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Ryan, L;Wenke, R;Carlini, J;Weir, KA;Shapiro, M;Baglot, N;Cardona, M;Tobiano, G;Sargeant, S;Muir, R;Hattingh, L

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Co-design of an Australian health service framework and implementation plan for involving consumers in research

Laura Ryan[A,*], Rachel Wenke[A,B,C], Joan Carlini[D,E], Kelly. A. Weir[F,G], Margaret Shapiro[D], Noela Baglot[D], Magnolia Cardona[H,I], Georgia Tobiano[J,K], Sally Sargeant[L], Rachel Muir[M,N,O] and Laetitia Hattingh[A,P,Q]

For full list of author affiliations and declarations see end of paper

***Correspondence to:**
Laura Ryan
Allied Health Research, Gold Coast Hospital and Health Service, Southport, Qld 4215, Australia
Email: laura.ryan2@health.qld.gov.au

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ABSTRACT

Objectives. The value of engaging health service users and their families (consumers) in research is increasingly being recognised in planning and evaluating health services to meet diverse needs. This project aimed to co-design a strategic consumer involvement framework and implementation plan for a public Australian hospital and health service. **Methods.** A co-design approach was used to adopt a framework and develop an implementation plan across five stages: (1) an initial consultation with key stakeholders, (2) a survey of health service staff about involving consumers in research at the health service, (3) three group sessions using Nominal Group Technique with health service consumers and staff that explored barriers and solutions to involving consumers, (4) data synthesis, and (5) a workshop of key stakeholders to develop and refine the implementation plan. Three consumer partners contributed to protocol development, research design, data analysis, and manuscript writing. **Results.** Survey and group session data highlighted a need for governance, infrastructure, capacity building, and leadership and culture within the organisation to support the involvement of consumers in research at the health service. These aligned with the South Australian Health and Medical Research Institute (SAHMRI) Framework domains. Implementation strategies were adjusted on the basis of insights from the local context to facilitate adoption within the health service. **Conclusions.** By better supporting consumers and researchers to work together in health service research, organisations can enhance the relevance, quality, and impact of their research efforts. This project provides a valuable blueprint for developing a local, contextualised approach to promoting effective consumer–researcher relationships in Australian public health services.

Keywords: consumer and community involvement, consumer engagement, health service research, patient and public involvement, public health.

KEY POINTS

- A five-stage co-design approach facilitated the adoption of a strategic consumer involvement framework and the development of an implementation plan.
- Consumer–researcher collaborations need organisational governance, infrastructure, capacity building, and leadership and culture.
- Targeted implementation strategies must be adapted on the basis of local context to improve uptake.
- Project methodology provides a blueprint for developing contextualised strategic approaches for consumer involvement in research in Australian public health services.

Introduction

Health service consumer involvement in research, also known as ‘patient and public involvement’ or ‘consumer and community engagement’, is crucial for generating health knowledge.[1] It involves research conducted ‘by’ or ‘with’ health service consumers

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(e.g. patients, families, carers, or consumer groups) rather than 'to', 'about', or 'for' them.[2] Benefits include improved research quality, relevance, credibility, and transparency.[3,4] Globally, efforts have increased to incorporate consumer voices in health research.[5,6] In Australia, this approach is gaining traction with support from major research councils such as the National Health and Medical Research Council (NHMRC).[7] However, challenges remain in effectively involving consumers in the health service sector.[8,9]

Organisations use strategic frameworks to facilitate consumer involvement in research.[5,10] These frameworks set intentions and provide a roadmap for supporting collaborations between consumers and researchers.[11] They identify leaders, demonstrate commitment (including resource allocation), assert values, and outline strategies and processes for consumer–researcher collaborations.[5,6,11] Strategic frameworks enhance the organisation's capacity for meaningful consumer involvement, leading to more impactful and inclusive research outcomes.

