




2023

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Recommended Citation

Adams C, Brown AJ. Partnering with healthcare: The experiences of consumer representatives. *Patient Experience Journal*. 2023; 10(1):4-9. doi: 10.35680/2372-0247.1819.

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Partnering with healthcare: The experiences of consumer representatives

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Abstract

The importance of consumer advocacy in person-centred healthcare service planning and delivery is growing. In Australia, the role of the "Consumer Representative" (known internationally as "Patient and Family Advisors") is to advocate for patients and their families' needs to improve service planning, healthcare design, and service evaluation. As the role of consumer representatives evolves and matures within the healthcare setting, it is crucial to comprehend their experiences and identify key insights to support and enhance their role within healthcare organizations. To achieve this, a focus group of four Consumer Representatives was conducted and their views were compiled into a single commentary. Our findings suggest that Consumers Representatives are driven by a desire to assist others, but they may feel dissatisfied if their role is perceived as tokenistic or lacks meaningful engagement. Consumer Representatives suggested various ways to improve consumer participation, including role clarification, meeting facilitation, and the development of supportive consumer networks.

Keywords

Consumer representatives, health consumers, codesign, patient engagement, patient experience, partnerships, advocacy

Introduction

It's inspiring to be a Consumer Representative, and I'm sure that patients benefit from this role. We understand that the role is relatively new within the healthcare system, but there are things that could be done better. We hope that this commentary promotes thoughts and discussion about the Consumer Representative role, learning from our shared experiences and developing the role to support the healthcare system.

Consumer Representatives can be defined as "a health consumer who has taken up a specific role to provide advice on behalf of consumers, with the overall aim of improving healthcare."¹ Consumer Representatives, also known as "Consumer Reps," have a specific role to advocate on behalf of consumers using their own perspectives and feedback from others.² This partnership with consumers aims to enhance service planning, healthcare design, and evaluation of healthcare services³ and has been recognised as a key component for high-quality healthcare. In 2012, the Australian Commission on Safety and Quality in Healthcare mandated "Partnering with Consumers" as a core competency standard for healthcare accreditation in Australia.^{2,4} Accordingly, in the last ten years, there has been increasing consumer engagement in healthcare. However, it is recognised that

consumer participation is inherently complex, which requires a shift in the way that consumers and healthcare providers define their roles and responsibilities.⁵ Effective integration of consumers into the healthcare setting can be challenging, which may be impacted by organizational hierarchies and power imbalances.⁶

For this paper, we have reversed the traditional perspective of "Partnering with Consumers" to focus on the experience of Consumer Representatives, hence the title "Partnering with Healthcare." This paper will explore the experience of Consumer Representatives in healthcare, including the benefits of being a consumer representative, common challenges for consumer representatives, and suggestions for improving consumer participation in acute hospital settings.

Method

Consumer involvement in research is often consultative,⁷ however this paper elevated consumer involvement to be co-creators of the study. A focus group was used to generate detailed knowledge about the experience of consumer representatives. Focus groups are a common method for qualitative data collection and interactions between participants helps to elicit information that would not be generated using other methods, such as individual

interviews.⁸ Consumer representatives were selected using purposeful sampling, which is a widely used technique in qualitative research to select respondents who have the required knowledge and experience, plus availability and willingness to participate.⁹

Consumer representatives were invited to join the focus group following completion of a co-design project in the healthcare network. Four out of the five consumer representatives participated in this study (JB, RF, KH, MS), which involved online focus groups using a semi-structured interview (facilitated by CA). Responses were recorded and transcribed. Next, the responses were collated into a single narrative, which was requested by consumer representatives to develop a unified and aligned group response. All efforts were made to maintain the authentic “voice of the consumer” and keep their comments intact, which and can be identified in the text as quotes. Additional information was added (by CA and AB) to help contextualise the consumer responses. There are, of course, a plurality of consumer representatives experiences. The single narrative in this paper captures the collective experience of the consumer representatives who participated in this research, but it does not capture the entirety of all consumer representatives’ experiences. In this paper, participants discuss their decision to become a consumer representative, reflect upon their experiences in this role (including benefits and challenges), and offer suggestions to improve the role of the consumer representative in the healthcare setting.

