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Consumer involvement in health service research: a cross-sectional survey of staff in an Australian public hospital and health service

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ABSTRACT

Objective. Consumer involvement is when patients (their families, friends, and caregivers) work with researchers on research projects. While health services are expected to support consumer–researcher collaborations, conducive environments still need to be developed, with limited research into how Australian health services support this practice. This study explores current consumer involvement in research activity and staff perceptions at an Australian tertiary hospital and health service. **Methods.** Research-active employees at a health service were invited to participate in an online cross-sectional survey. It assessed experience with and confidence in involving consumers in research, the perceived value of consumer involvement, and considerations related to challenges, facilitators, and solutions to enhance consumer involvement in health service research. **Results.** Among 83 respondents, including medical, nursing, and allied health professionals, 54 completed the survey. Approximately half had experience with involving consumers in research. Over 80% recognised that involving consumers enhanced research relevance. Identified barriers included challenges in finding (46.6%) and compensating (59.3%) consumers, as well as deficiencies in researcher skills, knowledge (32.2%), and time constraints (39%). Facilitators comprised access to experienced researchers and educational opportunities. Moreover, 87% advocated for increased support to involve consumers within health services, with the appointment of a designated consumer involvement officer deemed the most beneficial solution by 92.5% of respondents. **Conclusions.** While individual barriers inhibit consumer involvement in research, more prominent institutional factors such as financial and technical support may determine successful and meaningful collaborations. As health services evolve towards co-design models in research, the outcomes of this study will guide initiatives aimed at enhancing consumer involvement in the research process within Australian health services.

Keywords: co-design, community participation, consumer, consumer engagement, consumer involvement, hospital, hospital and health service, patient involvement, patient participation.

Introduction

Consumer involvement in research is now considered fundamental for those pursuing knowledge generation in the health sector.¹ Consumer involvement in research is when research is conducted ‘by’ or ‘with’ health consumers (e.g. patients, friends, family, carers, paid service workers, or consumer groups) rather than ‘to’, ‘about’, or ‘for’

them.^{1–5} The role of consumers in health research is widely acknowledged, but terminology such as participation, involvement, engagement, and partnership is contested and used interchangeably.^{6,7} In this Australian-based study, we use *consumer involvement*, reflecting its widespread usage.^{1,8–12} It refers to higher participation levels on the International Association of Public Participation (IAP2) Spectrum: involve, collaborate, and empower.¹³

Existing literature emphasises that involving consumers in research is important for three main reasons: (1) ensuring people's right to contribute to knowledge affecting their lives, (2) improving research trustworthiness and relevance, and (3) enhancing research accountability and transparency.^{4,14–18} While consumer involvement is now endorsed by major Australian research councils and funding bodies, including the National Health and Medical Research Council (NHMRC),^{1,9,19} translating this endorsement into practice necessitates a strategic commitment from organisations to involve consumers in research activities.

Our investigation is the initial phase of a larger project, encompassing a health service staff survey, group sessions with consumers and staff,²⁰ and a stakeholder workshop to gain multiple perspectives. The aim was to develop a framework for fostering meaningful consumer–researcher relationships within health service research initiatives. This paper presents findings from the first stage, focusing on surveying health service staff to explore their experiences and perspectives on involving consumers in research projects.

- (1) What consumer involvement in research activities is currently happening at the health service?
- (2) What are the staff perspectives about consumer involvement in research at the health service?

Method

Consumer involvement

Consumer involvement in this study is reported in consideration of the GRIPP2 reporting checklist²¹ (Supplementary material file S1). Three health service consumers were involved in all stages of this multi-stage project and are co-authors of this paper.

Study design

A cross-sectional survey design was used and is documented here as per the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting checklist for cross-sectional studies.²² A survey was chosen for data collection due to limited prior knowledge of the local context. Existing scholarship on consumer involvement in research guided survey development, eliminating the need for a preliminary exploratory step.²³

Participants and setting

The setting was a public hospital and health service in an Australian metropolitan area. A convenience sampling approach was used across all sites. The inclusion criteria allowed participation from current health service staff, including researchers, research-active clinicians, and those in management positions within relevant professional disciplines.

