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# BMJ Open

## At the Grassroots of Home and Community-based Aged Care: Strategies for Successful Consumer Engagement

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# At the Grassroots of Home and Community-based Aged Care: Strategies for Successful Consumer Engagement

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## ABSTRACT

### Objectives

(i) To describe the processes used to plan and conduct a stakeholder forum in aged care as a means of informing future uptake of consumer participatory research.

(ii) To discuss how capturing and drawing on stakeholders' experiences of aged care can generate new research ideas and inform the delivery of more person-centred aged care services.

### Key principles of consumer engagement

A stakeholder forum was used to evaluate the value and impact of social participation and quality of life tools as part of routine community aged care assessments. The stakeholder forum was developed using five key principles of consumer engagement activities: purposeful, inclusive, timely, transparent and respectful. The forum was co-designed with community aged care clients and care coordinators. Participants included community aged care clients and staff (care coordinators, project officers and executive members), a consumer group representative, researchers, and representatives from the Australian Government Department of Health. The forum fostered an environment of mutual respect and collective inquiry to encourage contributions from all participants.

### Impact of consumer engagement

The stakeholder forum facilitated not only an understanding of consumers' needs and existing gaps in aged care services, but also the circumstances that can enable or hinder the delivery and implementation of these services. This collective information can guide future research and policy at institutional, regional and national committees that relate to aged care.

**Keywords** consumer engagement, aged care, community, social participation

## BACKGROUND

A consumer is defined as a person who uses or is a potential user of community services, including their family and carers.[1] To successfully facilitate implementation of aged care research into practice, researchers must move beyond merely seeking to provide results to consumers throughout the research process.[2] Consumer engagement involves a collaborative and active partnership between multiple stakeholders including consumers, health professionals and/or researchers at various levels of the healthcare system (e.g. direct care, research, governance).[3]

In recent years, there has been a cultural shift in health and aged care toward consumers taking a more active role in their care.[4] Government bodies around the world, such as the Australian Commission on Safety and Quality in Health Care,[5] the United Kingdom (UK) National Health Service,[6] and the United States (US) Department of Health and Human Services,[7] have adopted consumer-centred care models. To date, this culture of consumer-directed care within aged care systems has not been strongly reflected in research. Studies are often viewed as being conducted on, rather than with consumers.[8] However, this is rapidly improving through the requirement of consumer involvement in research grant applications,[9] and organisations such as Consumers Health Forum of Australia (Australia's leading advocate on consumer health care issues),[10] Involve (the UK's leading public participatory in decision-making charity),[11] and the Patient-Centred Outcomes Research Institute (PCORI) in the US.[12]

The collaboration between researchers and consumers can occur at all stages of the research process, from generating new ideas to the application of evidence into the decision-making process.[3] Consumer engagement can take many forms, including stakeholder forums, focus groups, surveys, and advisory panels.[13, 14] Consumer involvement benefits both consumers and healthcare research in multiple ways. For consumers, involvement in the research process increases satisfaction with their care, adherence to treatment plans, and empowerment.[15-17] From the researcher's perspective, advantages include increased participation, assistance with designing protocols, choosing relevant outcomes, and securing funding.[13] Critically, consumer engagement ensures that research is relevant and therefore more likely to be considered useful by the broader community and contribute to policy changes.[3]

Here we report on one of the consumer engagement methods, stakeholder forums, which was used in our research to evaluate the use of social participation and Quality of Life (QoL) tools as part of routine community aged care assessments (Ageing Well project).[18] This co-design approach focused on recognising and understanding the values, beliefs, perceptions and ideas of the different stakeholders involved in aged care.[19] This approach provided the opportunity for real dialogue and interaction between consumers, researchers and other stakeholders about the research project and social participation issues. The stakeholder forum required careful planning and organisation to ensure it addressed the five key principles of consumer engagement activities as outlined by the Australian Government Department of Health: purposeful, inclusive, timely, transparent and respectful.[19]

The aims of this paper were: (i) to describe the processes used to plan and conduct a stakeholder forum in aged care as a means of informing future uptake of consumer participatory research, and (ii) to discuss how capturing and drawing on consumers' experiences of aged care can generate new research ideas and inform the delivery of more person-centred aged care services.

## KEY PRINCIPLES FOR CONSUMER ENGAGEMENT

### Purposeful

Consumer engagement was driven by the strategic priorities of the Ageing Well project: (i) ascertain the levels of social participation and QoL of community aged care clients, (ii) utilise the findings to enhance care planning, (iii) measure associations between community care services, social participation and QoL, and (iv) gain insight into stakeholders' perspectives of social participation and aged care issues.[20] The Ageing Well project's Working Group (research team, and executive members and care coordinators from the aged care provider involved in the project) met regularly to determine the stakeholder forum's aim, content and potential participants, alongside regular discussions about project progress and resolution of any emerging issues. The group agreed that the aim of the forum was to identify and discuss the key issues involved in enabling social participation and QoL in community aged care settings. The aim would be achieved by providing an overview of the Ageing Well project and facilitating discussions about social participation. Table 1 outlines the activities, processes and outcomes of the forum.

Prior to the stakeholder forum, community aged care clients and care coordinators were involved in focus groups as part of the Ageing Well project. Themes generated in these focus groups were used to guide the focus of the forum and ensure it was relevant for stakeholders. Three focus groups were conducted with both community aged care clients (n=21) and care coordinators (n=21) to understand their aged care needs and concerns. Thematic analysis was used to identify and refine the themes for potential discussion topics: access, effectiveness, timeliness and needs.[21] The community aged care clients and care coordinators ranked these potential discussion topics in order of preference. The two highest ranked topics selected by community aged care clients and care coordinators were: (i) access and barriers to community aged care services and social participation activities, and (ii) the needs of community aged care clients to help them maintain social participation in their community. By planning the stakeholder forum with community aged care clients and care coordinators, the research team were able to build connections with stakeholders and develop an understanding about their availability and interest to engage in the forum.[19]

### Inclusive

The Working Group sought to engage a purposive sample of stakeholders and sent invitations to community aged care clients and staff (care coordinators, project officers and executive members), consumer group representatives, researchers, and representatives from the Department of Health. This sample was selected to ensure individuals that had contributed to, influenced, or would be affected by the Ageing Well project were involved.[19] Invitations did not specify stakeholder requirements for attendance as the forum was open to stakeholders regardless of language, culture, age and physical ability, to encourage a wide variety of stakeholders to attend, and gain understanding of the different perspectives on social participation. The venue was selected in consideration of travelling distance and physical accessibility (getting to the venue and once at the venue).

A mixed group of participants attended the forum (n=23) and were able to work collaboratively to identify current aged care issues related to access and needs and generate solutions/preliminary models for future service use and access. To facilitate the discussions, participants were allocated to

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2  
3 smaller groups of five to six people with representatives from each stakeholder perspective (e.g.  
4 clients, staff, consumer representatives). Each group included a member of the research team to  
5 assist the discussions and record the group's ideas onto a shared visual reference. The groups then  
6 reconvened in a plenary session to feedback their ideas to the wider forum which sparked further  
7 discussion among all. Participants also had the opportunity to provide feedback at a video booth  
8 about their experience and additional information about the project if they wished (stakeholder  
9 forum video available from: <https://tinyurl.com/DACSSStakeholder2018>).

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11  
12 An icebreaker activity at the start of the forum, along with shared meal breaks and time to interact  
13 throughout the day provided participants with the opportunity to establish and build relationships  
14 with each other so they felt comfortable to express their opinions and thoughts. Participants from  
15 culturally and linguistically diverse backgrounds were made to feel comfortable through carefully  
16 considered seating with same-language speaking peers, the availability of translation support, and  
17 the use of clear and simple English during the forum.  
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### 20 21 22 **Timely**

23  
24 At the start of the project, the Ageing Well Working Group agreed to conduct two stakeholder  
25 forums (halfway point and end of the project) to report on the progress of the project, and to gain  
26 stakeholder feedback to guide the project and future research activities. The stakeholder forum was  
27 devised at the very beginning of the project which ensured that there was sufficient time to organise  
28 the different aspects of the forum. Invitations to attend the stakeholder forum were sent out three  
29 months prior to the event to allow potential participants enough time to consider if they could  
30 attend. To help the forum run on time, participants were provided with a clear agenda and time  
31 allocations for each activity prior to the forum, and again on the day. By conducting the first forum  
32 half-way through the project participants had the unique opportunity to consider the project  
33 findings as they emerged, and to reflect on how these findings related to their own experiences of  
34 social participation and community aged care services. The research team could then take the key  
35 points from the discussions and use them in a meaningful way to inform the remaining stages of the  
36 Ageing Well project and future aged care research.  
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### 42 43 **Transparent**

