



Exploring Consumers' Motivations and Experiences of Engaging as Partners in Cancer Research

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Abstract

Background and Objective Consumer engagement improves research quality and relevance but can be difficult to implement. This study aimed to explore the motivations and understand the barriers, if any, experienced by consumers before and when partnering with cancer research teams.

Methods Semi-structured interviews were conducted with consumers and the results analysed thematically. Two groups were recruited: consumers who were members of the consumer registry and patients who did not have previous experience of being a consumer in a researcher partnership.

Results Twenty-one interviews were conducted with a total of 22 participants aged between 26 and 74 years. Consumers motivation was driven by altruism to help others and personal benefits. Barriers to beginning and maintaining consumer engagement included consumers' perceptions of being appreciated by researchers and meaningful communication between researchers and consumers.

Conclusions Australian policy has made important steps towards consumer engagement in research. This study showed that demonstrating an appreciation for consumers and effective communication are key areas to consider when designing implementation strategies of these policies in the cancer research space in the future.

Key Points for Decision Makers

Appreciation of consumers and meaningful and ongoing communication throughout the research lifecycle is needed for the success of a research partnership.

Decision makers should carefully consider language used on advertising material that is targeting the recruitment of consumers.

1 Introduction

Consumer engagement in health and medical research improves quality [1, 2], relevance [1], and translation [3, 4] and is becoming increasingly mandated by key funding and governing research bodies globally [5–9]. While consumer engagement is now acknowledged as a critical component of research, recognition that researchers needed assistance to engage consumers began to emerge in the mid-2000s with publications amassing that offered practical guidance for consumer participation in health-related research and published frameworks that support, evaluate and report consumer involvement in research [10, 11].

There now exists a wealth of frameworks and guidelines to support the engagement of consumers in health-related research [10, 12]. In Australia, the Australian National Health and Medical Research Council in partnership with the Consumers Health Forum of Australia developed the *Statement on Consumer and Community Involvement in Health and Medical Research* (The Statement) in 2016 to guide consumer and community involvement [6]. The Statement was supplemented in 2020 with a toolkit of resources to assist researchers, research organisations,

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consumers and consumer/community health organisations in the planning, conduct and evaluation of research alongside consumers [5]. In the cancer sector, Cancer Australia partnered with Cancer Voices Australia to produce the National Framework for Consumer Involvement in Cancer Control in 2011 to improve “*meaningful consumer involvement at all levels of cancer control in order to improve outcomes and experiences for people affected by cancer engagement*” [13]. Similar efforts exist around the world such as in the UK (UK Standards for Public Involvement) [14], Canada (Strategy for Patient-Oriented Research) [15] and the USA (Cancer Moonshot Research Initiatives) [16].

The burgeoning number of frameworks and guidelines, however, has not resulted in a marked increase in partnerships between consumers and researchers [17]. Some issues that may be hindering consumer engagement include inconsistencies in what is defined as ‘engagement’ as well as other key terminology [18–22]. Additionally, contextual differences hamper the adoption of frameworks developed in specific research settings because of the lack of relevance and therefore transferability to other research settings [10, 12]. Evidence detailing how to achieve enduring consumer partnerships is also lacking with suggestions noting that any recommendations must be adapted to the needs of the consumers across different research settings [12, 23–25].

This qualitative study adds to the existing literature [13, 26] to provide an institute-specific exploration of consumers’ experiences of engagement within a cancer treatment and research centre. The aim of this research was to explore and understand the motivations and barriers, if any, that inhibit consumers from participating with cancer research teams. Specifically, (1) to explore consumers thoughts and feelings about partnering with research teams and (2) to examine the barriers that have prevented their partnering with research teams including the terminology used in this setting. The results of the study will be used to inform an institute-specific education package for staff and consumers to aid the development and maintenance of consumer partnerships in cancer research.

