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**Consumer engagement in health services in Queensland, Australia: A qualitative study about perspectives of engaged consumers.**

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**Conflict of interest**

The authors individually and collectively declare that there are no conflicts of interest associated with this study.

## **Abstract**

Successive health policies demonstrate unwavering commitment to partnering with consumers and communities. However, engaging consumers is complex and replete with priorities, perspectives and values that are firmly held, virtuous and different. In the context of political imperatives and different approaches to partnering with consumers in health services, we sought to explore consumers' experiences of engagement in public, private, primary care and non-government health services in Queensland, Australia. Participants identified themselves as consumers of health services and were currently, or had previously been, involved in planning, designing, delivering, monitoring, and/or evaluating health services; were aged over 18; and consented to being involved. This qualitative study used semi-structured individual interviews to collect data which was analysed thematically. Four themes were identified, (1) authentic engagement and representation: asking, listening and acknowledging; (2) a continuum of consumer expertise; (3) contested engagement: transgressing health services thresholds of tolerance; and (4) creating value for consumers and health services: reciprocity, trust, respect and remuneration. Findings demonstrated that 'rules of engagement' exist between consumers and staff employed in clinical, managerial, executive and administrative positions within health services in response to a legislated requirement that health services partner with consumers. The rules of consumer engagement centred on authenticity, transparency, expertise and individual capacity to transcend personal experience. If health services and the broader public are to fully benefit from safety and quality advances proposed by partnering with consumers, then it is essential that areas of contestation are identified and addressed.

## **Key words**

Consumer engagement; Partnering with consumers; Health Services; Quality and Safety; Patient and Public Involvement; Qualitative Methods;

**What is known about this topic**

- Partnering with consumers is enshrined in health services policy globally.
- Consumer engagement practice exists on a continuum from consultation to collaboration.
- Consumer engagement is conceptually virtuous and morally appealing, but not consistently understood.

**What this paper adds**

- Rules of engagement exist in health services and must be navigated by consumers if they are to successfully participate in health service consumer engagement activities
- Consumers' capacity to engage with health services exists on a continuum, with some consumers having novice expertise and others demonstrating well developed knowledge and skills for engaging with health services
- There are invisible barriers to consumer engagement that reside within health services. Consumers are often not aware of these barriers until they attempt to move into spaces where they are not welcome.

## **Introduction and background**

In Australia and globally, successive health policies demonstrate unwavering commitment to partnering with consumers, carers and communities (Nathan, Braithwaite, & Stephenson, 2014). The introduction of the National Safety and Quality Health Service Standards in 2012 and revised in 2017 (Australian Commission on Safety and Quality in Healthcare, 2017) shifted Australian health services from an accreditation model of safety and quality monitoring to a regulatory environment (McPhail, Avery, Fisher, Fitzgerald, & Fulop, 2015). ‘Partnering with consumers’, commonly referred to as ‘Standard 2’, is one of ten regulated standards (Australian Commission on Safety and Quality in Healthcare, 2017), thereby inextricably linking safety and quality with consumer engagement in Australian health policy and practice. In response to this regulated environment, clinicians, managers and decision-makers are required to show evidence that they engage consumers in planning, designing, monitoring, evaluating and delivering health services. However, engaging consumers at multiple levels and places within healthcare systems is complex (Farmer, Taylor, Stewart, & Kenny, 2018) and replete with priorities, perspectives and values that are firmly held, virtuous and different.

