC; Identified as a patient within target group and asked while in hospital if they would be part of it. Also, can ask for people via CAC; CAC (which does include some previous patients of the health service, therefore meets the definition for this research)

4.2.7.3 Incentives

Table 19 shows that 55% (n=6) respondents provided refreshments to patients involved in their healthcare projects.

Table 19 : Incentives
(multiple response)

Characteristic: incentives	Number of responses (n=11)	% total responses (n=20)	% respondents (n=11)
Q15: Please select from the list below any incentives that you currently provide to patients involved in healthcare projects			
Reimbursement of travel costs	2	10%	18%
Volunteer driver pick up	0	0%	0%
Refreshments	6	30%	55%
Photo in the internal newsletter	2	10%	18%
Financial payment to attend	5	25%	45%
Certification of participation	0	0%	0%
Meet and greet Executive Director / CEO	1	5%	9%
*Other	4	20%	36%
Total	20	100%	

*Other comments received: never offered an incentive to complete a survey; not currently working with patients; previously used refreshments, financial payments to attend; CAC members are paid but patients identified on the ward to be part of surveys and interviews are not incentivised at all; Nil

4.2.8 Tools and policies

4.2.8.1 Evaluation tools

Table 20 shows that 100% (n=27) of respondents' state that they do not have a process or tool to evaluate the effectiveness or value of patient involvement in projects within their organisations.

Table 20 : Evaluation Tools

Characteristic: evaluation tools		Number of responses (n=27)	(%) total responses
Q16: Do you have a formal process or tool to evaluate the effectiveness or value of patient involvement in healthcare projects? Please choose one answer below			
	Yes	0	0%
	No	27	100%
	Total	27	100%

4.2.8.2 Policies

Table 21 shows that 58% (n=15) respondents were unsure if their organisation had any policies or protocols to govern patient involvement in healthcare projects.

Table 21 : Policy

Characteristic: policy		Number of responses (n=26)	(%) total responses
Q17: Does your organisation have any policies or protocols to govern the involvement of patients in healthcare projects? Please choose one answer below			
	Yes	10	38%
	No	1	4%
	Unsure	15	58%
	Total	26	100%

4.2.9 Measurable value of patient involvement

As shown in Figure 6, 64% (n=134 of 208) agreed overall with the value statements; 77% (n=20) strongly agreed that by involving patients you gain an insight into their perspectives and needs; 62% (n=16) strongly agreed that involving patients results in improved services that address their needs and requirements; 54% (n=14) strongly agreed that involving patients improves communication and engagement with patients.
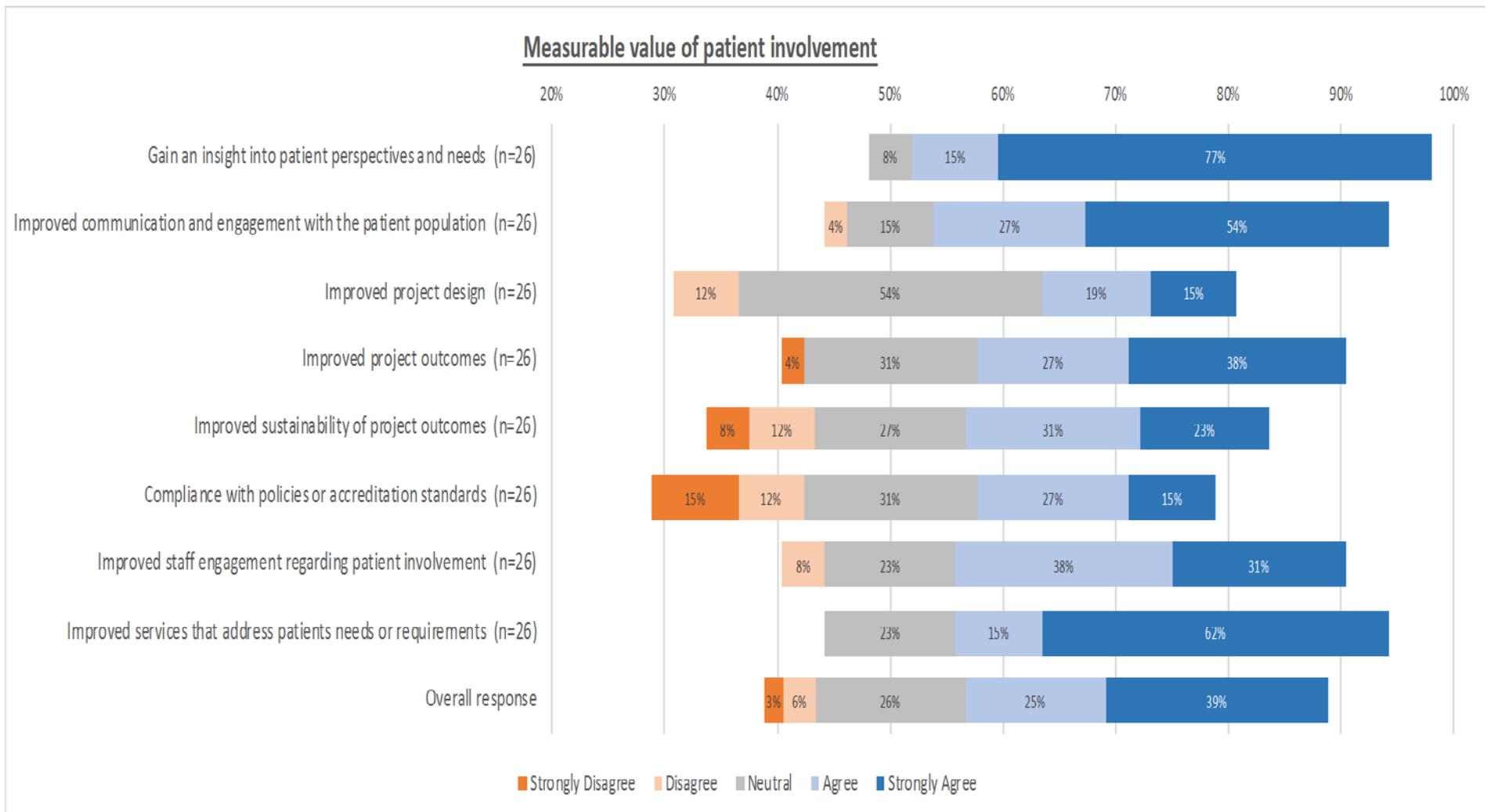
Measurable value of patient involvement

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Gain an insight into patient perspectives and needs (n=26)			8%	15%	77%
Improved communication and engagement with the patient population (n=26)		4%	15%	27%	54%
Improved project design (n=26)		12%	54%	19%	15%
Improved project outcomes (n=26)	4%		31%	27%	38%
Improved sustainability of project outcomes (n=26)	8%	12%	27%	31%	23%
Compliance with policies or accreditation standards (n=26)	15%	12%	31%	27%	15%
Improved staff engagement regarding patient involvement (n=26)		8%	23%	38%	31%
Improved services that address patients needs or requirements (n=26)			23%	15%	62%
Overall response	3%	6%	26%	25%	39%

Figure 6. Patient involvement

67

4.2.10 Perceived challenges of patient involvement

As shown in Figure 7, 54% (n=114 of 208) respondents disagreed with the statements overall ; 54% (14) strongly disagreed that the cost of involving patients was a challenge; 42 % (11) strongly disagreed that the impact on the project timeline was a challenge; 46% (12) strongly disagreed that patients lack knowledge; 39% (10) agreed that involving patients impacts on staff time, however 38% (10) disagreed.