2 Methods

This exploratory study used a qualitative approach to examine the experiences and motivations of consumers’ engagement as research partners [27, 28]. Ethics approval for the researcher (CB) to undertake semi-structured with consumers was granted by the Human Research Ethics Committee at the Peter MacCallum Cancer Centre, Melbourne, VIC, Australia (HREC LNR/55906/PMCC/2020).

2.1 Setting and Recruitment

This study was conducted at the Peter MacCallum Cancer Centre (Peter Mac), Australia’s only health service solely dedicated to caring for people with cancer. Peter Mac is an integrated cancer treatment and research centre and has an increasing need to engage consumers in research and forge partnerships with research teams. Peter Mac defines a consumer as “people who use health services, as well as their family and carers”. This includes people who have used a health service in the past or who could potentially use the service in the future. The term “consumer in a research partnership” is also used at the centre and this process is described as occurring “when consumers, carers, and community members are meaningfully involved in decision making to shape decisions about research priorities, policy and practice”.

Two groups of potential participants were sampled; consumers who were members of the Peter Mac consumer register and Peter Mac patients who did not have experience of being a consumer in a research partnership. Potential participants were invited from the Peter Mac consumer representative register or patients were approached during their attendance at Peter Mac for an appointment or treatment. These potential participants were screened for appropriateness by discussing their suitability to invite to this study with the relevant nurse unit manager. A description of the project and flyer including the contact details of the research team were provided. Consumers were also recruited through the mailing list of the well-being centre, advertisements on posters/screens throughout the institute, and liaising with community and support groups to promote the research. Participants were provided with a participant information and consent form that detailed the research and consent process.

2.2 Data Collection and Analysis

Semi-structured interviews were conducted in person, via telephone or via video conferencing software based on participants’ preferences. Interviews were audio-digitally recorded and transcribed verbatim by an approved external transcription agency. An interview guide was used and explored participants’ knowledge and understanding of the terms used to describe research engagement and consumers in oncology, opinions and beliefs about research partnerships, and barriers and enablers to becoming a research partner (Electronic Supplementary Material [ESM]). Questions about participants’ understanding of consumers in research partnerships included “Can you explain what a consumer is?” and “Can you explain what a

consumer in a research partnership is?” Participants were compensated with a \$50 gift voucher. Sample size was evaluated throughout the research process and interviews ceased when the sample held enough information power for analysis [29]. Information power was informed by the focused aims of the study, the combination of participants specific to the research questions, and the moderately strong dialogue and analysis approach.

Data were analysed following an iterative, inductive, codebook thematic analysis process [27, 28] to help organise, code and explore the data. The first three interviews were co-coded to ensure rigour, generating a preliminary list of ideas, categories and concepts. An additional seven interviews were double coded and a codebook describing the themes identified from the data was developed (ESM). Any differences in interpretation were discussed before the codebook was developed. The remainder of the interviews was coded using the codebook as a guide. Further data are available from the corresponding author on reasonable request. The resulting codes were then reviewed to identify patterns and note relationships among patterns. The themes developed were then reviewed to combine similar and overlapping items into the final themes. Illustrative quotes are used to exemplify the thematic findings with each quote attributed using gender, age range and whether the consumer was a member of the consumer registry.

3 Results

Twenty-one semi-structured interviews were conducted with consumers between January and March 2021. One interview included two consumers, therefore 22 participants were included in total. Interviews were conducted in person at Peter Mac ($n = 13$), via video conferencing [Zoom] ($n = 8$) or via telephone ($n = 1$). There were nine cancer types present in the interviews with breast cancer ($n = 6$) and prostate cancer ($n = 4$) accounting for almost half the participants (Table 1). Interviews were on average 29 min in length (range 10–70 min). The results below first describe participants’ motivations for becoming a consumer followed by the barriers that affect establishing and maintaining a research partnership and finally a description of participants views on the terminology used in this setting.