Engaging consumers as partners in health services is imprecise and value-laden. It implies equivalence (Farmer et al., 2018), reciprocity (Mathie et al., 2018) and positive regard (Scholz, Bocking, Banfield, Platania-Phung, & Happell, 2018). It also implies transparency, trust, collegiality, perspective taking, authenticity, and representativeness. It is linked with other virtuous concepts that are espoused in health services, such as person-centred care (Eaton, Roberts, & Turner, 2015; Munthe, Sandman, & Cutas, 2012; Price, 2006), person-centred goal setting (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012), shared decision making (Barry & Edgman-Levitan, 2012), patient generated outcome measures (Trujols et al., 2013), co-production (Batalden et al., 2016; Whitaker, 1980), co-

design (Robert et al., 2015; Steen, Manschot, & De Koning, 2011) and co-creation (Frow, McColl-Kennedy, & Payne, 2016; Hardyman, Daunt, & Kitchener, 2015; Voorberg, Bekkers, & Tummers, 2015). Thus, engaging, involving, including and partnering with consumers is enshrined in policy and legislation, idealised in practice and ubiquitous in academic literature.

Partnering, or engaging with consumers positions them as active rather than passive contributors to healthcare outcomes (Heaton, Day, & Britten, 2016; Ryan, 2012). Apart from contributing to quality and safe healthcare, actively engaged consumers contribute to consumer and clinician satisfaction, cost-efficient services, service accessibility, and to harnessing emerging advances in evidence and practice (Kodner, 2003; Mittler, Martsolf, Telenko, & Scanlon, 2013; Sarrami-Foroushani, Travaglia, Debono, & Braithwaite, 2014; Sharma, Conduit, & Hill, 2014). Engaging consumers as active partners in health care has the potential to humanise historically fragmented care systems (Kodner, 2003). To achieve these outcomes, consumers must move beyond merely giving opinions, instead engaging in multifaceted, diverse and extended roles that contribute to problem-solving and governance in health services (Farmer et al., 2018).

The road of consumer engagement is paved with opportunities and pitfalls (van den Heerik, van Hooijdonk, Burgers, & Steen, 2017). Philosophically, engaging consumers is underpinned by concepts of social justice, human rights, and value (Dunston, Lee, Boud, Brodie, & Chiarella, 2009; Nambisan & Nambisan, 2009; Palumbo, 2016). Although consumer engagement is often presented positively, and therefore highly valued, some consumer engagement activities have negative outcomes (Barile, Saviano, & Polese, 2014; Munoz, 2013). Authentic consumer engagement can lead to effective and visible changes in health services, whereas tokenistic engagement can be damaging to both consumers and health services (Cooper, Gillmore, & Hogg, 2016). Consumers can be positioned as being 'problematic' and viewed with suspicion when health services staff (i.e., staff employed

within health services – clinical, managerial, executive and administrative positions) perceive they have personal agendas, they can be seen as unrepresentative or under-representing their communities, and the motives and legitimacy of vulnerable populations can be called into question (Scholz et al., 2018).

In this context of political imperatives and apparent different approaches to, and results from, partnering with consumers in health services, we sought to explore consumers' experience of engaging as partners in health services. The research question that underpins this study is: What are consumers saying about being engaged in planning, delivering, monitoring and evaluating health services in Queensland?

### **Methods**

The current study is part of a larger mixed methods study exploring consumer engagement in Queensland, Australia. This paper reports qualitative data collected between November 2017 and June 2018 using semi-structured interviews and analysed thematically. Multi-site ethics approvals were obtained from Queensland Health (HREC/17/QPAH/193) and Griffith University (Ref: 2017/194).

#### *Recruitment*

Participants were recruited via email, which was directly forwarded by consumer engagement staff within health services, or a peak consumer representative body to their membership. Participants were eligible to participate if they identified as consumers of health services and were currently or had previously been involved in planning, designing, delivering, monitoring, and/or evaluating health services in Queensland; were aged over 18; and consented to being involved. Interested participants were provided contact details for the research team and invited to contact researchers. Participants were given a participant information sheet which detailed the research and consent process. A mutually agreed time for interview was arranged.

