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Consumer representative experiences of partnership with health workers in Australia

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We acknowledge the Consumer Representatives who participated in this research and thank them for giving their time. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

Consumer representative experiences of partnership with health workers in Australia

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Abstract

We examine the experiences of Consumer Representatives participating in consumer engagement activities across a public health service in NSW, Australia. A team of Consumer Representatives and staff members use a participatory, constructivist paradigm and a hermeneutic phenomenological approach to analyse ten interviews with Consumer Representatives over three years 2017-2019, and three focus groups in 2020. We explore these experiences and identify the linked contextual factors from their points of view. Consumer Representatives were prepared to invest their time, but they needed respect. “Respect” from a consumer perspective was being meaningfully included, supported and heard, and activities needed to be purposeful and relevant. They operated in a complex environment of people and systems that were sometimes frustrating and hindered partnership. Nevertheless, they were optimistic their involvement made a difference although this may take time. Using hermeneutic phenomenology enabled the results to be seen clearly after a comprehensive and highly iterative process engaging with participants-as-researchers. The results challenge the usual default position of engaging consumers in committees and reveal other opportunities to focus on patient-centred care, as mandated by Australian National Standards for hospital accreditation. Respect is identified as a practice necessary to enhance engagement. Health organisations may improve consumer engagement outcomes as mandated for accreditation by being aware of the experiences of Consumer Representatives giving their time to partner with staff members and health systems. Staff may mitigate Consumer Representative negative experiences by being mindful of the complex people and system environment within health that can impede successful engagement.

Keywords

Participant-researchers, consumer representatives, health consumers, consumer experience, consumer partnership, Heidegger, phenomenology, hermeneutic circle, power imbalance, respect, Australian national standards for quality and safety, patient-centred care, patient engagement

Background

Health care organisations partner with consumers and patients because it improves patient satisfaction and the safety and quality of healthcare.¹⁻⁴ Partnership with consumers has many benefits, including positive impact on service development, health literacy and healthcare provider perspectives.^{5,6} In Australia, “Partnering with consumers” is a standard mandated for the accreditation of hospitals and health facilities.⁷ The standards mandate that consumers should be involved systematically in planning, design, delivery, measurement and evaluation of care as partners.⁷

“Partnership” can be influenced by a number of factors intrinsic to relationships including communication and leadership⁸ within a context of influential historic-socio-political drivers.⁹ The depth of partnership is represented

on a spectrum from informing the public to empowering the public to be final decision makers.¹⁰ The higher the activity on this spectrum the deeper the partnership,¹¹ and deep engagement in the partnership can lead to the most significant impact.¹¹ However, the unequal power relations between consumers and health workers is recognised as a barrier to partnership,^{12,13} and the recognition of this imbalance challenges the systems in which such imbalances occur, to disrupt the notion of “us and them.”¹⁴

In New South Wales (NSW), Australia, the public health system is divided into fifteen Local Health Districts (LHDs), each responsible for serving the public health needs of its local population. The LHD where this study occurred serves a population of approximately one million residents, is culturally diverse and has significant income inequality. Here, there are over 90 language groups, one of

the largest urban Australian First Nations populations, and about half of all families speak a language-other-than-English at home. Engaging with consumers to understand the health needs of this community is complex and vitally important.

“Consumers,” for our purposes, are people who need or may need to be a patient of the health service. The term includes people who are “carers” of patients. “Carers” in Australia may be known as “family caregivers” elsewhere and are people who provide support and care to family members or other loved ones. “Consumer Representatives” are community members who volunteer to get involved with the health service more systematically in service improvement activities to represent the voice of consumers. They or their loved ones have had consumer experiences in public health that have motivated them to get involved in these activities. Typical activities may include committee membership, project team membership or documentation improvement, for example.

Research objective

Our objective was to understand Consumer Representative (CR) views on the factors that affect “partnership” with healthcare workers. A systematic review found there are few studies that formally evaluate consumer experiences of the process of being engaged.¹¹ While there is evidence that CRs hold positive attitudes about their value and potential for influence,¹⁵ there are also concerns relating to role, impact, conflict, intimidation, resources and equity.¹⁶

Our objectives were triggered by the launch of a local framework for engaging with consumers in 2014. A small number of community members (n=15) had previously been recruited in this LHD as voluntary advisors during the building of a new hospital or were randomly active on committees. When asked, they had unanimously indicated they wished to form a council to learn from each other and the LHD. A facilitator¹⁷ brought CRs together and the resulting Community and Consumer Partnership program (CCPP) adopted a collective approach as to how it should evolve.

Method

To amplify a truthful understanding of these experiences we were interested in researching *with* CRs (“participant-researchers”) rather than *about* them,¹⁸ consistent with a shared value of “Nothing about me, without me.” We therefore focused on a methodology that was participatory in nature. The scant literature about consumers as participant-researchers is mostly found within mental health research which highlights power imbalance as an impediment to partnership¹² Nevertheless, consumers are important in ensuring the ethics, relevancy and validity of research,¹⁹ although research institutions in Australia

acknowledge the lack of guidance for engagement with consumers as researchers.²⁰

As a methodological tactic, we wanted to explore the use of hermeneutic phenomenology to bring the voices of CRs to the forefront in identifying *their* constructed truth about their experiences.²¹⁻²³ We found no literature that attempted to understand CR experience by using this approach.

In the design and reporting of this research, we use a constructivist paradigm whose criteria for trustworthiness are credibility, transferability and dependability.²⁴ To demonstrate these criteria we have used the COREQ 32-item checklist.²⁵ COREQ is accepted as a robust system for designing and reporting qualitative research and is structured using three domains. We use the three domains used in the COREQ checklist here. The location in this paper of each item in the checklist is provided as an appendix.

Domain 1: Research team and reflexivity

Personal characteristics: The research team

Three CR participant-researchers and two staff members formed the current research team in early 2019, see Table 1. Although the RT had been formed prior to ethics approval in 2015, two of the CR P-Rs had resigned from their roles as CRs, and by end 2018 when analysis was to start, were no longer available. There was a total of nine research meetings between early 2019 and mid-2020. The discussions from these meetings were transcribed by two independent note-takers.

The principal investigator (PI) was employed as facilitator of the Community and Consumer Partnerships program and was particularly motivated by practices which levelled the playing field for consumers. She had completed a Ph.D. using hermeneutic phenomenology informed by the existentialist philosophers²³ and had previously conducted qualitative research of a participatory nature in another LHD in NSW. She had formal qualifications in counselling and had fifteen years of experience interviewing individuals and facilitating small and large groups. The PI maintained a research journal for the five-year period in which the data was collected, considered, analysed and reported, to capture reflections and progress and to ensure a clear audit trail over time. She was responsible for conducting the interviews and focus groups and undertaking preliminary coding and reporting for scrutiny with the team.