The Experience of Being a Consumer Representative

Becoming a Consumer Representative

Participants stated that they became consumer representatives following a positive personal experience with the hospital. All members of the focus group were long-standing consumer representatives and had been in the role for at least three years. The consumer representatives were attracted to this role as an opportunity to give back to the organization and the community when they had increased capacity, usually after retirement.

When I retired, I wanted to continue my relationship with the hospital. The hospital has such a lovely feeling and I wanted to do something to help. I wanted to do something valuable, and I enjoy connecting with patients. So, I went to the head of the department and asked if there was something I could do. They said yes, and then sent me off for the consumer training.

The consumer representatives also highlighted the importance of their relationship with hospital staff, which was generally positive.

I like the hospital. I like going there, and I like being involved. I like that my opinion matters. When I get asked my opinion as a consumer rep, it's satisfying. I enjoy helping people. When we get on to a committee where it's enjoyable and interesting, and you're learning something and you can contribute, it's good.

Most of the staff are good. For instance, when you come on to the ward, and you say that you're going to do some patient surveys, then the staff are great. They say, “Let me help you. Who do you want to see?”

Motivation for becoming a Consumer Representative

A key driver for becoming a consumer representative was to help identify and communicate what matters to patients. Consumer representatives identified that they could support the healthcare organization by interacting with patients and staff. Therefore, consumer representatives expressed a desire to help facilitate information from patients, in addition to providing their own thoughts and experiences.

The hospital does a really good job at trying to capture the patient journey and their experiences, but they still need to find out what patients need and want. Consumer Representatives can help hospitals to find out more information from their patients. The role is uniquely structured so consumer representatives have time to have meaningful conversations with patients and gain feedback that wouldn't otherwise be captured. For example, what do they really like about the hospital? What worked well for them? What didn't work well? And how can we help?

Consumer Representatives may have more time than many clinicians to support these discussions with patients and families. They recognise that multiple types of patient responses are required to understand the complexities around patient experience.

We can try to help the hospital capture that information. These questions often get very important answers that aren't captured by a structured survey. It allows the patient to really say the things that matter to them in a face-to-face environment. After all, we don't really know what patients want unless we ask them.

Challenges to Being a Consumer Representative

Whilst consumer representatives are driven by a desire to help and contribute, they may experience dissatisfaction with the role if they cannot fully realise these ambitions.

I didn't really know what a Consumer Representative was when I joined. I was hoping that there would be a bit more patient contact. I was interested in hearing from patients and doing something constructive, and I was hoping to do

something more valuable. Sometimes, the role can be frustrating, and I don't really know what I'm doing.

The majority of Australian healthcare services report that they are partnering with consumers, however the level and type of involvement varies considerably.¹⁰ Consumers find a lack of meaningful engagement demotivating and feel they are being used in a tokenistic way.

I want to do more. Sometimes, I don't know if I'm contributing that much. The consumer role itself can be a bit hard if you're not assigned to a particular area. Otherwise, you just float from project to project and it's not always as satisfying as it can be. It can feel a bit ad hoc. At times, it feels like you're just ticking a box, so that staff can say they have a consumer rep involved, but the role is not really valued. It feels like an administrative requirement.

Difficulties with healthcare meetings

Although consumers can support decision-making at all organizational levels (including high-level strategy and governance), consumers are commonly situated in one of the easiest and least engaging partnership activities: joining existing committees.¹⁰ Whilst meetings are important, these may create a feeling of distance from patients and frontline staff. This can be disconcerting for consumer representatives, particularly if frontline interactions are a primary motivator for undertaking the role.

I feel like there's an idea that a consumer rep has to be involved in a lot of meetings within the hospital. As far as I'm concerned, my work isn't about meetings - it's about communicating with patients. I enjoy being in touch with patients and discovering what the hospital authorities may not know about them. The patients see us as people they can trust, and I enjoy helping people.

To support their contribution during meetings, consumer representatives need to be prepared. Staff may have medical knowledge, but these terms may be unfamiliar to consumer representatives. Due to concerns about staff perceptions and responses, consumer representatives may be hesitant to voice their opinions in meetings.¹¹

I understand that it's very worthwhile for a consumer to be involved in meetings, but sometimes it's not very satisfying for the consumer rep. It would be more satisfying to be more involved, rather than just sitting in the meeting and not saying anything.

There's a lot of times that we don't really know what's going on. In some meetings, I don't know much about the topics they are discussing, and therefore I can't contribute that much. You don't want to feel like a fool and speak out of line when you don't know what staff are talking about in meetings. The meeting goes on for a long time, but

there are no concrete outcomes, so my role seems a bit nebulous.

