

# BMJ Open Interaction and innovation: practical strategies for inclusive consumer-driven research in health services

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## ABSTRACT

**Introduction** Despite advances in the co-creation of clinical research involving consumers in the last few decades, consumer engagement in health services research generally remains inconsistent and is too often treated as a perfunctory exercise.

**Objective** Drawing on a health services study on diagnostic test result management, communication and follow-up, we: (1) outline practical strategies used to enhance the contribution of health consumer representatives across all stages of health services research, including active involvement in prioritising objectives for data analysis and participating in data analysis and the dissemination of findings; and (2) describe the impact of continued engagement of consumers on the programme of research, the interpretation of findings and their translational potential.

**Key innovations** Key enabling innovations for engagement included: (1) planned opportunities for long-term consumer involvement across all stages of the research process from conception to dissemination; (2) enhanced consumer engagement capacity; (3) purposeful recruitment of appropriately trained consumers; (4) provision of support structures for active consumer involvement in research design, analysis and write-up; and (5) financial support for consumer involvement.

**Impact/Conclusion** Enhancing consumer contribution and establishing inclusive research design requires a negotiated, interactive, meaningful and transparent process. As a collaborative approach, consumer-driven research involvement offers opportunities for new, often unexpected or unexplored perspectives to feature across the whole research process. In a move away from tokenistic consumer involvement, consumers and researchers who participated in this novel and immersive research project identified inclusive research as a powerful tool to enhance health services research and its translation into effective policy.

## BACKGROUND

Patients are consumers of healthcare services; ‘the voices of the people served’<sup>1</sup> are increasingly seen as integral to improving the quality and safety of health services and care delivery.<sup>2,3</sup> ‘Consumers are people who use, have used or are potential users, of health

services including their family and carers’.<sup>4p.7, 5</sup> Consumer representatives occupy roles with specific responsibilities,<sup>4</sup> for example, speaking on behalf of consumer advocacy groups on committees for medical colleges and associations, presenting at conferences and training seminars and becoming involved in medical research. Consumer representatives do have lived experience of illness and using health services; yet their experiences may differ from those of the patients for whom they are advocating. Individuals often attach personal value statements to the different terms used to refer to ‘(health) consumer (representatives)’ and some patients prefer not to be called consumers. Thus, here we use the terms *consumer* and *patient advocate* interchangeably to reflect the preferences of all authors. All consumers involved in this project had lived experience of accessing health services and care.

Consumer involvement in health services research can lead to more efficient and effective health services and care delivery.<sup>2,6,7</sup> Despite advances in co-creation of clinical research with consumers in the last decades, however, the degree of consumer involvement remains inconsistent in health services research and is often treated as a tick-box exercise or a token effort at best.<sup>6,7</sup> In the Australian context, these inconsistencies and shortcomings exist despite research and healthcare policies outlining the importance of consumer involvement.<sup>8,9</sup> Further development of practical strategies for deeper and more meaningful involvement is required to realise the full potential of consumer-driven research.

## OBJECTIVE

In this paper, patient advocates and researchers share the practical strategies and outcomes of a programme of work designed to enhance the contribution of consumers in