The other members of the research team (Table 1) consisted of one staff member and three CRs.

P-R1 was a retired nurse with a wealth of her own health consumer experience. She was the carer of her husband who lived with multiple co-morbidities requiring frequent

Table 1. Role, Credentials and Occupations of Research Team

Code	Role	Credentials	Occupation or Background	Gender
PI	Collect data, interview consenting participants, run focus groups, preliminary coding & analysis, report writing	Staff member, Ph.D.	Counsellor, Facilitator of CCPP	Female
P-R1	Review interviews, discuss, review, confirm coding, identify themes, contribute to report	CR, post grad qualifications	Retired Clinical Nurse Consultant, Carer, Consumer (retired)	Female
P-R2	Review interviews, discuss, review, confirm coding, identify themes, contribute to report	CR, post grad qualifications	Retired GP, medical specialist (retired 2017), Carer, Consumer	Male
P-R3	Review interviews, discuss, review, confirm coding, identify themes, contribute to report	CR, post grad qualifications	Retired scientist, Consumer (retired 2017)	Female
S-1	Review interviews, discuss, review, confirm coding, identify themes, contribute to report	Staff member nursing, post-grad qualifications	Director service improvement	Female

P-R=Participant-Researcher S=Staff

public health services. She accompanied him to his medical appointments and many admissions to hospital, she advocated for him in these encounters and managed their household and joint affairs. P-R2 was a retired medical professional who had become a CR to voice his lived experiences as carer for parents living with cancer and dementia, children and grandchildren with significant ongoing need for healthcare services as well as his own healthcare experiences. He was motivated by a need to be a part of health service improvements from his consumer point-of-view. P-R3 became a CR after having significant experience as a direct consumer of healthcare services. She had worked in a non-healthcare setting in a science role. S1 expressed interest in being a part of the RT due to her background in engaging with CRs in service improvement projects and wanting to learn more about how to do this in a research context. Although two of the three P-Rs have a health provider background, they had strong credentials as CRs. As this research proceeded, it was clear that the healthcare background in two of the P-R enabled their deep appreciation of the complexity inside healthcare. This was valuable in providing context for their role as CR. It is perhaps unsurprising that each of the Consumer Representatives had completed higher education. They had previous interest in research and wanted to experience research in their roles as Consumer Representatives.

Relationship with participants

Participants felt included and supported by the CCPP team: *"It's not chairing a meeting; it's facilitating a meeting. There's a big difference between the two. Because I think [the facilitator and other staff member making up the team] working in tandem have a real ability to make people feel confident and drag out what it is they want to say and include them in the conversation."* C4-19

There were close relationships evidenced between Consumer Representatives:

"To begin with it was just a few of us and we didn't really communicate all that well, but it's developed now where there are strong relationships, friendships and you don't just talk to each other at meetings. If you know that somebody is not well, or they've got a problem or whatever. I mean I sometimes ring (another CR) and I spoke with (yet another CR) today and I'll try and get in contact with (this CR) because I know she was really suffering today." CR2-2019

CRs were supportive and caring of each other with a shared mantra of *"nothing about me without me,"* whose underpinning belief is that consumer participation in healthcare design is essential for healthcare improvement. There was a sense of collegiality between the PI, P-Rs and the larger community of CRs involved in the CCPP as they operated together as a collective in many of the projects that were available, aiming to improve the quality and safety of healthcare. The program was based on open relationships which over time facilitated trust.

Domain 2: Study design

Theoretical framework

As we were interested in the lived experiences of CRs and wanted to collectively arrive at a constructed truth about what it was to be a CR engaging with health staff, we were philosophically aligned with hermeneutic phenomenology which works with text to arrive at a collective agreement about the phenomenon under study. Importantly, we use a

Table 2. Numbers of CRs Opted for Interview or Focus Group (FG) During Study Period

Year	2017	2018	2019	2020
Number CRs in program	52	47	89	55
Number completing survey	15 (29%)	25 (53%)	41 (46%)	-
Number CRs opted for interview or FG (% of available pool)	6 (40%)	5 (20%)	10 (24%)	10
Actual interview or FG	3 JL, AS, KvO	2 PL, SR	5 KF, MF, SL, PJ, KC	3 FGs (10 participants)

“hermeneutic circle” which, as Gadamer describes,²¹ looks at the parts of a whole, dissecting, attempting to understand, and interpreting in order to “see” the whole picture. “Phenomenology” informed by Martin Heidegger strongly views individual experience as inextricably linked to their context.²³ The researcher, interpreting the data, makes sense of the data through the lens of his own context or experience. In this way, the researcher is always part of the research. This makes hermeneutics a very good approach for research where participants - or the people intrinsic to the research question - are researchers. There is no struggle with methodological perceptions of needing to separate out one’s own experience when interpreting. In this research, we study the phenomenon of “being a CR engaging with staff in health improvement activities.”

Participant selection

The study (LNR/15/WMEAD/56) invited all CRs to complete a short survey each year. The facilitator of the program distributed the opportunity at meetings at the beginning of each year, where a variety of opportunities for CR involvement were presented regularly. Participants could then opt-in to do the survey. CR participants were asked for their views on the engagement process and outcomes. At the end of the survey, CRs could opt-in for a face-to-face interview. In the year following, a number of CRs were purposively selected for an interview.

Table 2 shows the number of CRs involved in the program each year and the number who opted-in for interview in each year. The number of CRs completing the survey each year rose from 15 (29%) in 2017 to 41 (46%) in 2019, possibly reflecting growing numbers of CRs and for others, increasing experience and commitment to the program. Of these, increasing numbers of CRs opted-in for interview each year. Those who did not participate were not asked to explain their reasoning, as this opportunity to get involved was only one of many engagement opportunities offered to CRs who were volunteering their time across a number of interests.