44 Clear aims and structure were outlined prior to, and during the stakeholder forum. Once the  
45 discussion topics had been decided by the community aged care clients and care coordinators, they  
46 were sent to all stakeholders. Along with this information, participants were provided with the  
47 agenda for the day, instructions on how to reach the venue, and support to attend (e.g. taxi voucher  
48 or parking permit) if needed. Provision of this information before the stakeholder forum meant  
49 participants would be prepared and able to engage in the forum in a meaningful way.  
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52 At the beginning of the forum, the engagement process was explained, including everyone's roles  
53 and the purpose of the forum. Once introductions and an update on the Ageing Well project was  
54 completed, the focus of the forum shifted to the discussion topics predetermined by the community  
55 aged care clients and care coordinators. Participants were provided sufficient time to generate  
56 meaningful discussions and reflect on their experiences and concerns related to the selected topics,  
57 within the smaller group first and then a larger, overall discussion. This approach fostered an  
58 environment where everyone felt comfortable to share their thoughts and opinions freely. Everyone  
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1  
2  
3 was open to the ideas discussed and contributed their knowledge to the topics. There was freedom  
4 to discuss topics ranging from Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) accessibility  
5 issues, to transport needs of clients. At the conclusion of the stakeholder forum, the research team  
6 summarised the main conclusions of both discussion topics, and informed participants how their  
7 opinions and ideas would be used to guide future research.  
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## 11 **Respectful**

12  
13 Throughout the preparation and progress of the stakeholder forum, the research team encouraged  
14 the inclusion of all perspectives to foster an environment of mutual respect and collective inquiry in  
15 the discussion topics. This was achieved by allowing each participant to have their views heard and  
16 contributions acknowledged, both verbally in discussions, and by transparently recording (written  
17 and audio) the input of participants as valued and important information. To facilitate understanding  
18 and discussions, the research team ensured that the information communicated was presented in  
19 language accessible by all. The expertise and perspectives of the participants was further  
20 acknowledged through their involvement in the writing of this paper.  
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## 26 **IMPACT OF CONSUMER ENGAGEMENT**

27  
28 Participatory research approaches, such as consumer engagement processes, are used in healthcare  
29 to bring together service users, healthcare professionals and other key stakeholders with a vested  
30 interest in a particular issue, to develop, implement and evaluate health services. Our stakeholder  
31 forum successfully brought together multiple stakeholders to work collaboratively to inform the  
32 aged care service planning process and to facilitate quality improvement changes in practice. Unlike  
33 similar processes that only involve consumer representatives, our forum was unique in the inclusion  
34 of community aged care clients during the planning stage and at the forum. Our forum fostered co-  
35 learning, networking, and a positive sense of ownership of aged care services among participants,  
36 and generated innovative ideas from the grassroots of aged care. This was demonstrated through  
37 the positive experiences of the forum that participants shared with each other and the research  
38 team during the discussion topic feedback sessions, shared meal breaks, and at the video booth.  
39 Clients expressed their willingness to be involved in the Ageing Well project, and appreciated the  
40 time taken to consider their perspectives on the type of activities that can support older adults living  
41 in the community. Community aged care clients and care coordinators reflected that the discussion  
42 topics were relevant not only for themselves, but the wider population of older people living the  
43 community.  
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48 At the conclusion of the forum, stakeholders were invited to leave their details so they could be  
49 involved in future healthcare research projects. One indicator of success of this forum was that all  
50 stakeholders expressed interest in continuing their involvement in the Ageing Well project and other  
51 research activities. Four weeks after the forum was completed, all stakeholders were provided with  
52 a newsletter that summarised the aims and outcomes of the forum, along with a certificate of  
53 appreciation and photos from the forum. To further enhance the quality of future forums it would  
54 be beneficial to have stakeholders complete a feedback questionnaire at the end of the forum. This  
55 would further enhance the research team's ability to develop tailored consumer engagement  
56 activities.  
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3 The forum enabled stakeholders (policy makers, clients and care coordinators) who rarely meet in  
4 one place to reflect on their aged care experiences and work together to identify relevant needs and  
5 priorities for improvement of aged care services, and devise strategies to address these needs. This  
6 process facilitated not only an understanding of consumers' needs and existing gaps in aged care  
7 services, but also the circumstances that can impact the delivery and implementation of services.  
8 This type of consumer engagement activity is critical to ensure aged care research is tailored to the  
9 needs of consumers. Doing so supports consumer-centred aged care services that empower  
10 consumers to engage in decision-making about both their own care, and the care needs of the wider  
11 community.  
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## TABLE LEGEND

Table	Caption
1	Outline of the Ageing Well stakeholder forum

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The authors would like to acknowledge all stakeholders that participated and provided valuable contributions to the forum.

## AUTHOR'S CONTRIBUTIONS

All authors made substantial contributions to design of the work, analysis or interpretation of data, drafting and revising the manuscript, and final approval. All authors are in agreement 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.

## COMPETING INTERESTS

The authors declare that they have no competing interests.

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## ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was granted by the Macquarie University Human Research Ethics Committee (reference number: 5201700912). Participants provided written consent for their involvement in the stakeholder forum. They also provided written consent for photos and videos from the forum to be used for promotional and publication purposes.

## Reference List

1. Queensland Health. Queensland Health position statement: Consumers and community participation: To promote community engagement in health. Brisbane: Queensland Health; 2003 January 2003.
2. Krzyzanowska MK, Kaplan R, Sullivan R. How may clinical research improve healthcare outcomes? *Ann Oncol* 2011;22:vii10-vii5.
3. Carman KL, Workman TA. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. *Patient Educ Couns* 2017;100:25-9.
4. Sacristán JA, Aguarón A, Avendaño-Solá C et al. Patient involvement in clinical research: why, when, and how. *Patient Prefer Adherence* 2016;10:631-40.
5. Australian Commission on Safety and Quality on Health Care. Patient centred care: Improving quality and safety through partnership with patients and consumers. Sydney: ACSQHC; 2011.
6. National Health Service. Creating a patient-led NHS: Delivering the NHS improvement plan. London; 2005.
7. US Department of Health and Human Services. Personalized Health Care: Pioneers, Partnerships, Progress. Washington DC; 2008.
8. Thornton S. Beyond rhetoric: we need a strategy for patient involvement in the health service. *BMJ* 2014;348.
9. National Health and Medical Research Council. Statement on consumer and community involvement in health and medical research. Canberra: Consumers Health Forum of Australia; 2016. Contract No.: S01.
10. Consumers Health Forum of Australia. Consumers Health Forum of Australia. 2018 <https://chf.org.au/>; (accessed 04/03/2018).
11. National Institute for Health Research. INVOLVE. 1996 <http://www.invo.org.uk/about-involve/>; (accessed 07/12/2018).
12. Patient-Centered Outcomes Research Institute. Improving outcomes important to patients. 2011 <https://www.pcori.org/>; (accessed 07/12/2018).
13. Domecq JP, Prutsky G, Elraiyah T et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89.
14. Guise J-M, O'Haire C, McPheeters M et al. A practice-based tool for engaging stakeholders in future research: a synthesis of current practices. *J Clin Epidemiol* 2013;66:666-74.
15. Delaney LJ. Patient-centred care as an approach to improving health care in Australia. *Collegian* 2018;25:119-23.
16. Ruco A, Nichol K. Patient Engagement in Research and Innovation: A New Framework. *J Med Imaging Radiat Sci* 2016;47:290-3.
17. Minogue V, Girdlestone J. Building capacity for service user and carer involvement in research: The implications and impact of best research for best health. *Int J Health Care Qual Assur* 2010;23:422-35.
18. Brett L, Georgiou A, Jorgensen M et al. Ageing well: evaluation of social participation and quality of life tools to enhance community aged care (study protocol). *BMC geriatrics* 2019;[in press].
19. Australian Government. Stakeholder Engagement Framework. Report No. AA1000SE. Canberra: Commonwealth of Australia; 2015.
20. Australian Institute of Health Innovation. Ageing well - a social participation and engagement tool. 2017 <https://www.mq.edu.au/research/research-centres-groups-and-facilities/healthy-people/centres/australian-institute-of-health-innovation/news-and-events/news/news/ageing-well-a-social-participation-and-engagement-tool>; (accessed 13/12/2018).
21. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Thousand Oaks, California 2012. Available from: <http://methods.sagepub.com/book/applied-thematic-analysis>.

**Table 1. Outline of the Ageing Well stakeholder forum**

<b>Activity (Time)</b>	<b>Purpose (consumer engagement principle[s] addressed)</b>	<b>Outcome</b>
Morning tea (30min)	Opportunity for participants to meet. ( <i>inclusive</i> )	Provided a supportive environment to get to know each other and facilitate forum discussions.
Welcome to the research institute and overview of the forum agenda (15min)	Welcome participants and provide a clear understanding of how the forum would run. ( <i>purposeful, timely, transparent, respectful</i> )	Participants understood what activities would occur during the forum and how they could actively engage.
Ice-breaker activity (15min)	Participants got to know the other members in their smaller discussion groups, and then feed this information back to all participants. ( <i>inclusive, respectful</i> )	Provided insight into each participant's background, fostering a collaborative and supportive environment for the forum discussions.
Overview of the Ageing Well project (15min)	Inform participants about the purpose of the project, how it was progressing, and give them an opportunity to ask questions. ( <i>purposeful, transparent</i> )	Participants had an understanding of the Ageing Well project and how it related to the forum.
Discussion topic 1: Access and barriers to community aged care services and social participation activities (50min)	Participants discussed this topic, which was ranked as the most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss potential solutions and future directions to improve access. An example was issues related to transport, and current and potential strategies to overcome this barrier.
Lunch (50min)	An opportunity for participants to refuel and prevent mental fatigue. During this time a video booth was set up for participants to provide feedback on the Ageing Well project, the forum, and/or community aged care services. ( <i>inclusive, respectful</i> )	Participants were able to stay actively engaged throughout the forum and had a further opportunity to network with other participants.
Discussion topic 2: Needs of community aged care clients to help them maintain social participation in their community (50min)	Participants discussed this topic, which was ranked as the second most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss the needs and preferences of aged care clients. An example was the provision of a safe environment for lesbian, gay, bisexual, transgender and intersex older adults to participate in social participation activities.
Concluding remarks (15min)	The research team summarised the forum activities and how the discussion topics would guide future research and policies of the involved aged care provider. ( <i>transparent, respectful</i> )	Participants felt empowered and were able to understand how their input would be used to benefit aged care clients and services.

