

## Engaging consumers in health research: a narrative review

Ania Anderst<sup>1,5</sup> MPH, Research Associate

Karena Conroy<sup>1,2</sup> BSocSci(Hons), PhD, Head, Commissioned Research

Greg Fairbrother<sup>2,3</sup> RN, BA, MPH, PhD, Nurse Consultant, Patient and Family-Centred Care Research, Sydney Research

Laila Hallam<sup>2,4</sup> BBus, MBus, Health Consumer Representative, Health Consumer Advisor, Honorary Affiliate (CDRP)

Alan McPhail<sup>2</sup> BAppSc, MEngSc, PhD, Consumer Representative

Vicki Taylor<sup>2,3</sup> RN, ICUCert, BHA, Adjunct Associate Professor, Executive Director, Sydney Research

<sup>1</sup>The George Institute for Global Health, Level 5, 1 King Street, Newtown, NSW 2042, Australia.  
 Email: [kconroy@georgeinstitute.org.au](mailto:kconroy@georgeinstitute.org.au)

<sup>2</sup>Sydney Local Health District, Level 11, King George V Building, Missenden Road, Camperdown, NSW 2050, Australia. Email: [Greg.Fairbrother@health.nsw.gov.au](mailto:Greg.Fairbrother@health.nsw.gov.au); [Laila.Hallam@health.nsw.gov.au](mailto:Laila.Hallam@health.nsw.gov.au); [alan.mcphail@gmail.com](mailto:alan.mcphail@gmail.com); [vicki.taylor@health.nsw.gov.au](mailto:vicki.taylor@health.nsw.gov.au)

<sup>3</sup>University of Sydney, Faculty of Medicine and Health, Level 11, King George V Building, Royal Prince Alfred Hospital, Camperdown, NSW 2050, Australia.

<sup>4</sup>The University of Sydney, Centre for Disability Research and Policy (CDRP), 92–94 Parramatta Road, Camperdown, NSW 2050, Australia.

<sup>5</sup>Corresponding author. Email: [aanderst@georgeinstitute.org.au](mailto:aanderst@georgeinstitute.org.au)

### Abstract.

**Objective.** Consumer and community engagement (CCE) in research is increasingly valued in a contemporary healthcare environment that seeks to genuinely partner with consumers and the wider community. Although there is widespread agreement at research governance levels as to the benefits of CCE in research, there is little available research-based guidance as to how best to proceed with CCE organisationally and how to manage and overcome barriers. The aim of this narrative review was to draw together the available research, review findings and relevant governance-related material and to discuss these in light of a case series among research-engaged consumers in order to chart a practical way forward.

**Methods.** A narrative literature review about CCE in research was conducted. Following this, a case series among seven consumers who had been engaged as partners in health research was conducted. Finally, the lived experience of these consumers was explored against the findings of the narrative review.

**Results.** In all, 121 papers were identified and reviewed, 37 of which were used to inform the content of this paper. The most important benefits of CCE to both consumers and healthcare researchers were related to improvements in trust between consumer and researchers, and the increased relevance and ethics of research agendas ultimately pursued. Barriers to CCE were found to be pragmatic, attitudinal and organisational. Enabling factors that capitalise on the benefits and help address the barriers to meaningful CCE are outlined and discussed in light of a case series conducted among research-engaged consumers in Australia and internationally.

**Conclusion.** Best practice standards, organisational commitments and resources are needed to improve the status quo in Australia and to provide health research end-users with research outcomes that better align with their priorities and needs.

**What is known about the topic?** Consumer and community engagement (CCE) in research is increasing in prevalence and is likely to be beneficial to both consumers and healthcare providers and researchers.

**What does this paper add?** Following review of the available research findings and governance statements about CCE, enabling strategies are presented in light of a case series among Sydney-based research-engaged consumers.

**What are the implications for practitioners?** Barriers to consumer and community engagement can be overcome if well understood and tackled organisationally. The potential benefits of shifting to a fully consumer- or community-engaged healthcare research environment are multifactorial and represent a paradigm shift in favour of evidence-based patient and family-centred care.

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## Introduction

Healthcare consumers and providers have been seeking closer partnerships under patient- and family-centred frameworks for some years now.<sup>1,2</sup> There is an increasing body of evidence that has linked a patient–provider partnership approach to care and clinical, cost and patient satisfaction outcomes.<sup>3–5</sup> Providers have been seeking to blend individual patient preference with research findings and clinical expertise to provide care that is evidence based since the early 1990s.<sup>6</sup> More recently, however, attention has shifted to the engagement of healthcare consumers in the work of generating research findings, thus extending the scope of the patient–provider partnership approach beyond care provision to the development of the evidence bases that inform best care practice. In this sense, the promotion of consumer and community engagement (CCE) in research can be seen to represent the joint aspirations of consumers and providers. It aligns the two movements that have influenced healthcare in recent decades, namely patient- and family-centred care (PFCC) and evidence-based practice.