Selection Criteria

Consumer Representatives were purposively selected each year by the PI for interview to provide the broadest range of consumer experiences, CR experiences and years of involvement in the role. Activities included involvement in redevelopment of hospitals, governance committees including quality and safety committees), other service committees, service improvement projects, signage audits and various other activities involving CRs. We also selected for a range of years of experience (1-10) and included a peer worker from mental health – initially a patient - who had been a consumer advocate for more

Table 3. Diversity of Experience in Selected Interviewees

Code Name	Years of CR Experience	Variety of Activities	Consumer Role *
C1-17	2	Mental health/committees/projects	Carer
C3-17	3	Carer/committees/projects	Carer & consumer/patient
C3-17	3	Redevelopment reference group/ committees/	Carer
C1-18	2	LHD committees/ University committees/ governance and steering committees	Carer & consumer/patient
C2-18	10	MH peer/ mental health committees	Consumer/patient
C1-19	1	Projects	Consumer/patient
C2-19	5	Committees/ projects/ hospital redevelopment	Carer & consumer/patient
C3-19	5	Committees/ projects/ hospital redevelopment	Consumer & carer/patient
C4-19	1	Committees/projects	Carer & consumer/patient
C5-19	5	Quality and safety committees, Policy and procedures committees/projects	Carer

* “Carer” = Has experience as a family care-giver for patient in an LHD hospital, clinic or facility, with experience advocating for loved one/patient. “Consumer” = Has experience as a patient of an LHD hospital, clinic or facility.

Table 4. Attributes of Participants. All participants were Consumer Representatives, none were healthcare workers.

Code Name	M/F	Age	Background	Years Exp CR
C1-17 C2-20	F	60-70	Retired transport public service manager, family caregiver, community leader	2 5
C2-17	F	60-70	Retired HR professional, family caregiver, consumer of health services	3
C3-17 C6-20	F	70-80	Retired health professional, family caregiver and consumer of health services	4 6
C1-18 C5-20	M	60-70	Retired health professional, family caregiver, consumer of health services	2 4
C2-18	F	40-50	Employed peer-worker mental health, consumer of mental health services, consumer advocate	10
C1-19	F	30-40	Employed communications professional, consumer of health services	2-3
C2-19	M	70-80	Retired finance professional, community leader, consumer of health services	6
C3-19	F	70-80	Retired high school teacher, community leader, consumer of health services	6
C4-19	M	60-70	Retired education public service executive, family caregiver, consumer of health services	1-2
C5-19	F	60-70	Employed local government professional, retired professional, community leader	6
C1-20	F	50-60	Retired business professional, mental health consumer advocate, family caregiver	2-3
C3-20	F	40-50	Family caregiver, mother with children requiring health services, naturopath	4-5
C4-20	F	60-70	Retired technical professional, consumer of health services	3-4
C7-20	M	20-30	Student, consumer of mental health services	0-1
C8-20	F	60-70	Retired health professional; consumer health services	1-2
C9-20	F	40-50	Cancer survivor, consumer of health services	0-1
C10-20	F	60-70	Retired administration officer, consumer advocate; consumer of health services	6

than a decade. We also included in the final year of than a decade. We also included in the final year of interviews CRs who had enough experience to reflect on how the program had developed over time.

In the second year of interviews (2018), the three CRs who had been interviewed the previous year opted-in again. This left two available for interview. The following year there were again three CRs who opted-in who had already been interviewed. We selected five of the available seven for interview.

The opportunity to participate in a one-hour focus group (FG) was offered via email to all CRs (n=55) in 2020 to explore the phenomenon as it was clarifying through the analysis of the interviews. Mindful that hermeneutic phenomenology is not characterised by large numbers of participants to enable deep analysis of the text,²⁶ the data set include all ten semi-structured one-hour interviews with CRs and three FGs of CRs in 2020. Three participants in the FGs had been interviewed previously (C2-20 was interviewed in 2017; C6-20 interviewed in 2017 and C5-20 was interviewed in 2018); thus, there were 17 unique CR participants in the study.

CR interviewees were contacted by email, and a face-to-face interview organised at a time and location convenient for the CR. See Table 4 for attributes of the participants. All participants were Consumer Representatives in the program, and with the exception of a mental health peer-worker, were not paid in their roles. The mental health peer-worker had been a previous patient of the service.

Setting

The office of the principal investigator was universally nominated by interviewees as a safe setting and all participants preferred this location for a confidential interview. Each interview was conducted with no one else present with the exception of one where the spouse of the interviewee was present.

Data collection

Semi-structured interviews with CRs explored their experiences of partnership activities and the impact of those activities. Interviews were guided by an initial set of questions based on their viewpoints about engagement with staff. For example, *"Can you share with me your experiences of the engagement activities you have been involved with so far with staff?"* and *"What made that activity worthwhile (or not) from your point of view?"* The tone of interviews was conversational and exploratory. Interviews were audio

recorded with permission and took up to one hour. Repeat interviews were not conducted. Notes were taken after interviews to capture immediate interviewer impressions. Transcripts were de-identified and shared with the research team for review and confirmation of themes. Two of the research team had been interviewees prior to 2019 when the current RT was formed after two previous members of the RT were no longer available. With their permission, their identity was disclosed to the remainder of the research team. Reviewing these transcripts with previous interviewees enabled corroboration that transcripts of the interviews accurately represented the interviews with these two CRs.

Domain 3: Analysis and findings

Data analysis

The principal researcher undertook the draft coding using NVivo, then shared, discussed and edited these codes with the research team with the use of the coding tree which changed after each discussion. The final coding tree is presented in Table 5, demonstrating the frequency data sources for each category of data coded. Although there were a large number of data extracts in each data item,²⁷ we have exemplified only a few in Tables 6 & 7 to illustrate the two themes identified through the hermeneutic circle process.

Data saturation

Participant-researchers' lived experiences as CRs and consumers of healthcare frequently intersected with the data. For example, technical discussions about coding data during research meetings often resulted in general corroborations of the data using their own experiences as consumers. Discussions of issues became repetitive and there was a point where the RT realised that the data were revealing nothing particularly new. This was a clue that saturation had been reached and the data provided by CRs had a consistency that pointed to the themes.

Results

In this section, we present our results. The draft of this report was submitted to the 17 unique participants in this study, and the broader group of CRs across the Local Health District (n=55) who confirmed the themes as true for them. The participant-researchers when reviewing the draft document felt that providing comprehensive exemplars (Tables 6 & 7) was important in communicating to other non-researcher CRs: *"They are the most important part of the document ... a good educational tool for new CRs, the simplest way of describing the various experiences that current CRs run up against."* P-R2

Hearing the voice of the CR through data analysis yielded the first theme: "I am happy to invest my time as a CR, but I need to be respected." This is closely tied to the second theme which is about the context for engagement: "We

operate in a complex environment that affects our engagement, nevertheless I feel optimistic." We will describe these themes and in Tables 6 & 7 provide exemplars, with individual participants de-identified and coded. Consistent with the hermeneutic circle, we break down each theme to demonstrate how we arrived at the shared agreement about the phenomenon. There is considerable interplay between the two themes, as will be seen in the exemplars. We have deliberately avoided editorialising the voices of the CRs. Instead, we summarise the story as we have heard it along the way, illustrating our points with short examples from Tables 6 & 7.