3.1 Motivation to Become a Consumer in Research Partnership

Participants shared various descriptions of their own cancer experiences, with many motivated to become consumers by their altruistic desire to help others and contribute to the overall progression of cancer research and the design of the healthcare service. Participants saw the opportunity

Table 1 Participant characteristics ($n = 22$)

Characteristic	Number (%)
Age at interview (years)	Range 26–74
Median age	58.5
26–35	4 (18)
36–45	2 (9)
46–55	2 (9)
56–65	10 (45)
66–74	4 (18)
Cancer type	
Breast	6 (27)
Prostate	4 (18)
Haematological	3 (14)
Skin	3 (14)
Sarcoma	2 (9)
Bladder	1 (5)
Gastrointestinal	1 (5)
Late effects	1 (5)
Oesophageal	1 (5)
Consumer type	
Individual undergoing treatment	20 (91)
Family member	2 (9)
Previously worked as a consumer in a research partnership	
Yes	11 (50)
No	11 (50)
Retired	
Yes	8 (36)
No	14 (64)

to be involved as a consumer in research to pursue their own personal learning and interest in cancer after having their own experience of a cancer diagnosis and treatment. Some participants also saw partnering with research teams as supporting the development of new and experimental treatments that they or others may then benefit from if needed in the future.

3.2 Barriers to Partnering with Research Teams

3.2.1 A Perceived Lack of Appreciation

Participants were perceptive of the quality of the relationship forged with researchers with some describing their engagement in research partnerships as tokenistic where “having to talk to a consumer was a box that he [researcher] needed to tick” (female, 56–60 years, register consumer). These types of attitudes towards engagement as perceived by consumers posed barriers and resulted in consumers feeling there was a lack of appreciation or genuine inclusion in research partnerships.

“It’s not just a matter of here, throw this little two-hundred-word summary and oh I’ve had a consumer review it. That’s a load of garbage.” (female, 56–60 years, register consumer)

Some participants felt that researchers may benefit from some training about how best to collaborate with consumers in terms of how a consumer can contribute to research that would maximise benefits to the research approach and design and enhance the chance that the relationship partnership would succeed.

“I think some consulting and talking to consumers ... is not always the highest priority for a researcher and sometimes I think that people need to be educated in that process and understand what it is, ... that a patient, consumer could contribute and the sorts of questions they could help that researcher answer.” (male, 66–70 years, register consumer)

3.2.1.1 Acknowledgement of contribution The majority of participants emphasised the importance of having their contributions recognised by researchers in some form.

“If you’re really serious about a partnership in research I think it’s important that it’s recognised somewhere.” (male, 56–60 years, register consumer)

Participants reported different ways they appreciated having their contributions recognised. Some participants appreciated having their contributions acknowledged formally (i.e., via authorship) whereas for others the process placed more value on more personal approaches.

“... the project’s running and then it [a publication] comes out with some researchers’ names on it but there’s no mention of the consumer input. So, if being recognised as a researcher means that at some stage there’s a publication with your name on it, I think that’s a good thing.” (male, 56–60 years, register consumer)
 “And even little things, it’s the food they give us when we go in there for some of these meetings, nothing’s spared, it’s very well done, and it just makes you feel appreciated. And I must say as well, I got a handwritten card in the mail at the end of the year and that meant more I think that anything, it’s just so nice that someone took the time to do that I think is really lovely.” (female, 56–60 years, register consumer)

3.2.1.2 Financial remuneration Financial compensation was valued by some participants with some even suggesting that this levelled the playing field between them and other team members.

“... you go to a project preparation meeting when there’s researchers there and there’s research assis-

tants there all of whom are getting paid, then you’ve got the consumer person who’s there as a volunteer. And sometimes, you know, that can be ... you’re made to feel as though your inputs not as important. So, I think it [financial remuneration] is important ...” (male, 56–60 years, register consumer)

Whereas others felt that they had already been paid for their involvement by receiving their cancer treatment for free.