Consumer engagement is the active public involvement in research priority setting, question development, methodological choice and translational inquiry.<sup>7</sup> Underpinning published definitions of CCE in research is language that emphasises research being conducted with or by community members, not research that is conducted on, to or about them.<sup>8</sup> Engaging consumers and communities in health and medical research is now a core goal of both speciality-specific and primary health research communities around the world. Australian, European and North American funders now increasingly require evidence of CCE in any successful research grant submission.<sup>9,10</sup>

Beyond the conceptual alignment of PFCC and evidence-based practice, there are imperatives driving such a fundamental shift in the way best practice in healthcare research is understood and actioned by its practitioners and prescribed by its funders. Howe<sup>7</sup> highlights moral, methodological and policy reasons for CCE in research. In the moral context, the ‘nothing about us without us’ principle sums up this imperative. It is now widely accepted that involving consumers and community members in the prioritisation, conduct and governance of any activity that affects their health and quality of life outcomes is simply the right thing to do. More practically, consumer engagement in methodology development has the potential to positively affect study design choice, recruitment rates and the flow of study processes. CCE is likely to lead to better quality studies.<sup>11</sup> In policy terms, increased engagement has the potential to positively affect community ownership of research findings, translation of those findings (e.g. into practical solutions) and community benefits.

Although the reasons for a contemporary focus on CCE in research are substantial and persuasive, there remain to date limited examples of published research projects that reflect genuine and robust consumer–provider coproduction.<sup>12</sup> This

may be due to a lack of awareness among healthcare researchers as to the potential benefits associated with greater CCE<sup>7</sup> or a lack of clarity about how best to proceed under a consumer- or community-engaged approach. It may also be due to under-reporting of CCE-related aspects of published project work,<sup>13</sup> potentially caused by a lack of explicit guidance from journals to authors regarding the inclusion of CCE aspects of projects in submitted manuscripts. Research on how best to engage consumers and communities and the effects arising from such activities is increasing, although still modest. There are as yet few Australian studies on CCE in research, although interest and commitment levels are high, as evidenced by the inclusion of CCE-related goal setting in many key strategic groupings<sup>14,15</sup> and the positioning of CCE as an essential criterion in competitive mainstream research grant schemes. Against this background, the present paper reviews the CCE literature with an emphasis on findings that shed light on the benefits, barriers and enablers of CCE in research.

The aim of this review was to identify the key themes regarding CCE in health and medical research. This paper investigates the following questions: (1) what are the benefits of consumer engagement in health and medical research; and (2) what are the barriers and enablers to meaningful consumer engagement in health and medical research?

## Methods

A literature review was conducted in August 2018. The databases and search engines used included Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, EMBASE and Google Scholar. The search terms and strategy are given in **Box 1**. Articles that specifically addressed at least one of the following elements of consumer, community and stakeholder engagement in health and medical research were included: benefits, barriers and enabling factors.

Papers were included in the study if they were published in English and addressed one or more of the review questions. Papers published in the past decade were prioritised, with the

### Box 1. Database search strategy listing database search terms used

1. Consumer OR community OR patient OR citizen OR client OR user OR lay OR public
2. Participat\* OR engage\* OR involve\* OR consult OR empower OR collaborate OR inform
3. Health OR medical OR clinical OR biomedical
4. Research OR evaluation
5. 1 and 2 and 3 and 4
6. Limit 5 to English language and year 2008–current

exception of a small number of papers published before 2008 that provided substantial insight. Opinion articles were excluded.

After completing the initial search, general reading and citation tracking, a second search of the grey literature was conducted, adding to the total number of papers retrieved for review. After further reading, it became apparent that the literature did not adequately address the barriers, enablers and strategies for engaging with consumers from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander people and socially disadvantaged communities. A third search was conducted to address this gap, and the final search results were reviewed by two independent reviewers (AA, KC). The third search included the terms 'Aboriginal and Torres Strait Islander', 'culturally and linguistically diverse', 'health AND research' and 'community OR consumer'. Eight healthcare consumers known to have been engaged in research in the Sydney area were approached for informal discussion about their experience of CCE in research.

### *Search Results*

Of the 121 papers identified and reviewed, 37 were included to inform the content of this review paper (Table 1).<sup>11,12,14-48</sup> The 37 documents included literature reviews and systematic reviews, research articles (qualitative, quantitative, mixed methods and evaluation), government documents, guides and reports. The reports offered the results of consultations and surveys of consumers and researchers engaged in health research in Australia and the UK. The included research studies often used a combination of methods, such as semistructured interviews, consultations, workshops, focus groups and questionnaires.

## **Results and Discussion**

### *Benefits of consumer engagement*

There is increasing acknowledgement of the benefits experienced when engaging consumers and community members in the research that affects them.<sup>12</sup> Benefits include an improvement in research relevance,<sup>12,14-22</sup> recruitment and retention of study participants,<sup>12,15,23-25</sup> more efficient dissemination<sup>26</sup> and research translation,<sup>14</sup> as well as greater diversity within the research team.<sup>12</sup> Benefits can be specific to consumers, researchers or both.