Theme 1: "I am happy to invest my time as a CR, but I need to be respected."

Consistent with the hermeneutic circle,²² we will break the first theme down into three parts. Table 5 provides evidence of these parts. The reference for each quote in the text can be found in Tables 6 & 7.

1. I, the CR ...
2. ...am happy to invest my time
3. ...but I need to be respected

I, the Consumer Representative

CRs in this group included a wide variety of people with diverse work and personal backgrounds *"you're getting ... people with a lot of background knowledge and skill,"* most of whom were volunteers except one who was a paid peer-worker in the mental health service (Table 5). CRs bring a different perspective – frequently one of lived experience: *"Unless you've been a carer you're not going to know these things"* – and they are focused on patient-centred care (PCC): *"we bring in the other side of things that matter to consumers and that may then help set some priorities."* They want to advocate for patients at a system level: *"Why are we not thinking of the patient?"* At the same time, they recognise that they enjoy the social networks that are essential in the role of CR *"We enjoy the interaction. We enjoy the learning."* They also recognise improvements in their own health literacy: *"We're learning more and more about the health system"* and perceive they make a difference in health service improvement: *"I can see big improvements from when we first started."*

... am happy to invest my time

CRs consistently discuss their investment of time. Frequent last minute meeting cancellations are frustrating. Considerable time is wasted reviewing a significant volume of documentation for a meeting that does not occur: *"you find out one day before the meeting is scheduled that it is cancelled ... the items on the agenda run to 52 pages - which is unbelievable."* It takes time to build relationships and understand various parts of the health agenda when participating in meetings: *"I'd be prepared to stay on the committee to develop that."* When staff are mindful of the CR experience in committees and to some extent accommodate their needs, CRs are happy to invest their time and feel it is worthwhile: *"I've had quite*

Table 5. Coding Tree

Code	Description	Data items	Data extracts
Theme 1:	I am happy to invest my time as a CR but I need to be respected	-	-
I am a CR	CRs see things through a different lens. This builds staff awareness; enables representation of other perspectives	8	26
I bring my background and get benefit	CRs bring a personal background; they have reasons for being a CR; they learn new things and meet new people	6	24
Investing my time	Last minute committee changes, too much documentation too late, activities that go nowhere mean I have invested a lot of time but there is little outcome.	7	20
I will limit my time commitment	CRs consider having a set 'contract' with some kind of assessment by CR of the experience of engagement to determine ongoing commitment	2	7
I feel cynical / frustrated	There is a note of cynicism with talk of tokenism about being engaged with projects and committees inside health.	8	11
But I need to be respected		4	6
Being heard	Two CRs are better than one CR on a committee, and we need more CRs across the LHD. CRs longevity of experience builds their confidence.	6	13
Being in relationship	We build trust as the relationship is built. We understand each other's goals and accommodate each other's. Am I as a CR included at all levels? Is the CR value being acknowledged? We have different value but equal to staff. Being in a respectful relationship means having a conversation about the topic before creating drafts and documents. Co-design thinking, which is timely, clear, responsive, inclusive, kind with good manners is important.	10	42
Purpose makes a difference	Are consumer interests addressed? Are we on the same page? Is the issue important to the CR? To what extent are CR interests acknowledged and included, or even drive the project/committee?	10	30
Being responded to	How responsive is the staff team to input by CR? Do they provide feedback? Do they close the loop?	9	22
Being supported	Staff avoid use of jargon, provide glossaries, get to the point. CRs are supported during activities. Good manners are important. Being oriented to the project and wanting to know more about the health service before engaging. Being active in co-designing is important to the CR who wants to be included in identifying issues and included in discussions.	10	29
Theme 2:	We operate in a complex environment that affects our engagement, nevertheless I feel optimistic		
Staff engagement	The idea of us vs them is heard. There is churn in staff attending committees. This is linked to leadership and purpose.	12	45
Politics behind health	The social and political climate, models used, changes in funding sources, insecure funding contribute to the context for being a CR. Hospital culture and politics, and the bureaucracy in public health is observed as significant in how a CR operates.	7	24
Power imbalance	It's not a level playing field. Power is often held in the hands of bureaucracies, health professionals, doctors sometimes, or even a person with positional power.	5	16
Leadership important	From CR point-of-view, a formal role to ensure the culture of the health service team is inclusive, thoughtful, considerate, with good sponsorship, is important.	10	37
Type of engagement offered	It is not always committees that offer meaningful engagement. Other activities may be more so. There are differences between committees – e.g. how long they function, whether they are supporting a hospital accreditation standard, governance, or projects – and this affects CR interest in engaging.	7	20
CCPP itself	The effect of the program itself in providing support to CRs	6	24
Nevertheless, I feel optimistic	notwithstanding the sometimes-unfortunate experiences, CRs remain optimistic.	9	17

* "Data items" is the number of documents used in the analysis. There were ten documents for ten interviews, and one document for each focus group – a total of thirteen documents. "Data extracts" are distinct quotations within data items which illustrate the interpretation through the hermeneutic circle.

good experiences ... (meetings) haven't been cancelled at the last minute and there's always somebody to ask questions to at the end ... I'm quite happy being on the committee." Alternatively, especially for those CRs with poor committee experiences they prefer short and outcome-oriented engagement activities: *"I've probably enjoyed those shorter activities more than being on a committee."*

Investing time in what are seen as "tick-box" engagement activities is not meaningful (*"Sometimes I think I'm just there because they need someone, kind of a number, you know?"*), and this is also relevant for activities which invite CR participation but which discontinue without reaching an outcome (*"we were all frustrated that we'd get to a certain point and then stop with the project leads and that's when the meetings stopped"*), with no or little explanation. As CRs participate in a range of activities over time across the health system they see time wasted with what they perceive as "reinventing the wheel" when facilities fail to learn from successful achievements in sister facilities: *"if they're not sure how to do it over there come and look at [other LHD hospital] and see what happened."* Effective chairing of meetings is seen as useful in not wasting time.

... but I need to be respected

To "respect" is to admire (someone or something) deeply, as a result of their abilities, qualities, or achievements; to have due regard for the feelings, wishes, rights, or traditions of; and to avoid harming or interfering with.²⁶ Respect as identified by CRs confirms this definition, specifying several elements: being heard, being in relationship, being supported and having meaningful purpose.