### *Data collection*

Two researchers conducted phone interviews in the privacy of their offices. Interviews were digitally recorded and transcribed verbatim by an approved external transcription agency. Interviews lasted between 12 minutes and 1 hour 17 minutes, with an average of 38 minutes. Typically, variations in interview length reflected greater or lesser consumer engagement experience. Prior to interview, all participants affirmed they had received and read the participant information sheet and consented to interview. Participants were asked to describe their experience of being engaged as a consumer within health services. Example questions included: (1) Which health service are you currently engaged with? (2) How are you engaged? (3) What types of things are you asked to do? (4) How difficult or easy is it to do those things? And why? (5) What support do you need to be able to engage with the health service? (6) Are you remunerated for the work that you do? Participants were given a 20.00AUD gift voucher in recognition of their time.

### *Data analysis*

Transcribed interviews were checked for accuracy. All interviews were read twice by two researchers and collectively coded a priori on a response by response basis (Bazely, 2013). Preliminary coded data were further categorised into higher order codes by asking two questions of the data in the context of the research question: What is this specifically? and What is this an example of? (Glaser & Strauss, 1967). Higher order codes were further developed in collaboration with the research team. An iterative process of constant comparison continued until the most parsimonious representation of the data became evident (Bazely, 2013; Glaser & Strauss, 1967). To maintain anonymity, participants have been allocated an identification code (P001, P002, etc.).



## Results

Thirty-eight consumers (9 males, 29 females) participated. Participants engaged in a range of tasks across Hospital and Health Services, Primary Health Networks and Non-Government Organisations including document reviews (e.g., policy documents, posters and brochures, patient communication and correspondence), attending issue specific workshops and projects (e.g., maternity services, oral health, mental health, handwashing, hospital design), participating in training and education as both trainees and mentors (e.g., consumer representative training, educating new staff about the role of consumers), volunteering (e.g., providing directional assistance to patients and visitors at hospital), and being members of advisory committees and networks. Some participants were engaged in regular activities, others were ad hoc. Some committees and networks dealt with everyday business of health services, while others provided strategic advice and direction.

Four themes explained how consumers engaged in health services across Queensland; namely, (1) authentic engagement and representation: asking, listening and acknowledging; (2) a continuum of consumer expertise; (3) contested engagement: transgressing health services thresholds of tolerance; and (4) creating value for consumers and health services: reciprocity, trust, respect and remuneration. Each theme is described in detail below.

### *Theme 1: authentic engagement and representation: asking, listening and acknowledging*

Irrespective of the type or duration of consumer engagement, an iterative process of asking, listening to, and acknowledging was important:

I do get a kick out of any time that I can see I've made a difference. It does give me a bit of a buzz. I think 'Oh, wow', because often you sit there wondering if they're [health staff] really listening. (P031)

Although the ask-listen-acknowledge sequencing was important, it was often incomplete—health staff missed one or more parts of the sequence and/or omitted the sequencing at one or more times during the engagement period. Staff sometimes ‘told’ rather than ‘asked’ participants and did not always allow time or space for them to consider their response or to discuss issues:

...we meet quarterly, but a lot of that, the stuff is already done, and when we meet, the agenda’s really tight, and they [health staff] punch it along... be lucky if it’s five or ten minutes to discuss each thing, and really, we’re not really discussing it. (P026)

As much as authentic engagement depended on health services staff asking, listening to, and acknowledging participants, participants also needed to ask, listen to, and acknowledge their communities. Local issues were often unique and not always well understood or managed by health services. Even in geographically close communities, demographics and issues could differ: “...Very, very different. I mean, completely different demographics, but we’re all in the same [health service] region...” (P011). Participants also did not always have direct experience of locally relevant issues: “We didn’t realise how bad it [a particular community issue] was, so it’s been a huge thing we’ve taken on” (P010). Strategies to understand local issues involved talking to people: “The consumer involvement I get is if I’m at a club meeting or something in the community and people will talk... so that’s the only way I was getting feedback. It’s still a great way of hearing what’s going on” (P011). Thus, asking, listening to, and acknowledging were essential to authentic consumer engagement processes and needed to be heeded by health staff and participants alike.