The results of a systematic review concluded that consumer involvement in healthcare projects is often low.¹² Consumer partnership occurs on a continuum, from consultation and simple information exchange.⁷ Engaging with consumers involves more than adding consumer representatives to existing staff meetings. The voice of consumers and patients can be captured in a range of ways, and healthcare organizations need to determine the most appropriate way to involve consumer representatives.

Recommendations to Enhance Consumer Participation

To be an effective consumer representative requires support by the healthcare organization. Our focus group provided several suggestions to enhance the experience of consumer representatives, which can be relatively simple to implement.

Improve role clarity for Consumer Representatives

Consumer representatives may need enhanced clarity about the role and responsibilities, which may be supported by effective on-boarding and ongoing training by dedicated support personnel.

I think we need more structure as a Consumer Representative. I feel like it's quite loose. What responsibility do we have? The role could be a bit more formalized in some way. So, when you apply to be a consumer rep, people would say, this is what we expect from you, and this is how we can support you. Let us know if you're interested in a certain area and then we'll try and find something that is conducive to what you would like to contribute.

This comment reinforces the need to understand the unique skills, experiences, and motivations of the consumer representatives, and to align this with work projects that might be engaging and fulfilling. This needs to commence from the very beginning of consumer involvement in the healthcare organization.

The first thing they should do is find out about YOU. In particular, what you're good at and what your interests are. Then, try to find the places where you're most useful - not just throwing people in, left, right, and centre. It's about finding out what you can contribute. This would be a big step. There's other stuff I could do at the hospital, and other skills that I have, but I feel like nobody really knows this about me.

More purposeful allocation to projects

When allocating consumer representatives to improvement projects, thoughtful consideration can

ensure suitability for project requirements. This needs to be considered as part of project planning, which includes scoping the purpose and expectations of the consumer representative. This will help to ensure a good fit with project requirements, which will be beneficial to both consumer representatives and project staff.

It is important to put the right people in the right project. Staff should be able to select which consumer reps come on to a project based on what their skill set is, and what they've been doing. Otherwise, sometimes people come in, and then they can't necessarily contribute. That just adds frustration on both sides.

As such, healthcare organizations can assist with purposeful placement of consumer representatives into projects. This will reduce feelings of tokenistic or ad hoc placement of consumers on to activities, and demonstrate necessary consideration about the consumer's unique personality, skills, and experiences.

It shouldn't just be: You're a volunteer, so you just automatically get accepted into things. It should be like, well, are you the right person to add value to this project? It's an application process. For example, one project that I worked on had quite a competitive process to get in into it. It was a good thing. Everybody in that program liked doing that type of work, so it really fed into what we were good at and what we enjoyed doing.

Increase staff understanding about the role of Consumer Representatives

Consumer engagement may be effective when the views of the consumer are representative of the wider population.¹¹ To fully appreciate the contributions of consumer representatives, it was noted that staff need to understand the role of the consumer representative. This may require additional awareness building and staff training.

But some staff don't really understand the role of a Consumer Representative. It would be good if the hospital departments talked about how they use consumer reps to improve understanding of the role and the benefits that we contribute.

To improve the understanding of the Consumer Representative role, it was suggested to review the role title and associated terminology. This role has different titles internationally, which may add to the confusion and lack of role clarity.

One suggestion is to change the name from "Consumer Representative" to "Patient Representative." It doesn't really say much. It's counterintuitive. It sounds pretty commercialized, you know - a "consumer." We're talking about hospitals. We're talking about patients. The name is confusing for patients. I think calling us "Patient

Representatives" would be better because it makes more sense to patients and staff.

Consumer representatives also highlighted the commitment from healthcare executives that is required to drive meaningful, person-centred change and improvement across the organization.

To get changes made, it needs to come from the top. It might be hard for a consumer rep to say, "I think you need to change the way you do things." Consumer representatives may not be taken as seriously as they should be. Some hospital leaders see our role just as being a requirement by the Department of Health, but it's critical that senior staff value our feedback and support us in this role.

Research indicates that a consistent factor for consumer integration is having support from people in power.⁶ Consumer representatives need to be recognised and valued as equal members of the care team.