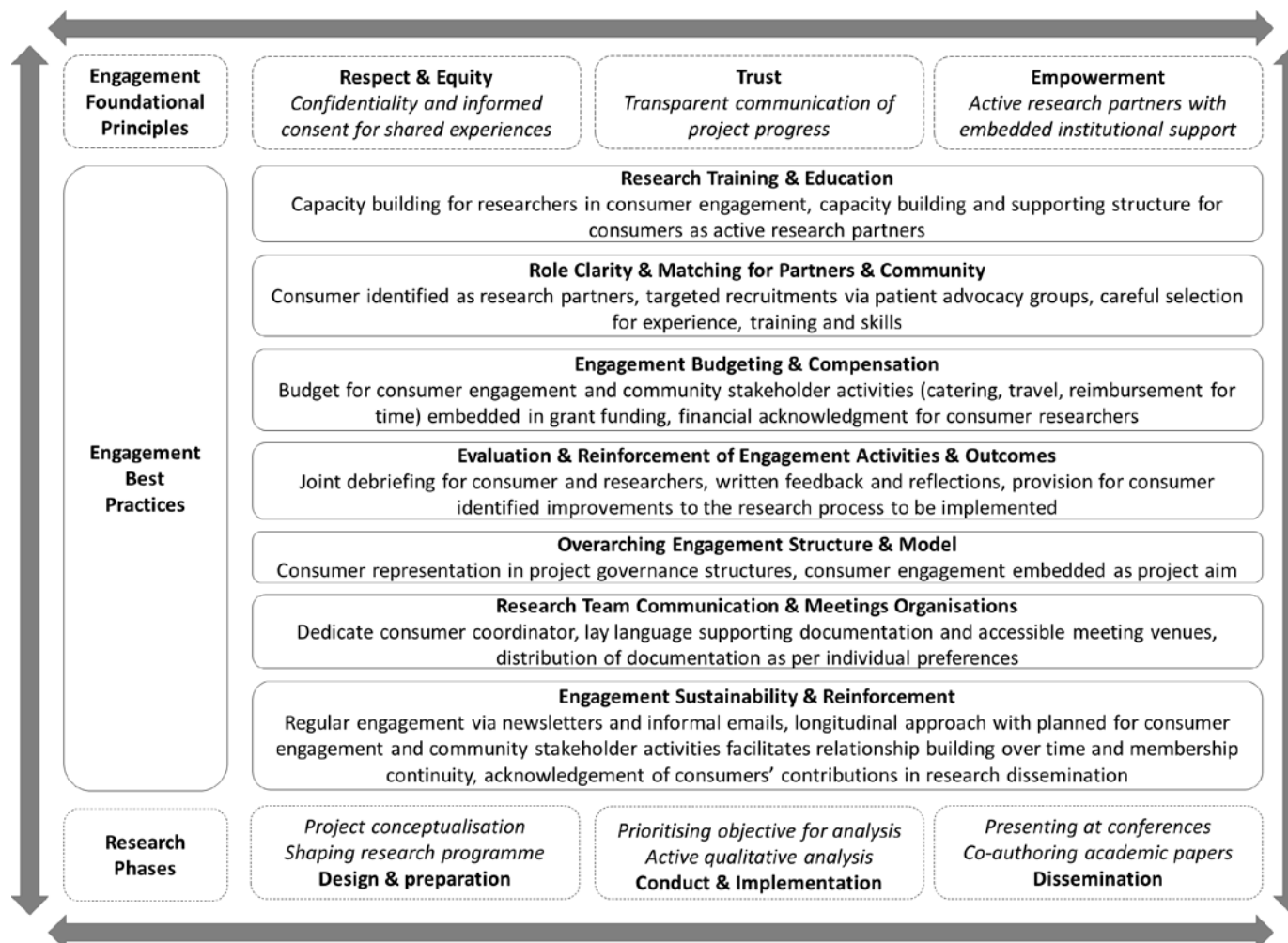


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**Figure 1** Outline of practical strategies undertaken matched to foundational framework by Harrison *et al.*<sup>6</sup>

all stages of a health services research project on test-result management, communication and follow-up. Drawing on this ongoing project funded by a National Health and Medical Research Council (NHMRC) partnership grant with New South Wales (NSW) Health Pathology and the Australian Commission on Safety and Quality in Health Care, we:

1. outline practical strategies used to enhance the contribution of health consumer representatives across all stages of health services research, including active involvement in prioritising objectives for data analysis and participating in data analysis and dissemination of findings;
2. briefly describe the impact of continued consumer engagement on the programme of research, the interpretation of findings and its translational potential.

## KEY INNOVATIONS FOR CONSUMER ENGAGEMENT IN HEALTH SERVICES RESEARCH

Figure 1 matches practical strategies adopted in the described programme of work to an evidence-based framework<sup>6</sup> of foundational principles and best practice activities for consumer engagement. Here, we discuss

longitudinal involvement, capacity building, targeted recruitment, supporting structure and financial acknowledgement as select key innovations.