*Theme 2: a continuum of consumer expertise*

Consumer expertise, which underpinned consumer engagement activities was believed to exist on a continuum: "...if you see your consumers on a continuum, with a broad range of skills and a spectrum of training and development that can take them through to participation at the board level of the hospital..." (P042). Some participants were unfamiliar with the internal machinations of health services, and, although experts by experience, had novice expertise about health services. Others utilised wide-ranging and advanced engagement skills, often at a strategic level.

All participants had lived experience about a particular condition or issue, but novice consumers had little experience of interacting with the health system beyond a role of patient, carer or service user. These participants used their lived experience to provide issue specific information: "We discussed with the [government] ministers and stuff like that how to improve Aboriginal healthcare, and improve the way that the Aboriginal community is treated within the healthcare [system]... like for our maternity care" (P009). Participants with novice consumer engagement expertise could develop skills over time. However, some only engaged for a short time, and although enthusiastic, found that competing life priorities and/or ongoing group changes meant their enthusiasm waned.

The majority of participants had experiential knowledge relevant to committee membership and function, or had broad health experience. They drew on these experiences to engage differently. These participants had mid-range expertise and were highly committed to being an engaged consumer. They read widely and researched information they believed was appropriate to their engagement work. They transcended their own experiences of the health system, taking the view that: "I want it to be constructive... a lot of consumer engagement people go in there and just beat up on the agency or whatever. I don't like doing that. I just think that's a waste of time..." (P034). They took the perspective of others and combined

multiple sources of information and knowledge to identify solutions to issues and they advocated for change. They were passionate and committed to making a real difference for communities: "...There's kind of bonds developing amongst the people in the group who are really committed at the grassroots level to really seeing [named intervention] make a difference to people's lives..." (P042).

A smaller number of participants had high level engagement expertise. These participants actively sought to represent a broader community. Participants with high level expertise advocated to health services on behalf of consumers and they advocated to consumers on behalf of health services when and as they deemed appropriate: "I'm continually listening to people and advising people on what they can and can't do... I'd love to be able to educate the public on how the system works" (P031). Participants with high level expertise were leaders and mentors.

In summary, participants described various levels of expertise. Although all had lived experience, some consumers had novice engagement expertise, the majority had mid-level expertise and a smaller number had highly developed engagement expertise. As their consumer engagement expertise expanded, participants increasingly took the perspective of other consumers, communities and of health services. They transcended their own experiences and advocated for, and sometimes led service and system change.

### *Theme 3: contested engagement – transgressing health services thresholds of tolerance*

Consumer engagement was not always positive and some participants described a process whereby health staff disengaged. Several participants described a point in time when they believed their input was no longer welcomed. They often did not know what had occurred, but intuited that the consumer engagement ground on which they stood was contested. They presumed that they had been too outspoken, or had upset the status quo in some way that meant their input was no longer welcome:

I feel like the people at [named service] won't speak to me anymore because I've made too many waves [been too outspoken]... it doesn't feel right. But, if I still want to work with them, I just have to bite my tongue, and I shouldn't really feel like that. (P014)

One participant described an invisible tolerance threshold, which, when transgressed by being too outspoken or by upsetting the status quo, precipitated resistance and retaliation from health services staff:

If you engage where it's [consumer engagement] passive and it's more [that] you go, 'Yep, looks great', and 'Look, we're working together and everything you're saying is great,' it works really well. But, if there's any kind of, 'Oh, we don't think that's right', or 'We really think that's a bad idea,' or, 'We don't think you should do X, we think you should do Y,'... you hit resistance. And often it's passive resistance. It's the delay in catch-up, non-attendance at meetings, long delays in emails. You know, that kind of disengagement... I definitely think there's support if you fit within a tolerance. And outside of that, you get almost blacklisted. (P027)