A prominent benefit for researchers is gaining fresh insights from hearing the perspective of those with the lived experience of the health condition being researched, or their carer.<sup>16,19</sup> Ensuring that the research purpose and outcomes are grounded in the real-life experiences of consumers is considered an invaluable benefit, improving research relevance and acceptability.<sup>16,18,19</sup> Engaging consumers provides an opportunity for the researcher to be alerted to issues in the research aim, design, recruitment strategy, outcome measures, consent process and ethics.<sup>18</sup> Consumers provide input into study assessment tools, creating more user-friendly and accessible versions.<sup>27</sup> Engagement allows for recruitment, data collection techniques and retention strategies to be revised and improved.<sup>12,15,23-25</sup> Consumers may provide suggestions on how to increase the effectiveness of recruitment by revising proposed recruitment methods<sup>12</sup> or provide suggested reasons why recruitment numbers are low.<sup>20</sup> A study on patient engagement in mental health

research found that trials involving consumers in the design or implementation of the research were 1.63-fold more likely to achieve recruitment targets than trials that simply consulted consumers, and up to 4.12-fold more likely to achieve targets if the level of consumer involvement was high.<sup>24</sup> Engaging people from specific communities, especially those from CALD communities, improves recruitment because people speaking the same language tend to invite their peers.<sup>28</sup> Consumer engagement may also lead to a greater diversity in the research team, providing richer and more relevant research.<sup>12</sup>

Consumers benefit greatly from engaging in research when capacity building activities are built into the process. Reported benefits include gaining new skills, such as data collection and analysis,<sup>11,12</sup> improved access to information on current treatment or management of their illness and problem-solving abilities relating to their illness,<sup>11</sup> as well as increased confidence and empowerment upon stepping into a role in the research community.<sup>11,16,17,20,27</sup> Notably, capacity building is an essential element of Aboriginal and Torres Strait Islander health research, with community members learning research skills, being mentored and supported and having employment opportunities directly linked to the research project.<sup>29,30,49</sup>

Beneficial to both the researcher and the consumer is a strengthening of research relevance,<sup>16</sup> translation<sup>11</sup> and improved research ethics,<sup>12,15</sup> as well as the potential for wider societal benefits as a result of greater community support of research.<sup>12,15</sup> Engagement increases the likelihood of the research being relevant to those most affected.<sup>16</sup> Sharing findings with consumers in an appropriate and accessible format, tailored to particular consumers, increases the uptake of research findings among those consumers.<sup>11,19</sup> Consumers can provide valuable input in reviewing ethics applications, improving ethical standards by seeing issues that are not immediately obvious to researchers.<sup>12</sup> Engagement fosters a mutually beneficial relationship that can lead to broad societal health benefits. When trust is built between consumers and researchers, consumers sceptical of research may cultivate a more positive attitude and greater understanding of research, leading to improved research literacy<sup>15</sup> and wider community support of research itself.<sup>11,14,19</sup>

### *Barriers to consumer engagement*

Australia does not have a national strategy to implement consumer and community engagement in health research,<sup>31</sup> and funding bodies have only recently begun to prioritise consumer-driven research.<sup>10</sup> The key barriers to engagement are time and resources. Structural barriers, such as limited organisational policies and support, lead to a lack of time, resources and capacity, and subsequently tokenism. Other barriers include researchers' negative attitudes, consumers finding researcher language inaccessible and poor clarification of roles. Table 2 lists the key themes located regarding barriers to consumer engagement, often experienced by both researchers and consumers.

Interrelationships may arise between barriers, most evidently between the challenge of time, resources and tokenism. Researchers who engage with consumers on a superficial level could be doing so due to lack of time, resources or capacity for engagement, or even scepticism of the benefit of consumer input.<sup>32,37</sup> Given that a lack of time for researchers to build relationships and