Recruitment

Promotional materials, including a project overview, survey links, and participant information sheets with ethical statements, were distributed electronically via health service platforms, professional networks, and directly to principal investigators of internal research projects. Participation was anonymous, and consent was obtained at the beginning of the survey.

Survey

Data was collected through an internal online survey. The comprehensive survey covered respondents' experiences and perceptions of the value, facilitators, barriers, and improvement strategies within the health service. Demographics (gender, role, experience) were also included. The survey was created using SurveyMonkey, refined based on advisory team feedback, and pilot tested with two clinician-researchers for clarity. The survey featured Likert-scale and multiple-choice questions and included 27 questions: 7 on demographics, 16 on consumer involvement experiences, and 4 on participation in subsequent project stages. Questions on consumer involvement were guided by an established interview framework⁴ and the Theoretical Domains Framework (TDF).²⁴ Survey respondents were provided with a definition of consumer involvement in research to facilitate a clear understanding of the term throughout the survey (refer to Supplementary material file S2).

Data analysis

Survey responses were downloaded from SurveyMonkey and put into a Microsoft Excel spreadsheet for data analysis. Quantitative analysis (descriptive, frequencies, and percentages) was undertaken by two members of the research team and subsequently reviewed by remaining team members, including consumer advisors. Subgroup analyses were performed on professional groups. Statistical support was sought in consultation with the health service biostatistician for the quantitative components. Fisher's exact test was used to understand relationships between professional discipline, knowledge, and previous experience involving consumers in research.

Ethics approval was obtained from Gold Coast Hospital and Health Service (GCHHS), Health Research Ethics Committee (HREC/2023/QGC/94895). Research governance

approval was given by the Gold Coast Hospital and Health Service (SSA/2023/QGC/94895).

Results

Out of 90 initial respondents, 7 were removed for gross incompleteness, 29 partially completed the survey, and 54 completed it in full. Partially completed surveys were included to maximise data utilisation and acknowledge respondent effort.²⁵ Completion rates varied, affecting the total responses per question. On average, respondents took 8 min and 32 s to complete the survey. Demographic details are provided in Table 1.

Table 1. Respondent demographics and professional experience.

Respondent demographics	
Gender <i>N</i> = 76	
Female	76.3% (58)
Male	23.68% (18)
Professional background <i>N</i> = 77	
Medical	20.8% (16)
Nursing and Midwifery	29.9% (23)
Allied Health	19.5% (15)
Research	15.6% 12
Dual position (researcher and clinician)	3.9% 3
Other	10.4% 8
Health service experience <i>N</i> = 77	
Less than 2 years	14.3% (11)
2–10 years	42.9% (33)
10–20 years	29.8% (23)
More than 20 years	13% (10)
Educational background (*multiple answers permitted) <i>N</i> = 77	
Certificate/diploma	18.2% (14)
Bachelor's degree	54.6% (42)
Honour's degree	13% (10)
Master's degree	42.9% (33)
Higher research degree	26% (20)
Other	13%
Research in current role <i>N</i> = 77	
Full-time (38 or more hours per week)	16.9% (13)
Part-time (less than 38 h per week)	33.8% (26)
Occasionally (not on a weekly basis)	27.3% (21)
Never	16.9% (13)
Other (please specify)	5.2% (4)

Knowledge and experience of consumer involvement

The survey sought to determine the current landscape of involving consumers in research at the health service. Responses relating to self-reported knowledge about consumer involvement in research varied. Thirty-four respondents (48.6%) reported they knew how to involve consumers in their research, with 49.3% (*n* = 35) having previously engaged consumers. Thirty-six respondents (51.4%) either reported not knowing how to involve consumers in research (30%, *n* = 21) or were uncertain (21.4%, *n* = 15), with 46.5% (*n* = 33) having not previously involved consumers in their research. There were no statistically significant associations between professional discipline and either knowledge of (*P* = 0.437) or previous experience (*P* = 0.307) with the involvement of consumers in research.