Participants noted that they couldn't be too outspoken or vocal: "...it's very difficult to complain, especially when you know you have to go back there for treatment" (P002). They understood that bringing personal issues into the consumer engagement space could be met with resistance, "...one of the things I don't like, is and I'm sure it's everywhere, is the wall they put, management puts up when you talk about your own issues. It's like a protective wall, a barrier they put up..." (P031), which was like walking a tightrope of "...trying to have momentum and then trying not to rock the boat of the organisation" (P027). Consequently,

participants needed to be mindful of the cultural and social landscape of the organisation, understand their ascribed role and be solution focused, because:

...it [dis-engagement] really takes a toll. And on the morale of the consumers, where you go, we – you try and engage and do your best. But, if there's this legacy – adversarial or not really a partnership, your ability to influence, yeah, it's hard and it gets you down a bit. (P027)

In summary, not all consumer engagement experiences were positive. There was some evidence that health staff could and did contest consumer engagement activities within their organisations. When staff contested consumer engagement activities, it appeared to be because consumers were outspoken or crossed an invisible line—after which the status quo shifted. Nevertheless, as described next, when participants were effectively engaged, value was created.

*Theme 4: creating value for consumers and health services: reciprocity, trust, respect and remuneration*

Participants noted that consumer engagement was not uniformly valued across health services. Rather, it was sometimes an 'add-on' to the main business of health care. Reciprocity, trust, respect and remuneration were essential to creating value for consumers and health services. Participants valued the reciprocity inherent in consumer engagement, and described their role as a way of giving back to health services and to their communities: "I didn't realise that I could give so much back to the community through my lived experience" (P005). Consumer engagement was exciting and able to make a real difference to the lives of others: "so, if my contribution makes life easier for even one person, then that's been a success" (P007).

Participants needed to respectfully engage with health staff and organisations and show they could be trusted with sensitive information: “They [health staff] will share with me patient experiences, which God Almighty, just about blow the mind. And that’s all confidential. But they really have a commitment of doing better all the time” (P011). When participants showed that they could be trusted and were reliable, then consumer engagement was valued: “Oh, it’s the most important thing that the health care professionals do, actually value consumer voices, I think was the most important thing” (P033), and new opportunities were created:

I find being involved as a consumer advisor in this health care area, it’s really very satisfying and I’ve had positive experiences, where, you know, I’ve seen them sort of move up a gear, even in, like the [named health service], to be invited for the first time ever as a consumer to attend a business planning day. (P012)

Health services also needed to be trustworthy and engage respectfully. Participants reported that they did not always feel they were included in important decisions that directly impacted them. However, consumer engagement across health services was improving: “...when I think back to consumer involvement 20 years ago... it’s very different and I think the organisation is generally well intentioned and probably compared to other places has a lot of consumer involvement” (P003).

Some participants believed that remuneration was an expression of value: “Also, the remuneration factor adds value to it [consumer role]. It makes it feel like I’m not just going to make up numbers or something” (P015). Although important, remuneration was a contested form of acknowledgement. Some participants were in paid roles, some were reimbursed for

particular items (e.g., fuel, accommodation, time), and others received no remuneration.

Remuneration was inconsistent and unrelated to the type of activity, or the time taken:

...When I was with the [named organisation]... you were given a, I think they called it a sitting fee, and it might have been \$85 or something, per meeting. When I joined [named committee] as a consumer rep [representative] what they remunerate me [for] is mileage reimbursement which is probably \$40 a meeting. Then when I go to [named organisation meeting] which is only once a quarter they give you a flat fee of \$150. And I'm just like, 'My God, isn't that interesting'.... (P011)

Some participants were willing to volunteer their time to support health services: "And I do see this as a voluntary act of citizenship really – my involvement in health care improvement. But when I get paid, it's really nice" (P012), while others actively sought remunerated opportunities. Although some participants were willing to volunteer their time, they did expect that they would be appropriately remunerated for out-of-pocket expenses. However, bureaucratic processes for being remunerated sometimes involved large amounts of paperwork, which could be onerous for participants.