46% (12) disagreed that patients not arriving for project meetings was a challenge; 69% (18) disagreed that it was unclear why the patient was being involved; 61% (16) disagreed that patients would feel intimidated; 61% (16) disagreed that staff would feel threatened by patient questions or input.
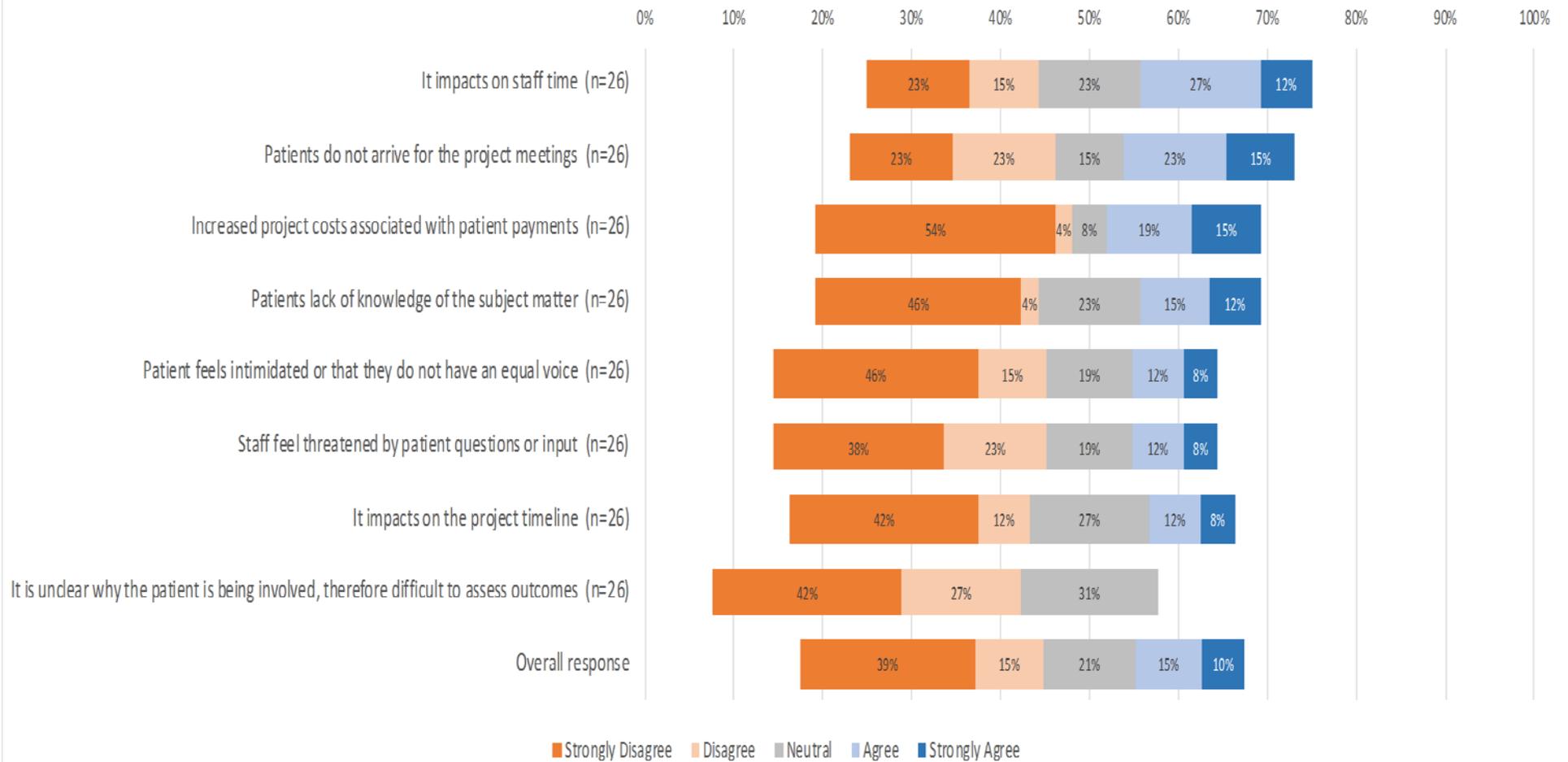
Figure 7. Challenges of patient involvement

4.2.11 Staff opinion of patients' perspective

4.2.11.1 Do patients want to be involved?

As shown in Table 22, 69% (n=18) stated that in their opinion, patients want to be involved in healthcare projects.

Table 22 : Staff Opinion -1

Characteristic: staff opinion	Number of responses (n=26)	(%) total responses
Q20: In your opinion, do patients want to be involved in healthcare projects? Please choose one answer		
Yes - they do	18	69%
No – they don't	0	0%
Maybe	8	31%
Total	26	100%

4.2.11.2 Are some patients not suitable?

As shown in Table 23, 55% (n=11) indicated that patients with known aggressive behavior are not suitable to be involved in healthcare projects.

Table 23 : Staff Opinion -2
(multiple response)

Characteristic: staff opinion	Number of responses (n=20)	% total responses (n=50)	% respondents (n=20)
Q21: Please select any patient groups from the list below that you feel should NOT be involved in healthcare projects.			
Patients with impaired cognition	10	20%	50%
Unwell patients	5	10%	25%
Terminally ill patients	2	4%	10%
Patients with a Mental Health condition	2	4%	10%
Patients under 18 years of age	2	4%	10%
Patients with known aggressive behaviour	11	22%	55%
Patients with an active/ unresolved formal complaint	10	20%	50%
Patients who present as an emergency	2	4%	10%
Patients who require an interpreter	0	0%	0%
*Other	6	12%	30%
Total	50	100%	

*Other comments provided:
- *It would depend on the project scope and deliverables*
- *It depends on your target population healthcare projects are varied and there may be projects where these population groups form part of the target group. Patients with aggressive behaviour present a safety issue, however if the project is related to a service that targets these patients then you have to find a way of safely including them. You have to consider if the patient with a complaint is going to be biased in their interaction, but a complaint could be unrelated to what your project is about and may have no bearing.*
- *I think this depends on the project, projects that target any of these patient groups may have a case to involve any of these patient groups*
- *All should be considered – depends on what rationale is for patient input*

- *Any recovered patient, or patient who is sufficiently well to indicate an interest (but not those with unresolved complaints) should be candidates for participation*
- *Any patient that declines involvement*

4.2.11.3 Are some projects not suitable?

As shown in Table 24, 54% (n=14) indicated that they were unsure if there are types of projects that are not suitable or appropriate to involve patients in.

Table 24 : Staff Opinion -3

Characteristic: staff opinion	Number of responses (n=26)	(%) total responses
Q22: Are there any types of healthcare projects that you feel are not suitable or appropriate to involve patients in? Please choose one answer		
Yes – there are	9	34.5%
No – there are not	3	11.5%
Maybe	14	54%
Total	26	100%

4.2.12 Summation of questionnaire responses

Table 25 provides a summation of the questionnaire responses and main findings.