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## ABSTRACT

### Objectives

(i) To describe the processes used to plan and conduct a stakeholder forum in aged care as a means of informing future uptake of consumer participatory research.

(ii) To discuss how capturing and drawing on stakeholders' experiences of aged care can generate new research ideas and inform the delivery of more person-centred aged care services.

### Key principles of consumer engagement

A stakeholder forum was conducted as part of Ageing Well, a two-year project evaluating the value and impact of social participation and quality of life tools as part of routine community aged care assessments at a large Australian provider. The forum was co-designed with community aged care clients and care coordinators and aimed to coproduce implementation strategies with a targeted representation of stakeholders. The stakeholder forum was developed using five key principles of consumer engagement activities: purposeful, inclusive, timely, transparent and respectful. The forum fostered an environment of mutual respect and collective inquiry to encourage contributions from all participants. This article outlines practical guidance on utilising a consumer engagement framework and the lessons learned.

### Discussion

The stakeholder forum facilitated not only an understanding of consumers' needs and existing gaps in aged care services, but also the circumstances that can enable or hinder the delivery and implementation of these services. This collective information can guide future research and policy at institutional, regional and national committees that relate to aged care.

**Keywords** consumer engagement, aged care, community, social participation



## BACKGROUND

### Consumer engagement in research

A consumer is defined as a person who uses or is a potential user of services, including their family and carers.[1] While consumers are increasingly taking a more active role in their own care, this culture has not been strongly reflected in research. Researchers are often viewed as conducting research on, rather than with consumers.[2] However, it is increasingly being recognised that to successfully facilitate implementation of research into practice, researchers must move beyond merely providing results, to actively engaging consumers throughout the research process.[3] Consumer involvement benefits both consumers and healthcare research. For consumers, involvement in the research process increases satisfaction with their care, adherence to treatment plans, and provide empowerment.[4-6] From the researcher's perspective, advantages include increased participation, assistance with designing protocols, choosing relevant outcomes, and securing funding.[7] Critically, consumer engagement ensures that research is relevant and therefore more likely to be considered useful by the broader community and contribute to policy changes.[8]

Consumer engagement requires a collaborative and active partnership between multiple stakeholders including consumers, health professionals and/or researchers at various levels of the healthcare system (e.g. direct care, research, governance).[8] Coproduction of research therefore represents a shift in power from researchers or decision-makers to consumers.[9] The collaboration between researchers and consumers can occur at all stages of the research process, from generating new ideas to the application of evidence into the decision-making process.[8] Consumer engagement can be incorporated into research using varied methods, including stakeholder forums, focus groups, surveys, and advisory panels.[7, 10] Although there are substantial ethical and procedural reasons to support the coproduction of research with consumers, there is currently a lack of practical, evidence-based guidance on how best to do so.[11] A lack of practical guidance may lead to tokenistic consumer involvement, rather than close collaboration with a targeted population.

### The Ageing Well project

Ageing Well is a two-year research project that aims to evaluate the implementation of social participation and Quality of Life (QoL) tools by aged care staff as part of routine community aged care assessments.[12] The specific aims of the Ageing Well project are to: (i) ascertain the levels of social participation and QoL of community aged care clients, (ii) utilise the findings to enhance care planning, (iii) measure associations between community care services, social participation and QoL, and (iv) gain insight into stakeholders' perspectives of social participation and aged care issues.[12, 13] In order to facilitate the implementation and uptake of the tools into the work practice of aged care staff, we sought to coproduce implementation strategies with a targeted representation of stakeholders from two metropolitan and one regional area of New South Wales (NSW), Australia.

This paper reports on one of the consumer engagement methods used in the project, stakeholder forums. The stakeholder forum required careful planning and organisation to ensure it addressed the five key principles of consumer engagement activities as outlined by the Australian Government Department of Health: purposeful, inclusive, timely, transparent and respectful.[14] This framework was originally developed to facilitate better health outcomes and equity through greater consumer engagement.[14] The five key principles are consistent with current consumer engagement standards and practice across public and private healthcare sectors, both in Australia and internationally.[14] The well-established International Association for Public Participation Two's

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3 (IAP2's) Public Participation Spectrum outlines the different levels of participation of the consumers  
4 in engagement activities.[15] The IAP's Public Participation Spectrum demonstrates that as the  
5 consumer's role in engagement activities increases so does the impact they have on related  
6 decisions.[15] The Key Principles of Consumer Engagement framework was selected for the  
7 development of the stakeholder forums to facilitate collaboration with consumers (second highest  
8 level of engagement on the IAP2's Public Participation Spectrum), which meant their involvement  
9 and decisions would have a greater impact on the setup and content of the stakeholder forums. This  
10 framework was deemed fit-for-purpose for our stakeholder forums as it was a simple model that  
11 encouraged active consumer engagement in healthcare research, and allowed us to capture the  
12 diverse opinions of both community aged care clients and staff to help shape policy, planning and  
13 service provision.  
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17 Given the lack of practical evidence in this area, researchers seeking to engage consumers in  
18 research must make judgements based on the individual circumstances of each project.[11]  
19 Therefore this paper offers insights from our experience of a coproduced research project in aged  
20 care. The aims of this paper are: (i) to describe the processes used to plan and conduct a stakeholder  
21 forum in aged care as a means of informing future uptake of consumer participatory research,  
22 including the use of a conceptual framework to guide this process and (ii) to discuss how capturing  
23 and drawing on consumers' experiences of aged care can generate new research ideas and inform  
24 the delivery of more person-centred aged care services.  
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## 29 **KEY PRINCIPLES FOR CONSUMER ENGAGEMENT**

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31 ***Purposeful: Begin every engagement with a clear understanding of what we want to achieve.***[14]  
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33 The framework applied in this study enabled consumer engagement from the outset of the project,  
34 rather than merely as recipients of the research. The Ageing Well project's Working Group (research  
35 team and executive members and care coordinators from the aged care provider involved in the  
36 project) met regularly to determine the stakeholder forum's aim, content and potential participants,  
37 alongside regular discussions about project progress and resolution of any emerging issues. The  
38 group agreed that the aim of the forum was to identify and discuss the key issues involved in  
39 enabling social participation and QoL in community aged care settings. The aim would be achieved  
40 by providing an overview of the Ageing Well project and facilitating discussions about social  
41 participation. Table 1 outlines the activities, processes and outcomes of the forum.  
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45 The first stage of coproduction focussed on identifying aged care consumer priorities. Prior to the  
46 stakeholder forum, focus groups were conducted with both community aged care clients (n=21) and  
47 care coordinators (n=21) to generate themes to guide the focus of the forum. This ensured its  
48 relevance for stakeholders, and a better understanding of their aged care needs and concerns.  
49 Themes relating to aged care staff and clients' aged care experiences were extracted from  
50 transcriptions of audio-recorded focus groups.[16] Researchers met periodically throughout data  
51 collection to reach consensus on themes. The themes were then categorised into potential  
52 discussion topics for the stakeholder forum: access, effectiveness, timeliness and needs.[16]  
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55 As another stage of consumer engagement of the research, the identified themes were presented to  
56 the community aged care clients and care coordinators prior to the stakeholder forum. They were  
57 then asked to rank these potential discussion topics in order of preference. The two highest ranked  
58 topics that were selected by community aged care clients and care coordinators were: (i) access and  
59 barriers to community aged care services and social participation activities, and (ii) the needs of  
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3 community aged care clients to help them maintain social participation in their community, and  
4 became the topics of discussion of the stakeholder forum. By planning the stakeholder forum with  
5 community aged care clients and care coordinators, the research team built connections with  
6 stakeholders and were able to set the priorities for the research together.[14] By meeting  
7 stakeholders during Working Group meetings and focus groups, the research team were able to  
8 discuss the aims of the stakeholder forum with potential participants and gauge levels of availability  
9 and interest to engage in the forum. However, doing so required investment of time and planning to  
10 include aged care consumers in this way.[11] The resourcing requirements of consumer engagement  
11 must therefore be considered in their own right.[11]  
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17 **Inclusive: *Identify relevant stakeholders and make it easy for them to engage.*[14]**