Being heard requires the confidence to speak up, *"I'm starting to use my voice a little bit now ... It took a while to actually get a bit comfortable"* and having deliberate systems to strengthen the voice of the consumer: *"I think [other CR] and I as a combination are being heard so I'm quite happy."* Being in relationship requires good communication, (*"there is lots of discussion, always checking back in and communicating what's been done and what hasn't been addressed"*), getting feedback for the input provided by CRs (*"We gave so much feedback about all sorts of things, but never got any feedback as to what they did with that information"*), being included from the outset and building trust with staff and others in the team (*"the more we work with the same committee the better it gets"*). Interestingly, CRs identify that sometimes they are the longest-standing and reliable member of a committee (*"CRs tend to be the most reliable attendees at meetings"*).

CRs feel supported by staff when their health literacy is considered during conversations and acronyms are avoided (*"Look, the challenge certainly is coming up to speed, hearing a lot of acronyms"*). They feel supported when staff provide orientation to the people, business and environment of the committee (*"She described the whole service*

and we described our involvement with various committees and our background ... It's been a really functional relationship"), even providing a "buddy" to offer support before, during and after committee engagements (*"In the beginning [staff member] coddled us very successfully"*). Having meaningful purpose is also a part of being respected. When consumer interests are important to the committee or team, they feel respected for their time and input, noting that sometimes it is their voice that can make a project happen: *"We ... reported that to the committee. Things changed from there. The carpark was quite dangerous. So, things were done in the carpark."*

Theme 2: "As a Consumer Representative, I operate in a complex environment inside health, and it can make partnering with staff challenging. Nevertheless, I feel optimistic."

The individual CR perceives layers of contextual factors which affect partnership. The size and complexity of the organisation itself can be overwhelming: *"I still haven't really figured out the mammoth size of the organisation and all the issues with it."* Staff, as part of the environment for CRs, offer engagement opportunities and their own behaviour and attitudes affect CR experiences. CRs sense that at times they are *"the other ... the challenge we have is that some staff see us as interlopers into their territory."* They observe frequent changes in staff, *"and then you turn up and only 20% are the same the rest are stand-ins or fill-ins."* The change is observed to cause a loss of the historical gains or strategies that have been built: *"Thank goodness [staff member] is still there because at least there's one person ... who's seen the history of the committee."* This applies to leadership of teams, where the chairperson is seen to be highly influential: *"The personality of the chairperson makes such a difference as to how the committee is run and how the people within the committee feel about speaking out."* This is both positive and at times negative, depending on their ability to lead a co-designed agenda where this is appropriate.

Beyond the people environment, the politics and culture behind health is observed to influence partnership. This includes the way health is funded, affecting the time available to focus on patients as people, and a sense that public health has become a "business" rather than a public service: *"you move away from a service that was there to support the community ... to a commercial operation that has a completely different motivation and that of course is the [bottom line]."* CRs identify power imbalance as an important contextual element. In the context of a stigmatised health condition, the CR may experience clear power imbalance. *"I think there are staff that don't think that way, but I do think there are staff that do."* This starts between staff and consumers at a patient level and manifests in *"the eye-roll"* to invalidate consumer input to discussions. In committees, CRs identify powerful managers may maintain control of decisions preventing co-design of solutions: *"it's really frustrating and you question what are we doing here?"* CRs observe patients to worry that if they ask for help,

Table 6. Exemplar Evidence for Theme 1

1. I, the Consumer Representative ...	
I see things differently; I have lived experience:	<i>"I was able to identify things that maybe they hadn't thought too much about ... Unless you've been a carer you're not going to know these things and why would you, because they are only things you learn through experience" C3-17</i>
I bring my professional and personal background:	<i>"Consumer Council has a whole pool of people that are really interested but I feel that sometimes staff don't recognise that, how to utilise it. Which is strange because essentially you're getting ... people with a lot of background knowledge and skill" C1-19</i>
I am here to build staff awareness of consumer experience:	<i>"So, we bring in the other side of things that matter to consumers and that may then help set some priorities I guess about what is done and what's important" C1-17</i>
I advocate for patients at a system level:	<i>"Why are we not thinking of the patient? ... there has got to be a way that we can meet those medical needs and observe the modesty and privacy needs of the patient. If that nurse was in hospital, would she want to be having a shower without any shower curtain and the door possibly left open? Would the doctor like that? I don't think so" C2-17</i>
I want to improve health services:	<i>"My motivation to get involved was because I was an inpatient for three months. Had a very up and down experience ... so I wanted to make a change." C1-19</i>
I benefit. I enjoy meeting other people, learning new things	<i>"We enjoy the interaction. We enjoy the learning" C4-19</i>
I enjoy building relationships with other CRs over time:	<i>"There are strong relationships, friendships and you don't just talk to each other at meetings. If you know that somebody is not well ... I sometimes ring [another CR] and I spoke with [yet another CR] today and I'll try to contact her because I know she was really suffering today" C3-19</i>
I build my health literacy as I learn more about the health system and its complexity:	<i>"... But not just that. The (Consumer Council) meeting itself has developed from just hearing little bits of information to having guest speakers where we learn and that's really important, to me anyway, we're learning more and more about the health system and how we can help get it better all the time" C2-19</i>
I sense we make a difference:	<i>"It is such a fantastic opportunity to have an impact as a consumer because this would have been unheard of 10 years ago ... I can see big improvements from when we first started" C2-17</i>
2. ... am happy to invest my time	
There are too many last-minute committee changes and I have already reviewed a lot of documentation	<i>"People put a lot of time and energy in (preparing for a meeting) and you find out one day before the meeting is scheduled that it is cancelled. That's happened to me on a couple of occasions... the items on the agenda run to 52 pages - which is unbelievable" C2-17</i>
It takes a long time to get to know people and to understand the business of the committee	<i>"I'd be prepared to stay on the committee to develop that. I think with some committees it may be, as consumers, that we engage with them for a particular length of time because this is very specialised stuff" C2-20</i>
I like short sharp meaningful engagement activities	<i>"I'm the sort of person who likes to come and do something, in and out and that's it. I get a bit bored I suppose with things that go on and on and on, which they do in health, and you don't always get a positive outcome. I've probably enjoyed those shorter activities more than being on a committee" C6-20</i>
When time not wasted, I am quite happy	<i>"I've had quite good experiences ... (meetings) haven't been cancelled at the last minute and there's always somebody to ask questions to at the end ... I'm quite happy being on the committee" C4-20</i>
Tick box engagement is not meaningful	<i>"Sometimes I'm not sure of what my place is. Sometimes I think I'm just there because they need someone, kind of a number, you know? Like they need to tick off, they need someone with [condition] problems. That's how I feel sometimes" C7-20</i>
Sometimes I have been involved in an activity and it just suddenly stops - I feel cynical and frustrated	<i>"Like the other people who were at the meetings all the time, we were all frustrated that we'd get to a certain point and then stop with the project leads and that's when the meetings stopped - I didn't push ahead with it as I didn't see it as a good use of my time" C2-20</i>
A lack of consistency across the LHD leads to time wastage:	<i>"We should be working not to reinvent the wheel ... if they're not sure how to do it over there come and look at [other LHD hospital] and see what happened. Rather than sit there and wonder what to do about the problem, you know" C2-19</i>
If there is a sense of purpose and time being invested productively, CRs are happy to be involved	<i>"So that it doesn't waste anybody's time, if it only takes an hour to run a meeting then that's what you do, but in the end, you have to have some sort of summation of what you've achieved at that meeting. Then you need to move on. So, the direction for those that are attending to actually get work done and so that you come back to the next meeting having attended to the actions." C5-19</i>