Table 25 : Phase 1 - Summation of Findings

Criteria	Major finding
Demographics	A response was received from all five HSP's; 40 % (n=12) respondents were from SMHS, 77 % (n=23) were female and 60 % (n=18) were over 40 years of age.
Position and experience	Sampling reflected the population of project staff and their various positions. 40 % (n=12) respondents were Senior Project Officers with 50% (n=15) having between 1 to 5 years' experience of working in healthcare projects; 47% (n=14) have over 6 years of experience.
Qualifications	Project staff have multiple qualifications: 49% (n=14) respondents were PRINCE2® certified, and 34% (n=10) completed Fundamentals of Project Management; low rates of university level qualifications were evident and 17% (n=5) respondents had no qualifications.
Skills	Project staff can use multiple methodologies with or without qualifications: 52 % (n=15) respondents use CSR and 48% (n=14) use LEAN; 10% (n=3) use no methodologies. Staff are using improvement methodologies but may not have the associated qualifications as only 24% (n=7) respondents stated that they had either CSR (DMAIC) or LEAN qualifications.
Staff perspectives	96% (n=26) respondents agreed that patients add value to projects, that it is best practice to involve patients in healthcare projects and that involvement should be representative of the patient population. Only 26% (n=7) respondents indicated that they had received specific

	training in patient involvement, although 66% (n=18) were confident to involve patients. Only 30% (n=8) reported that they had patient recruitment processes in their organisation, yet 78% (n=21) respondents think that their organisation is committed to patient involvement.
Patient involvement	70% (n=19) respondents had involved a patient in a project during their career; 50% (n=9) respondents included 1-5 patients in a project in the last 12 months.47% (n=9) had involved patients in projects with a short duration of 1-6 months. 74% (n=14) respondents had involved patients in CSR projects, whereas only 21%(n=4) had involved them in new building projects and only 16% (n=3) in building redesign projects. No respondents had involved patients in Information Technology projects.
Patient perspectives, recruitment and incentives	79% (n=15) respondents gained patient perspectives via surveys, with 58 % (n=11) respondents recruiting patients via either staff nomination or patient self-nomination. 55% (n=6) used refreshments and 45% (n=5) had used financial payments as incentives.
Evaluation tools and policies	100% (n=27) respondents reported that there were no tools in the organisations for evaluating patient involvement. 58% (n=15) were unsure if their organisation had any policies or protocols governing patient involvement.
Perceived benefits of patient involvement	92 % (n=24) respondents agreed that the most benefit of patient involvement was to gain an insight into the patient perspectives and needs. 81% (n=21) agreed that involving patients improved communication and 77% (n=20) agreed that involving patients improved services to meet their needs and requirements.
Perceived challenges of patient involvement	39% (n=10) agreed that the most challenging aspect of patient involvement is the impact on staff time, although 38% (n=10) disagreed with this. 54% (n=14) strongly disagreed that the cost of involving patients was a challenge; 42 % (n=11) strongly disagreed that the impact on the project timeline was a challenge; 46% (n=12) strongly disagreed that patients lack knowledge; 46% (n=12) disagreed that patients not arriving for project meetings was a challenge. 69% (n=18) disagreed that it was unclear why the patient was being involved.61% (n=16) disagreed that patients would feel intimidated. 61% (n=16) disagreed that staff would feel threatened by patient questions or input.
Staff opinion	69% (n=18) respondents though that patients want to be involved in projects, but 54% (n=14) were unsure if there may be types of projects that would not be suitable to involve them in. There are types of patients who were identified as unsuitable to be involved in projects; 55% (n=11) thought those patients who had aggressive behaviour ; 50% (n=10) thought those patients with impaired cognition; 50% (n=10) thought those patients who have an active or unresolved formal complaint would not be suitable.

The next section describes further analysis of some of the questionnaire responses by performing various crosstabulation exercises.

4.3 Crosstabulation

Some of the questionnaire responses were manually imported into the quantitative software analysis tool SPSS™, Version 25 (IBM Analytics, 2016), to analyse potential bivariate (two variable) findings, as the Qualtrics™ software provided univariate (one variable) findings only (O'Leary, 2014). The crosstabulation exercises in SPSS™ were completed to check if there were any associations between variables, specifically checking for a p value of less than 0.05 (O'Leary, 2014), using Fisher's Exact test due to the low cell counts (Pallant, 2013). The results display the p values found for each variable and only those below 0.05 display the crosstabulation finding in more detail.

4.3.1 Involved patients

This relates to question 9 in the questionnaire "Have you ever involved patients in your projects?". Table 26 describes the findings (p value) of associations between multiple variables (variable 2) with involved patients (variable 1).

Table 26 : Crosstabulation - Involved Patients

Rationale – to check if:	Variable 1	Variable 2	n=	*p value
Staff having a qualification of any kind (yes or no – not specific) has an association with them involving patients	Involved patients	Qualifications	27	0.175
Staff using a methodology of any kind (yes or no - not specific) has an association with them involving patients	Involved patients	Methodologies	27	0.513
Staff years of experience has an association with them involving patients	Involved patients	Experience	27	1.000
Staff in different health services are more likely to involve patients	Involved patients	Health Service Provider	27	0.187
Male or female staff are more likely to involve patients	Involved patients	Gender	27	1.000
Age of staff has an association with them involving patients	Involved patients	Age	27	0.188
Staff position has an association with them involving patients	Involved patients	Position title	27	0.046
Involving patients is linked to the staff perception of the patients wanting to be involved	Involved patients	Staff opinion	26	0.667
Involving patients is linked to organisations having policies or protocols in place	Involved patients	Polices or protocols	26	0.116
Involving patients is linked to staff perceptions of some projects not being suitable to involve patients in	Involved patients	Not suitable	26	0.592
Staff who do not use any methodology has an association with them involving patients	Involved patients	No methodology	27	0.513
Staff who have other qualifications than those listed has an association with them involving patients	Involved patients	Other qualifications	27	0.206

Note. *_Fisher's Exact Test: Exact Sig. (2 sided)_

4.3.1.1 Findings

As shown in Table 26 , the only finding with a p value less than 0.05 was between 'involved patients' and 'position title' _(n=27; p=0.046);_ suggesting that there may be an association between the level of the employee in the organisation and whether

they involve patients in their projects or not. In this study, 91% of Senior Project Officers who responded involved 53% of the total number of patients involved, as shown in the SPSS™ Output tables (Table 27).

Table 27 : SPSS™ Result Tables (Crosstabulation & Chi-Square)

Involved patients and Position title Crosstabulation

Involved patients	Count	Project Coordinator	Project Manager	Senior Project Officer	Project Officer	Other	Total
Yes	Count	2	4	10	1	2	19
	% within Involved Patients	10.5%	21.1%	52.6%	5.3%	10.5%	100.0%
	% within Position Title	100.0%	80.0%	90.9%	25.0%	40.0%	70.4%
	% of Total	7.4%	14.8%	37.0%	3.7%	7.4%	70.4%
No	Count	0	1	1	3	3	8
	% within Involved Patients	0.0%	12.5%	12.5%	37.5%	37.5%	100.0%
	% within Position Title	0.0%	20.0%	9.1%	75.0%	60.0%	29.6%
	% of Total	0.0%	3.7%	3.7%	11.1%	11.1%	29.6%
Total	Count	2	5	11	4	5	27
	% within Involved Patients	7.4%	18.5%	40.7%	14.8%	18.5%	100.0%
	% within Position Title	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
	% of Total	7.4%	18.5%	40.7%	14.8%	18.5%	100.0%

Chi-Square Tests

Tests	Value	df	Asymptomatic Significance (2 – sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	9.451[a]	4	.051	.047	
Likelihood Ratio	9.881	4	.042	.080	
Fisher's Exact Test	8.353			.046	
Linear-by-Linear Association	5.440[b]	1	.020	.019	.014
N of Valid Cases	27				

4.3.2 Number of patients involved

Table 28 describes the findings (p value) of multiple variables (variable 2), the same as Table 26, but with a different constant variable being the number of patients involved (variable 1). This relates to question 10 in the questionnaire "How many patients have you involved in your healthcare projects in the last 12 months?".