18 One of the challenges of coproduction of research is that engagement of stakeholders requires  
19 additional work and time to recruit willing and relevant participants, in addition to recruitment for  
20 the intervention study itself.[11] The Ageing Well Working Group sought to engage a purposive  
21 sample of stakeholders and sent invitations to community aged care clients and staff (care  
22 coordinators, project officers and executive members), consumer group representatives,  
23 researchers, and representatives from the Department of Health. This sample was selected to  
24 ensure the involvement of individuals that had contributed to, influenced, or would be affected by  
25 the Ageing Well project.[14] With the assistance of the aged care provider's care coordinators and  
26 executive members, we actively identified and targeted minority and diverse groups such as  
27 stakeholders from Culturally and Linguistically Diverse (CALD) backgrounds, with varying levels of  
28 education, oldest-old (80 years and older), the Lesbian, Gay, Bisexual, Transgender and Intersex  
29 (LGBTI) community, and regional areas. This targeted approach enabled a mixed group of  
30 participants to attend the forum (n=23). This included clients and staff from multiple CALD  
31 backgrounds (four Turkish, one Jewish and one Italian), six clients who did not have an education  
32 level above high school, one oldest-old client, one project officer who represented the LGBTI  
33 community, and two male stakeholders.  
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39 Thoughtful seating arrangements and interpersonal skills are required to carefully manage group  
40 dynamics to enable inclusion in a mixed group.[11] Stakeholder forum participants were required to  
41 work collaboratively to identify current aged care issues related to access and needs and generate  
42 solutions/preliminary models for future service use and access. To facilitate the discussions,  
43 participants were allocated to smaller groups of five to six people with representatives from each  
44 stakeholder perspective (e.g. clients, staff, consumer representatives). To support the participation  
45 of the CALD community, we positioned clients who did not speak English as their main language with  
46 a staff member who spoke their predominant language to allow for maximum participation. Each  
47 group included a member of the research team to facilitate the discussions and record the group's  
48 ideas onto a shared visual reference. The groups then reconvened in a plenary session to feedback  
49 their ideas to the wider forum which sparked further discussion among all. Participants also had the  
50 opportunity to provide feedback at a video booth about their experience and additional information  
51 about the project if they wished (stakeholder forum video available from:  
52 <https://tinyurl.com/DACStakeholder2018>).  
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56 To help facilitate an inclusive environment during the stakeholder forum a number of social activities  
57 were incorporated throughout the day, such as an icebreaker activity at the start of the forum,  
58 shared meal breaks and time to interact. These activities provided participants with the opportunity  
59 to establish and build relationships with each other so they felt comfortable to express their  
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3 opinions and thoughts. The researchers also ensured they used clear and simple English throughout  
4 the forum to help participants, in particular those from CALD backgrounds and with lower  
5 educational levels, understand the discussion topics and feel comfortable to express their opinions.  
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7  
8 Consumer engagement in these activities also requires travel and administrative support .[11] The  
9 venue for the stakeholder forum was selected in consideration of travel distance and physical  
10 accessibility to and once at the venue. This included providing parking for a bus for those requiring  
11 physical assistance to attend. Video conferencing capabilities were also setup at the venue as an  
12 option for those in regional areas to participate. However, this was not taken up due to  
13 technological barriers identified by regional staff who reported their information technology system  
14 would not support video conferencing. This issue highlights the need for earlier and greater  
15 consideration of technological requirements in regional areas to help avoid such issues and allow for  
16 inclusion of participants regardless of location.  
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21 **Timely: *Involve stakeholders from the start and agree on when and how to engage.*[14]**  
22

23 Consumer engagement can be challenging for researchers as it requires the establishment and  
24 maintenance of relationships over time, and sometimes multiple collaborations with the same  
25 organisation. The Ageing Well project arose from a previous program of research with the same  
26 aged care provider in which staff worked together with researchers to choose the social  
27 participation and QoL tools they thought would best suit their clients. Our collaboration, built on  
28 invested time and effort, resulted in a working and harmonious relationship between researchers,  
29 the aged care provider and its clients to coproduce research. Current research supports that  
30 undergoing this process builds trust.[17] Our process of engaging with the aged care provider also  
31 ensured research goals aligned with operational goals and client needs. This engagement was a key  
32 element that should be used in future consumer engagement activities as it contributed to the  
33 success of the stakeholder forum and was highly relevant to all participants. The forum was  
34 particularly timely for the provider as it offered the opportunity for executive staff to hear feedback  
35 from clients and staff that was important and relevant in the current context of the Australian aged  
36 care sector, which is undergoing major reforms to ensure it meets current and future needs of the  
37 ageing population.[18]  
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40  
41 At the start of the Ageing Well project, the Working Group proposed that we would conduct two  
42 stakeholder forums (halfway point and end of the project) to report on the progress of the project,  
43 and to gain stakeholder feedback to guide the project and future research activities. As the focus of  
44 the stakeholder forums were on reporting the project's progress and how this would influence the  
45 project going forward, it was not relevant for a forum to be held at the start of the Ageing Well  
46 project. Planning for the stakeholder forum was commenced at the very beginning of the project to  
47 ensure that there was sufficient time to organise the different aspects of the forum. Invitations to  
48 attend the stakeholder forum were sent out three months prior to the event to allow potential  
49 participants enough time to consider if they could attend. To help the forum run on time,  
50 participants were provided with a clear agenda and time allocations for each activity prior to the  
51 forum, and again on the day. By conducting the first forum half-way through the project participants  
52 had the unique opportunity to consider the project findings as they emerged, and to reflect on how  
53 these findings related to their own experiences of social participation and community aged care  
54 services. The research team could then take the key points from the discussions and use them in a  
55 meaningful way to inform the remaining stages of the Ageing Well project and future aged care  
56 research.  
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5 **Transparent: *All stakeholders are open and honest in their engagement and set clear***  
6 ***expectations.[14]***  
7

8 The conceptual framework used for the stakeholder forum highlights that coproduced research is as  
9 much accountable to consumers as it is to researchers. This requires conscious planning and effort  
10 on the part of researchers to promote transparency and accountability.[11] Clear aims and structure  
11 were outlined prior to, and during the stakeholder forum. Once the discussion topics had been  
12 decided by the community aged care clients and care coordinators, they were sent to all  
13 stakeholders. Along with this information, participants were provided with the agenda for the day,  
14 instructions on how to reach the venue, and support to attend (e.g. taxi voucher or parking permit) if  
15 needed. Provision of this information before the stakeholder forum meant participants would be  
16 prepared and able to engage in the forum in a meaningful way.  
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18  
19 At the beginning of the forum, the engagement process was explained, including everyone's roles  
20 and the purpose of the forum. Once introductions and an update on the Ageing Well project was  
21 completed, the focus of the forum shifted to the discussion topics predetermined by the community  
22 aged care clients and care coordinators. Participants were provided sufficient time to generate  
23 meaningful discussions and reflect on their experiences and concerns related to the selected topics,  
24 within the smaller group first and then a larger, overall discussion. This approach was used to ensure  
25 participants felt comfortable to share their thoughts and opinions freely, and to be open to the ideas  
26 discussed and contribute their knowledge to the topics. Topics ranged from LGBTI accessibility  
27 issues, to transport needs of clients. At the conclusion of the stakeholder forum, the research team  
28 summarised the main conclusions of both discussion topics, and informed participants how their  
29 opinions and ideas would be used to guide future research to promote social participation of older  
30 adults in the community.  
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33 We were provided with anecdotal positive feedback from attendees on the stakeholder forum, even  
34 when discussing barriers to social participation and service provisions. Stakeholders appeared to  
35 take this opportunity to express their opinions on the topics as well as strategies to overcome  
36 identified barriers. However, in future workshops we would conduct a satisfaction survey at the end  
37 of the session for participants to record their feedback, and provide any potential areas of  
38 improvement in a more rigorous manner. This process will be incorporated into the second  
39 stakeholder forum at the end of the Ageing Well project to help guide future research and ensure it  
40 is relevant to all stakeholders.  
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47 **Respectful: *Acknowledge and respect the expertise, perspective, and needs of stakeholders.[14]***  
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49 Engaging consumers in the coproduction of research requires professional etiquette and courtesy to  
50 ensure a positive experience of participating in research.[11] Throughout the preparation and  
51 progress of the stakeholder forum, the research team encouraged the inclusion of all perspectives to  
52 foster an environment of mutual respect and collective inquiry in the discussion topics. This was  
53 achieved by allowing each participant to have their views heard and contributions acknowledged,  
54 both verbally in discussions, and by transparently recording (written and audio) the input of  
55 participants as valued and important information. To facilitate understanding and discussions, the  
56 research team ensured that the information communicated was presented in language accessible by  
57 all. The expertise and perspectives of the participants was further acknowledged through their  
58 involvement in the writing of this paper. When conducting consumer engagement activities with a  
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3 mixed group of stakeholders there is always the potential challenge of managing different views and  
4 opinions that can occur between stakeholder groups. However, this was not an issue in the  
5 stakeholder forum as all participants openly discussed their views and listened to each other without  
6 any negative or disrespectful comments.  
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## 10 **DISCUSSION**