Determining a suitable framework for a specific context is challenging. Greenhalgh *et al.*'s systematic review identified 65 relevant frameworks with varied purposes, strengths, and limitations, concluding no single framework is universally applicable.[5] Although frameworks exist for health research institutes and some health services, empirically informed frameworks for the Australian health service context are lacking.[5] Of the 65 frameworks identified by Greenhalgh *et al.*, only one was from Australia, the Consumer Involvement Framework developed by the South Australian Health and Medical Research Institute (SAHMRI).[5,11]

The SAHMRI Framework outlines four key domains – governance, infrastructure, capacity building, and leadership and culture – that are essential for embedding consumer involvement in health research.[11] By providing a structured approach, the SAHMRI Framework serves as a useful model for organisations seeking to enhance consumer–researcher collaborations and maximise the impact of their research efforts.[11] However, unlike some countries,[6] Australia's fragmented healthcare system varies by state and territory, meaning that frameworks such as the SAHMRI Framework cannot be broadly applied and require careful consideration of appropriateness for different contexts.[12]

Furthermore, although Australian health services have access to various resources and external frameworks to guide collaboration with consumers, such as the Health Consumers Queensland Framework and the Western Australian Health Translation Network's Consumer and Community Involvement Handbook, these resources often focus on the consumer–researcher relationship and the collaboration process.[13,14] They tend not to address how organisations can create the conditions that foster these relationships, further highlighting the need for local research to inform organisational strategies.

The objective of this project was to systematically gather local knowledge about consumer involvement in research at an Australian hospital and health service without an existing framework. This process focused on understanding consumer and staff practices and viewpoints for enhancing consumer involvement in research. Findings would inform a strategic framework and implementation plan to support consumer–researcher collaborations. We illustrate how local insights informed the strategic direction by detailing the journey from project design to adopting an established framework and adapted implementation strategy.

Methods

Co-design approach

This project used a co-design approach, engaging stakeholders to collaboratively adopt a consumer involvement framework. Co-design involves active collaboration to address specific health issues, services, or initiatives.[15] Health service consumers, researchers, local academics, and key stakeholders (including health professionals, clinicians, and leaders) were involved in this project. Through various studies and activities, this collaboration informed the adoption of a framework and the development of an implementation plan for the health service.

We adhered to the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) to report consumer involvement in this study.[16] Consumers for this project were recruited via the health service's Consumer Advisory Group, as they expressed interest in developing a consumer research framework, had prior research experience, and were remunerated as part of their existing roles. These consumers were involved in the initial discussions and throughout the project lifecycle, including being named authors in publications. One consumer served as a principal investigator, and another two were associate investigators. Their contribution also influenced project design; for example, they recommended adding a stage to investigate local consumer perspectives. In addition, they helped to develop the survey, assisted with recruitment, facilitated group sessions, and shared their experiences during crucial project stages, including analysis and synthesis.

The primary challenge of involving consumers was managing expectations regarding what could be achieved within the project's timeframe and budget. Decisions on how to proceed were reached through a consensus approach, and all consumers remained in the project from start to finish. Their main request was for education and support to fulfil their roles as facilitators during group sessions, which was promptly provided. The involvement of consumers in this project has yielded significant positive outcomes, notably the adoption of a framework and the development of an implementation plan, which has received endorsement from the health service.

Site

This project occurred at an Australian public hospital and health service in a city with approximately 600,000 people.[17] This health service provides a comprehensive range of

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secondary and tertiary health services across four hospital sites, comprising one tertiary hospital dedicated to training and research. Additionally, the health service encompasses two health precincts and two community health centres.

Project overview

The project encompassed five stages, including (1) an initial stakeholder consultation, (2) a staff survey of 83 health service staff about their activities and perceptions of involving consumers in research, (3) three Nominal Group Technique sessions (with a total of 10 consumers and 14 staff) that explored barriers and solutions to involving consumers in research, (4) a data synthesis stage (where the framework was adopted and the implementation plan developed), and finally (5) a workshop with 15 key stakeholders to refine the implementation plan (see Fig. 1).

Stage 1: stakeholder consultation

Key stakeholders in the health service (researchers and consumers) and within the local community (academics) were invited by email to participate in a consultation about the involvement of consumers in research at the health service. The email informed them of the overall objective, namely, to determine how the health service should support consumers and researchers working together on research. It included documents about involving consumers in research to orientate stakeholders to this topic and mission, such as Greenhalgh *et al.*'s systematic review.[5] The meeting explored initial ideas and priorities relevant to how the health service should guide and support consumer involvement in research. For example, whether a bespoke framework was required. Attendees included three health service consumers, four health service researchers, and six local academics with expertise in consumer involvement in research.