Table 28 : Crosstabulation - Number Involved

Rationale – to check if:	Variable 1	Variable 2	N=	*p value
Staff having a qualification (yes or no – not specific) has an association with the number of patients they involve	Number involved	Qualifications	18	0.779
Staff using a methodology (yes or no - not specific) has an association to more patients being involved	Number involved	Methodologies	18	0.222
Staff years of experience has an association with the number of patients they involved	Number involved	Experience	18	0.195
Staff in different health services are involving more patients	Number involved	Health Service Provider	18	0.633
Male or female staff are involving more patients	Number involved	Gender	18	1.000
Age of staff has an association with them involving more patients	Number involved	Age	18	0.738
Staff position has an association with involving more patients	Number involved	Position title	18	0.035
Involving more patients is linked to the staff perception of the patients wanting to be involved	Number involved	Staff opinion	17	0.278
Involving more patients is linked to organisations having policies or protocols in place	Number involved	Polices or protocols	17	0.166
Involving more or less patients is linked to staff perceptions of some projects not being suitable to involve patients in	Number involved	Not suitable	17	0.715
Staff who do not use any methodology has an association with them involving patients	Number involved	No methodology	18	0.222
Staff who have other qualifications than those listed has an association with them involving patients	Number involved	Other qualifications	18	0.431

Note. *Fisher's Exact Test: Exact Sig. (2 sided)

4.3.2.1 Findings

As shown in Table 28, the only finding with a p value less than 0.05 was between 'number involved' and 'position title' (*n=18; p= 0.035*); suggesting an association between the level of the employee in the organisation and the number of patients that are involved in their projects. In this study, 70% of the Senior Project Officers who responded involved 78% of the total number of patients involved in the range '1-5 patients involved in the last twelve months', as shown in SPSS™ output tables (Table 29).

Table 29 : SPSS™ Result Tables (Crosstabulation & Chi-Square)

Number involved and Position title crosstabulation

Number involved	Count	Project Coordinator	Project Manager	Senior Project Officer	Other	Total
1-5	Count % within Number involved % within Position title % of Total	0 0.0% 0.0% 0.0%	2 22.2% 50.0% 11.1%	7 77.8% 70.0% 38.9%	0 0.0% 0.0% 0.0%	9 100.0% 50.0% 50.0%
6-10	Count % within Number involved % within Position title % of Total	2 50.0% 100.0% 11.1%	1 25.0% 25.0% 5.6%	0 0.0% 0.0% 0.0%	1 25.0% 50.0% 5.6%	4 100.0% 22.2% 22.2%
Over 20	Count % within Number involved % within Position title % of Total	0 0.0% 0.0% 0.0%	1 20.0% 25.0% 5.6%	3 60.0% 30.0% 16.7%	1 20.0% 50.0% 5.6%	5 100.0% 27.8% 27.8%
Total	Count % within Number involved % within Position title % of Total	2 11.1% 100.0% 11.1%	4 22.2% 100.0% 22.2%	10 55.6% 100.0% 55.6%	2 11.1% 100.0% 11.1%	18 100.0% 100.0% 100.0%

Chi-Square Tests

Tests	Value	df	Asymptomatic Significance (2 – sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	12.115[a]	6	.059	.044	
Likelihood Ratio	14.011	6	.030	.037	
Fisher's Exact Test	10.363			.035	
Linear-by-Linear Association	.548[b]	1	.459	.503	.264
N of Valid Cases	18				

4.3.3 Qualifications and methodologies

Specific qualifications and methodologies used by project staff were crosstabulated to analyse if certain qualifications that staff had or specific methodologies that staff used had an impact on whether patients were involved.

4.3.3.1 Qualifications

In this study, there was no association found between qualifications and patient involvement during crosstabulations (Table 30). However, on checking the individual responses to the questionnaire, two project staff who stated that they had Six-Sigma qualifications also stated that they had involved patients; suggesting that there may be an association between Six-Sigma qualification and patient involvement.

Table 30 : Crosstabulation – Qualifications

Rationale – to check if:	Variable 1	Variable 2 Qualifications	n=	*p value
Staff with DMAIC qualification involved patients	Involved patients	DMAIC	27	0.136
Staff with PRINCE2 Foundation (PRINCE2F) qualification involved patients	Involved patients	PRINCE2F	27	0.658
Staff with PRINCE2 Practitioner (PRINCE2P) qualification involved patients	Involved patients	PRINCE2P	27	1.000
Staff with Fundamentals of Project Management (FPM) qualification involved patients	Involved patients	FPM	27	0.201
Staff with LEAN qualification involved patients	Involved patients	LEAN	27	1.000

Note. *Fisher's Exact Test: Exact Sig. (2 sided)

4.3.3.2 Methodologies

Table 31 details the findings (p value) of crosstabulations between various methodologies (variable 2) and patient involvement (variable 1), which suggests an association between staff using Six-Sigma methodology and patient involvement in their projects (*n=27; p=0.026*).

Table 31 : Crosstabulation – Methodologies

Rationale – to check if:	**Variable 1**	**Variable 2 Methodologies**	**n=**	***p value**
Staff who use CSR methodology involve patients	Involved patients	CSR	27	0.087
Staff who use LEAN methodology involve patients	Involved patients	LEAN	27	0.087
Staff who use Six-Sigma methodology involve patients	Involved patients	Six-Sigma	27	0.026
Staff who use PDSA methodology involve patients	Involved patients	PDSA	27	0.666
Staff who use PRINCE2 methodology involve patients	Involved patients	PRINCE2	27	1.000
Staff who use PMBOK methodology involve patients	Involved patients	PMBOK	27	1.000

Note. **Fisher's Exact Test: Exact Sig. (2 sided)*

As shown in the SPSS™ Output tables (Table 32),100% of staff who used Six-Sigma methodology involved patients in their projects.

Table 32 : SPSS™ Results Tables (Crosstabulation & Chi-Square)

Involved patients and Six Sigma crosstabulation

Involved patients		Six Sigma - Yes	Six Sigma - No	Total
Yes	Count	9	10	19
	% within involved patients	47.4%	52.6%	100.0%
	% within Six sigma	100.0%	55.6%	70.4%
	% of total	33.3%	37.0%	70.4%
No	Count	0	8	8
	% within involved patients	0.0%	100.0%	100.0%
	% within Six sigma	0.0%	44.4%	29.6%
	% of total	0.0%	29.6%	29.6%
Total	Count	9	18	27
	% within involved patients	33.3%	66.7%	100.0%
	% within Six sigma	100.0%	100.0%	100.0%
	% of total	33.3%	66.7%	100.0%

Chi-Square Tests

Tests	Value	df	Asymptomatic Significance (2 – sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.684[a]	1	.017	.026	.020
Continuity Correction[b]	3.752	1	.053		
Likelihood Ratio	8.085	1	.004	.026	.020
Fisher's Exact Test				.026	.020
Linear-by-Linear Association	5.474[c]	1	.019	.026	.020
N of Valid Cases	27				

4.3.4 Summation

The crosstabulation exercise has resulted in finding three positive associations of patient involvement and the number of patients involved with position title, and Six-Sigma methodology as summarised in Table 33.