Table 6. Exemplar Evidence for Theme 1 (Cont'd.)

3. I need to be respected	
Gaining confidence to speak up requires experience:	<i>"They've sent me to training and all that kind of stuff so they help me a lot. I think ... I'm starting to use my voice a little bit now ... It took a while to actually get a bit comfortable" C7-20</i> <i>"The more experience you have with being a CR, the more I think you're likely to speak out and participate. I think maybe some people are a bit apprehensive or anxious of speaking out in case what they say is seen as inconsequential or silly" C3-17</i>
Strengthening the voice of the consumer is important	<i>"I think [other CR] and I as a combination are being heard so I'm quite happy" C4-20</i>
Being in relationship with good communication	<i>"Good (engagement activities) have good communication ... everyone working well. In mine there is lots of discussion, always checking back in and communicating what's been done and what hasn't been addressed" C3-20</i>
Closing the loop – getting feedback	<i>"We gave so much feedback about all sorts of things, but never got any feedback as to what they did with that information. It was quite frustrating" C3-20</i> <i>"We are fed a lot of information that the health department wants us to hear I guess but it doesn't go anywhere. Then the next meeting there's another group of people who come to talk to us and we will give them feedback in the room but that then seems to just fall by the wayside" C1-20</i>
Being included as part of the team:	<i>"They are very good people, very professional very welcoming, they wanted a consumer rep but there wasn't a lot I could contribute so I raised the issue at the meeting, and I think it was something that was mulling around their minds too, some consumer-related activities that are related to the work of the committee ... and consumer engagement is on the agenda now" C2-20</i>
Being included from the outset	<i>"I think part of the problem was that they were well into the pilot before the contact was made ... so I don't know what they thought I could contribute" C1-17</i>
Knowing others in the team	<i>"I put my hand up for that because I'm very comfortable with the building and ... we all got to know a whole pile of people which is pretty unusual but it's also so much smaller than [other hospital] a lot of people can know a lot of other people" C8-20</i>
It takes time to develop the relationships	<i>"we have found the more we work with the same committee the better it gets. Whether we are training them or they are trusting us more I'm not quite sure what it is" C2-17</i>
CR sometimes the long-standing member	<i>"CRs tend to be the most reliable attendees at meetings" C-20</i> <i>"the chairperson changed so often as did the members and it was a really chaotic meeting. I was on that committee for over four years" C6-20</i>
CR interests are progressed	<i>"... I have managed to get two rooms that have never been in acute wards before. That came from a carer perspective. I wanted a "transition room" [ward orientation] ... those things just don't happen now ... I would say it's possible for us to make a meaningful contribution" C1-20</i>
My interests are aligned with staff, but CRs can make it happen	<i>"We ... reported that to the committee. Things changed from there. The carpark was quite dangerous. So, things were done in the carpark. Once we made a few comments, staff also commented, because they use the stairs more than we do... So, it makes the staff more aware to ...question things as well" C2-19</i> <i>"I said I'm going to come in and help you with the big day ... I think that made it better, they understood that I understood what they were doing. The communication flowed better after that" C10-20</i>
Having staff consider my health literacy	<i>"Look, the challenge certainly is coming up to speed, hearing a lot of acronyms. Acronyms... every agency has acronyms, but health seems to excel in them" C4-19</i>
Being orientated: knowing who is in the room, having understandable background information about the business and the people of the service engaging me	<i>"We put through our profiles including headshot and the director arranged for every member of the executive committee to prepare their own ... they were forwarded to us. The CRs also met the director, where she described the whole service, and we described our involvement with various committees and our background. So, in the first meeting everyone was prepared, and we had a good idea about the department, we had background information for everyone ... at the first meeting they introduced themselves and we introduced ourselves. It's been a really functional relationship right from the start and it really should be the model for other committees ..." C5-20</i>
Having a staff buddy	<i>"In the beginning [staff member] coddled us very successfully - she made sure that if any decisions were made in meetings that were pertinent to our committee but which we were not involved, she would give us that information and that's a vital part to us being able to participate fully" C1-20</i>

powerful health workers might discriminate in their care, so they avoid being seen as “a whiner.” At the same time, CRs note that having a powerful chairperson “*is probably a better way of doing things because he has the power.*”

A further contextual factor is the nature of engagements offered to CRs. They challenge the meaningfulness of the committee as a way of engaging. Whereas there is a view that governance committees need consumer representation, sometimes a committee may “*be a good idea that doesn't really work in the long run.*” CRs suggest that an evaluation of the meaningfulness of committees may lead to a contractual arrangement where over time they “*look at which of these committees we want to put our time into.*” On the other hand, time limited engagements are sometimes more meaningful and enjoyable. For example, being an independent member on a recruitment panel, collaborating with staff on patient-centred training, or involvement in medical student examinations.

One important contextual factor is the CCPP itself where the regular meetings, discussions and contact is seen to build CR capacity and relationships and is valued as an important support: “*Because I think [the Community and Consumer Partnerships team] working in tandem have a real ability to make people feel confident and drag out what it is they want to say and include them in the conversation.*”

Throughout these data, a consistent note of optimism is heard, notwithstanding the hurdles that have been identified in this research. There is a belief that progress is being made: “*I think we are being accepted a lot more than we used to be, and I think, you know, we are going in the right direction.*”

Discussion

We have sought to understand the experience of what it is to be a CR engaging with staff to improve health systems. Using a hermeneutic circle underpinned by Heideggerian phenomenology allowed us to get close to such an understanding, and importantly to bring a focus on the complex environment in which CRs operate. Having a research team consisting of three of the 17 participants and sharing the draft report for discussion among all the CRs across the LHD enabled us to confirm the constructed truth in the findings.