Stage 2: survey

A cross-sectional survey, utilising Likert scales and open-ended questions, was distributed to all staff within the health service.[18] The survey explored staff perceptions of involving consumers in research, including questions assessing confidence in undertaking projects with consumers, the perceived value of involving consumers in research, types of engagement activities utilised, and considerations regarding challenges, facilitators, and potential solutions for improving consumer–researcher relationships within the health service.

Stage 3: Nominal Group Technique (NGT) sessions

A Nominal Group Technique (NGT) methodology was employed, engaging three groups composed of consumers and health service staff.[19] NGT generates and prioritises

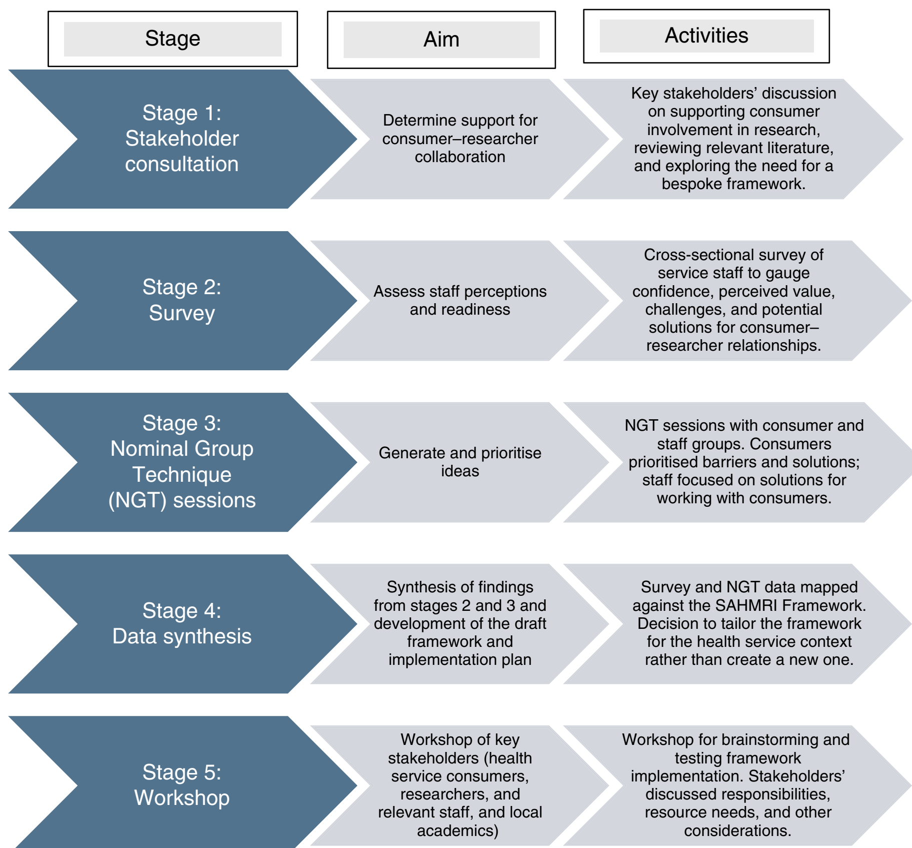

Fig. 1. Stepwise process showing co-design stages. SAHMRI = South Australian Health and Medical Research Institute.

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Table 1. Workshop process.

Introduction	Introduction to framework and workshop.
Break-away	Workshop attendees separated into small groups. Each group had one section of the framework and implementation plan to focus on.
Silent generation of ideas	Small group had 5 min of silently generating ideas using sticky notes on a matrix.
Small group discussion of ideas	Each participant shared a few ideas within their small group.
Reunite	Small groups reconvened with all workshop attendees.
Sharing of ideas	Each small group nominated a 'spokesperson' who presented an overview of their aspect of the framework.
Discussion of ideas (with all the workshop attendees)	Wider group discussion of what has been presented.
Summary and close	Attendees were reminded of the opportunity to review the final document.

ideas from participants while facilitating equal participation and minimising group consensus bias.[20] The consumer NGT session asked participants to prioritise the barriers and solutions to working with researchers at the health service. The two staff NGT sessions asked participants to prioritise solutions for working with consumers at the health service.