“No because I think research in our health system, you know, it’s to benefit the people. Like I don’t feel that you have to be compensated for that, you know, ‘cause the trials benefit you so it’s part of healthcare. Yeah, so no.” (female, 56–60 years, register consumer)

It may be essential to offer a choice to consumers so they might elect for recognition that might be the most meaningful to them.

“And I know there’s lots of discussion about how you do it. Some people don’t want to be paid, some people are happy to have a donation to a charity, others are happy to have a gift card and so on. But I think it’s important that at least the offer’s made ‘cause it just makes you feel as though you’re being appreciated and as a reward for your time.” (male, 56–60 years, register consumer)

3.2.1.3 Power imbalance between consumers and researchers Participants reported a perceived or actual power imbalance when partnering with research teams. This was influenced by factors such as financial reimbursement, perceived importance of academics and professionals in the medical area, language used and examples of research gatekeeping.

“I think some of the advocates, consumers are frightened a bit and get overawed by these hugely educated people with PhDs.” (female, 65–60 years, register consumer)

Participants expressed concerns about research gatekeeping by researchers that may make them less likely to provide input.

“So, people can be polite on steering committees, people can be very polite in committees, people can be very polite on boards, listen, but frankly at the end of the day it’s very easy to ignore a plea or suggestion from one, two, three consumers because it’s a bit more work or we wouldn’t understand or whatever. And, yeah, staff, paid people are the gatekeepers... But I think, you know, so many times I’ve seen where I’ve offered a suggestion or actually said something’s wrong or that’s not correct English, whereas I think

oh, it's just dismissed sometimes.” (male, 66–70 years, register consumer)

3.2.2 Meaningful Communication Between Researchers and Consumers

Suboptimal communication was seen as an important barrier to an effective research partnership. Participants reported wanting to ensure they had clearly understood the aims and goals of the research before providing any input. Medical language and jargon also impact communication.

“... I think researchers use a particular kind of language particularly in health-related stuff, and if they have to communicate with a consumer in lay language, I think that helps ultimately with translation of the research results in the end.” (male, 56–60 years, register consumer)

Communication that was targeted at a consumer's level and made them feel involved was reported as essential by participants in growing a successful research partnership.

“I suppose somebody who can talk, who can explain well what the research is about, somebody who makes you feel involved, you know, who gives you that feeling of being part of the team, as you say the partnership.” (female, 56–60 years, non-register consumer)

Participants reported a lack of ongoing communication was a significant barrier to a meaningful partnership. They felt they were provided with snippets of the research lifecycle.

“I had the benefit of actually being involved in two different research projects like that where one is constantly knowing what's going on and the other one, I have no idea what we're doing.” (male, 56–60 years, register consumer)

Poor communication may result in a low awareness of research opportunities from the outset.

“Interviewer: And how do you think researchers could be more transparent with what we do?

Consumer: Tell us you exist [laughs]” (female, 46–50 years, non-register consumer)

3.2.2.1 Describing a consumer: open to interpretation Participants varied in their interpretation of the term ‘consumer’ with many questioning its suitability in the healthcare context because of the connotations with the consumption of material goods and the suggestion of choice in requiring cancer services.

“Because everyone associates consumer with shopping. [laughs] Yeah, it's a default thought process that

you would associate the word consumer with shopping” (female, 46–50 years, non-register consumer)
 “I think to me a consumer is what ... you choose to be a consumer; you choose to go and buy something or contribute to something. Whereas when you're unwell you're here not by choice but because you have to be, so you're here to get treatment.” (female, 56–60 years, register consumer)

Participants were also quite varied in their approval of the term. Some participants liked the term and felt it to be empowering and affected the power dynamic between consumers and researchers while others felt it helped them move away from the ‘sick role’.

“Yeah, I think patient implies we focus too much on being sick. I think we've got to improve things and focus on being healthy. So, I don't like patient. I like consumer.” (male, 56–60 years, register consumer)

Whereas others preferred the use of patients. They felt it humanised them to the research team; however, they acknowledged the term did not include carers. Others noted that they did not identify with the term patient after they progressed past active treatment. Despite the variety of interpretation and approval of the term, there was no consensus from the participants on an appropriate alternative.