Respondents identified their experience with specific components of the International Association for Public Participation (IAP2) Spectrum.¹³ Most often, research was driven by researchers, with consultation (62.1%, *n* = 18), involvement (62.1%, *n* = 18), and collaboration (34.5%, *n* = 10) with consumers. Only four respondents (13.8%) were involved in consumer-led projects.

In relation to the different stages of research, the majority of respondents had involved consumers in the conceptualisation and design of research (69%, *n* = 20). In comparison, fewer had experience in working with consumers to identify and prioritise research topics (21.1%, *n* = 7), implementation (20.7%, *n* = 6), and research evaluation (17.2%, *n* = 5).

Confidence in involving consumers

Findings relating to confidence in involving consumers in research are reported in Fig. 1. Areas of greater confidence when involving consumers in research included networking and consulting with consumers about research (49.2%, *n* = 32), identifying research issues and prioritising research goals (49.2%, *n* = 32), and disseminating research findings (50.8%, *n* = 33). Areas where respondents reported not feeling confident included recruitment of consumers (46.2%, *n* = 30), undertaking research funding applications with consumers (46.2%, *n* = 30), and monitoring and evaluating research impact with consumers (44.6%, *n* = 29).

Valuing consumer involvement

Respondents placed a high value on the involvement of consumers in research and understood the benefits of involving consumers in their research (refer to Fig. 2). The majority (88.5%, *n* = 54) agreed that consumers brought 'a lived experience' and other expertise to the research team, enhancing the relevance of research to the target population. Furthermore, 86.9% (*n* = 53) reported that consumers increased the credibility of research within consumer groups, and 82% (*n* = 50) agreed that the involvement of