Stage 4: data synthesis

Two research team members mapped the survey and NGT data, revealing significant alignment with the SAHMRI Framework.[11] The mapping of solutions across the studies is located in Supplementary Item S1. Given this alignment, the research team and advisory group collectively deemed it appropriate to tailor the existing SAHMRI Framework to suit the specific context of the health service.[11] Adopting a well-established and evidence-based framework rather than creating a new one was considered prudent.

Stage 5: workshop

There were two aims for the workshop: (1) to brainstorm and test ideas for the operationalisation of the framework and draft implementation plan, and (2) to promote engagement in and ownership of the Framework among organisational stakeholders. Key stakeholders were emailed and invited to an in-person workshop. They were provided with a copy of the draft framework and implementation plan beforehand to familiarise themselves with the content.

Workshop attendees were welcomed and directed to four pre-allocated small groups composed of a combination of consumers, academics, and health service personnel. Each small group had a researcher from the research team assigned to support group members (termed 'small group leaders'). Each small group was given a matrix written on butcher paper representing one aspect of the framework (refer to Supplementary Item S2 for an example of the matrix template for the workshop). A member of the research team facilitated the workshop, and another member of the research team scribed during the wider group discussion. The workshop involved a combination of ideas generation and discussion at the individual, small-group and wider-group levels. The questions posed to the group included identifying who should be responsible for a specific strategy previously suggested by consumers or clinicians participating in the NGT or survey, who else should be involved, what resources were available and lacking, and any other considerations. The workshop process is summarised in Table 1.

Ethics

Ethical 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

Stage 1: stakeholder consultation outcomes

A meeting was held in November 2022, where it was decided that research methods had to be utilised to understand the local landscape of consumer involvement in research at the health service and to adopt or develop a framework and plan. During this discussion, the project was conceived, and it was agreed to survey staff and use NGT methodology to explore the prioritised barriers and solutions to involving consumers in research at the health service from the perspective of consumers and staff. All parties who attended this meeting agreed to be involved in the project, and a core research team of three consumers, three clinician–researchers and one academic was formed. The remaining four academics and a clinician–researcher constituted an advisory group. They provided feedback on key points throughout the project.

Stage 2: survey results

A survey was conducted in June 2023 with 83 staff members (including 16 doctors, 23 nurses, 15 allied health professionals, 12 researchers, and 17 staff members from dual, other, or

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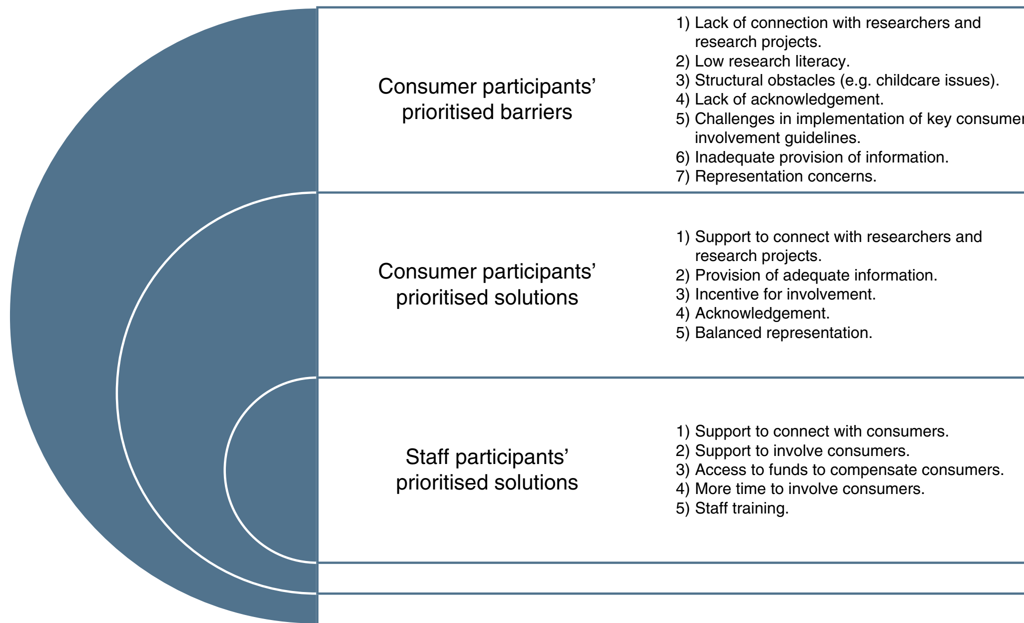