“Just possibly not referring to them as consumer but still a patient or a visitor basically ... More humanising to be honest, and to maybe make the person that's using the research to maybe take on board their opinion a bit more, yeah, maybe respectfully as well rather than looking at it too objective[ly]” (female, 36–40 years, non-register consumer)

“Consumer would probably be more relevant to me now because from now on I'm just attending the screening appointments and stuff like that rather than like ongoing treatment.” (female, 31–35 years, non-register consumer)

“I prefer patient, but then of course that doesn't cover carers or advocates in general.” (female, 56–60 years, register consumer)

The term ‘consumer in a research partnership’ was much more appealing to consumers as they appreciated the implied collaboration with the inclusion of the term partnership and felt it valued their input and described a shared role with investigators.

“I like the partnership, I love the partnership part because it makes the consumers feel like we really are part of the team, you know, not just an add-on. A partnership sounds as though you're valued, and you really are, you know, in there working with the researchers.” (female, 56–60 years, non-register consumer)

4 Discussion

It is clear from our results that despite consumers possessing motivation to become partners in cancer research, consumers perceive key barriers to the formation of research partnerships. Barriers described that were unique to this study included an awareness of opportunities for a partnership. Other findings were consistent with existing research in other therapeutic areas that suggest ongoing meaningful communication between consumers and researchers [30–32], appreciation of consumers for their input, and power imbalances existing between consumers and research teams. Results from this study provide key insight from the consumer perspective that barriers in initiating and maintaining a consumer-researcher partnership seen in other therapeutic areas may also exist in a cancer hospital setting (Fig. 1).

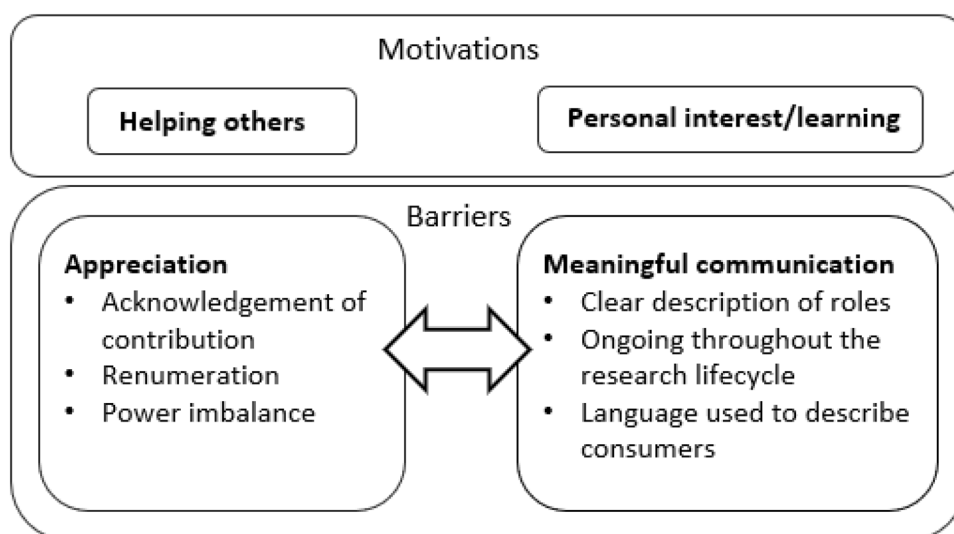
Half of the included participants were enrolled on the Peter Mac consumer registry. The registry produces a monthly newsletter detailing opportunities for consumers in research as well as contact information for a coordinator for any questions. A strength of this study is the inclusion of both members and non-members of this registry ensuring initial barriers to consumer engagement were not overlooked. Terminology used to describe consumer engagement differs globally [19–22] and preferences may be distinct from those receiving active care [33]. Dislike for the term ‘consumer’ reflected an interpretation of the word consumer as affiliated with the consumption of services/goods as well as a choice to consuming those services. However, support for the term arose from a desire to move away from the ‘sick role’ and was thought to improve perceived power imbalances in consumer-researcher partnerships [21].