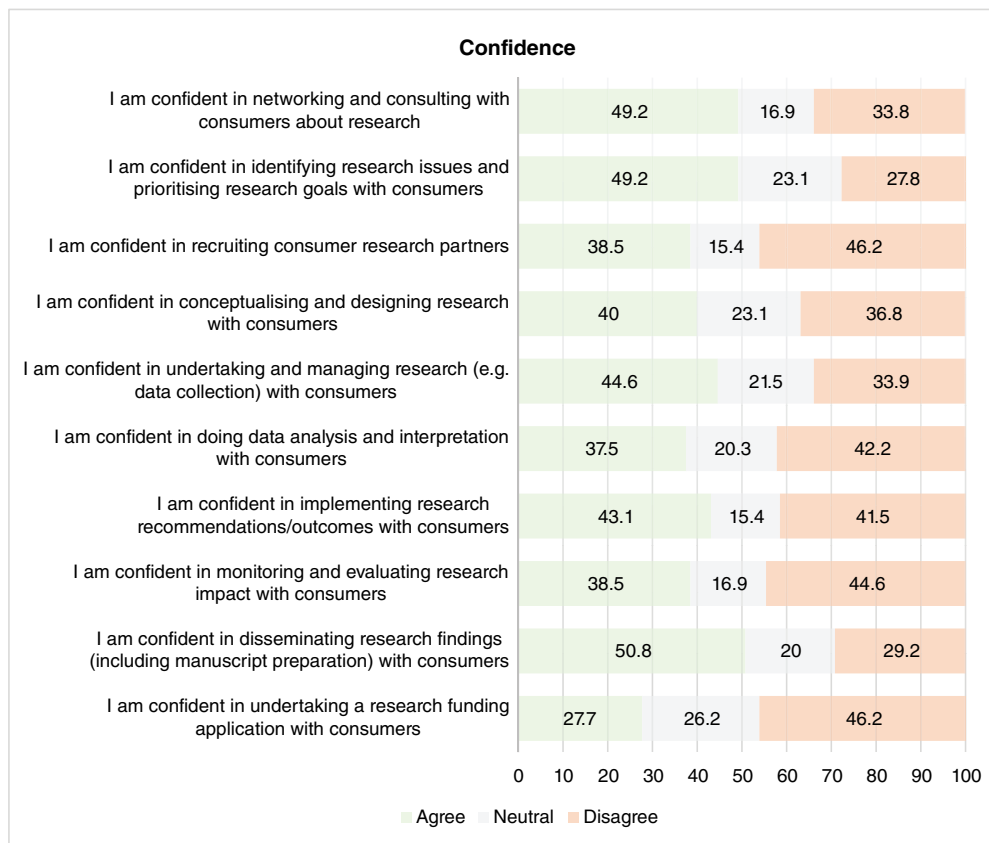


Fig. 1. Confidence in undertaking consumer involvement activities.

consumers leads to more culturally responsive research. Finally, many respondents agreed that the involvement of consumers is often tokenistic (50.8%, $n = 31$).

Challenges to consumer involvement

Fig. 3 reports challenges to involving consumers in research. Key challenges in involving consumers in research included difficulty finding consumers (46.6%, $n = 27$), lack of funds to pay consumers for their time (59.3%, $n = 35$), and staff not having the relevant skills and knowledge to involve consumers in research (32.2%, $n = 19$). Eight (13.8%) respondents reported difficulty in managing power dynamics within the research team where they had involved consumers. Finally, 58.3% ($n = 35$) of respondents felt it was difficult to involve consumers in research at the health service where the study took place.

Facilitators of consumer involvement

Perceived facilitators of involving consumers in research are reported in Fig. 4. Respondents were uncertain about the factors facilitating consumer involvement in research within the health service. This uncertainty was evidenced by the prevalence of neutral responses – indicating neither

agreement nor disagreement – being frequently chosen in relation to the statements provided. Only 14.8% ($n = 8$) of respondents reported that the health service adequately supported researchers in involving consumers, while 86.8% ($n = 46$) thought that more should be done. Interestingly, 84.9% of respondents agreed that people whose opinions they valued approved of the involvement of consumers in their research. Key facilitators assisting respondents with involving consumers included having a more experienced researcher in the research team (51.9%, $n = 27$) and education and training (40.4%, $n = 21$).

Solutions to consumer involvement

Respondents supported all the proposed solutions to aid the involvement of consumers in research (refer to Fig. 5). However, a designated consumer involvement officer was viewed as the most useful solution for supporting them to involve consumers in research (92.5%, $n = 49$), closely followed by information linking researchers to external (87%, $n = 47$) and internal (85.2%, $n = 46$) training. Prompts in the health service's research protocol template and ethics application form were viewed as less helpful solutions; however, 64.8% ($n = 35$) of respondents still agreed this would help.