Table 33 : Crosstabulations - Summation of Findings

Variable 1	Variable 2	N=	*p value
Involved patients	Position title	27	p=0.046
Number involved	Position title	18	p=0.035
Involved patients	Six-Sigma Methodology	27	p=0.026

Note. *Fisher's Exact Test: Exact Sig. (2 sided)

Senior Project Officers were involving patients in their projects, mostly between 1-5 patients. Only two respondents stated that they had Six-Sigma qualifications (7%); respondent #15, a Senior Project Officer, and respondent # 30, a Manager. Both respondents stated that they use Six-Sigma methodology, and both indicated that they had involved patients in their projects. Of the nine respondents who stated that they use Six-Sigma methodology five were Senior Project Officers, three were Project Managers and one was a Manager. Therefore, nine staff were using this methodology with only two of them being qualified. Although in this study there were a small number of Six-Sigma qualified staff, there was an association found between Six-Sigma qualification and patient involvement (100%), as well as the use of Six-Sigma methodology, with or without a qualification, (*n=27; p=0.026* as per Table 33).

The purpose of Phase 1 was to gather staff perspectives on patient involvement in healthcare projects in the form of quantitative data and this section has described the findings from the questionnaire. The qualitative findings from the focus group in Phase 2 are described in the next section (4.4).

4.4 Phase 2 Qualitative phase

Phase 2 is the qualitative phase of the study which involved conducting a semi-structured focus group. Four project staff attended the focus group out of the six project staff who agreed to participate. Participants were all female, under 40 years of age, worked in different hospitals in SMHS and were employed at different seniority levels ; 1 was a Project Manager (PM); 2 were Senior Project Officers (SPOs); and 1 was a Project Officer (PO).This information was verbally provided as an introduction at the start of the focus group meeting. Two members of the group disclosed that they had included patients in their projects 'frequently'; one member had involved a patient 'recently' and one member had no experience with patient involvement. This meant that we had a small group of varying experience and one person who was raising perceptions or ideas about the topic. The focus group discussions were audio taped, transcribed and imported into NVivo™ for thematic analysis.

4.4.1 Focus group questions

As discussed in methodology sections ([section 3.5.7](#)) and ([section 3.6.3](#)), the questions for the focus group were generated from conducting a mapping exercise to analyse any gaps or areas for further discussion from the questionnaire responses. This mapping exercise raised gaps in knowledge regarding the impact to the project timeline, measuring the impact of patient involvement and the level of patient involvement required. Five questions were constructed for further discussion at the focus group, which were approved by the supervisors (Table 34).

Table 34 : Focus Group Questions

Type of question:	Question:
Introductory	*Q1. What are your thoughts about involving patients in these projects?*
Transition	*Q2. Why would involving patients in your project impact on your project timeline?*
Focus	*Q3. How can we evaluate the impact that patient involvement has on our projects?*
Summarising	*Q4. How can we assess the level of patient involvement required in each project?*
Concluding	*Q5. Is there anything else that anyone feels we should have talked about today but didn't?*

4.4.2 Focus Group results

As detailed earlier (section 3.6.6), the transcript of the focus group audio recording was imported into the NVivo™ software package (version 12) for thematic analysis. There were five major themes (or nodes) found during thematic analysis, containing fourteen sub-themes (Figure 8), which are discussed in the next sections.
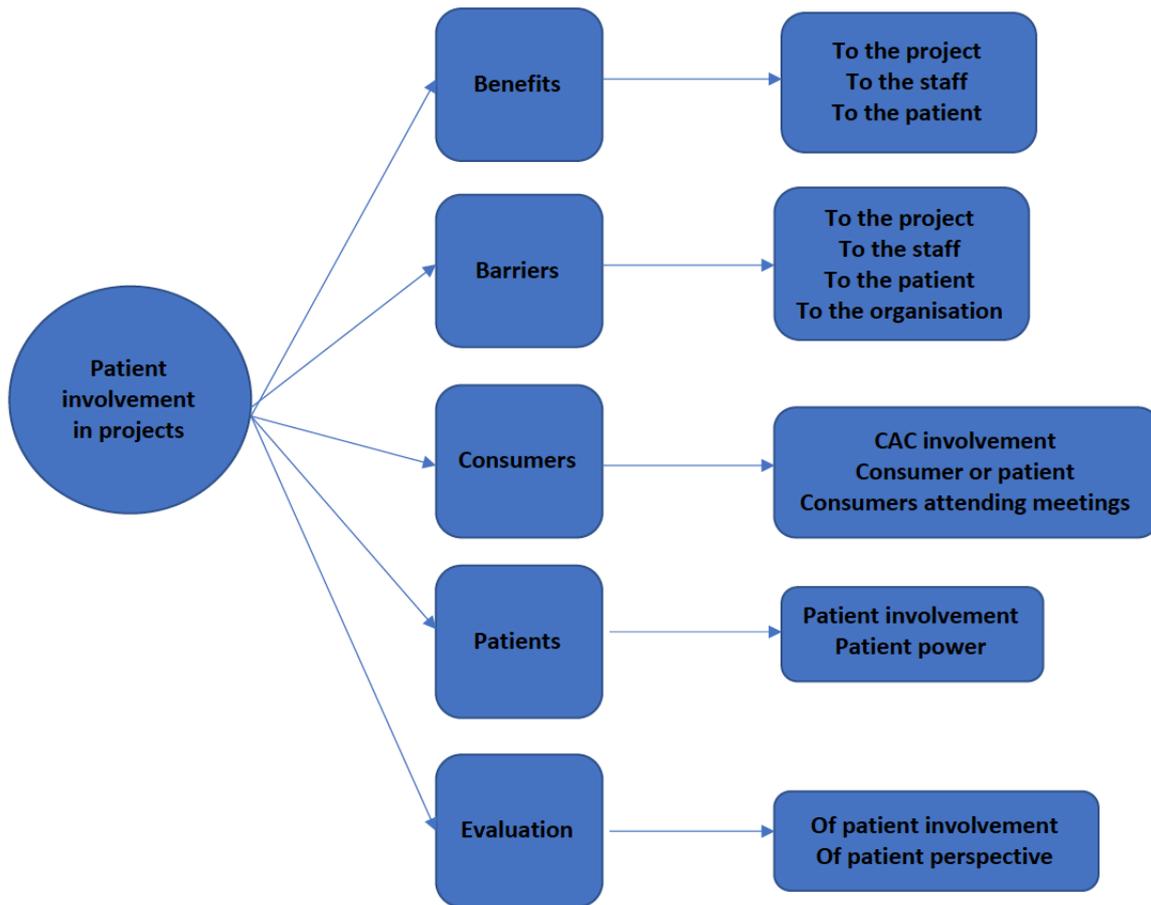
Figure 8. NVivo™ final themes – nodes and sub-nodes

4.4.3 Benefits

The benefits of patient involvement were determined as a major node, as positive benefits of patient involvement were greatly considered by project staff. This node was divided into three sub–nodes: Benefits to the project; Benefits to the staff and benefits to the patient.

4.4.3.1 Benefits to the project

The group defined how consumer feedback helped drive their projects and was either aligned with the project team goals or totally changed the direction of the project.

"the feedback that we received for the last project from the consumers really helped us drive our outcomes in the way that we wanted to proceed with the project".
"it changed the direction".