11  
12 Consumer engagement in research brings together service users, healthcare professionals and other  
13 key stakeholders with a vested interest in a particular issue, to develop, implement and evaluate  
14 health services. Our stakeholder forum successfully brought together multiple stakeholders to work  
15 collaboratively to inform the aged care service planning process and to facilitate quality  
16 improvement changes in practice. For the Ageing Well project, close involvement of aged care staff  
17 and clients allowed for evaluation of an iteratively coproduced model, and feedback received at the  
18 initial stakeholder forum will be used to guide the final forum. We as the researchers were able to  
19 further develop our relationship with the aged care provider and their clients facilitating buy in to  
20 the next phase of the research, as well as test some of our ideas for future grants. Clients and aged  
21 care provider staff involved in the stakeholder forum were able to share their experiences with  
22 people they would not normally have the opportunity to do so with (e.g. Department of Health  
23 representatives, the aged care provider's executive members and clients that lived in different  
24 areas), and also gained a better understanding of the research and how their contributions had  
25 influenced the Ageing Well project. The Department of Health representatives reporting gaining a  
26 greater understanding of the Ageing Well project than what was possible from review of the grant  
27 application alone and attendance of the stakeholder forum influenced them to consider how they  
28 could change the grant application form to gain a better insight into future projects.  
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33 Unlike similar processes that only involve consumer representatives, we targeted involvement of  
34 community aged care clients, including minority and diverse groups during the planning stage and at  
35 the forum. This required thoughtful planning and preparation in line with the consumer engagement  
36 framework adopted for the stakeholder forum to foster co-learning, networking, and a positive  
37 sense of ownership of aged care services among stakeholders, and generate innovative ideas from  
38 the grassroots of aged care. This was demonstrated through the positive experiences of the forum  
39 that participants shared with each other and the research team during the discussion topic feedback  
40 sessions, shared meal breaks, and at the video booth. Clients expressed their willingness to be  
41 involved in the Ageing Well project, and appreciated the time taken to consider their perspectives  
42 on the type of activities that can support older adults living in the community. Community aged care  
43 clients and care coordinators reflected that the discussion topics were relevant not only for  
44 themselves, but the wider population of older people living the community.  
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49 At the conclusion of the forum, stakeholders were invited to leave their details so they could be  
50 involved in future healthcare research projects. One indicator of success of this forum was that all  
51 stakeholders expressed interest in continuing their involvement in the Ageing Well project and other  
52 research activities. Four weeks after the forum was completed, all stakeholders were provided with  
53 a newsletter that summarised the aims and outcomes of the forum, along with a certificate of  
54 appreciation and photos from the forum. To further enhance the quality of future forums it would  
55 be beneficial to have stakeholders complete a feedback questionnaire at the end of the forum. This  
56 would further enhance the research team's ability to develop tailored consumer engagement  
57 activities.  
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3 Ultimately, this forum enabled stakeholders (policy makers, clients and care coordinators) who  
4 rarely meet in one place to reflect on their aged care experiences and work together to identify  
5 relevant needs and priorities for improvement of aged care services, and devise strategies to address  
6 these needs. This process facilitated not only an understanding of consumers' needs and existing  
7 gaps in aged care services, but also the circumstances that can impact the delivery and  
8 implementation of services. This type of consumer engagement activity is critical to ensure aged  
9 care research is tailored to the needs of consumers. Doing so supports consumer-centred aged care  
10 services that empower consumers to engage in decision-making about both their own care, and the  
11 care needs of the wider community.  
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14  
15 Future research should involve utilising the topics, stories and feedback obtained from stakeholders  
16 during forums to inform and reflect on how consumer engagement can improve research outcomes.  
17 The primary facilitator of consumer engagement in our research lay in our investment in a strong  
18 foundation of trust with the aged care provider. This included multiple working group meetings,  
19 examining opportunities and aligning with the provider's aims. Ultimately, by working collaboratively  
20 over a long period of time, encompassing multiple research opportunities (psychosocial tool  
21 selection, software implementation),[19, 20] a successful forum was made possible.  
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24 The direct benefit of consumer engagement to research is not always able to be quantified.[11]  
25 Coproduction of this research with aged care consumers required significant investment of time and  
26 resources, and required skill, respect and courtesy to build trust and engagement with stakeholders.  
27 The benefits of this process are demonstrated through the establishment and reinforcement of  
28 relationships between the different stakeholders, the codevelopment of new research ideas through  
29 the stakeholder discussions, and the ongoing interest and involvement of the different stakeholders  
30 in the Ageing Well project.  
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**TABLE LEGEND**

Table	Caption
1	Outline of the Ageing Well stakeholder forum

For peer review only



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The authors would like to acknowledge all stakeholders that participated and provided valuable contributions to the forum.

## AUTHOR'S CONTRIBUTIONS

LB was the major contributor to the conception, drafting and revision of the manuscript. AG, MJ, JS and JW received funding for the Ageing Well project. JS, AN, MJ and MM, made substantial contributions to the conception, drafting and revision of the manuscript. JW and AG made substantial contributions to the drafting and revision of the manuscript. WL, EG and FH made substantial contributions to the review and revisions of the manuscript. All authors read and approved the final manuscript, and are in agreement 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.

## COMPETING INTERESTS

The authors declare that they have no competing interests.

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## ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was granted by the Macquarie University Human Research Ethics Committee (reference number: 5201700912). Participants provided written consent for their involvement in the stakeholder forum. They also provided written consent for photos and videos from the forum to be used for promotional and publication purposes.

## Reference List

1. Queensland Health. Queensland Health position statement: Consumers and community participation: To promote community engagement in health. Brisbane: Queensland Health; 2003 January 2003.
2. Thornton S. Beyond rhetoric: we need a strategy for patient involvement in the health service. *BMJ* 2014;348.
3. Krzyzanowska MK, Kaplan R, Sullivan R. How may clinical research improve healthcare outcomes? *Ann Oncol* 2011;22:vii10-vii5.
4. Delaney LJ. Patient-centred care as an approach to improving health care in Australia. *Collegian* 2018;25:119-23.
5. Ruco A, Nichol K. Patient Engagement in Research and Innovation: A New Framework. *J Med Imaging Radiat Sci* 2016;47:290-3.
6. Minogue V, Girdlestone J. Building capacity for service user and carer involvement in research: The implications and impact of best research for best health. *Int J Health Care Qual Assur* 2010;23:422-35.
7. Domecq JP, Prutsky G, Elraiyah T et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89-.
8. Carman KL, Workman TA. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. *Patient Educ Couns* 2017;100:25-9.
9. Flinders M, Wood M, Cunningham M. The Politics of Co-Production: Risks, Limits and Pollution. 2016;12:261.
10. Guise J-M, O'Haire C, McPheeters M et al. A practice-based tool for engaging stakeholders in future research: a synthesis of current practices. *J Clin Epidemiol* 2013;66:666-74.
11. Oliver K, Kothari A, Mays N. The dark side of coproduction: do the costs outweigh the benefits for health research? 2019;17:33.
12. Brett L, Georgiou A, Jorgensen M et al. Ageing well: evaluation of social participation and quality of life tools to enhance community aged care (study protocol). 2019;19:78.
13. Australian Institute of Health Innovation. Ageing well - a social participation and engagement tool. 2017 <https://www.mq.edu.au/research/research-centres-groups-and-facilities/healthy-people/centres/australian-institute-of-health-innovation/news-and-events/news/news/ageing-well-a-social-participation-and-engagement-tool>; (accessed 13/12/2018)].
14. Australian Government Department of Health. Health Stakeholder Engagement Framework. In: Health Do, editor. Updated: 20 November 2018 ed. Canberra: Commonwealth of Australia; 2017.
15. International Association for Public Participation. IAP2's public participation Spectrum. 2014 [https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2\\_Public\\_Participation\\_Spectrum.pdf](https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spectrum.pdf); (accessed 06/12/2018)].
16. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Thousand Oaks, California 2012. Available from: <http://methods.sagepub.com/book/applied-thematic-analysis>.
17. Boaz A, Hanney S, Borst R et al. How to engage stakeholders in research: design principles to support improvement.(Report). 2018;16.
18. Australian Government Department of Health. Aged care reform. 2019 <https://agedcare.health.gov.au/aged-care-reform>; (accessed 28/07/2019)].
19. Siette J, Georgiou A, Jorgensen M et al. Integrating social engagement instruments into Australian community aged care assessments to enhance service provision. 2018;26:810-8.
20. Douglas HE, Georgiou A, Tariq A et al. Implementing Information and Communication Technology to Support Community Aged Care Service Integration: Lessons from an Australian Aged Care Provider. 2017;17.

**Table 1. Outline of the Ageing Well stakeholder forum**

<b>Activity (Time)</b>	<b>Purpose (consumer engagement principle[s] addressed)</b>	<b>Outcome</b>
Morning tea (30min)	Opportunity for participants to meet. ( <i>inclusive</i> )	Provided a supportive environment to get to know each other and facilitate forum discussions.
Welcome to the research institute and overview of the forum agenda (15min)	Welcome participants and provide a clear understanding of how the forum would run. ( <i>purposeful, timely, transparent, respectful</i> )	Participants understood what activities would occur during the forum and how they could actively engage.
Ice-breaker activity (15min)	Participants got to know the other members in their smaller discussion groups, and then feed this information back to all participants. ( <i>inclusive, respectful</i> )	Provided insight into each participant's background, fostering a collaborative and supportive environment for the forum discussions.
Overview of the Ageing Well project (15min)	Inform participants about the purpose of the project, how it was progressing, and give them an opportunity to ask questions. ( <i>purposeful, transparent</i> )	Participants had an understanding of the Ageing Well project and how it related to the forum.
Discussion topic 1: Access and barriers to community aged care services and social participation activities (50min)	Participants discussed this topic, which was ranked as the most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss potential solutions and future directions to improve access. An example was issues related to transport, and current and potential strategies to overcome this barrier.
Lunch (50min)	An opportunity for participants to refuel and prevent mental fatigue. During this time a video booth was set up for participants to provide feedback on the Ageing Well project, the forum, and/or community aged care services. ( <i>inclusive, respectful</i> )	Participants were able to stay actively engaged throughout the forum and had a further opportunity to network with other participants.
Discussion topic 2: Needs of community aged care clients to help them maintain social participation in their community (50min)	Participants discussed this topic, which was ranked as the second most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss the needs and preferences of aged care clients. An example was the provision of a safe environment for lesbian, gay, bisexual, transgender and intersex older adults to participate in social participation activities.
Concluding remarks (15min)	The research team summarised the forum activities and how the discussion topics would guide future research and policies of the involved aged care provider. ( <i>transparent, respectful</i> )	Participants felt empowered and were able to understand how their input would be used to benefit aged care clients and services.