Improve consumer participation in meetings

It is important that staff help to support consumer representatives to participate actively, and more fully, in meetings. This might also be supported by the style of meeting facilitation, which reflects acknowledgement that consumers bring different knowledge and insights to the meeting than healthcare staff.

In some meetings, I rarely get asked what I think as a Consumer Representative. Often in a meeting, I just have to speak up, put my hand up, and say, "I'm a Consumer Representative and from my point of view, this is what I think". It's not particularly formalized in the agenda. If the agenda for meetings included a formal section for feedback from the Consumer Representative, then that could help. It might help to make the consumer role feel more supported.

In addition, the meeting facilitator can ensure purposeful efforts to include consumer representatives can be made in meetings, such as actively asking for consumer feedback and suggestions. Key components for effective consumer engagement include trust, mutual respect, and careful listening.⁵

Staff can make you feel valued if they involve you and ask: "What do you think?" I was involved in the refurbishment of a section of the hospital. There were numerous Zoom meetings, and the manager would say to me, "Well, as a consumer rep, what do you think is important?" And that's good. She's engaging with me. Being asked my opinion as a consumer rep was satisfying. Also, the staff reaction is critical. We have meetings with the project managers, and they refer back to points that

you've made. They'll say, "Your point about so and so... we've incorporated that." It makes you feel worthwhile.

For example, in meetings, a recurring section can be added to the agenda for consumer input. This provides protected time for consumer representatives to voice their thoughts and opinions, which may be particularly useful if consumers are hesitant to speak up. Additionally, this also helps to ensure that consumer feedback is readily incorporated into organizational processes, in alignment with national quality and safety framework.

Feeling valued and supported

Consumer representatives repeatedly commented about the importance of being valued and supported in their role.

Consumer Representatives need to feel valued. The hospital can help by asking consumer reps what they need. That's really important. Listening to people. Encouraging and empowering them. People want feedback, so let your consumer reps know what is good about what they're doing.

Consumer representatives did not feel that they needed to be paid for their contributions; however, they acknowledged that reimbursement of expenses (such as travel and parking) would be useful.

I think that it's fine to give car parking vouchers and things, but I don't think we need to be paid. I think that it would attract a different kind of person to do this role if you're paying people. I do end up spending a fair bit on travelling and parking, so parking vouchers would be really useful. Also, maybe an occasional meal voucher or something, which helps you feel valued.

The primary motivation of consumer representatives was to contribute in a meaningful way, so they wanted to feel acknowledged and appreciated for their contribution. This could be achieved by communication and positive feedback, rather than financial incentives.

Fostering a supportive network of Consumer Representatives

For consumer representatives to succeed in their position, they require support from hospital staff, including clinical staff and healthcare leadership. Another important source of support can be gained from each other, thereby fostering a community for the consumer representatives.

As Consumer Representatives, it helps to learn from each other. When we get together as a group, we can share information. I would like to hear more about what the other consumers are doing in their areas. Meetings could be structured so that every consumer rep has time to talk about what each of us are doing. It could lead to things

getting more shared across the organisation too. It's nice to be part of a team, bouncing ideas off each other.

Accordingly, healthcare organizations can increase the capabilities and capacities of consumer representatives by developing consumer network and build a sense of community for consumer representatives. This helps to nurture team approach, reduce feelings of isolation, and support shared learnings and experiences.

Conclusion

Consumer Representatives exhibit a strong sense of commitment to their role and demonstrate a desire to assist others. They possess an understanding of the value of their contributions in supporting patient care, but this may not be entirely realized or comprehended by healthcare organizations. While Consumer Representatives find their roles to be extremely fulfilling, they may also experience feelings of frustration, undervaluation, and tokenism. They have put forward practical solutions to enhance and support the consumer representative role, which include the improvement of role clarity and expectations, raising staff awareness and training, better facilitation in meetings, and the establishment of a supportive network of Consumer Representatives.

Consumer Representatives play a pivotal role in the engagement activities of health services. However, their experiences are frequently disregarded and undervalued. This article highlights the distinctive outlook that Consumer Representatives bring to health services' consumer engagement work. It is imperative to gain a better understanding of Consumer Representatives' experiences, as this not only facilitates the recognition and appreciation of their role and contributions but also serves as a mechanism to inform and continuously improve health services' consumer engagement work.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author, CA, upon reasonable request.

Conflict of Interest Disclosure

The authors declare that there is no conflict of interest.

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