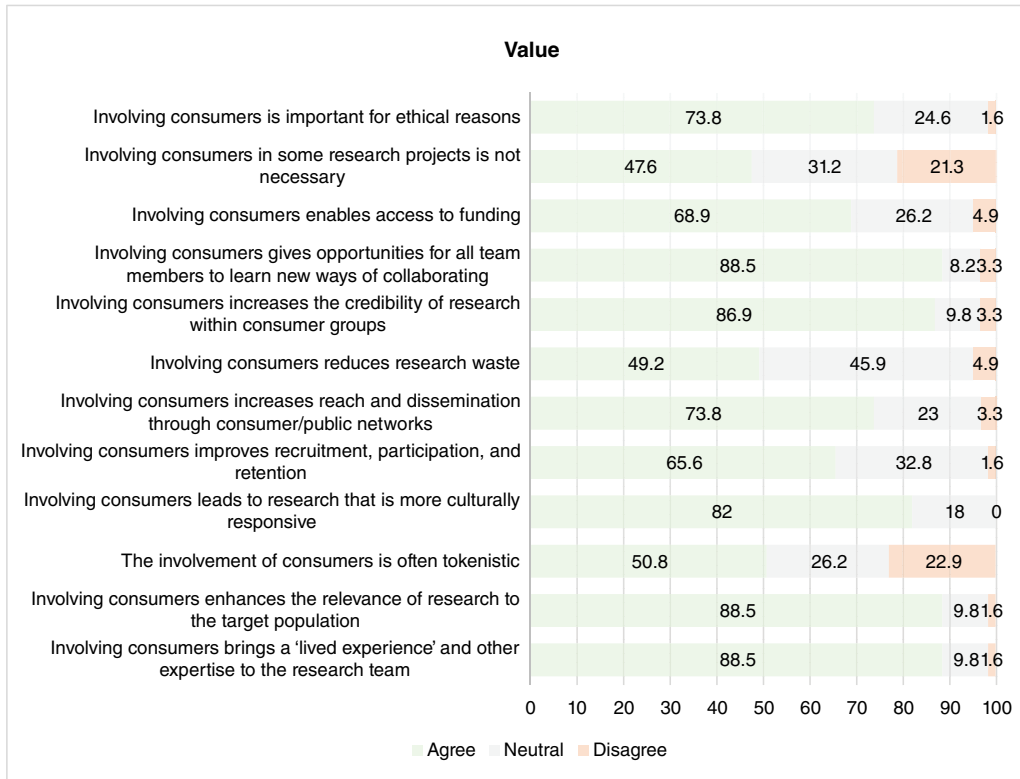


Fig. 2. Valuing consumer involvement.

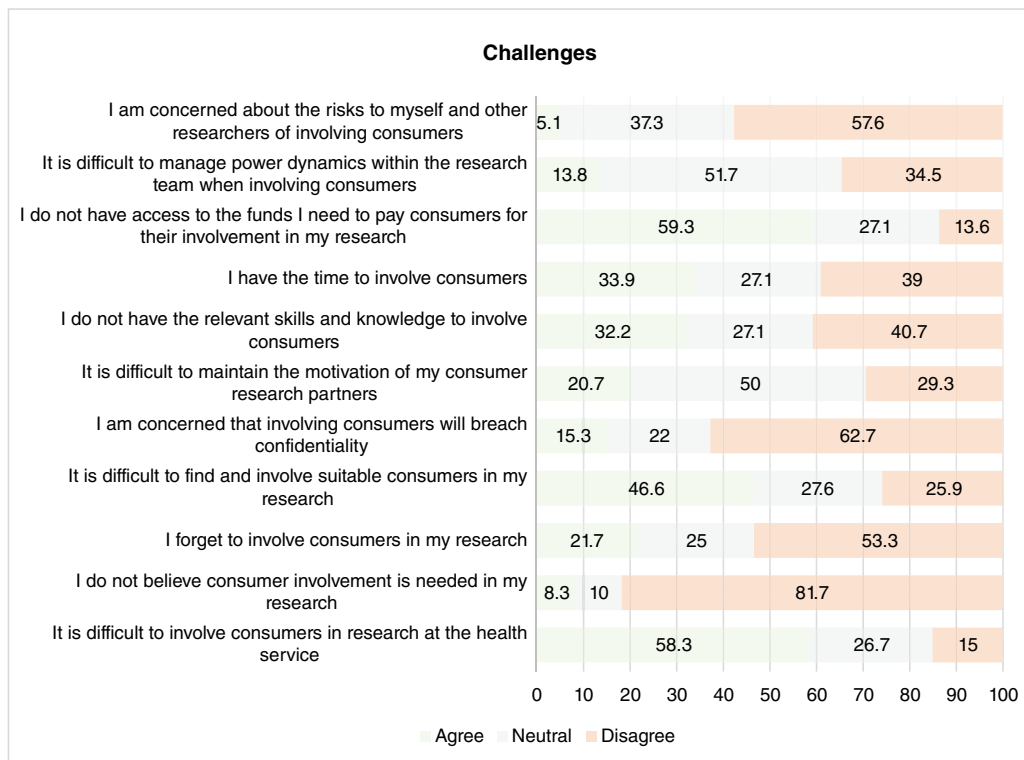


Fig. 3. Challenges to consumer involvement.