# BMJ Open

## At the Grassroots of Home and Community-based Aged Care: Strategies for Successful Consumer Engagement

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# At the Grassroots of Home and Community-based Aged Care: Strategies for Successful Consumer Engagement

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## ABSTRACT

### Objectives

(i) To describe the processes used to plan and conduct a stakeholder forum in aged care as a means of informing future uptake of consumer participatory research.

(ii) To discuss how capturing and drawing on stakeholders' experiences of aged care can generate new research ideas and inform the delivery of more person-centred aged care services.

### Key principles of consumer engagement

A stakeholder forum was conducted as part of Ageing Well, a two-year project evaluating the value and impact of social participation and quality of life tools as part of routine community aged care assessments at a large Australian provider. The forum was co-designed with community aged care clients and care coordinators and aimed to coproduce implementation strategies with a targeted representation of stakeholders. The stakeholder forum was developed using five key principles of consumer engagement activities: purposeful, inclusive, timely, transparent and respectful. The forum fostered an environment of mutual respect and collective inquiry to encourage contributions from all participants. This article outlines practical guidance on utilising a consumer engagement framework and the lessons learned.

### Discussion

The stakeholder forum facilitated not only an understanding of consumers' needs and existing gaps in aged care services, but also the circumstances that can enable or hinder the delivery and implementation of these services. This collective information can guide future research and policy at institutional, regional and national committees that relate to aged care.

**Keywords** consumer engagement, aged care, community, social participation

## BACKGROUND

### Consumer engagement in healthcare research

A healthcare consumer is defined as a person who uses or is a potential user of healthcare services, including their family and carers.[1] While consumers are increasingly taking a more active role in their own care, this culture has not been strongly reflected in research. Researchers are often viewed as conducting research on, rather than with, consumers.[2] However, it is increasingly being recognised that to successfully facilitate implementation of research into practice, researchers must move beyond merely providing results, to actively engaging consumers throughout the research process.[3] Consumer involvement benefits both consumers and healthcare researchers. For consumers, involvement in the research process increases satisfaction with their care, adherence to treatment plans, and provides empowerment.[4-6] From the researcher's perspective, advantages include increased participation, assistance with designing protocol and choosing relevant outcomes, and securing funding.[7] Critically, consumer engagement ensures that research is relevant and therefore more likely to be considered useful by the broader community and contribute to policy changes.[8]

Consumer engagement requires a collaborative and active partnership between multiple stakeholders including consumers, health professionals and/or researchers at various levels of the healthcare system (e.g. direct care, research, governance).[8] Coproduction of research therefore represents a shift in power from researchers or decision-makers to consumers.[9] The collaboration between researchers and consumers can occur at all stages of the research process, from generating new ideas to the application of evidence into the decision-making process.[8] Consumer engagement can be incorporated into research using varied methods, including stakeholder forums, focus groups, surveys, and advisory panels.[7, 10] Although there are substantial ethical, practical and procedural reasons to support the coproduction of research with consumers, there is currently a lack of practical, evidence-based guidance on how best to do so.[11] A lack of practical guidance may lead to tokenistic consumer involvement, rather than close collaboration with a targeted population.

### The Ageing Well project

Ageing Well is a two-year research project that aims to evaluate the implementation of social participation and Quality of Life (QoL) tools by aged care staff as part of routine community aged care assessments.[12] The specific aims of the Ageing Well project are to: (i) ascertain the levels of social participation and QoL of community aged care clients, (ii) utilise the findings to enhance care planning, (iii) measure associations between community care services, social participation and QoL, and (iv) gain insight into stakeholders' perspectives of social participation and aged care issues.[12, 13] In order to facilitate the implementation and uptake of the tools into the work practice of aged care staff, we sought to coproduce implementation strategies with a targeted representation of stakeholders from two metropolitan and one regional area of New South Wales (NSW), Australia.

This paper reports on one of the consumer engagement methods used in the project, stakeholder forums. The stakeholder forum required careful planning and organisation to ensure it addressed the five key principles of consumer engagement activities as outlined by the Australian Government Department of Health: purposeful, inclusive, timely, transparent and respectful.[14] This framework was originally developed to facilitate better health outcomes and equity through greater consumer engagement.[14] The five key principles are consistent with current consumer engagement standards and practice across public and private healthcare sectors, both in Australia and

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3 internationally.[14] The well-established International Association for Public Participation Two's  
4 (IAP2's) Public Participation Spectrum outlines the different levels of participation of the consumers  
5 in engagement activities.[15] The IAP2's Public Participation Spectrum demonstrates that as the  
6 consumer's role in engagement activities increases, so does the impact they have on related  
7 decisions.[15] The Key Principles of Consumer Engagement framework was selected for the  
8 development of the stakeholder forums to facilitate collaboration with consumers (second highest  
9 level of engagement on the IAP2's Public Participation Spectrum), which meant their involvement  
10 and decisions would have a greater impact on the setup and content of the stakeholder forums. This  
11 framework was deemed fit-for-purpose for our stakeholder forums as it was a simple model that  
12 encouraged active consumer engagement in healthcare research, and allowed us to capture the  
13 diverse opinions of both community aged care clients and staff to help shape policy, planning and  
14 service provision.

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18 Given the lack of practical evidence in this area, researchers seeking to engage consumers in  
19 research must make judgements based on the individual circumstances of each project.[11]  
20 Therefore this paper offers insights from our experience of a coproduced research project in aged  
21 care. The aims of this paper are: (i) to describe the processes used to plan and conduct a stakeholder  
22 forum in aged care as a means of informing future uptake of consumer participatory research,  
23 including the use of a conceptual framework to guide this process and (ii) to discuss how capturing  
24 and drawing on consumers' experiences of aged care can generate new research ideas and inform  
25 the delivery of more person-centred aged care services.

## 30 KEY PRINCIPLES FOR CONSUMER ENGAGEMENT

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32 **Purposeful: *Begin every engagement with a clear understanding of what we want to achieve.***[14]

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34 The framework applied in this study enabled consumer engagement from the outset of the project,  
35 rather than merely as recipients of the research. The Ageing Well project's Working Group (research  
36 team and executive members and care coordinators from the aged care provider involved in the  
37 project) met regularly to determine the stakeholder forum's aim, content and potential participants,  
38 alongside regular discussions about project progress and resolution of any emerging issues. The  
39 group agreed that the aim of the forum was to identify and discuss the key issues involved in  
40 enabling social participation and QoL in community aged care settings. The aim would be achieved  
41 by providing an overview of the Ageing Well project and facilitating discussions about social  
42 participation. Table 1 outlines the activities, processes and outcomes of the forum.

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45 The first stage of coproduction focussed on identifying aged care consumer priorities. In order to  
46 ensure that the aims of the stakeholder forum of both researchers and consumers were aligned,  
47 focus groups with both community aged care clients (n=21) and care coordinators (n=21) were  
48 conducted prior to the stakeholder forum. This ensured the generation of aims that were reflective  
49 of participants' needs and concerns in aged care and further establishing the core stakeholder forum  
50 themes. This initial coproduction confirmed their relevance for all stakeholders including  
51 researchers. Themes relating to aged care staff and clients' aged care experiences were extracted  
52 from transcriptions of audio-recorded focus groups.[16] Researchers met periodically throughout  
53 data collection to reach consensus on themes. The themes were then categorised into potential  
54 discussion topics for the stakeholder forum: access, effectiveness, timeliness and needs.[16]

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58 As another stage of consumer engagement of the research and to further ensure alignment of  
59 researcher and stakeholder aims for the stakeholder forum, the themes identified in the focus  
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3 groups were presented to the community aged care clients and care coordinators prior to the  
4 stakeholder forum. They were then asked to rank these potential discussion topics in order of  
5 preference. The two highest ranked topics that were selected by community aged care clients and  
6 care coordinators were: (i) access and barriers to community aged care services and social  
7 participation activities, and (ii) the needs of community aged care clients to help them maintain  
8 social participation in their community. These became the topics of discussion of the stakeholder  
9 forum. By planning the stakeholder forum with community aged care clients and care coordinators,  
10 the research team built rapport with stakeholders and in the process were able to set the priorities  
11 for the research together.[14] By meeting stakeholders during Working Group meetings and focus  
12 groups, the research team were able to discuss the aims of the stakeholder forum with potential  
13 participants and gauge levels of availability and interest to engage in the forum. However, doing so  
14 required investment of time and planning to include aged care consumers in this way.[11] The  
15 resourcing requirements of consumer engagement must therefore be considered in their own  
16 right.[11]  
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23 ***Inclusive: Identify relevant stakeholders and make it easy for them to engage.[14]***