Developing an effective research partnership requires a genuine attempt at relationship building [34] and acknowledgement of the expertise of both parties [30]. Meaningful ongoing communication strongly underpinned the results as a key factor for successful research partnerships and has been described previously in other therapeutic areas [30, 31]. Consumers are commonly engaged at the beginning of research but rarely in the execution or translation phases [12, 35]. This failure to conclude research outcomes with consumers in research partnerships may hinder ongoing partnerships, however, with even fewer studies focusing on maintaining these partnerships longer term [32]. When interviewed, researchers suggest a lack of time and resources as barriers to recommendations in a real-world setting [26, 35]. Our results are similar to those previously reported, calling for an approach targeting individual as well as organisation and system-level changes [26].

There is an increasing number of resources available from reputable sources to guide researchers in engaging consumers in research [5, 36] as well as proper reporting [37, 38]. Resources specific to the cancer setting have been published by Cancer Australia [4] as well as the Victorian Comprehensive Cancer Centre [39]. Despite the depth of resources available, researchers report navigating consumer engagement as challenging with barriers including an uncertainty of how to undertake meaningful involvement while avoiding tokenism [40]. It is unclear if the resources currently available to facilitate consumer engagement are reaching researchers or if they do not have the logistical means or support to enact them. A lack of funding and time to deliver recommendations and a difficulty in accessing suitable consumers have been reported previously by researchers [26, 40, 41].

Organisational change including improvements in funding for consumers may have an enormous impact on overcoming partnership barriers. Financial reimbursement is one

Fig. 1 Motivations and barriers to partnering with cancer research teams



method in which consumers are recognised and valued for their input [39]. Interestingly, some of our participants felt they had already been paid for their contributions as they had received their treatment in the public health sector, whereas others felt financial reimbursement was a strong tool for overcoming power imbalances that existed between consumers and researchers. Our results suggest that one approach will not suit all research partnerships. In a study by McKenzie and colleagues [40] that interviewed researchers about barriers to consumer engagement, researchers reported that consumers should be remunerated for their time and that asking for voluntary participation was inappropriate. However, it may be important to note that early consumer involvement in projects may become unachievable as funding is generally severely limited in the planning and grant writing stages.

The imbalance of power and ‘ownership’ of the research is commonly reported as a barrier in the literature [21, 26]. Commonalities were seen in this study with financial reimbursement and research gatekeeping seen as contributed factors. Recent research suggests that researchers receive communication and interpersonal skills to create an environment to address power imbalances, which may however be at odds with their training as health professionals and researchers [26]. Opportunities for training for researchers in this area are new and emerging, with much of the previous training being targeted towards consumers [42]. However, without experience or training, efforts by researchers can become tokenistic [26]. Training for researchers may be a method of overcoming some of these barriers and promoting successful and longer term consumer-researcher partnerships. Future research is needed to guide the development of strategies to implement recommendations, specific to the individual and system level of a research setting and to overcome barriers to initiating and maintaining effective consumer-researcher partnerships whilst measuring their impact.

4.1 Study Limitations

The limitations of the results drawn from this research arise from the number of interviews and the potential bias of participants who were willing to participate. It is possible that those who had negative experience or significant barriers to partnering with researchers may have influenced participation. Participants were drawn from one institute and thus experiences at other health systems may be different. A limitation of this study is that consumers were not included as part of the research team. Including consumers may have enriched the results of this study.

5 Conclusions

This study is just the beginning of important work to realise meaningful partnerships between the research community and consumers. Australian policy has made important steps to ensuring engagement across health settings, yet implementation at the hospital/organisational level remains challenging. This study showed that demonstrating appreciation for consumers and meaningful communication are issues that need to be considered. A broader implementation approach will be important to facilitate changes in individual and collective behaviour to strengthen the engagement of consumers in research in the future.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40271-023-00667-2>.