The group discussed how patients knew the current standard of care and how the change would affect future patients, adding great insight to assist with the success and sustainability of the project. Patient stories generated new data and were powerful change agents in projects, as staff described how the stories highlight the deficiencies in service from the patients' point of view. The patient stories encouraged and empowered staff to have a cause for change and engaged more with the project. The group described how patients could assist with benefits realisation to articulate and understand how the project will improve their care or service. Project staff also stated that patients could assist with setting realistic and achievable goals for the project.

During the project scoping stage, project staff described how the Project Manager could advise executive that the project was likely to take three months longer to allow enough time for true patient involvement. Project staff stated how project scoping needs some thought as to how the patient involvement can be a mutually beneficial environment for staff and patients. Project staff supported that it would be possible to involve a patient during the scoping stage, or once the draft scoping had been completed, to assess exactly where patient involvement is required.

"they could help you scope out parts of your project".

The group explored how patient perspectives can be gained via surveys, collecting data, providing opinions, representing other patients and by demonstrating support for the project. There was group agreement of how much patients can add to projects in a voluntary capacity.

"we've got a representative, they are giving us so much".

4.4.3.2 Benefits to the staff

Project staff described how they have witnessed conversations with patients having a powerful impact on other healthcare staff, which can ultimately change their behaviour and drive their passion to improve their services.

"conversations with patients can have hugely powerful impacts on staff".

Project staff described how project teams may behave in a more professional manner and may act on their best behaviour if patients are attending the meetings.

Staff in general may be more guarded about what they say and how they are presenting themselves to the public.

4.4.3.3 Benefits to the patient

Project staff explored their feelings that the organisation can overlook the patient perspective if they are not involved in healthcare projects, and how project staff and project teams can just assume what is required.

"we need that perspective because sometimes organisations lose sight of that and that's what we're here for".

4.4.4 Barriers

Barriers to patient involvement was found to be the largest node in the data set with the most associated sub-nodes. The group described in detail their frustrations and the barriers they faced when involving patients in projects, at multiple points during the focus group. They discussed their perspectives of the barriers that they face in terms of: Barriers related to the project; Barriers related to the staff; Barriers related to the patient and Barriers related to the organisation.

4.4.4.1 Barriers related to the project

All members of the group agreed that a decision-making framework would be useful when working with patients in a project environment, as this is usually at the discretion of managers or the project team. There is currently no guidance for project staff, and this was seen as a barrier caused by an absence of protocol or policy.

Project staff advised that project meetings are generally pre- scheduled every fortnight, and they were concerned that patients might not attend every meeting. The group also considered how patients may not be used to meeting etiquette or have any experience in meetings or how to communicate effectively in a meeting and would therefore need training.

"training cos you may need to spend some time educating your patient or public reps on how they work, you know how you see the meetings working".

One staff member advised how their current working groups have no patient or CAC representative as the project team deemed it not appropriate at this stage.

"I guess that we don't really feel that CAC involvement or consumer at that point is totally appropriate".

Representation of the patient cohort was discussed as being difficult for project staff and project teams to understand.

"it's difficult because you could have one person being the representative but are they a true representation of your cohort or who you wanna impact or you might have got someone who volunteered for this and cos their keen".

The group members agreed that involving patients negatively impacts on the project timeline, is often not planned for at the start of a project and that Project Managers really need to build patient involvement into their project timeline.

"I think because sometimes it is so difficult and does extend the timeline it's not just something that's always in the forethought of our mind like at the start because it really can be a game changer".

Sometimes, project staff can wait over three months for ethics and governance approvals before they can speak with patients; so, the project teams often make a conscious decision to not include patients in their projects, as they do not have the luxury of lead in time. Some of the projects only have three months to start and finish and therefore cannot afford to wait for these approvals. So, quick access to patients is an organisational barrier.

"I do sometimes think it impacts negatively on your project timeline and I guess that's due to the fact that sometimes approvals and ethics and all of those kinds of structures that are put in place to ensure that there's protection from both sides is lengthy, it's really time consuming, it involves a lot of paperwork especially for inpatients, so I guess for outpatients you are probably able to access patients a little easier".

The group explored other administrative factors that hamper time such as patients who don't have an email address or don't check their emails, so a phone call or letter is required. The time taken by project staff to organise volunteer transport or taxi vouchers is lengthy and frustrating. Patients can also be ill, or relapse in condition which must be respected, therefore they cannot always attend meetings. All these factors delay the timeline which is often quite tight and restrictive.

"we have consumers and they may not be active with the service at the time that they're engaged in the project, but there is a significant potential for their wellness to fluctuate, for them to be exposed to triggers in meetings and discussions, and that all has to be managed as well, which can take up project time".

Group members expressed frustration that they have to allocate time to educate the patient about the project and the progress to date.

"because the organisational staff might have a lot of pre-existing knowledge about the project and the concepts, but your consumer reps might not".

4.4.4.2 Barriers related to the staff

The group considered the importance of ensuring that clinical or administrative staff are aware of any changes occurring in their area and that their opinions are acknowledged, as they will be the people expected to implement the change. Change management especially involving staff and project team members was noted to be difficult at times.

Project staff reported a level of anxiety and fear pertaining to the involvement of patients in their projects and seemed to take on this huge burden of risk on behalf of the organisation. The group stated the words "fear" or "worry" several times and that they had "quite a real fear" about involving patients.

"that does bring an element of fear because you want our patients to be involved but the general public don't understand the complexity of a health organisation, they just see it from their perspective".

Some group members had never involved a patient or never invited them to a working group meeting, and this would be a huge cultural shift for staff and the organisations to work through. Staff were worried about 'airing their dirty laundry' in public if non-health staff were present and worried about leaks to the media.

"you don't wanna look like you're not doing a good job".

Involving patients was viewed as difficult to accomplish and hard to evaluate by the group. The organisational system and structure did not support the staff with training, recruitment and management of patients. There were no tools in place to evaluate the benefit of involving patients. Project staff were not quite ready to involve patients yet stating they had "a long way to go" before this could happen and that they were worried about disclosing health business to patients.

"there's always gonna be that fear that if you have an open discussion about something that may have not been done that well or appropriately or by mistake that you know that will come back to haunt you'.

4.4.4.3 Barriers related to the patient

Group members expressed difficulty with standardisation and comparison in that often the patients in their projects were not constant i.e. they attend the Emergency Department, Emergency Theatre or Outpatient clinic once but do not return for the same condition or service, making follow up and pre-and post-change comparisons

impossible. Staff felt that a barrier was when they cannot ask a patient if the service had improved, because they may have only used the service prior to the improvement or post the improvement.

"one issue with that is that we can't take those results and then re-do the survey again at the end to see whether we've made any improvements".

The group discussed how follow up in the community can be particularly troublesome and time consuming for project staff, when they are required to contact patients once they are no longer on hospital grounds. The group identified that people often change addresses, phone numbers and emails without updating their details at the hospital, which inhibits follow up. The group discussed that if the project involves current patients who are receiving treatment, appropriate times for access to them would also need to be considered. Concerns were raised that project staff cannot access patients in real time in the wards and departments and that the patient's memory of events may be altered when surveyed too long afterwards.

Group members expressed concern that there can also be small cohorts of patients in highly specialised areas, which seems to be a barrier of population sampling. They were concerned that sometimes it is only one person's opinion at a set point in time; therefore, questioning validity. The issue of specialist care areas such as mental health was raised as a concern due to the nature of the patient's illness and stability, and all group members felt that this area of patient involvement needs much improvement.