**Table 1. List of publications informing narrative review**

Author and year	Title
Brett J. <i>et al.</i> (2014) <sup>11</sup>	A systematic review of the impact of patient and public involvement on service users, researchers and communities
Happell <i>et al.</i> (2018) <sup>12</sup>	How did I not see that? Perspectives of nonconsumer mental health researchers on the benefits of collaborative research with consumers
National Health and Medical Research Council (2016) <sup>14</sup>	Statement on consumer community involvement in health and medical research
Health Consumers Alliance of SA Inc. (2014) <sup>15</sup>	A consumer and community engagement framework for the South Australian Health and Medical Research Institute
Hubbard <i>et al.</i> (2007) <sup>16</sup>	A review of literature about involving people affected by cancer in research, policy and planning and practice
Lawn <i>et al.</i> (2016) <sup>17</sup>	What researchers think of involving consumers in health research
Saunders <i>et al.</i> (2011) <sup>18</sup>	Enriching health research through consumer involvement – learning through atypical exemplars
McKenzie <i>et al.</i> (2016) <sup>19</sup>	Barriers to community involvement in health and medical research. Researcher perspectives on consumer and community involvement in research: a qualitative study
Hewlett <i>et al.</i> (2006) <sup>20</sup>	Patients and professionals as research partners: challenges, practicalities, and benefits
Barber <i>et al.</i> (2011) <sup>21</sup>	Evaluating the impact of service user involvement on research: a prospective case study
Saunders <i>et al.</i> (2010) <sup>22</sup>	Status, challenges and facilitators of consumer involvement in Australian health and medical research
Staley (2009) <sup>23</sup>	Exploring impact: public involvement in NHS, public health and social care research
Ennis L. <i>et al.</i> (2013) <sup>24</sup>	Impact of patient involvement in mental health research: longitudinal study
Sacristan <i>et al.</i> (2016) <sup>25</sup>	Patient involvement in clinical research: why, when, and how
Shippee <i>et al.</i> (2015) <sup>26</sup>	Patient and service user engagement in research: a systematic review and synthesized framework
De Wit <i>et al.</i> (2013) <sup>27</sup>	Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences
Rhodes <i>et al.</i> (2002) <sup>28</sup>	A service users' research advisory group from the perspectives of both service users and researchers
Jamieson <i>et al.</i> (2012) <sup>29</sup>	Ten principles relevant to health research among Indigenous Australian populations
Gwynn <i>et al.</i> (2015) <sup>30</sup>	Aboriginal and Torres Strait Islander community governance of health research: turning principles into practice
Foroushani <i>et al.</i> (2012) <sup>31</sup>	Consumer and community engagement: a review of the literature
Snape <i>et al.</i> (2014) <sup>32</sup>	Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study
Buck <i>et al.</i> (2014) <sup>33</sup>	From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials
Domecq <i>et al.</i> (2014) <sup>34</sup>	Patient engagement in research: a systematic review
McKenzie (2014) <sup>35</sup>	Planning for consumer and community participation in health and medical research: a practical guide for health and medical researchers
Patricia <i>et al.</i> (2015) <sup>36</sup>	ReseArch with Patient and Public invOLvement: a RealisT evaluation – the RAPPORT study
Thompson <i>et al.</i> (2009) <sup>37</sup>	Health researchers' attitudes towards public involvement in health research
Hughson <i>et al.</i> (2016) <sup>38</sup>	A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials
Bonevski <i>et al.</i> (2014) <sup>39</sup>	Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups
Todd <i>et al.</i> (2018) <sup>40</sup>	Involving consumers in health research: what do consumers say?
Saunders <i>et al.</i> (2007) <sup>41</sup>	Operationalising a model framework for consumer and community participation in health and medical research
Research4Me (2017) <sup>42</sup>	Involving health consumers in health and medical research: enablers and challenges from a consumer perspective
Banfield <i>et al.</i> (2018) <sup>43</sup>	Lived experience researchers partnering with consumers and carers to improve mental health research: reflections from an Australian initiative
Cartwright (2011) <sup>44</sup>	Patient and public involvement toolkit
National Health and Medical Research Council (2018) <sup>45</sup>	Keeping research on track II: a companion document to ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders
Callander <i>et al.</i> (2011) <sup>46</sup>	Consumers and carers as partners in mental health research: reflections on the experience of two project teams in Victoria, Australia
Payne <i>et al.</i> (2011) <sup>47</sup>	Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation
McKenzie (2007) <sup>48</sup>	Consumer and community participation in health and medical research: a practical guide for health and medical research organisations. Perth: The University of Western Australia School of Population Health and Telethon Institute for Child Health Research

tokenism in engagement are the two most prominent barriers, it is likely that they are related. Lack of relevant training for researchers may also lead to tokenism, stifling their capacity to effectively engage with consumers in research.

Importantly, some barriers are pertinent among marginalised populations, such as CALD communities, the elderly,

Aboriginal or Torres Strait Islander people and low-income earners. Particular attention should be paid to the barriers preventing the engagement of marginal groups, because there is strong evidence to suggest that White, middle class, educated males dominate health research, whereas those who are socially disadvantaged, elderly and from CALD backgrounds are

**Table 2. Barriers to consumer engagement**

Barrier	Examples
Time	Researchers lack time to build relationships, <sup>31,32</sup> develop lay information, orientate consumers <sup>22</sup> and manage consumer engagement activities <sup>18</sup> Delayed engagement <sup>14</sup> Consumers find engagement time intensive <sup>11,19,33,34</sup>
Resources (funding, costs, training)	Inadequate funding specific to consumer engagement <sup>14,18,33</sup> Consumer involvement often excluded from funding requirements <sup>19</sup> Perceived cost <sup>22</sup> Lack of training for researchers and consumers <sup>14,15,33</sup> Underestimating training needs <sup>33</sup>
Organisational and policy barriers	Lack of organisation support and policies <sup>19</sup> Lack of a national strategy <sup>31</sup>
Tokenism	Researchers' engagement superficial <sup>11,14,20,32,34,35</sup> Consumer engagement considered a 'tick-the-box' exercise <sup>33</sup> Limited representation: only one person from a cultural group representing the group <sup>19</sup>
Finding the 'right' people	Difficulty finding consumers with sufficient interest, commitment and understanding of research <sup>36</sup> Difficulty finding a balance of opinions <sup>19</sup> and 'true' representation <sup>36</sup>
Attitudes and balance of power	Power imbalance and conflict, <sup>14,15</sup> difficulty sharing power over research <sup>11,16,31,32,37</sup> Conflicting attitudes towards engagement among both consumers and researchers <sup>15</sup> Researchers' negative attitudes, <sup>11,37</sup> including patronising, paternalistic or superior attitudes, <sup>19</sup> difficulty accepting the views of consumers, <sup>11,17</sup> fear of criticism <sup>23</sup> Consumers not feeling heard, or their views marginalised <sup>28</sup>
Fear of 'scope creep'	Striking a balance between retaining academic rigour and consumer perspective <sup>11</sup> Fear that consumer input may cause research to become unfeasible ('scope creep') <sup>34</sup>
Managing expectations, clarifying roles	Managing consumer expectations <sup>19,21,36</sup> Poor communication and lack of clarity regarding roles <sup>11,14,17,18</sup>
Inaccessible language	Language used in research inaccessible to consumers <sup>15,35</sup> Researchers' use of scientific or technical language, <sup>14,32</sup> jargon and acronyms <sup>33</sup>
Capacity	Research fatigue and emotional burden among widely researched patient groups, <sup>11,15</sup> including among Aboriginal people <sup>19</sup> Managing health conditions <sup>20,33</sup> Geographic distance <sup>31,33</sup> Consumers feeling a burden of responsibility associated with being a 'bridge' between the research team and the community <sup>11</sup> Limited mobility among people with disabilities and the elderly <sup>38</sup> Some consumers from culturally and linguistically diverse backgrounds may have low English proficiency and low health literacy <sup>31,38</sup>
Confidentiality	Researchers' concern that consumers could 'leak' confidential information <sup>19</sup>