This research pointed to many complex interweaving factors affecting CRs partnering with staff, however we identified three that appeared to be linked. The second theme highlighted the persistent power imbalance operating at its most basic level between patients and their carers and health professionals, carried over between CRs and staff members. The power imbalance is seen to affect practical expressions of respect for CRs as they invest their time attempting to build partnership. These data

corroborate other research identifying the power imbalance as an important barrier to partnership with consumers.^{12,13} This, coupled with the assumption that committees are the default structure for partnership with CRs, is problematic when systems to build respect are not in place. We will discuss each of these separately before raising questions for future researchers based on our findings.

Respect

Consumers are happy to go through a time-consuming process to gain experience and confidence as a CR and they enjoy the camaraderie with other CRs and growth in health literacy that the role offers. The proviso is to be respected throughout the process. Being respected surfaced as a key element involved in the satisfaction experienced as a CR. The goal of the CR is to build a culture for “patient-centred care” which is: “*an obligation to care for (patients) on their terms... Patients are known as persons in context of their own social worlds, listened to, informed, respected, ...and their wishes are honored.*”²⁸

CRs expect respect as part of the process of partnering with healthcare staff. In analysing the context for partnership, questions were raised about how respect operates at every level from the executive through to front line staff caring for patients. How does respect operate within the historic-socio-political drivers around healthcare? In aiming to rationalise the costs of healthcare has the focus on respect for staff and patients been diminished? “*Twenty years ago, I used to look forward to going to work, but around 2000 there was a shift to ‘cost before care’, you couldn't do this or that because of cost. It was unsettling. Now it has moved on to ‘treat em and street ‘em.’*” P-R1

From the consumer's point of view, respect is a practice. Being respected by staff – by inviting more than one CR to join a committee, by providing a staff “buddy” to welcome the CR and support their health literacy, by inviting consumer input to how the “business” of the committee could better serve PCC and focused on meaningful outcomes with good communication – resulted in positive and productive experiences. When these supports were not in place, experiences were poor and unsatisfactory, and CRs considered limiting their investment of time to only those activities that were assessed as practically more respectful.

Power

The roots of participatory research are in social movements and civil society organisations where human power inequities are central.²⁹ Participant-researchers in this study consistently described their role as CRs, in parallel with the role of patient, had characteristics of a struggle and this recognition was seen as being honest. “*We have to be honest, for CRs to be taken seriously we need to*

Table 7. Exemplar Evidence for Theme 2

The size and complexity of the organisation	<i>"I still haven't really figured out the mammoth size of the organisation and all the issues with it. It will take some time for me to really unravel it and really make an impact... Understanding who the players are and then getting more confidence in voicing my opinion and, yeah, that's something that will take time" C1-19</i>
The staff around me make a difference ... us vs them:	<i>"It's very important staff understand that consumers are people just like them ... one of the challenges we face is that staff often see consumers as "those over there", it's a bit like in business where you have the "us and the them"... The challenge we have is that some staff see us as interlopers into their territory" C4-20</i>
... a lot of staff turnover:	<i>"A lot of the committee come and go and that's another problem we have. You have one group of people on the committee and then you turn up and then only 20% are the same the rest are stand-ins or fill-ins ... and we don't know who they are, they don't know who we are" C2-17</i>
... means the history is lost	<i>"that matters because you can get a flow, you can have a decent thing happening with people being there all the time. It's a leadership thing. Thank goodness [staff member] is still there because at least there's one person ... who's seen the history of the committee" C4-20</i>
Leadership affects engagement:	<i>"When there is strong leadership from the committee chair and good communication there is a difference in engagement from CRs and staff" C3-20</i> <i>"I think the personality of the chairperson makes such a difference as to how the committee is run and how the people within the committee feel about speaking out and their relationship with other people on the committee" C4-20</i>
The politics and culture behind health ... The way health is funded	<i>"There's no time and that's the challenge I think. There's a set time, have an operation, this is the standard to get that patient out of hospital and that's what the focus is rather than the patient as a person. ... I think it's a challenge in medicine generally and the funding is part of that" C1-18</i> <i>"...you move away from a service that was there to support the community ... to a commercial operation that has a completely different motivation and that of course is the [bottom line]. ... And it's a really blunt tool. Rather than sit down and systematically look at what don't we need to continue to do, what can we do better and where can we derive those savings ... it's balance-sheet thinking, it takes it away from the old-style notion of satisfying the people who need the service" C4-19</i>
When CRs move to paid peer work, stigma of the condition can lead to poor engagement:	<i>"I think stigma is still around. I think there are staff that don't think that way, but I do think there are staff that do. They haven't been able to make the transition from consumer to worker ..." C2-18</i>
When the powerful disregard consumer input:	<i>"...there are times when you say something you might get the eye-roll. Or being told by a senior medical practitioner ... when we brought the consumer's voice to the table, I was told that point of view was not actually valid." C2-18</i>
Unmoveable decisions made by executive who hold the power:	<i>"... where there seems to be an executive decision which is not moveable ... your committee (is) asked to work on a particular project ... both the staff and the CRs identify a problem and get told, well that can't be changed or altered ... it's really frustrating and you question what are we doing here" C5-20</i>
Patients worry powerful health workers might discriminate in their care:	<i>"I said, why didn't you eat your lunch didn't you want it? She said no I'm starving... And she wouldn't ring the bell because she thought ... she was 84 or five at that stage ... she didn't want to bother them ... they'll also put a mark on my thing that I'm a whinger" C3-19</i>
Although I recognise that power can get things done:	<i>"So, the chair came from fairly high level ... then without any information we got this email from the general manager saying he would be chairing it in future ... but I do think that what he's doing is probably a better way of doing things because he has the power" C5-19</i>
Some engagements may not be fit-for-purpose:	<i>"it's these more generic committees ... I'm not sure that there's a meaningful contribution from anyone, they just seem to sort of be a good idea that doesn't really work in the long run" C1-20</i> <i>"I think with governance committees we should be there at the table but it's some of the other smaller committees ... perhaps a contract would be good and then the Consumer Council look at which of these committees we want to put our time into"</i>
Some time-limited offerings are more meaningful:	<i>"I was an independent member on two recruitment panels which I really enjoyed. I was hesitant initially but the others on the panel were very kind ... I asked if I could ask my own question from a consumer point of view, and they welcomed that" C6-20</i> <i>"I did some teach-back sessions with community health nurses. I did for a couple of years the examining of year one and two medical students at Westmead and that was really interesting" C6-20</i>
The Community and Consumer Partnerships program supports us:	<i>"... we've really, really grown, not just in numbers but in the way that people are a lot more confident within themselves now and they're quite willing to come out and talk ... And we used to be able to get away fairly quickly after the (Consumer Council) meeting but now you can't... the relationships ... they're really interested, you know in what is happening within your life and you in them" C2-19</i> <i>"It's not chairing a meeting it's facilitating a meeting. There's a big difference between the two. Because I think [the Community and Consumer Partnerships team] working in tandem have a real ability to make people feel confident and drag out what it is they want to say and include them in the conversation" C4-19</i>
Nevertheless, I feel optimistic	<i>"...each time I can just see us going higher and higher and having more influence with the system. And I think they're starting to listen to us" C6-20</i> <i>"I think it's slowly sinking in, and I think we are being accepted a lot more than we used to be, and I think, you know, we are going in the right direction" C2-17</i> <i>"it's a big and diverse organisation and I think cultural change is slow. But I'd be hopeful that we can see something in the next couple of years" C1-17</i> <i>"Very confident (that CRs can have an impact). I think that it is making grounds, although it's slow, it is slow, but I think with time and with confidence we can influence" C1-19</i>