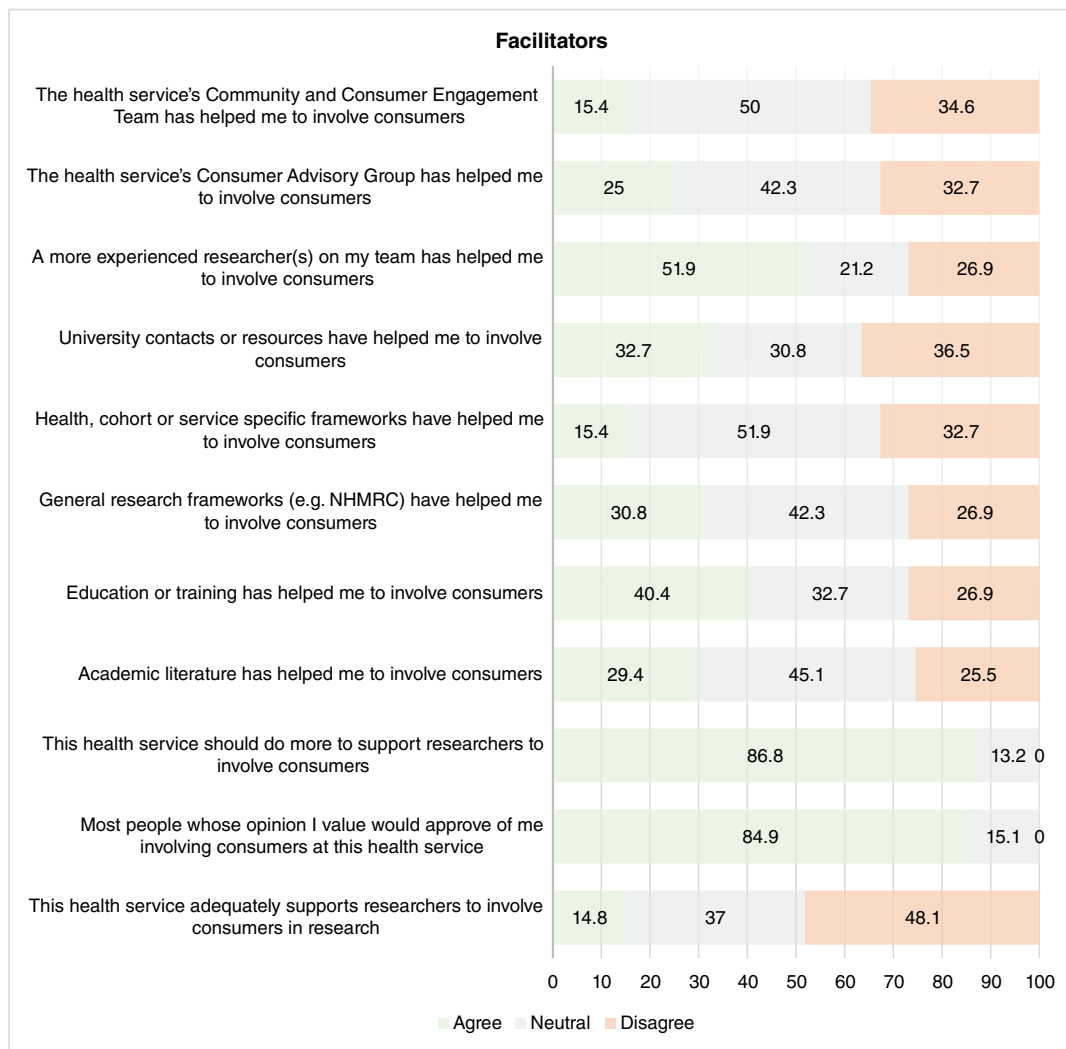


Fig. 4. Facilitators of consumer involvement.