under-represented, compromising research generalisability.<sup>39</sup> Low English proficiency and low health literacy are some of the key barriers faced by some people in the CALD community, whereas Aboriginal and Torres Strait Islander people may not trust researchers due to past exploitation.<sup>38</sup>

#### *Enablers to meaningful consumer engagement*

Key facilitators of engagement exist at both the individual and structural level. At the individual level, consumer engagement is enabled by early and fit-for-purpose engagement, the use of accessible and culturally appropriate language,<sup>14,35,40</sup> allowing time to plan,<sup>41</sup> a flexible approach,<sup>15,16,36,42</sup> inclusivity of diverse groups,<sup>14,35</sup> face-to-face meetings<sup>11,43</sup> and the number of consumers involved.<sup>33</sup> Involving consumers as early as possible in the planning stage is an important facilitator of successful engagement.<sup>14,18,23,33,35,42,44</sup> Early engagement allows consumers to set research priorities, increasing effects on the design and applicability of the research,<sup>23,26</sup> as well as providing time for the researcher and consumer to build mutual understanding,<sup>36</sup> clarify roles and negotiate consumer contributions,<sup>26,33,42</sup> solve any issues early on and ensure sufficient budgeting.<sup>35</sup>

It is recommended that a minimum of two consumers is engaged to prevent intimidation and isolation<sup>15,33</sup> and to maximise input.<sup>44</sup> Planning the appropriate type of engagement for the specific research and population context fosters engagement,<sup>33</sup> as does acknowledging that 'one size does not fit all' and being open to a range of strategies.<sup>33,40,43</sup> A generally flexible approach allows for any unexpected changes in needs and prevents roles from becoming too prescriptive.<sup>15,16,36,42</sup> Flexibility in time is especially important in research conducted with Aboriginal and Torres Strait Islander people, where plans may need to change due to unforeseen community events.<sup>29,45</sup> Researchers' positive attitude and openness to hearing different perspectives is a key facilitator,<sup>32</sup> alongside good communication skills and regular correspondence.<sup>35</sup> Meeting face to face rather than over the telephone is suggested,<sup>11</sup> particularly in mental health research and studies involving under-researched communities, because face-to-face contact provides a more personal connection and improves familiarity with the researcher.<sup>43</sup> Using accessible and culturally appropriate language according to consumer need is useful, especially among CALD consumers<sup>23,40</sup> and Aboriginal and Torres Strait Islander

people.<sup>29</sup> In some cases, engagement is facilitated by written materials being translated into the consumer groups' language.<sup>38</sup>

Structural enablers of consumer engagement include resource allocation,<sup>16</sup> training,<sup>15,16,32</sup> organisational commitment in the form of supportive culture and policies<sup>18,46</sup> and engagement being a requirement of research funding schemes.<sup>17,22</sup> Providing adequate resources for engagement is a major contributor to success because it signals to researchers that engaging research end-users is valuable.<sup>11,14,16,41,47</sup> Resources can come in the form of funds to cover consumer expenses,<sup>23,35</sup> commitment to a staffed consumer liaison position,<sup>18,48</sup> provision of guidelines and practical tools or training.<sup>22</sup> Training in consumer engagement helps overcome common misconceptions, improves understanding of barriers to engagement and provides both the researcher and consumer the skills to work in partnership.<sup>14–16,23,32</sup> Consumers may be trained in specific research skills, enhancing their abilities to support the research, whereas researchers may benefit from group facilitation, interview, focus group and public consultation training.<sup>23,44,46</sup>

#### Case series

Seven consumer representatives with the lived experience of a medical condition engaged in health research and one community engagement advocate discussed their experiences with two consumer advocates from the Sydney Local Health District. The experiences of enablers and barriers of consumer engagement in health research largely aligned with the findings from the published literature, and provided real-life examples of how incorporating CCE in research can succeed or falter. The key enablers in the consumers' experience were organisational commitment (e.g. 'the key is having support at some of the top levels'), researchers' belief in the value of CCE, early involvement (e.g. 'If I get involved after the design stage... then they typically have to go back and rewrite the ethics application'), the use of accessible language and time. One consumer representative reported that 'the more important driving factor is you've got to believe that there's value in having consumers involved in research'. At times consumer representatives reported their experience of researchers not considering the value of consumer input, and researchers tending to leave the consumer to 'rubber stamp something' once studies were already underway. Ways in which consumers felt valued included being acknowledged (e.g. at the beginning of presentations and in publications), being asked their opinion on relevant matters, being provided training opportunities, being paid for their time and researchers and clinicians being open to helping consumers understand the research. Several consumers highlighted the need for both consumers and researchers to be trained. Almost all consumers experienced inadequate funding as a barrier to their engagement. Some consumers found that researchers' insensitivity to the consumers' medical condition limited the consumer engagement experience by putting an emotional and mental burden on the consumer to repeatedly explain their lived experience. The lack of diversity of consumers was also highlighted as an issue, with consumers saying that it is rare to find people from regional areas and people from non-White Anglo-Saxon backgrounds, in a consumer role. Themes raised in the discussions that had not been highlighted in the published literature included the need for consumers and researchers to work in close and ongoing partnership, and the

power of the personal commitment of 'champions' (i.e. individual researchers or clinicians who actively supported consumers by providing them with opportunities to contribute).