### Consumer involvement across the research process

*'It is relatively unusual (to shape the direction of the research) right at the beginning, as so often the whole thesis is designed and then the consumers are brought in afterwards'.* Mary Potter, consumer advocate

The vision for and commitment to a longitudinal approach to consumer engagement is reflected in three major strategies: (1) project conceptualisation, (2) governance structures and (3) patient advocate involvement in shaping research direction, data analysis and dissemination.<sup>2 6 7</sup>

The NHMRC grant proposal was developed in collaboration with Health Consumers NSW (HCNSW), the consumer representative organisation for NSW, Australia. AB, Executive Director of HCNSW, is an associate investigator on the project and a member of the project steering committee ensuring consumer representation in the project governance structures. The commitment to prolonged consumer engagement is embedded as

a dedicated project aim, and, as one central approach, a consumer reference group (CRG) was formed to ‘enhance the contribution of consumers to the establishment of safe and effective test result management systems’.<sup>10</sup> To break down barriers to participation for patients without any training as consumer representatives,<sup>3 11</sup> the researchers gathered and combined the insights of frontline patients accessing emergency department (ED) services *and* experienced consumers with research or health system knowledge.

Consumer representatives were recruited to a CRG and were integral attendees at a stakeholder forum held to launch the project.<sup>12</sup> The half-day forum allowed the five attending consumers to shape the direction of the research project. Their insights highlighted the need for consumers to be involved on a micro-level—in managing their own healthcare—*and* on a macro-level—driving change and innovation in health services and policy development.<sup>12</sup> Their insights informed further qualitative data collection, for example, questions for the subsequent semi-structured interviews conducted with clinicians, radiology and laboratory staff, and frontline patients across three NSW EDs. These interviews served to map and compare work processes and to describe patient experiences in the diagnostic test management cycle.

Qualitative interview data were initially analysed by the research team, before launching an innovative consumer-driven programme to involve members of the CRG as active research partners in a full-day Data Analysis Workshop.<sup>11</sup> During this workshop, patient advocates and researchers worked in three groups studying the interview transcripts; some consumer representatives assigning open codes in the transcript margins. In the group discussions that followed, participants shared their initial impressions. Researchers facilitated discussions to identify patterns and themes, which were captured on post-it notes and/or butchers paper to share with the larger group.

As in the examples outlined in [table 1](#), patient advocates (often unknowingly) validated, concretised and questioned themes previously identified by the researchers. They also added their themes thus increasing understanding and interpretation of data from their lived experience. The full analysis and findings from the qualitative data analysis workshop are currently being prepared for publication.

Members of the CRG and HCNSW are actively involved in the dissemination of findings from the workshop through academic and general outlets, as co-presenters at

academic conferences,<sup>13</sup> coauthors for academic journal articles<sup>12</sup> including this paper and featured guests in blog posts.<sup>14–16</sup> In addition, the CRG identified the need for collaborative work to develop policy briefs to promote the translation of research findings and drive practice change which is ongoing.

### Capacity building

*“I did the HCNSW consumer training which gave me a better understanding and appreciation of what we are asking of the patient advocates”.* Mary Dahm, consumer coordinator and project lead

Because the project is driven by the vision of prolonged consumer engagement, the project lead took on the dedicated role of consumer coordinator, responsible for recruitment of patient advocates to the CRG and serving as a first point of contact and liaison between patient advocates and the research team.<sup>17</sup> The consumer coordinator took an academic approach via immersion in the relevant literature on consumer engagement in health services research and additionally sought to gain firsthand, practical experience by becoming a patient advocate. By completing the consumer training<sup>18</sup> and volunteering as a patient advocate in the local health district, the researcher gained crucial experience and an understanding of potential pitfalls for consumer involvement in research.

The research team is continuously involved in activities to build their capacity for consumer engagement<sup>19</sup> and keeps abreast with the latest developments in the field by attending and presenting at local patient-centred conferences (eg, Patient Experience Symposium),<sup>20 21</sup> and attending dedicated institute seminars and meetings with national and international leaders in the field (eg, a representative from Canada’s Patient and Community Engagement Research programme,<sup>22</sup> or the Australian peak bodies (Consumer Health Forum (CHF), HCNSW)).