Discussion

This study provides insight into consumer involvement in research within an Australian hospital and health service context. The survey explored staff experiences and perceptions, including competencies, concerns, and opportunities regarding consumer involvement. This study focuses on a specific organisational context unlike prior studies covering diverse health organisations and institutions.^{3,26} It offers guidance for Australian health services to strategically address challenges in consumer–researcher collaborations, enhancing meaningful consumer involvement through targeted efforts and resource allocation.¹⁴

Approximately half of the surveyed staff had experience and felt knowledgeable about involving consumers in research, while the other half had limited exposure or understanding. This aligns with other recent research indicating a general lack of familiarity and expertise among health service researchers with involving consumers in

research.^{3,27} This trend highlights the widespread challenge of limited exposure and expertise among health service staff in involving consumers in research. Addressing this is crucial for targeted interventions, training, and support systems to enhance consumer involvement in health service research, necessitating organisational frameworks and budgetary planning.

Our findings show that health service staff value consumer involvement in research and recognise the benefits. However, there was also an acknowledgment of tokenistic involvement, highlighting a growing awareness of the need for more meaningful engagement. These findings contribute to evidence showing a shift in health researcher attitudes towards greater consumer involvement.²⁷ While efforts to promote consumer involvement in health service research can leverage these acknowledged benefits,^{14–16} it is important to consider that staff with reservations may not have participated in our survey. Addressing and possibly changing perspectives within this subgroup may require additional initiatives.