#### Conclusion

The published literature and case series of consumer representatives provides a cohesive picture of the benefits, barriers and enablers to engaging consumers in health research. Although the benefits of consumer engagement are widely published, multiple barriers continue to prevent sustained and organised engagement in the Australian health research landscape. Best practice standards, organisational commitments and resources are needed to improve the status quo in Australia and provide research end-users with research outcomes that better align with their priorities and needs. As barriers are addressed and enablers actioned, the likelihood for the realisation of an evidence-based patient and family centred care will be enhanced.

#### Competing interests

The authors declare that they have no competing interests.

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#### References

- 1 Delaney LJ. Patient-centred care as an approach to improving health care in Australia. *Collegian* 2018; 25: 119–23. doi:10.1016/j.colegn.2017.02.005
- 2 Australian Commission on Safety and Quality in Health Care (ACSQHC). Patient centred care – improving quality and safety through partnership with patients and consumers. Sydney: ACSQHC; 2011. Available at: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/patient-centred-care-improving-quality-and-safety-through-partnerships-patients-and-consumers> [verified 8 June 2020].
- 3 Luxford KPD, Dunbar N, Poole N. Patient-centred care: improving quality and safety by focusing care on patients and consumers. Sydney: Australian Commission on Safety and Quality in Health Care; 2010. Available at: [https://www.researchgate.net/publication/272790469\\_Patient-Centred\\_Care\\_Improving\\_Quality\\_and\\_Safety\\_by\\_Focusing\\_Care\\_on\\_Patients\\_and\\_Consumers\\_Discussion\\_Paper](https://www.researchgate.net/publication/272790469_Patient-Centred_Care_Improving_Quality_and_Safety_by_Focusing_Care_on_Patients_and_Consumers_Discussion_Paper) [verified 8 June 2020].
- 4 Foot C, Gilbert H, Dunn P, Jabbar J, Seale B, Goodrich J, Buck D, Taylor J. People in control of their own health and care: the state of involvement. London: The King's Fund; 2014. Available at: [https://www.kingsfund.org.uk/sites/default/files/field/field\\_publication\\_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf](https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/people-in-control-of-their-own-health-and-care-the-state-of-involvement-november-2014.pdf) [verified 8 June 2020].
- 5 World Health Organization (WHO). WHO global strategy on people-centred and integrated health services: interim report. Geneva: WHO; 2015. Available at: <https://www.who.int/servicedeliverysafety/areas/people-centred-care/global-strategy/en/> [verified 8 June 2020].
- 6 Sackett DL, Rosenberg WMC, Muir Gray JA, Haynes RD, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ* 1996; 312: 71.