### Targeted recruitment

*“Your presentation”<sup>21</sup> certainly resonated for me. I’m very interested in consumer/carer access to test results and would be happy to participate in a consumer forum looking at what your research has found”.* Dean Martin, consumer

Careful selection of consumers based on their particular experiences, training and skills can facilitate successful engagement and optimise project outcomes.<sup>6 7</sup> To recruit suitable members for the CRG, targeted advertisements outlined the scope of the project, time commitments, reimbursement and relevant experience (ie, familiarity

**Table 1** Examples of new insights provided by patient advocates in data interpretation

#### Patient advocates

► Validated	► Concretised	► Questioned	► Added
That time pressures affect test-related communication in ED.	That patient access to results in ED <i>is not the default</i> .	The idealised views on timeliness of information transfer in transitions of care.	The real risk linked to the loss of information in transitions of care.

with test result management in a hospital environment as a patient or carer). Advertisements were distributed internally among the members of HCNSW, the consumer council of one local health district and publicised on the HCNSW online presences (website, newsletter, Twitter). Additional informal recruitment occurred via presentations of initial project findings at conferences oriented towards patients/health consumers,<sup>21</sup> attracting interest from patient advocates who volunteered involvement.

The recruitment approach attracted consumers with varied sets of skills, knowledge and experiences related to consumer engagement and/or research while simultaneously having personal experience as patients and/or carers.<sup>18 23</sup> Furthermore, targeted recruitment meant that participating patient advocates could provide diverse perspectives, for example, through having received training regarding the Australian health system, exposure to or previous participation in research projects or substantial experiential knowledge of navigating the health system as a patient or carer. Interested participants contacted the consumer coordinator who followed up with an informal phone call to discuss the project in more detail and to ask questions. Phone calls were deliberately kept informal to facilitate trust and relationship building.<sup>3 6 7</sup> Based on mutual agreement, and once all questions had been answered, consumers were officially recruited as a member of the CRG.

### Support structures

*“For a patient to be included in medical research can be daunting, but being prepared and informed gave us a sense of ease and belonging. [W]e were all able to proceed to examining the pathways of testing at a much more effective level”.* Maureen Williams, patient advocate

As an innovation to consumer engagement in health services research, the interactive full-day Data Analysis Workshop was held to allow consumers to provide their insights and interpretation of relevant topics, as well as to develop qualitative data analysis skills.<sup>7</sup> Apart from drawing on academic and grey literature to identify best practice, the consumer coordinator reached out via Twitter and received >10 real-world tips and tricks for successful consumer engagement from researchers and consumer representatives.<sup>24</sup> Based on the obtained learnings, patient advocates were provided with support structures to build their capacity as active research partners<sup>11</sup> well ahead of the actual workshop. Supporting structures included targeted written documentation before the event, direct and immediate guidance from researchers in the lead up to and during the workshop, team-based analysis exercises with the input of other consumers and researchers, and joint debriefing, feedback and support in the dissemination of workshop findings.

On recruitment to the CRG, participants received supporting documents regarding the project. Several weeks ahead of the workshop, consumers received targeted information outlining multiple possible topics to be analysed during the workshop. To facilitate a truly

consumer-driven approach, patient advocates were asked to rate possible topics for analysis by importance.<sup>2</sup> Two topics were selected based on their ratings, and consumers received further detailed briefing documents including:

- ▶ a brief outline of roles and expectations for consumers and researchers;
- ▶ an introduction to qualitative research methodology and analysis principles;
- ▶ excerpts from interviews to allow consumers to become immersed in the data before the workshop<sup>25</sup>;
- ▶ administrative information (eg, agenda, map of the venue).

These documents were provided in either digital or paper formats as per individual preferences.<sup>4</sup> Patient advocates appreciated the distribution of briefing documents, which according to their comments on open-ended feedback forms were ‘excellent’, ‘timely’ and gave them a ‘good overview of opinions’, and ‘time to think about the issues’.

The workshop itself included 10 consumers and 5 researchers who split into three groups. Each consumer group was supported by two researchers to facilitate discussion, take notes and guide the analysis of each topic. Immediately after and in the weeks following the workshop, consumers and researchers participated in joint debriefing and feedback activities which are strong indicators for ongoing successful engagement.<sup>6</sup>

Consumers appreciated the researchers’ openness to further input following the workshop. Their feedback reflected that all consumers were interested in ongoing collaboration as research partners. Patient advocates offered suggestions for improvement such as inclusion of frontline patients, more time for networking and further research methodology workshops. Especially the latter sentiment, for increased research capacity building, was echoed by the researchers with further activities currently being scoped but contingent on available funding. As part of the debriefing activities, consumers also reviewed a short summary of the workshop findings and a few wrote a short reflective account of their experience in the workshop at the researchers’ request. These reflections formed the basis for current and future conference presentations<sup>13</sup> and academic publications, including this paper.