In summary, when participants were deeply engaged, respected, trusted, asked, listened to and acknowledged for their input they could become powerful advocates for consumers and for health services. Active, passionate and engaged participants who understood the perspective of others including the health system were able to contribute positively to consumer engagement activities and roles within the health system. The following quote positively demonstrates consumer engagement in action:

And you know, their [health staff's] willingness and openness to learn, and it's a challenge for them, because you get ingrained ways of working and



doing things and there has to be people there [in the health service] who agitate for change. And when they invite somebody in who doesn't know anybody else, but they make it a really good experience for you by making sure that, you know, they all wear name badges and roles so that, you know, I'm the only person in the room who doesn't know anyone. They know everybody. But then during the process as well, to actually invite you to speak. To have a turn to speak like everybody else does, and to value that, and then to even follow up with a letter that says, you know, 'Wow, we were delighted with the fact that you came so well prepared, and you blew our minds because you helped us to think about things in different ways.' And so, I get a real lot of fulfilment out of that kind of positive feedback and I think, I wish that could be replicated and we could recruit many more consumers, you know, who have the ability to do that. (P012)

However, health services did not always engage the full capacity and expertise of participants. Health services staff sometimes contested consumer's experience. The following quote demonstrates consumer engagement that was not utilised to its full potential:

...I got quite a bit frustrated with this committee, because one of the things they were reviewing was a [named clinical process] and they basically wouldn't have me on that group, that working group because it was for clinical only. I just made a bit of a noise about that saying, 'Look, actually clinic [staff] aren't the only people. You're doing it [clinical work] to the consumer.' And I really kept on having this conversation with them about this [clinical process] is all about interactions and conversations and consumers are fifty percent of it [clinical interactions]... I found it an

incredibly frustrating committee. One of its challenges was that it was set up to implement a strategy that was developed without much consumer input... So [because of changes in government policy] I got grafted onto this [committee] with people who really hadn't expected to have to work with the consumer, and it was a real challenge at times because I would keep getting told things like, 'Yes, but we've got deliverables'... Anyway, I think there are lots of hard questions about [the issue at hand] and they've avoided all of them and done all the 'let's have nice conversations'. (P021)

## **Discussion**

In this study, we sought to explore and understand participants' experience of engaging in partnership with health services across Queensland, Australia. The findings demonstrated that 'rules of engagement' exist between consumers and health services staff in response to a legislated requirement that health services partner with consumers. The rules of consumer engagement centred on authenticity, transparency, expertise and individual capacity to transcend personal experience. Depending on whether or not consumers and health services staff could successfully navigate unspoken and hidden rules, the activities and outputs of consumer engagement activities were either contested or valued. Consumer engagement roles can be stressful (Blut, Heirati & Schoefer, 2019). Therefore it important to prepare consumers to be involved in engagement processes in culturally appropriate ways.

The importance of continuously asking, listening to and acknowledging consumers was consistent with a desire for authentic partnering. Authenticity is well recognised in the literature, is relationship- and values-based, and requires, among other things, compassion, perspective taking, reciprocity, trust, confidentiality, respect, and empathy (Lloyd & Carson, 2011; Smith & Dransfield, 2019; Woolf, Zimmerman, Haley, & Krist, 2016). However, a contested space in which the rhetoric of authentic partnering had not translated into everyday

practice also existed (Glimmerveen, Ybema, & Nies, 2018; Hahn et al., 2016; Stewart, Watson, Montague, & Stevenson, 2008; Wellard, Lillibridge, Beanland, & Lewis, 2003). Here, we argue that, from the perspective of participants in this study who were actively engaged with health services in response to Standard 2: ‘Partnering with Consumers’, accreditation criteria for partnering with consumers did not consistently equate to authentic partnering practice. This finding is supported by others who noted that accreditation standards set a minimum bar for health services in Australia, thus only partially supporting excellent partnership practice (McPhail et al., 2015).