- 7 Howe A. Principles of patient and public involvement in primary care research, applied to mental health research. A keynote paper from the EGPRN Autumn Conference 2017 in Dublin. *Eur J Gen Pract* 2018; 24: 167–70. doi:10.1080/13814788.2018.1470620
- 8 Gray-Burrows KA, Willis TA, Foy R, Rathfelder M, Bland P, Chin A, Hodgson S, Ibegbuna G, Prestwich G, Samuel K, Wood L, Yaqoob F, McEachan RRC. Role of patient and public involvement in implementation research: a consensus study. *BMJ Qual Saf* 2018; 27: 858–64. doi:10.1136/bmjqs-2017-006954
- 9 Absalom K, Holch P, Woroncow B, Wright E, Velikova G. Beyond lip service and box ticking: how effective patient engagement is integral to the development and delivery of patient-reported outcomes. *Qual Life Res* 2015; 24: 1077–85.
- 10 Australian Government. Medical Research Future Fund: 2018–2020 priorities consultation discussion paper. Canberra: Australian Government; 2018. Available at: [https://consultations.health.gov.au/health-economics-and-research-division/medical-research-future-fund-consultation-for-the-supporting\\_documents/MRFF%20P2%20Consultation%20Discussion%20Paper%20%20FINAL.pdf](https://consultations.health.gov.au/health-economics-and-research-division/medical-research-future-fund-consultation-for-the-supporting_documents/MRFF%20P2%20Consultation%20Discussion%20Paper%20%20FINAL.pdf) [verified 8 June 2020].
- 11 Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient* 2014; 7: 387–95. doi:10.1007/s40271-014-0065-0
- 12 Happell B, Gordon S, Bocking J, Ellis P, Roper C, Liggins J, Platania-Phung C, Scholz B. How did I not see that? Perspectives of nonconsumer mental health researchers on the benefits of collaborative research with consumers. *Int J Ment Health Nurs* 2018; 27: 1230–9. doi:10.1111/inm.12453
- 13 Staniszewska S, Adebajo A, Barber R, Beresford P, Brady L-M, Brett J, Elliot J, Evans D, Haywood KL, Jones D, Mockford C, Nettle M, Rose D, Williamson T. Developing the evidence base of patient and public involvement in health and social care research: the case for measuring impact. *Int J Consum Stud* 2011; 35: 628–32. doi:10.1111/j.1470-6431.2011.01020.x
- 14 National Health and Medical Research Council (NHMRC). Statement on consumer community involvement in health and medical research. Canberra: NHMRC; 2016. Available at: <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research> [verified 8 June 2020].
- 15 Health Consumers Alliance of SA Inc. (HCASA). A consumer and community engagement framework for the South Australian Health and Medical Research Institute. Adelaide: HCASA; 2014. Available at: [https://www.sahmri.org/m/downloads/20140606\\_Health\\_Consumers\\_in\\_Research\\_Report\\_FINAL.pdf](https://www.sahmri.org/m/downloads/20140606_Health_Consumers_in_Research_Report_FINAL.pdf) [verified 8 June 2020].
- 16 Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N. A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Educ Couns* 2007; 65: 21–33. doi:10.1016/j.pec.2006.02.009
- 17 Lawn S. What researchers think of involving consumers in health research. *Aust J Prim Health* 2016; 22: 483–90. doi:10.1071/PY15089
- 18 Saunders C, Girgis A. Enriching health research through consumer involvement – learning through atypical exemplars. *Health Promot J Austr* 2011; 22: 196–202. doi:10.1071/HE11196
- 19 McKenzie AHB, Haines H, Hanley B, Alpers K. Barriers to community involvement in health and medical research. Researcher perspectives on consumer and community involvement in research: a qualitative study. Perth: The University of Western Australia School of Population Health, Telethon Kids Institute and The University of Notre Dame; 2016. Available at: [https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/barriers\\_report\\_finalweb.pdf](https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/barriers_report_finalweb.pdf) [verified 8 June 2020].
- 20 Hewlett S, de Wit M, Richards P, Quest E, Hughes R, Heiberg T, Kirwan J. Patients and professionals as research partners: challenges, practicalities, and benefits. *Arthritis Rheum* 2006; 55: 676–80. doi:10.1002/art.22091
- 21 Barber R, Beresford P, Boote J, Cooper C, Faulkner A. Evaluating the impact of service user involvement on research: a prospective case study. *Int J Consum Stud* 2011; 35: 609–15. doi:10.1111/j.1470-6431.2011.01017.x
- 22 Saunders C, Girgis A. Status, challenges and facilitators of consumer involvement in Australian health and medical research. *Health Res Policy Syst* 2010; 8: 34. doi:10.1186/1478-4505-8-34
- 23 Staley K. Exploring impact: public involvement in NHS, public health and social care research. Eastleigh UK: National Institute for Health Research; 2009. Available at: <https://www.invo.org.uk/posttypepublication/exploring-impact-public-involvement-in-nhs-public-health-and-social-care-research/> [verified 8 June 2020].
- 24 Ennis L, Wykes T. Impact of patient involvement in mental health research: longitudinal study. *Br J Psychiatry* 2013; 203: 381–86. doi:10.1192/bjp.bp.112.119818
- 25 Sacristán JA, Aguarón A, Avendaño-Solá C, Garrido P, Carrión J, Gutiérrez A, Kroes R, Flores A. Patient involvement in clinical research: why, when, and how. *Patient Prefer Adherence* 2016; 10: 631–40. doi:10.2147/PPA.S104259
- 26 Shippee ND, Domecq Garces JP, Prutsky Lopez GJ, Wang Z, Elraiyah TA, Nabhan M, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin PJ, Montori VM, Murad MH. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect* 2015; 18: 1151–66. doi:10.1111/hex.12090
- 27 de Wit M, Abma T, Koelewijn-van Loon M, Collins S, Kirwan J. Involving patient research partners has a significant impact on outcomes research: a responsive evaluation of the international OMERACT conferences. *BMJ Open* 2013; 3: e002241. doi:10.1136/bmjopen-2012-002241
- 28 Rhodes P, Nocon A, Booth M, Chowdrey MY, Fabian A, Lambert N, Mohammed F, Walgrove T. A service users' research advisory group from the perspectives of both service users and researchers. *Health Soc Care Community* 2002; 10: 402–9. doi:10.1046/j.1365-2524.2002.00376.x
- 29 Jamieson LM, Paradies YC, Eades S, Chong A, Maple-Brown L, Morris P, Bailie R, Cass A, Roberts-Thomson K, Brown A. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust* 2012; 197: 16–18. doi:10.5694/mja11.11642
- 30 Gwynn J, Lock M, Turner N, Dennison R, Coleman C, Kelly B, Wiggers J. Aboriginal and Torres Strait Islander community governance of health research: turning principles into practice. *Aust J Rural Health* 2015; 23: 235–42. doi:10.1111/ajr.12182
- 31 Foroushani PSTJ, Eikli M, Braithwaite J. Consumer and community engagement: a review of the literature. Sydney: UNSW, Agency for Clinical Innovation and Centre for Clinical Governance Research; 2012. Available at: [https://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0010/165592/Consumer-and-community-engagement-literature-review.pdf](https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/165592/Consumer-and-community-engagement-literature-review.pdf) [verified 8 June 2020].
- 32 Snape D, Kirkham J, Britten N, Froggatt K, Gradinger F, Lobban F, Popay J, Wyatt K, Jacoby A. 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: e004943.
- 33 Buck D, Gamble C, Dudley L, Preston J, Hanley B, Williamson PR, Young B, EPIC Patient Advisory Group. From plans to actions in patient and public involvement: qualitative study of documented plans and the accounts of researchers and patients sampled from a cohort of clinical trials. *BMJ Open* 2014; 4: e006400.
- 34 Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, Brito JP, Boehmer K, Hasan R, Firwana B, Erwin P, Eton D, Sloan J, Montori V, Asi N, Abu Dabrh AM, Murad MH. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014; 14: 89.
- 35 McKenzie AHB. Planning for consumer and community participation in health and medical research: a practical guide for health and medical