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Declarations

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Conflict of interest Laura E. Forrest is a member of the editorial board of *The Patient* journal. Jamie L. Waterland, Cassandra Beer and Rowan Forbes Shepherd have no conflicts of interest that are directly relevant to the content of this article.

Ethics approval Ethics approval for the researcher (CB) to undertake semi-structured with consumers was granted by the Human Research Ethics Committee at the Peter MacCallum Cancer Centre, Melbourne, VIC, Australia (HREC LNR/55906/PMCC/2020).

Consent to participate Participants were provided with a participant information and consent form that detailed the research and consent process.

Consent for publication Not applicable.

Availability of data and material The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

Code availability Not applicable.

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References

- Synnot AJ, Cherry CL, Summers MP, et al. Consumer engagement critical to success in an Australian research project: reflections from those involved. *Aust J Prim Health*. 2018;24(3):197–203.
- Wiles L, Kay D, Luker J, et al. Consumer engagement in health care policy, research and services: a systematic review and meta-analysis of methods and effects. *PLoS One*. 2022;17(1):e0261808.
- Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. *J Comp Eff Res*. 2015;4(2):133.
- Cancer Australia. Consumer engagement. 2023. <https://www.canceraustralia.gov.au/about-us/who-we-work/consumer-engagement>. Accessed 30 Jan 2023.
- National Health and Medical Research Council. Consumer and community engagement. 2020. <https://www.nhmrc.gov.au/about-us/consumer-and-community-involvement/consumer-and-community-engagement>. Accessed 30 Jan 2023.
- National Health and Medical Research Council. Statement on consumer and community involvement in health and medical research. Consumers Health Form of Australia; 2016.
- Department of Health. MRFF strategy and priorities. 2018. <https://www.health.gov.au/initiatives-and-programs/medical-research-future-fund/about-the-mrff/mrff-strategy-and-priorities>. Accessed 5 Feb 2023.
- National Institute for Health Research (INVOLVE project). 2023. <https://www.invo.org.uk/about-involve/>. Accessed 30 Jan 2023.
- National Health Service. Equity and excellence: liberating the NHS. 2010. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf. Accessed 30 Jan 2023.
- Greenhalgh T, Hinton L, Finlay T, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect*. 2019;22(4):785–801.
- McKenzie A, Hanley B. Consumer and community participation in health and medical research: a practical guide for health and medical research organisations. 2nd ed. Perth: Telethon Institute for Child Health Research; 2012. www.nhmrc.gov.au/guidelines/publications/s01.
- Domecq JP, Prutsky G, Elraiyah T, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res*. 2014;14(1):89.
- Cancer Australia and Cancer Voices Australia. National framework for consumer involvement in cancer control. Canberra (ACT): Cancer Australia; 2011.
- UK standards for public involvement. 2019. <https://sites.google.com/nih.ac.uk/pi-standards/home>. Accessed 29 Dec 2023.
- Canadian Institutes of Health Research. Strategy for patient-oriented research (SPOR): putting patients first: patient engagement framework. 2014. <http://www.cihr-irsc.gc.ca/e/48413.html>. Accessed 29 Dec 2023.
- Cancer Moonshot Research Initiatives. Establish a network for direct patient engagement. <https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/implementation/patient-engagement>. Accessed 29 Dec 2023.
- Costa Alencar AB, Selig, WKD, Geissler J, et al. Adopting recommendations for implementing patient involvement in cancer research: a funder's approach. *Res Involve Engag*. 2023;9(1):6.
- Schuster ALR, Hampel H, Paskett E, et al. Rethinking patient engagement in cancer research. *Patient*. 2023;16(2):89–93.
- Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf*. 2016;25(8):626.