Fig. 2. Findings from Nominal Group Technique sessions. Figure reflects data originally reported in Ryan *et al.* (2024).[19]

undisclosed roles). Approximately half of the respondents reported prior experience with involving consumers in research and self-reported abilities in engaging consumers in research. Respondents valued the involvement of consumers in research, with most agreeing that consumers enhanced the relevance of research to the target population. However, critical barriers to the involvement of consumers in research included lack of funds to remunerate consumers, difficulties connecting with consumers, inadequate skills and knowledge, and insufficient time. Key facilitators to involving consumers in research included the need to be linked with experienced researchers, and access to education and training opportunities. Most respondents agreed that the health service should offer more support to facilitate consumer–researcher relationships in research, with potential solutions suggested across four domains: infrastructure, capacity building, leadership and culture, and governance.[18]

Stage 3: Nominal Group Technique (NGT) findings

NGT sessions were held in August and September 2023. Ten consumers and 14 staff members (including one medical doctor, three nurses, three allied health professionals, three researchers, one clinician-researcher and three from other professions) participated across three sessions, each lasting 1–3 h. Findings from the NGT sessions are reported in Fig. 2.[19]

Stage 4: data synthesis

Data synthesis was conducted in September and October 2023. The health service's framework was developed from the key domains from the SAHMRI Framework (infrastructure, capacity building, leadership and culture, and governance),[11] which were merged with the International Association of Public Participation (IAP2) Spectrum of Involvement[21] (refer to Fig. 3). Including the IAP2 Spectrum reflected a commitment to consistency and alignment with concurrent initiatives across the state. All the recommendations from the SAHMRI Framework were adopted without modification and termed

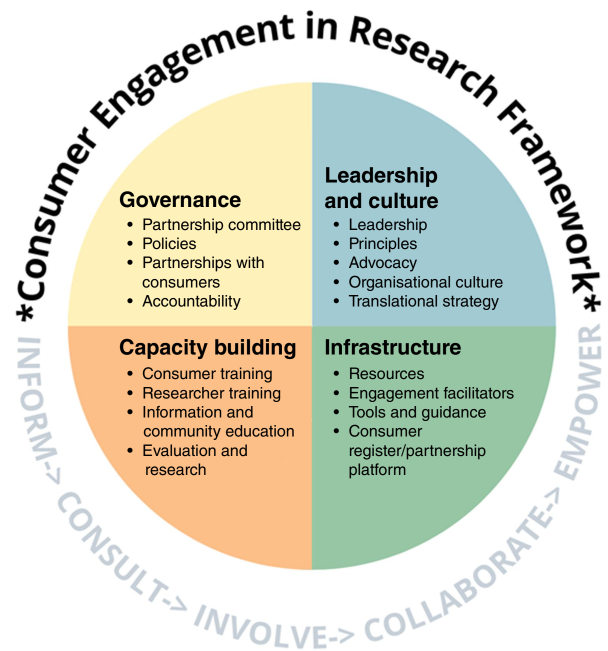

Fig. 3. Consumer Involvement Framework. *Adapted from Miller *et al.* (2017).[11]

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'implementation strategies'. These strategies served as broader approaches to address the relevant domains.

Solutions were subsequently linked to the relevant strategies, delineating the specific actions required to achieve the broader goals. The solutions were either sourced directly from the SAHMRI Framework or tailored to fit the local context on the basis of insights gathered from the survey and NGT data. For example, the SAHMRI Framework's approach to establishing some 'guiding principles' for involving consumers was not a finding from our studies but was viewed by the team and advisory group as an essential component to enhancing the involvement of consumers in research at the health service and was therefore included as an implementation solution.[22] The plan to 'develop a local education program/hub and link researchers to external education about consumer engagement in research' was identified during the NGT sessions and incorporated into the implementation plan. All the research team members, including the consumers and the advisory group, had the opportunity to contribute to the draft implementation plan.