- researchers. Perth: University of Western Australia School of Population Health and Telethon Institute for Child Health Research; 2014.
- 36 Wilson P, Mathie E, Keenan J, McNeilly E, Goodman C, Howe A, Poland F, Staniszewska S, Kendall S, Munday D, Cowe M, Peckham S. ReseArch with Patient and Public involvement: a RealisT evaluation – the RAPPORT study. *Health Serv Deliv Res* 2015; 3.38: 1–208.
  - 37 Thompson J, Barber R, Ward PR, Boote JD, Cooper CL, Armitage CJ, Jones G. Health researchers' attitudes towards public involvement in health research. *Health Expect* 2009; 12: 209–20.
  - 38 Hughson JA, Woodward-Kron R, Parker A, Hajek J, Bresin A, Knoch U, Phan T, Story D. A review of approaches to improve participation of culturally and linguistically diverse populations in clinical trials. *Trials* 2016; 17: 264.
  - 39 Bonevski B, Randell M, Paul C, Chapman K, Twyman L, Bryant J, Brozek I, Hughes C. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol* 2014; 14: 42. doi:10.1186/1471-2288-14-42
  - 40 Todd AL, Nutbeam D. Involving consumers in health research: what do consumers say? *Public Health Res Pract* 2018; 28: e2821813. doi:10.17061/phrp2821813
  - 41 Saunders C, Crossing S, Girgis A, Butow P, Penman A. Operationalising a model framework for consumer and community participation in health and medical research. *Aust New Zealand Health Policy* 2007; 4: 13. doi:10.1186/1743-8462-4-13
  - 42 Research4Me, Health Consumers NSW. Involving health consumers in health and medical research: enablers and challenges from a consumer perspective. Sydney: Research4Me, Health Consumers NSW; 2017. Available at: [http://www.hcnsw.org.au/wp-content/uploads/2018/11/Involving\\_health\\_consumers\\_in\\_health\\_and\\_medical\\_research\\_online\\_print.pdf](http://www.hcnsw.org.au/wp-content/uploads/2018/11/Involving_health_consumers_in_health_and_medical_research_online_print.pdf) [verified 8 June 2020].
  - 43 Banfield M, Randall R, O'Brien M, Hope S, Gulliver A, Forbes O, Morse AR, Griffiths K. Lived experience researchers partnering with consumers and carers to improve mental health research: reflections from an Australian initiative. *Int J Ment Health Nurs* 2018; 27: 1219–29. doi:10.1111/inm.12482
  - 44 Cartwright JCS. Patient and public involvement toolkit. Oxford, UK: Blackwell Publishing; 2011.
  - 45 National Health and Medical Research Council (NHMRC). Keeping research on track II: a companion document to ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: guidelines for researchers and stakeholders. Canberra: NHMRC; 2018. Available at: <https://www.nhmrc.gov.au/about-us/resources/keeping-research-track-ii#block-views-block-file-attachments-content-block-1> [verified 8 June 2020].
  - 46 Callander R, Ning L, Crowley A, Childs B, Brisbane P, Salter T. Consumers and carers as partners in mental health research: reflections on the experience of two project teams in Victoria, Australia. *Int J Ment Health Nurs* 2011; 20: 263–73. doi:10.1111/j.1447-0349.2010.00731.x
  - 47 Payne JM, D'Antoine HA, France KE, McKenzie AE, Henley N, Bartu AE, Elliot EJ, Bower C. Collaborating with consumer and community representatives in health and medical research in Australia: results from an evaluation. *Health Res Policy Syst* 2011; 9: 18. doi:10.1186/1478-4505-9-18
  - 48 Mckenzie AHB. Consumer and community participation in health and medical research: a practical guide for health and medical research organisations. Perth: The University of Western Australia School of Population Health and Telethon Institute for Child Health Research; 2007. Available at: <https://www.telethonkids.org.au/globalassets/media/images/pagessections/research/help-shape-our-research/the-green-book-mar08.pdf> [verified 8 June 2010].
  - 49 Bovill M, Bar-Zeev Y, Gruppetta M, O'Mara P, Cowling B, Gould GS. Collective and negotiated design for a clinical trial addressing smoking cessation supports for Aboriginal and Torres Strait Islander mothers in NSW, SA and QLD – developing a pilot study. *Aust J Prim Health* 2017; 23: 497–503. doi:10.1071/PY16140