The decision regarding involvement of an actual patient or a consumer representative is important to get right, and the level of involvement required is also crucial. The difference between a patient and a consumer being involved was also highlighted as an issue for project staff, as sometimes a patient who has lived experience of a system or process that is being improved or changed is vital.

"the differential between the patient and the consumer I think is really important as well".

The group perceived that there was a long journey ahead of organisations before they are meaningfully involving actual patients in healthcare projects, as they discussed tokenism and use of consumer groups rather than patients. In this

example, 'on the floor' was clarified with the group as meaning actual patients who are in the wards, departments or clinics, rather than consumer representatives.

"I still think we have got a long way to go involving patients that are actually on the floor".

4.4.4.4 Barriers related to the organisation

The group described how they need to try to balance the patient input with the expectations and drivers of the project, or the organisation, which can cause difficulties. One staff member described how in one of the projects patients supported the project in the short term but became disengaged and did not support in the long term. The group agreed that patient involvement should not be an afterthought or add on to bolster the project and should not be implemented just to 'tick a box'. Clear decision making is required and important, as it may not be appropriate to involve patients in all situations. Project staff described how patients may not understand the concepts or that they may see things very differently to staff. The group agreed that organisations need to set the expectations at the very beginning which often they don't do well and there needs to be a mutual understanding between the organisation and the patient.

"I think an organisation also has to manage its interface with the community effectively and they know a lot of things that the consumers don't necessarily know".

The group were nervous about involving patients in decision making or voting as this has not been done historically and stated that the project team would probably need an overarching project scope first. They examined how there would need to be some protective mechanisms in place if patients were involved in decisions during meetings due to liability, governance, and accountability as they "sit outside of the organisational structure". They considered how meetings may be more transparent with patients in attendance, however the usual decision makers may feel uneasy and this may impact the kind of conversation that transpires.

"there's no reason why not … you'd have to be very … careful".

The group had a firm belief that patients would probably not be involved for projects emanating from the Chief Executive's office, as these would be very corporate in nature. This was agreed and acknowledged by all group members, suggesting that the patients wouldn't understand or have anything useful to contribute in these situations. Almost as if this would be too high level for the patients.

The group agreed that patient involvement would not be supported in projects with associated political risk for the organisation or those that are 'contentious'. Project staff stated high levels of anxiety about the organisations reputation and image, media impact, legal issues, and complaints if patients are directly involved.

"an anxiety about the organisations reputation and image if you're involving patients".

One staff member described that it may not be appropriate at certain points in a project to involve patients, especially when there are contentious issues or things going wrong. The staff may be hesitant due to organisational risk concerns and the potential perceived affect that this disclosure could have on staff morale in general.

"you don't always want it to be bad news stories cos you know that's not good for your staff morale".

The group described instances of low staff support for healthcare projects as they are not a clinical priority, and a general lack of resources from the organisation to assist with involving patients. Therefore, resourcing for projects needs to be carefully planned for.

"lots of people end up throwing their hands up and going it's too hard, it's too hard".

One staff member recounted her experiences with managing claims for patient travel, which was extraordinarily time consuming and laborious with inefficient processes between the hospital site and the Health Support Services (HSS) who process the payments.

"consumer reps who were reimbursed for their time and so there were time sheets that had to be kept and logged and you can just imagine all the communications back and forward with the managers who had to sign these off and then HSS".

The group defined their frustrations with balancing the wealth of ideas received from patients versus the finances and technology available within WA Health to implement these ideas.

"they can't understand why there isn't an app for this or why there isn't a touch screen for that".

The group stated how difficult it is to balance patient's technological ideas with outdated infrastructure and lack of budget and how so often old solutions are re-implemented, which diminishes the patient input and causes frustration for all concerned. This often stifles innovation and true patient involvement.

"patients understand that yes we do put forward solutions but in the fiscal environment there could be some constraints but having some sort of way of not discouraging those opinions".

4.4.5 Consumers

Consumer involvement in the form of the different hospitals Consumer Advisory Committees (CAC's) was discussed by project staff in terms of the involvement of the CAC; consumer input versus actual patient involvement and consumers attending meetings.

4.4.5.1 CAC involvement

The group explored how the CAC members provide valuable support to healthcare projects and how they can use their experience and knowledge as a consumer to relate more to the patients. The CAC members may sometimes have been a patient in the hospital recently and can therefore use their experience to the advantage of the project.

"we actually had a member of the consumer advisory committee actually ask patient questions, so they were able to get a bit more out of them from their own perspective and their own experience".

The group discussed how CAC members may not have been a patient recently, but how in general CAC's try to recruit a broad range of consumers with different backgrounds and healthcare experiences.

"I do feel as though we are in a place that we can and should be tapping into that expertise they do try and recruit to have people that have got expertise in the different areas of the hospital so not all just have a knowledge of outpatients".

One staff member advised how the organisation has involved the CAC a lot more over the last few years and that they are now committee members on various committees in the hospital, including at executive level; but it is a big impost on their time as they are all volunteers. Involving the CAC is becoming more the norm in the organisation and less difficult for staff to access a consumer representative.

"we've come a long way over the last couple of years so I'm feeling less uneasy about involving from that perspective".

However, inviting a CAC representative to be on the working group just to 'tick a box' was discussed as an easy way out for Project Managers in the future.

"I also think there's a risk that people go oh its ok we involved the consumer cos we had a CAC representative, but they just came and sat there, they weren't encouraged to participate, or they didn't feel comfortable to participate but we've ticked the box that we had a consumer representative".

"on paper we've got two representatives coming to our monthly implementation group meetings".

Sometimes, even with the best intention and planning, the group advised that the consumers are still not involved.

"we started our workshops without a CAC member, although we've got it in our terms of reference, as that is something that we want to include".

4.4.5.2 Consumer or patient involvement

The group considered how CAC members may have been patients recently but not necessarily in the specialty that the project is being conducted in. The CAC members can often advise who the best person for the project would be, as they do recruit people from various backgrounds with varied healthcare experiences. The group agreed that Project Managers need to decide if they want a person who has been an actual patient in the specialty concerned or a consumer representative for the patient group from the CAC.

"we've recently done a drive for CAC members, so I'll need to follow that up to see whether there is somebody that is the most appropriate member to be on there or if we need to involve the patient …".

4.4.5.3 Consumers attending meetings

The group commented how for multi-site projects, the project teams ensure they have CAC members from the different hospitals and communities to provide good consumer representation of the different populations in SMHS. However, they expressed concern that the CAC members attend on their own time and terms and are not always available.

"they may not be able to make certain working group meetings and so you sometimes may have to work around when they're available; they are not always there like we are".

One staff member expressed a future intent to have a CAC member on a working group.

"we will plan on having a consumer advisory committee member on the working group".

4.4.6. Patients

4.4.6.1 Patient involvement

Patient involvement in projects was stated as being extremely important and critical by all group members.

"we all agree consumer participation engagement is so important and critical"

The group also discussed the importance of involving future patients i.e. consumers in their projects.

"I think it's important to capture both current patients but also the consumers that could become patients".

The group commented how they need patients to be involved in projects to ensure that the organisation can deliver care appropriately and this needs to be factored in to the project scoping phase. They also discussed how project staff need to think outside the box and ensure that the patients get something out of their involvement. Group members agreed that it is common-sense to involve actual patients to gain their perspectives.

"it would make sense that you involve people actually using that particular service".

The group defined how patients should be involved in projects which would add benefit, especially for longer term projects.

"I definitely see where a patient being involved would have been of benefit".