Stage 5: workshop outcomes

A workshop was delivered in November 2023. Fifteen stakeholders attended the workshop, which lasted 90 min and included members of the research and advisory teams and personnel from the health service's communication and engagement department, research office, and governance office. They identified, refined and prioritised implementation ideas across the SAHMRI domains: infrastructure, capacity building, leadership and culture, and governance.[11] Following the workshop, members of the research team carefully reviewed and organised the prioritised ideas, aligning them with the project objectives and ensuring consistency with the adopted framework. All ideas were incorporated into a revised, detailed version of the draft implementation plan. An example of this plan is provided as Supplementary Item S3. The plan was sent to the workshop attendees (and other key stakeholders at the health service) for an opportunity to provide final written feedback before finalisation. A final report – which covered the project, the adopted framework, and the implementation plan – was presented to the Executive at the health service and was endorsed.

Discussion

Our project highlights that data from health service consumers and staff on the barriers to and solutions for research collaborations aligned with a framework developed by a research institution in another Australian jurisdiction.[11] Specifically, it identified the need for four key domains – governance, infrastructure, capacity building, and leadership and culture – to foster consumer involvement in research at the health service level. Given that two different approaches in South Australia and Queensland independently arrived at the same four-factor framework, organisations in other locations could consider bypassing the step of developing their own framework and instead adopt the SAHMRI Framework. This would enable them to focus on tailoring local implementation strategies rather than duplicating efforts. By leveraging an established and validated framework, organisations could accelerate consumer involvement in health research while ensuring a consistent and effective approach.

Although this overarching framework provides a valuable guide, it was crucial to develop local solutions to effectively operationalise these concepts within a specific context.[5] A local and tailored approach is viewed as having greater success in achieving the outcomes associated with involving consumers in research.[5] This paper highlights the integration of broader understandings surrounding the involvement of consumers in research with local solutions to tailor a framework and develop an implementation plan that is practical and aligns with initiatives beyond a specific organisation. Furthermore, this project used a co-design approach, and it is an example of what can be achieved between consumers, researchers, and other key stakeholders when collaborative partnerships are fostered and actively engaged in the research process.

The literature emphasises the importance of frameworks to aid organisations in facilitating and fostering consumer–researcher partnerships. However, there still needs to be more evidence regarding the successful implementation of these frameworks and their effectiveness in achieving their intended goals. Greenhalgh *et al.*'s systematic review highlighted that usability, particularly evidenced by actual usage, was notably lacking across a high proportion of frameworks.[5] Although frameworks are being developed and advocated for in the literature, their implementation is less understood.

The final report of the SAHMRI Framework highlighted some 'early wins', including the initiation of plans to establish a series of research priority-setting partnerships. This suggests that progress has been made in implementing aspects of their framework.[22] However, the authors have not yet reported whether the implementation of the framework has been evaluated and if it has resulted in increased or more meaningful consumer–researcher relationships. As we progress into a more consumer engagement-oriented domain, it becomes increasingly important to evaluate the implementation of such frameworks and assess their outcomes to understand their actual value and inform future practices.

Efforts have been made to find ways to evaluate the success of consumer involvement in research initiatives, such as a Canadian Public and Patient Engagement Evaluation Tool (PPEET).[23] This tool establishes key principles for evaluating quality involvement: integrity of design and process, influence and impact, a participatory culture, and collaboration with a shared purpose.[23] Furthermore, there is a growing understanding of the effectiveness of specific strategies for promoting the

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involvement of consumers.[24,25] For example, a recent scoping review suggests that allocating proper funding and time to projects with consumers leads to greater consumer engagement.[26] Therefore, frameworks could be assessed by evaluating the effectiveness of their specific strategies.