acknowledge that it is a struggle.” P-R1. The participatory approach, with a focus on the Heideggerian importance of context²³ identified how the power imbalance inherent in the culture around health, acted as a barrier to partnership for the Consumer Representatives participating in this study.

Alternatives to committees

Where committees have systematically built respectful supports for CRs into their structure, CRs have the confidence to ask questions that stimulate health workers to think differently about issues: *“What are you doing about that?” Even if it just makes people stop and think.” P-R3* However, this research uncovered other examples where systems to support and strengthen the voice of the CR are not in place, and committee experiences for CRs are poor.

The committee structure is often used to promote activities targeting the National Standards for accreditation. Within National Standards three to eight, patient-centred care is explicitly promoted:

1. Actively involve patients in their own care
2. Meet the patient’s information needs
3. Share decision making

For P-Rs these discussions raised questions: Is consumer participation in a committee, on the whole, resulting in these three actions occurring? Could there be other ways to progress PCC?

Issues of meaningful outcomes, variable support for participation of the CR and high staff turnover disrupting committee outcomes challenge the idea that committees are the best structure for partnering with consumers. When committees are not delivering outcomes that enhance PCC, more satisfactory alternatives that are time limited, evaluated, and deliver meaningful outcomes improving PCC may need to be considered.

Conclusions

Health organisations may improve consumer engagement outcomes as mandated for hospital accreditation, by being aware of the experiences of CRs giving their time to partner with staff members and health systems. Many negative experiences may be avoided with mindfulness about the complex people and system environment in healthcare systems, as these can impede successful partnership.

This research has raised questions about CR experiences of respect in their attempts to build partnership with staff working in healthcare, and whether current models for managing costs within healthcare are an impediment to partnership. The same questions were raised about staff experiences of respect due to larger contextual factors.

We challenge the automatic assumption that partnership is based on consumers as members of committees. This research uncovered experiences where shorter, thoughtful consumer-staff collaborations were rewarding, and delivered shared goals. In this research, when practical supports for consumer partnership are not systematically provided, partnership experiences are poor and may not contribute to Patient-Centred Care as mandated by the Australian standards for healthcare accreditation.

Directions for Future Research

Our research has suggested that respect is a practice. It consists of behaviours that support and strengthen the consumer voice in activities with staff, that avoid wasting the CRs time, and work towards a co-designed, health literate agenda where all members of the group share the same goal. We suggest that future research should evaluate the experiences of Consumer Representatives when the practice of respect is in place when health systems engage consumers to collaborate in service improvement activities. This study did not focus on the experiences of staff during staff-consumer service improvement activities. However, future research could explore staff experiences to understand how the contextual factors identified in this research affect staff experiences of progress towards shared goals in healthcare improvement activities.

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Appendix

No.	Item	Guide questions/description	Reported on page
Domain 1: Research team and reflexivity			
Personal Characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	4
2	Credentials	What were the researcher's credentials? E.g., PhD, MD	4,5
3	Occupation	What was their occupation at the time of the study?	4,5
4	Gender	Was the researcher male or female?	4,5
5	Experience and training	What experience or training did the researcher have?	4,5
Experience with participants			
6	Relationship established	Was a relationship established prior to study commencement?	6
7	Participant knowledge of the interviewer	What did the participants know about the researcher? E.g., <i>personal goals, reasons for doing the research</i>	6
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? E.g., <i>bias, assumptions, reasons and interests in the research topic</i>	4
Domain 2: Study design			
Theoretical framework			
9	Methodological orientation and theory	What methodological orientation was stated to underpin the study? E.g., <i>grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	6,7
Participant selection			
10	Sampling	How were participants selected? E.g., <i>purposive, convenience, consecutive, snowball</i>	7,8,9
11	Method of approach	How were participants approached? E.g., <i>face-to-face, telephone, mail, email</i>	7,8,9
12	Sample size	How many participants were in the study?	Table 2 7
13	Non-participation	How many people refused to participate or dropped out? Reasons?	Table 2 7,8
Setting			
14	Setting of data collection	Where was the data collected? E.g., <i>home, clinic, workplace</i>	11
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	11
16	Description of sample	What are the important characteristics of the sample? E.g. <i>demographic data, date</i>	Table 4 10
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	11
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	11
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	11
20	Field notes	Were field notes made during and /or after the interview or focus group?	11
21	Duration	What was the duration of the interviews or focus group?	11
22	Data saturation	Was data saturation discussed?	12
23	Transcripts returned	Were transcripts returned to participants for comment and /or correction?	11
Domain 3: Analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	11,12
25	Description of the coding tree	Did authors provide a description of the coding tree?	Table 5 13
26	Derivation of themes	Were themes identified in advance or derived from the data?	12
27	Software	What software, if applicable, was used to manage the data?	11
28	Participant checking	Did participants provide feedback on the findings?	12
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g., <i>participant number</i>	15-24 Tables 6&7
30	Data and findings consistent	Was there consistency between the data presented and the findings?	15-24
31	Clarity of major themes	Were major themes clearly presented in the findings?	15-24
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	n/a*

* We have presented the themes identified by the majority of the data.