24 One of the challenges of coproduction of research is that engagement of stakeholders requires  
25 additional work and time to recruit willing and relevant participants, in addition to recruitment for  
26 the intervention study itself.[11] The Ageing Well Working Group sought to engage a purposive  
27 sample of stakeholders and sent invitations to community aged care clients and staff (care  
28 coordinators, project officers and executive members), consumer group representatives,  
29 researchers, and representatives from the Department of Health. This sample was selected to  
30 ensure the involvement of individuals that had contributed to, influenced, or would be affected by  
31 the Ageing Well project.[14] With the assistance of the aged care provider's care coordinators and  
32 executive members, we actively identified and targeted minority and diverse groups such as  
33 stakeholders from Culturally and Linguistically Diverse (CALD) backgrounds, with varying levels of  
34 education, oldest-old (80 years and older), the Lesbian, Gay, Bisexual, Transgender and Intersex  
35 (LGBTI) community, and regional areas. This targeted approach enabled a mixed group of  
36 participants to attend the forum (n=23). This included clients and staff from multiple CALD  
37 backgrounds (four Turkish, one Jewish and one Italian), six clients who did not have an education  
38 level above high school, one oldest-old client, one project officer who represented the LGBTI  
39 community, and two male stakeholders.  
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44 Thoughtful seating arrangements and interpersonal skills are required to carefully manage group  
45 dynamics to enable inclusion in a mixed group.[11] Stakeholder forum participants were required to  
46 work collaboratively to identify current aged care issues related to access and needs and generate  
47 solutions/preliminary models for future service use and access. To facilitate the discussions,  
48 participants were allocated to smaller groups of five to six people with representatives from each  
49 stakeholder perspective (e.g. clients, staff, consumer representatives). To support the participation  
50 of the CALD community, we positioned clients who did not speak English as their main language with  
51 a staff member who spoke their predominant language to allow for maximum participation. Each  
52 group included a member of the research team to facilitate the discussions and record the group's  
53 ideas onto a shared visual reference. The groups then reconvened in a plenary session to feedback  
54 their ideas to the wider forum, which sparked further discussion among all. Participants also had the  
55 opportunity to provide feedback at a video booth about their experience and additional information  
56 about the project if they wished (stakeholder forum video available from:  
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60 <https://tinyurl.com/DACStakeholder2018>).

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3 To help facilitate an inclusive environment during the stakeholder forum, a number of social  
4 activities were incorporated throughout the day, such as an icebreaker activity at the start of the  
5 forum, shared meal breaks and time to interact. These activities provided participants with the  
6 opportunity to establish and build relationships with each other so that they felt comfortable to  
7 express their opinions and thoughts. The researchers also ensured they used clear and simple  
8 English throughout the forum to help participants, in particular those from CALD backgrounds and  
9 with lower educational levels, understand the discussion topics and feel comfortable to express their  
10 opinions.  
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13 Consumer engagement in these activities also requires travel and administrative support .[11] The  
14 venue for the stakeholder forum was selected in consideration of travel distance and physical  
15 accessibility to and once at the venue. This included providing parking for a bus for those requiring  
16 physical assistance to attend. Video conferencing capabilities were also setup at the venue as an  
17 option for those in regional areas to participate. However, this was not taken up due to  
18 technological barriers identified by regional staff who reported their information technology system  
19 would not support video conferencing. This issue highlights the need for earlier and greater  
20 consideration of technological requirements in regional areas to help avoid such issues and allow for  
21 inclusion of participants regardless of location.  
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### 26 27 **Timely: *Involve stakeholders from the start and agree on when and how to engage.*[14]**

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29 Consumer engagement can be challenging for researchers as it requires the establishment and  
30 maintenance of relationships over time,[11] and sometimes multiple collaborations with the same  
31 organisation. The Ageing Well project arose from a previous program of research with the same  
32 aged care provider in which staff worked together with researchers to choose the social  
33 participation and QoL tools they thought would best suit their clients. Our collaboration, built on  
34 invested time and effort, resulted in a working and harmonious relationship between researchers,  
35 the aged care provider and its clients to coproduce research. Current research supports that  
36 undergoing this process builds trust.[17] Our process of engaging with the aged care provider also  
37 ensured research goals aligned with operational goals and client needs. This engagement was a key  
38 element that should be used in future consumer engagement activities as it contributed to the  
39 success of the stakeholder forum and ensured its relevance to all participants. The forum was  
40 particularly timely for the provider as it offered the opportunity for executive staff to hear feedback  
41 from clients and staff that was important and relevant in the current context of the Australian aged  
42 care sector, which is undergoing major reforms to ensure it meets current and future needs of the  
43 ageing population.[18]  
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47 At the start of the Ageing Well project, the Working Group proposed that we would conduct two  
48 stakeholder forums (halfway point and end of the project) to report on the progress of the project,  
49 and to gain stakeholder feedback to guide the project and future research activities. As the focus of  
50 the stakeholder forums was on reporting the project's progress and how this would influence the  
51 project going forward, a forum was not held at the start of the Ageing Well project. Joint planning  
52 for the stakeholder forums was commenced at the very beginning of the project to ensure that there  
53 was sufficient time to organise the different aspects of the forum. Invitations to attend the  
54 stakeholder forum were sent out three months prior to the event to allow potential participants  
55 enough time to consider if they could attend. To help the forum run on time, participants were  
56 provided with a clear agenda and time allocations for each activity prior to the forum, and again on  
57 the day. By conducting the first forum half-way through the project, participants had the unique  
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3 opportunity to consider the project findings as they emerged, and to reflect on how these findings  
4 related to their own experiences of social participation and community aged care services. The  
5 research team could then take the key points from the discussions and use them in a meaningful  
6 way to inform the remaining stages of the Ageing Well project and future aged care research.  
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11 **Transparent: *All stakeholders are open and honest in their engagement and set clear***  
12 ***expectations.[14]***  
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14 The conceptual framework used for the stakeholder forum highlights that coproduced research is as  
15 much accountable to consumers as it is to researchers. This requires conscious planning and effort  
16 on the part of researchers to promote transparency and accountability.[11] Clear aims and structure  
17 were outlined prior to and during the stakeholder forum. Once the discussion topics had been  
18 decided by the community aged care clients and care coordinators, they were sent to all  
19 stakeholders. Along with this information, participants were provided with the agenda for the day,  
20 instructions on how to reach the venue and support to attend (e.g. taxi voucher or parking permit) if  
21 needed. Provision of this information before the stakeholder forum meant participants would be  
22 prepared and able to engage in the forum in a meaningful way.  
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25 At the beginning of the forum, the engagement process was explained, including everyone's roles  
26 and the purpose of the forum. Once introductions and an update on the Ageing Well project was  
27 completed, the focus of the forum shifted to the discussion topics predetermined by the community  
28 aged care clients and care coordinators. Participants were provided sufficient time to generate  
29 meaningful discussions and reflect on their experiences and concerns related to the selected topics,  
30 within the smaller groups first before a plenary discussion. This approach was used to ensure  
31 participants felt comfortable to share their thoughts and opinions freely, and to be open to the ideas  
32 discussed and contribute their knowledge to the topics. Topics ranged from LGBTI accessibility issues  
33 to transport needs of clients. At the conclusion of the stakeholder forum, the research team  
34 summarised the main conclusions of both discussion topics and informed participants how their  
35 opinions and ideas would be used to guide future research to promote social participation of older  
36 adults in the community.  
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40 We were provided with anecdotal positive feedback from attendees on the stakeholder forum, even  
41 when discussing barriers to social participation and service provisions. Stakeholders appeared to  
42 take this opportunity to express their opinions on the topics as well as strategies to overcome  
43 identified barriers. However, in future workshops we would conduct a satisfaction survey at the end  
44 of the session for participants to record their feedback and provide any potential areas of  
45 improvement in a more rigorous manner. This process will be incorporated into the second  
46 stakeholder forum at the end of the Ageing Well project to help guide future research and ensure it  
47 is relevant to all stakeholders.  
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52 **Respectful: *Acknowledge and respect the expertise, perspective, and needs of stakeholders.[14]***  
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54 Engaging consumers in the coproduction of research requires professional etiquette and courtesy to  
55 ensure a positive experience of participating in research.[11] Throughout the preparation and  
56 progress of the stakeholder forum, the research team encouraged the inclusion of all perspectives to  
57 foster an environment of mutual respect and collective inquiry in the discussion topics. This was  
58 achieved by allowing each participant to have their views heard and contributions acknowledged,  
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3 both verbally in discussions, and by transparently recording (written and audio) the input of  
4 participants as valued and important information. To facilitate understanding and discussion, the  
5 research team ensured that the information communicated was presented in language accessible by  
6 all. The expertise and perspectives of the participants was further acknowledged through their  
7 involvement in the writing of this publication. When conducting consumer engagement activities  
8 with a mixed group of stakeholders there is always the potential challenge of managing different  
9 views and opinions that can occur between stakeholder groups. However, this was not an issue in  
10 the stakeholder forum as all participants openly discussed their views and listened to each other  
11 without any negative or disrespectful comments.  
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## 16 **DISCUSSION**