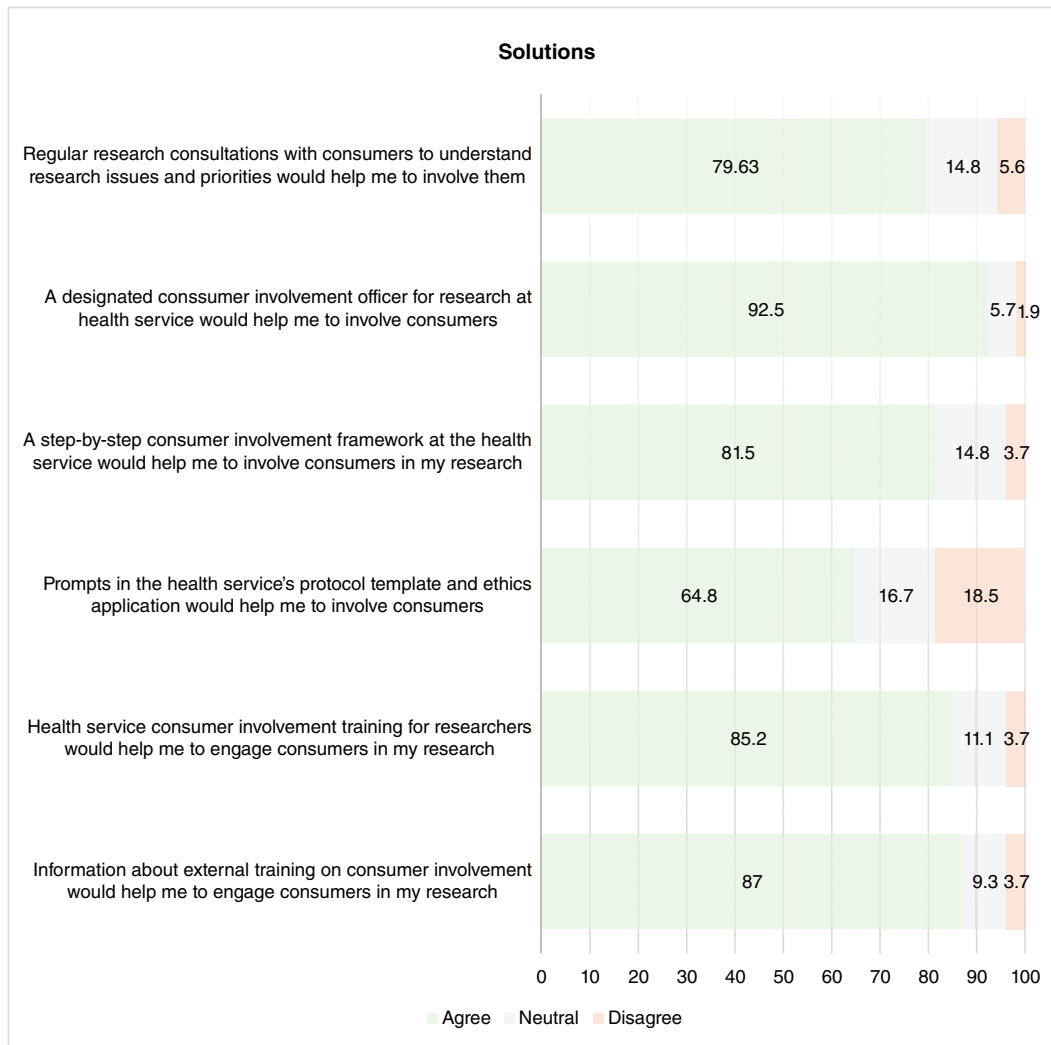


Fig. 5. Solutions to consumer involvement.

Survey respondents appreciated the benefits of involving consumers in research; however, significant challenges for health service staff were evident. These align with barriers observed in Australian health research, including limited project resources, recruitment difficulties, staff skills gaps, resistance to involvement, and organisational constraints.^{3,18,28-30} Addressing these barriers demands systemic support, without which full consumer involvement in research appears improbable.

Power struggles can hinder consumer involvement in research when researchers resist sharing authority.^{18,30-32} Power struggles may emerge when researchers feel threatened by the possibility of losing control over the research process and are reluctant to share authority in generating knowledge.³³ Some researchers include consumers superficially, while unconscious biases may undervalue their contributions.³⁴ Both parties benefit from recognising and leveraging consumers' unique social capital to balance power dynamics and improve research outcomes.³⁵ Respondents to

our survey may have overlooked power dynamics in teams with consumers, focusing instead on more pressing challenges such as consumer–researcher connection and compensation. This oversight might stem from a lack of awareness about power issues in these collaborations, hindering efforts to address and resolve such disparities.³⁵

The survey identified opportunities for health services to help staff overcome obstacles in consumer involvement. Respondents supported organisational backing, highlighting the need for enhanced support in building consumer relationships. These needs align with existing literature, underscoring the importance of general support, access to external training, consumer recruitment assistance, compensation funding, and extended project timelines.^{3,4,27,36} Research into the efficacy of these strategies is evolving. For example, a 2016 study on a consumer involvement education program showed increased understanding among participants.³⁷ However, other studies have called for more tailored training programs for researchers and greater

transparency in content development methods.³⁸ This emphasises the importance of adaptive strategies and ongoing assessment to meet evolving needs.

Limitations and strengths

Out of 90 initial participants, 54 completed the survey, with 30 dropping out before question 10 of 27. The survey, approved by research and advisory teams and pilot tested, averaged an 8 minute completion time, aligning with engagement guidelines,³⁹ although this includes incomplete responses. Respondents less familiar with consumer involvement may have found detailed questions challenging or irrelevant. Another limitation is the single-site focus, which limits generalisability. This study benefited from insights from health professionals from diverse specialties across various practice areas within the health service. It also had a diverse team of health service researchers, university academics, and consumers providing varied perspectives.

Conclusion

As Australian health staff and organisations face growing pressure to involve consumers in research, understanding the Australian health service context is crucial. The study provides considerations for Australian health services to strategically enhance efforts and allocate resources to address the evolving demands and challenges of consumer–researcher collaborations.

Supplementary material

Supplementary material is available [online](#).

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Data availability. The data that support this study cannot be publicly shared due to ethical or privacy reasons and may be shared upon reasonable request to the corresponding author if appropriate.

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