Feedback forms and reflections highlighted that in the experience of the involved consumers the overall level of care and support was unprecedented and regarded as testament to the fact that, in this project the patient experience was being valued. The inclusion of patients was a hallmark of the project, clearly moving beyond tokenism. Contrasting their experience with participation in other listening forums and research projects, consumers perceived their involvement as more positive and engaging and praised the clear focus on the aims of the workshop and the facilitated analytical discussions.

## Financial acknowledgement

*"The consumers were treated probably better than the actual researchers from the point of view of reimbursement for our time, concerns about parking and how to access the meeting. You see that gives an indication and reflects the value of our involvement".* Mary Potter, consumer advocate

While researchers are employed in paid positions to conduct research studies, consumers are often expected to essentially consult for free.<sup>4</sup> While more and more recommendations exist on how consumers should be remunerated or reimbursed for their time, no binding national policy requirements exists in Australia.<sup>2</sup> Further complicating the issue is that patient advocates are often people with chronic illness or disabilities who may receive a range of government pensions that they could lose if their earnings exceeded a certain (usually very low) threshold. The researchers leading this project wanted to acknowledge the value of the consumers' lived experience and experiential knowledge.<sup>26</sup> Thus, in addition to establishing an inclusive programme of research emphasising mutual capacity building<sup>19 27</sup> and providing catered tea breaks to encourage networking,<sup>6</sup> researchers followed the HCNSW recommendation<sup>28</sup> and offered financial compensation in form of shopping vouchers commensurate with the longitudinal nature of the engagement and duration of CRG meetings.<sup>6</sup> We provided further financial support via taxi vouchers to ensure that access to transport was not a barrier to participation. Financial acknowledgement was often unexpected but well received by consumer participants. As advocated by the most recent 'Statement on Consumer and Community Involvement in Health and Medical Research' coauthored by CHF and NHMRC,<sup>8</sup> organisational and research project budgets need to plan adequate funding to ensure long-term consumer engagement across all research stages.<sup>9 19</sup>

## IMPACT OF CONSUMER ENGAGEMENT

The collaborative approach taken by researchers and patient advocates in this project provides further evidence for consumer participation in health services research as a powerful tool to identify areas in which safety and quality improvements in the health system can be made. The input of consumers who were engaged as active research partners shaped the programme of research and provided new insights in the interpretation of data and hold immense translational potential. For example, in the data analysis workshop, consumers identified themes that had not been previously identified by the researchers. Thus, patient advocates were able to add new perspectives, elucidate risk of potential harm and give weight to the argument for improvement or change. Consumers also improved their research capacity and formed an emerging group of interested advocates with lived experience of health services, who can now be more actively involved as partners in the planning, grant writing and governance processes of future projects.

Enhancing consumer contribution and establishing inclusive research design requires a rigorous, negotiated, interactive, immersive and transparent process. As a collaborative approach, consumer-driven research involvement offers opportunities for new, often unexpected or unexplored perspectives to feature across the whole research process. In a move away from perfunctory consumer involvement,<sup>9</sup> consumers and researchers who participated in our innovative and immersive research project identified inclusive research as a powerful tool to enhance health services research and its translation into effective policy. Our paper describes collaboration associated with a specific project. While we draw some important general lessons from our paper, we understand that different circumstances and goals associated with different projects will provide different challenges. However, researchers can leverage the presented strategies to enhance the contribution of consumers in a range of health services research. The practical steps provide a strong foundation for a flexible, respectful and collaborative approach to consumer-driven analysis and interpretation of study findings and ensure that research is done *with*, not just *for*, consumers, thus moving away from tokenistic to genuine inclusive research and driving meaningful practice and policy change.

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**Contributors** AG conceived the project and obtained funding. MRD, AB and AG made substantial contribution to the development and application of the consumer engagement strategies in the project. MRD, R-AH, JL, JT and AG contributed to the planning and facilitation of the project workshop. MRD and JL collected the data that were analysed during the workshop. DM, MW, BO, JB and MP prioritised and contributed to analysis and interpretation of data during the workshop. MRD drafted the manuscript with input from DM, MW, BO, JB and MP. All authors contributed to the critical revision of the paper and approved the final manuscript for publication. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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**Competing interests** DM wishes to declare that he is an appointed member of the Australian Digital Health Agency's Consumer Advisory Committee. The other authors declare that they have no competing interests.

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