DeBortoli *et al.* propose eight key measurable outcomes that could be considered when evaluating a framework, including:

1. trust
2. empowerment
3. respect
4. confidence in the outcomes of the research
5. transparency of the research process
6. satisfaction with the consumer engagement program
7. knowledge and experiences of consumers
8. degree of consumer engagement[26]

Thus far, we have yet to find evidence that these outcomes have been used to evaluate an organisational framework. It also remains to be seen how this could be implemented in practice. For example, would a framework incorporate these proposed outcomes into its evaluation criteria, and if so, how would it effectively operationalise and measure each of these constructs? Additionally, what methodologies or tools would be used to gather data on these outcomes, and how would the results be analysed and interpreted to provide meaningful insights into the success of these strategies? These critical questions need to be addressed to effectively evaluate the impact and success of any framework aimed at supporting consumer–researcher relationships with an organisation.

The literature lacks transparency on the economic implications of implementing organisational strategic frameworks, especially in the financially constrained Australian public health sector.[12] Consumer involvement frameworks entail costs for staffing, governance, resource development, and establishment of registries. Without clear insights into initial and ongoing costs, implementing these frameworks becomes more challenging.[27] This highlights the need for comprehensive economic assessments to ensure feasibility and sustainability. Although such an assessment has not been conducted for this framework yet, future evaluations are expected to address this gap.

A key strength of this project was the active involvement of consumers throughout its lifecycle. However, a limitation was the lack of consumer diversity in the research team, as the team was recruited from the service's Consumer Advisory Group, potentially excluding individuals with different health experiences and limited research backgrounds. This issue is well documented in the literature, highlighting the challenges consumers from diverse backgrounds may face in engaging with health service research.[28,29] Barriers to involvement can vary significantly and may include language difficulties that limit comprehension and communication, cultural differences that influence trust in research processes, socioeconomic constraints such as financial difficulties or limited access to technology, and additional support needs for individuals with disabilities or health conditions.[28–33]

To address these challenges, the implementation plan for this work includes a commitment to develop strategies to ensure equitable opportunities and the safe participation of marginalised consumer groups in research. Existing literature has outlined various approaches for effectively engaging individuals from diverse backgrounds, including community-based participatory research models, inclusive environments, remuneration, and the involvement of trusted community peers and leaders to facilitate engagement.[29–31,34] Future work must build upon these solutions to ensure that consumer involvement in the health service remains inclusive, equitable, and accessible to all.

Conclusion

The involvement of consumers in health research has emerged as a crucial aspect of maintaining quality research standards. Consequently, Australian hospitals and health services face the imperative to facilitate meaningful relationships between consumers and researchers. This paper offers valuable insights into achieving this goal by tailoring an existing framework and implementation plan. By providing a roadmap for effective collaboration, this research contributes to advancing the quality and relevance of healthcare research practices.

Supplementary material

Supplementary material is available online.

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Author affiliations

[A]Allied Health Research, Gold Coast Hospital and Health Service, Southport, Qld 4215, Australia.

[B]School of Health Sciences & Social Work, Griffith University, Qld 4221, Australia.

[C]Faculty of Health Sciences and Medicine, Bond University, Robina, Qld 4226, Australia.

[D]Consumer Advisory Group, Gold Coast Hospital and Health Service, Southport, Qld 4215, Australia.

[E]Department of Marketing, Griffith Business School, Griffith University, Gold Coast Campus, Qld 4111, Australia.

[F]Melbourne School of Health Sciences, The University of Melbourne, Vic 3010, Australia.

[G]The Royal Children's Hospital Melbourne, Parkville, Vic 3052, Australia.

[H]School of Population Health, The University of New South Wales, Sydney, NSW 2052, Australia.

[I]Institute for Evidence-Based Healthcare, Bond University, Robina, Qld 4226, Australia.

[J]NHMRC CRE in Wiser Wound Care, Griffith University, Qld 4222, Australia.

[K]Nursing and Midwifery Education and Research Unit, Gold Coast Hospital and Health Service, Southport, Qld 4215, Australia.

[L]Faculty of Health, Southern Cross University, Gold Coast, Qld, Australia.

[M]School of Nursing and Midwifery, Griffith University, Qld 4222, Australia.

[N]Emergency Department, Gold Coast University Hospital, Gold Coast Hospital and Health Service, Southport, Qld 4215, Australia.

[O]Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Kings College London, UK.

[P]School of Pharmacy and Medical Sciences, Griffith University, Qld 4222, Australia.

[Q]School of Pharmacy, The University of Queensland, Qld 4102, Australia.

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