It was agreed that a patient can represent other patients, however the group also highlighted the importance of caring for the welfare of the patient being involved. The group explored how an improved patient perspective provides context to the project team rather than staff making assumptions about how patients would feel.

"I think it would actually be of benefit to have a patient or some sort of interface with the patients to say how would you feel if you had 5 blood tests versus 10 blood tests".

One member stated that organisations want patient involvement as that is the key interface of their business: how will it work for the patient; what education do they need; how will this drive their care into the future? They discussed how they used to be able to sit on a patient's bed and freely ask them questions which they are unable to do now.

"A face to face current perspective would be ideal".

The group stated how they need to gain more insight into their patients' perspectives so that they understand more and can build better processes or services according to their needs.

4.4.6.2 Patient power

The group explored how pre-and post-implementation patient stories are useful to articulate the change from a patient perspective and change the mindset of staff.

"the patients' stories are very powerful".

One staff member described how patients and consumers can be very powerful advocates to make decisions about their care or services provided, and how each person brings something different to the project.

"each party brings something slightly different to the table you know, consumers know lots about what's happening out there in the real world, they know about services, they can feedback on the experiences and the quality of care as they see it, they can feedback on your comms materials, it's so powerful in so many ways".

4.4.7 Evaluation

4.4.7.1 Evaluation of patient involvement

All members of the group struggled to articulate how they would evaluate the patient involvement component of the project, especially if only one patient was involved.

"I can't off the top of my head think",

and

"how do you do it?".

They expressed that evaluation of patient involvement could be loosely tied to implementation and project success, or improved Safety and Quality key performance indicator results. However, the group found it difficult to distinguish and separate how much of this can be attributed to project management, change management, and staff input versus the patient involvement component in isolation.

"I think it depends on what kind of activities the patients are contributing to also impacts how you evaluate that"

One staff member stated that re-interview of patients after changes have been implemented may provide some evaluation points. Another idea raised was a retrospective audit of projects or Quality Improvement activities, which may provide some evaluation answers and also gaining some staff experiences of patient involvement to provide data. There seemed to be a genuine intent to evaluate the patient involvement component, but with no set structure in place in the organisation.

"I definitely feel like we do try and evaluate the impact I just don't know how well we do it".

4.4.7.2 Evaluation of patient perspectives

The group discussed how voice of the patient surveys and six monthly follow up surveys were the main ways to evaluate patient perspectives of their involvement.

"I think one way to evaluate is that your gonna have to follow up, you would have to take all their details and say that we will follow up post this project in six months' time or whatever to gather your feedback".

Some members discussed an intent to conduct future voice of the patient surveys by visiting the waiting rooms to ask patients pre-determined questions. The project staff would know survey dates in advance so would ensure this is planned well and has a governance structure and set ground rules.

"establishing those ground rules from the beginning".

The group explored how they can use alternative methods of gathering patient perspectives rather than by directly asking patients; using the Governance, Evidence, Knowledge, Outcomes (GEKO) database for QI projects and the Clinical Incident Monitoring System (CIMS) reports, as well as patient complaints history.

"through our GEKO and our CIMS and our patient complaints".

4.4.8 Summary

Many of the issues raised correlates with evidence found in the literature such as tokenistic behaviour, increased time factor and lack of resourcing. However, staff were generally positive about involving patients in their projects and could articulate the potential benefits of this approach.

The word count in NVivo™ demonstrated that the most frequently used word was 'think' at seventy-seven counts (Figure 12). Thus, recognising that the focus group had successfully captured staff thoughts and perspectives which was the purpose and intent of the focus group meeting.

Figure 9. NVivo™ word cloud

The purpose of Phase 2 was to analyse the qualitative data from the focus group discussions. The next section discusses the results of Phase 3 which is the final data synthesis phase.

4.5 Phase 3 Data Synthesis phase

The quantitative and qualitative data sets were further reviewed and compared to test for synergies and analyse comparisons or deviations. The researcher reflected on the findings from the questionnaire responses and the focus group discussions as described in the following section.

4.5.1 Demographics

The questionnaire offered more demographic data than was the intent of the focus group; however, all staff who attended the focus group were female which correlates with the higher percentage of female staff who responded to the questionnaire, and the predominant gender employed in health (Workplace Gender Equality Agency, 2016; World Health Organization, 2008). There was a range of positions of staff who answered the questionnaire and those that attended the focus group, providing varied perspectives from differing job roles and hierarchical status.

4.5.2 Synergies

The results from the questionnaire and the focus group support the guiding hypothesis that patients were not being involved in all healthcare projects for a variety of reasons. During the questionnaire, 70% of respondents reported that they had involved patients in a project during their career, although some respondents referred to consumers rather than patients; one member of the focus group stated that they had never involved a patient in their projects; two other focus group members had minimally involved patients, as most of their involvement was with CAC members rather than actual patients.

The main positive synergies found between the questionnaire responses and the focus group discussions were an agreement that patients do add value to healthcare projects, that it is important to involve them, that their insights and perspectives were invaluable, and that patient representativeness requires consideration. Results from both phases concluded that surveys were the main method of gaining patient input and that the involvement of the CAC was commonplace. Both phases identified that patient involvement can and should be measured, but no measurement tools were available in the organisations.

Interestingly, the focus group participants did not naturally discuss whether the patients want to be involved in healthcare projects, which was a distinct question in the questionnaire. This may have been because the intent of the focus group was based on staff perspectives only; rather than they did not appreciate or consider this issue.

4.5.3 Barriers

The main barrier identified during both phases was the impact of patient involvement on staff time. However, the focus group members were more definite that patient involvement also impacted the project timeline whereas the questionnaire responses mostly disagreed with this. There was also a difference in the clarity of purpose of patients being involved in projects, as the focus group respondents did not think the purpose was clear; whereas, the questionnaire responses mostly did.

In the questionnaire, increased project costs were not seen as a barrier, but the focus group members discussed how administration of these costs were a significant processing barrier which affected their time.

Both phases identified that patient recruitment was problematic and that staff training was required. Although both phases identified that patient involvement had the potential to be measured, the focus group had difficulty in articulating how this could be measured. There was a noted absence of evaluation tools in any organisation and staff confusion about the existence of any guiding organisational policies or protocols regarding patient involvement.

4.6 Summary

During data synthesis, findings can converge or complement each other or be found as divergent or contradictory to each other, as described by Heale & Forbes (2013). The findings from the questionnaire and the focus group mostly converged; some contradictory findings were noted by the researcher in the barriers (or challenges) section.

Project staff perceived that patients can add value to healthcare projects; although, they were not involving them in all projects and there is no guiding framework for practice. Staff position, qualifications and choice of improvement methodology positively impacted patient involvement. Staff described the opportunities and barriers that they perceived and although they were confident to involve patients, they lacked the skills and training required; a very small number of staff in the qualitative phase described a level of fear and anxiety about involving patients on behalf of their organisation. The executives in the organisation may not be aware that this lack of training and anxiety existed for project staff, which may be able to be reduced in future through discussion, training and associated policy development.

Project staff described a genuine intent to measure and evaluate patient involvement in their projects but did not have an evaluation tool or reporting mechanism to enable this. This may be an issue within the culture of the organisations if patient

involvement is seen purely as a tick-box exercise, not something to be measured, monitored and reported on.

The findings from the three phases within this study have been described in this chapter. The next chapter (5) will discuss the findings further, relating them back to the research questions and current research evidence where relevant, and discussing any limitations within this study.