Findings from this study showed that participants needed to expertly apply extensive circumstantial and situational experience for their input into health services to be valued. Similar to findings of other studies, participants needed to demonstrate partnering expertise, especially with regard to the understanding what and whose perspective/s they were representing when providing input (Nathan et al., 2014; Scholz et al., 2018). These findings suggest that perspectives are important and that health services need to be clear about whether they are seeking consumers to represent individual and actual experience, individual and transcended experience, or the collective experience of multiple consumers. Recent discussions about the differences between inputs made by ‘patients’ (i.e., those who have individual experience of health services) compared with those made by ‘public’ (i.e., collective viewpoints that are achieved by transcending individual experience) (Fredriksson & Tritter, 2017; McCoy, Warsh, Rand, Parker, & Sheehan, 2019) supports our finding that consumer expertise is not unitary or unchanging, but exists on a dynamic continuum. However, clarity about the purpose of engaging consumers is necessary (Gill & Gill, 2015). Clarity in this area will assist determine the expertise that is required and will support health services to target those consumers with the most relevant expertise. It is also possible that clarity will ensure consumers do not transgress into forbidden territory within health services.

In the current study, we found that some participants believed their health care, or that of their loved one was jeopardized because of transgressions in their consumer engagement role. That is, they sometimes felt vulnerable. This type of conflict is likely to be associated with concepts of power, autonomy, vulnerability, choice and control. However, consumer vulnerability, which occurs when thresholds of tolerance are transgressed, appears to be poorly understood or articulated in the consumer engagement literature. The importance of ‘constructive conflict’, which occurs by attending to experiential diversity and perspective taking, and by having robust mechanisms for confronting claims made by different stakeholders has been highlighted in the literature (Cuppen, 2012). We propose that ‘constructive conflict’ alongside experiences of jeopardy, vulnerability and retaliatory action by health services, specifically in the context of engaging consumers as partners in health services requires further investigation.

Finally, participants in this study reported that engaging with a specific aim of improving the quality and safety of health services was valuable and valued when it was underpinned by reciprocity, trust, respect and remuneration. Value is a refreshing and often cited reason for partnering with consumers. It is supported in policy and research (McCoy et al., 2019) and reported to make an important difference to health services staff and to consumers alike (Fredriksson & Tritter, 2017; Sarrami-Foroushani et al., 2014). Some authors have noted that it is important for health services to align their business values with those of consumers (Sangiorgi & Junginger, 2015). Remuneration, which participants in this study described as inconsistent and contested, was intrinsically linked with participants’ perceptions and beliefs about value and needs to be made transparent to consumers and health services. In the context of the findings of this study, where consumer engagement was both highly valued and equally contested, we argue that there is a real need to align values and to understand what works, for whom, and under what circumstances when engaging with

consumers to ensure safe and high quality health care. By doing this, we can also understand more about who benefits and who does not benefit from engaging and partnering with consumers in health services.

This study has several limitations. First, we did not define the type of consumer engagement experience that consumers were required to have. Although the differences in consumer experiences that were reported is also a strength of this study, the findings from the study may not be transferable across partnership activities. Second, we explored consumer participation across multiple types of service in Australia – government, non-government, primary care and tertiary care. Therefore, the findings of this study may not generalizable to a particular or specific health care setting. Third, this study may only be applicable to the Australian context. Although there are consumer partnering activities occurring in health services internationally, findings from the Australian context might not be transferrable more broadly.

### **Conclusion**

Engaging consumers as partners in health services is enshrined in policy and legislated in Australia as it is internationally. In this study, we sought to understand consumers' experience of partnering with health services in Queensland, Australia. Although participants believed that their input was valued by health services, their engagement experience was inconsistent and participants described multiple areas of contestation. If health services and the broader public are to fully benefit from safety and quality advances proposed by partnering with consumers, then it is essential that these areas of contestation are identified and addressed. Most importantly, this study points to a need to further explore the invisible rules of engagement that are experienced by consumers as they enter and engage in partnership spaces with health services.

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