- Thompson J, Barber R, Ward PR, et al. Health researchers' attitudes towards public involvement in health research. *Health Expect*. 2009;12(2):209–20.
- Snape D, Kirkham J, Britten N, et al. Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study. *BMJ Open*. 2014;4(6):e004943.
- Farmer J, Taylor J, Stewart E, et al. Citizen participation in health services co-production: a roadmap for navigating participation types and outcomes. *Aust J Prim Health*. 2017;23(6):509.
- Pii KH, Schou LH, Piil K, et al. Current trends in patient and public involvement in cancer research: a systematic review. *Health Expect*. 2019;22(1):3–20.
- Miller CL, Mott K, Cousins M, et al. Integrating consumer engagement in health and medical research: an Australian framework. *Health Res Policy Syst*. 2017;15(1):9.
- Gunatillake T, Shadbolt C, Gould D, et al. Embedding consumer and community involvement within an established research centre: moving from general recommendations to an actionable framework. *Res Involv Engag*. 2020;6(1):64.
- Ayton D, Braaf S, Jones A, et al. Barriers and enablers to consumer and community involvement in research and healthcare improvement: perspectives from consumer organisations, health services and researchers in Melbourne, Australia. *Health Soc Care Community*. 2022;30(4):e1078–91.
- Clarke V, Braun V. Using thematic analysis in counselling and psychotherapy research: a critical reflection. *Couns Psychother Res*. 2018;18(2):107–10.
- Terry G, Hayfield N, Clarke V, et al. Thematic analysis. In: Willig C, Rogers WS, editors., et al., *The SAGE handbook of qualitative research in psychology*. London: SAGE Publications Ltd; 2017. p. 17–37.
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753–60.
- Ehrlich C, Slattery M, Kendall E. Consumer engagement in health services in Queensland, Australia: a qualitative study about perspectives of engaged consumers. *Health Soc Care Community*. 2020;28(6):2290–8.
- DeBortoli E, Soyer HP, Milne D et al. Measurable outcomes of consumer engagement in health research: a scoping review. *Front Public Health*. 2022;10: 994547.
- Gonzalez M, Ogourtsova T, Zerbo A, et al. Patient engagement in a national research network: barriers, facilitators, and impacts. *Res Involv Engag*. 2023;9(1):7.
- Deber RB, Kraetschmer N, Urowitz S, et al. Patient, consumer, client, or customer: what do people want to be called? *Health Expect*. 2005;8(4):345–51.
- Hahn DL, Hoffman AE, Felzien M, et al. Tokenism in patient engagement. *Fam Pract*. 2017;34(3):290–5.
- Lawn S. What researchers think of involving consumers in health research. *Aust J Prim Health*. 2016;22(6):483–90.
- IAP2 Australasia. Quality assurance standard for community and stakeholder engagement. Wollongong (NSW): International Association for Public Participation Australasia (IAP2); 2015.
- Staniszewska S, Brett J, Mockford C, et al. The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. *Int J Technol Assess Health Care*. 2011;27(4):391–9.

38. Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engag*. 2017;3:13.
39. Victorian Comprehensive Cancer Centre Alliance. Consumer engagement. 2023. <https://vcccalliance.org.au/our-work/consumer-engagement/>. Accessed 5 Feb 2023.
40. McKenzie A, Bowden J, Zalberg JR, et al. A snapshot of consumer engagement in clinical trials in Australia: results of a national survey of clinical trial networks and research organisations. *Res Involv Engag*. 2022;8(1):3.
41. McKenzie A, Bulsara C, Haines H, et al. Barriers to community involvement in health and medical research: researcher perspectives on consumer and community involvement in research: a qualitative study. UniPrint & UniDesign; 2016. https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-ourresearch/barriers_report_finalweb.pdf.
42. Horobin A, Brown G, Higon F, et al. Co-producing public involvement training with members of the public and research organisations in the East Midlands: creating, delivering and evaluating the lay assessor training programme. *Res Involv Engag*. 2017;3(1):7.