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18 Consumer engagement in research brings together service users, healthcare professionals and other  
19 key stakeholders with a vested interest in a particular issue, to develop, implement and evaluate  
20 health services. Our stakeholder forum successfully brought together multiple stakeholders to work  
21 collaboratively to inform the aged care service planning process and to facilitate quality  
22 improvement changes in practice. For the Ageing Well project, close involvement of aged care staff  
23 and clients allowed for evaluation of an iteratively coproduced model, and feedback received at the  
24 initial stakeholder forum will be used to guide the final forum. We as the researchers were able to  
25 further develop our relationship with the aged care provider and their clients, facilitating buy-in to  
26 the next phase of the research, as well as test some of our ideas for future grants. Clients and aged  
27 care provider staff involved in the stakeholder forum were able to share their experiences with  
28 people they would not normally have the opportunity to do so with (e.g. Department of Health  
29 representatives, the aged care provider's executive members and clients that lived in different  
30 areas), and also gained a better understanding of the research and how their contributions had  
31 influenced the Ageing Well project. The Department of Health representatives reporting gaining a  
32 greater understanding of the Ageing Well project than what was possible from review of the grant  
33 application alone. Their attendance of the stakeholder forum further influenced them to consider  
34 how they could change the grant application process to gain a better insight into future projects.  
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40 Unlike similar processes that only involve consumer representatives, we targeted involvement of  
41 community aged care clients, including minority and diverse groups, during the planning stage and  
42 at the forum. This required thoughtful planning and preparation in line with the consumer  
43 engagement framework adopted for the stakeholder forum to foster co-learning, networking, and a  
44 positive sense of ownership of aged care services among stakeholders and generate innovative ideas  
45 from the grassroots of aged care. This was demonstrated through the positive experiences of the  
46 forum that participants shared with each other and the research team during the discussion topic  
47 feedback sessions, shared meal breaks, and at the video booth. Clients expressed their willingness to  
48 be involved in the Ageing Well project and appreciated the time taken to consider their perspectives  
49 on the type of activities that can support older adults living in the community. Community aged care  
50 clients and care coordinators reflected that the discussion topics were relevant not only for  
51 themselves, but the wider population of older people living the community.  
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55 At the conclusion of the forum, stakeholders were invited to leave their details so they could be  
56 involved in future healthcare research projects. One indicator of success of this forum was that all  
57 stakeholders expressed interest in continuing their involvement in the Ageing Well project and other  
58 research activities. Four weeks after the forum was completed, all stakeholders were provided with  
59 a newsletter that summarised the aims and outcomes of the forum, along with a certificate of  
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3 appreciation and photos from the forum. To further enhance the quality of future forums it would  
4 be beneficial to have stakeholders complete a feedback questionnaire at the end of the forum. This  
5 would ensure that the feedback is accurately captured and enhance the research team's ability to  
6 develop tailored and meaningful consumer engagement activities. Future forums, depending on  
7 their focus, should consider other factors that may drive further success. For instance, larger  
8 stakeholder forums may consider the logistics regarding stakeholder's transport options, broader  
9 consumer representatives as well as additional representatives and timing. For forums that wish to  
10 generate future research directions, alternative activities that promote discussion, such as rating  
11 cards, could be used.  
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15 Ultimately, this forum enabled stakeholders (policy makers, clients and care coordinators) who  
16 rarely meet in one place to reflect on their aged care experiences, to: i) work together to identify  
17 relevant needs and priorities for improvement of aged care services; and ii) devise strategies to  
18 address these needs. This process facilitated not only an understanding of consumers' needs and  
19 existing gaps in aged care services, but also the circumstances that can impact the delivery and  
20 implementation of services. This type of consumer engagement activity is critical to ensure aged  
21 care research is tailored to the needs of consumers. Doing so supports consumer-centred aged care  
22 services that empower consumers to engage in decision-making about both their own care, and the  
23 care needs of the wider community.  
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27 Future research should use the topics, stories and feedback obtained from stakeholders during  
28 forums to inform and reflect on how consumer engagement can improve research outcomes. The  
29 primary facilitator of consumer engagement in our research lay in our investment in a strong  
30 foundation of trust with the aged care provider. This included multiple working group meetings,  
31 examining deficiencies and aligning with the provider's aims. Ultimately, by working collaboratively  
32 over a long period of time, encompassing multiple research opportunities (psychosocial tool  
33 selection, software implementation),[19, 20] a successful forum was made possible.  
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37 The direct benefit of consumer engagement to research is not always able to be quantified.[11]  
38 Coproduction of this research with aged care consumers required significant investment of time and  
39 resources, and required skill, respect and courtesy to build trust and engagement with stakeholders.  
40 The benefits of this process are demonstrated through the establishment and reinforcement of  
41 relationships between the different stakeholders, the co-development of new research ideas  
42 through the stakeholder discussions, and the ongoing interest and involvement of the different  
43 stakeholders in the Ageing Well project.  
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**TABLE LEGEND**

Table	Caption
1	Outline of the Ageing Well stakeholder forum

For peer review only

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The authors would like to acknowledge all stakeholders that participated and provided valuable contributions to the forum.

## AUTHOR'S CONTRIBUTIONS

LB was the major contributor to the conception, drafting and revision of the manuscript. AG, MJ, JS and JW received funding for the Ageing Well project. JS, AN, MJ and MM, made substantial contributions to the conception, drafting and revision of the manuscript. JW and AG made substantial contributions to the drafting and revision of the manuscript. WL, EG and FH made substantial contributions to the review and revisions of the manuscript. All authors read and approved the final manuscript, and are in agreement 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.

## COMPETING INTERESTS

The authors declare that they have no competing interests.

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## ETHICAL APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was granted by the Macquarie University Human Research Ethics Committee (reference number: 5201700912). Participants provided written consent for their involvement in the stakeholder forum. They also provided written consent for photos and videos from the forum to be used for promotional and publication purposes.

## Reference List

1. Queensland Health. Queensland Health position statement: Consumers and community participation: To promote community engagement in health. Brisbane: Queensland Health; 2003 January 2003.
2. Thornton S. Beyond rhetoric: we need a strategy for patient involvement in the health service. *BMJ* 2014;348.
3. Krzyzanowska MK, Kaplan R, Sullivan R. How may clinical research improve healthcare outcomes? *Ann Oncol* 2011;22:vii10-vii5.
4. Delaney LJ. Patient-centred care as an approach to improving health care in Australia. *Collegian* 2018;25:119-23.
5. Ruco A, Nichol K. Patient Engagement in Research and Innovation: A New Framework. *J Med Imaging Radiat Sci* 2016;47:290-3.
6. Minogue V, Girdlestone J. Building capacity for service user and carer involvement in research: The implications and impact of best research for best health. *Int J Health Care Qual Assur* 2010;23:422-35.
7. Domecq JP, Prutsky G, Elraiyah T et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89-.
8. Carman KL, Workman TA. Engaging patients and consumers in research evidence: Applying the conceptual model of patient and family engagement. *Patient Educ Couns* 2017;100:25-9.
9. Flinders M, Wood M, Cunningham M. The Politics of Co-Production: Risks, Limits and Pollution. 2016;12:261.
10. Guise J-M, O'Haire C, McPheeters M et al. A practice-based tool for engaging stakeholders in future research: a synthesis of current practices. *J Clin Epidemiol* 2013;66:666-74.
11. Oliver K, Kothari A, Mays N. The dark side of coproduction: do the costs outweigh the benefits for health research? 2019;17:33.
12. Brett L, Georgiou A, Jorgensen M et al. Ageing well: evaluation of social participation and quality of life tools to enhance community aged care (study protocol). 2019;19:78.
13. Australian Institute of Health Innovation. Ageing well - a social participation and engagement tool. 2017 <https://www.mq.edu.au/research/research-centres-groups-and-facilities/healthy-people/centres/australian-institute-of-health-innovation/news-and-events/news/news/ageing-well-a-social-participation-and-engagement-tool>; (accessed 13/12/2018)].
14. Australian Government Department of Health. Health Stakeholder Engagement Framework. In: Health Do, editor. Updated: 20 November 2018 ed. Canberra: Commonwealth of Australia; 2017.
15. International Association for Public Participation. IAP2's public participation Spectrum. 2014 [https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2\\_Public\\_Participation\\_Spectrum.pdf](https://www.iap2.org.au/Tenant/C0000004/00000001/files/IAP2_Public_Participation_Spectrum.pdf); (accessed 06/12/2018)].
16. Guest G, MacQueen KM, Namey EE. Applied Thematic Analysis. Thousand Oaks, California 2012. Available from: <http://methods.sagepub.com/book/applied-thematic-analysis>.
17. Boaz A, Hanney S, Borst R et al. How to engage stakeholders in research: design principles to support improvement.(Report). 2018;16.
18. Australian Government Department of Health. Aged care reform. 2019 <https://agedcare.health.gov.au/aged-care-reform>; (accessed 28/07/2019)].
19. Siette J, Georgiou A, Jorgensen M et al. Integrating social engagement instruments into Australian community aged care assessments to enhance service provision. 2018;26:810-8.
20. Douglas HE, Georgiou A, Tariq A et al. Implementing Information and Communication Technology to Support Community Aged Care Service Integration: Lessons from an Australian Aged Care Provider. 2017;17.



**Table 1. Outline of the Ageing Well stakeholder forum**

<b>Activity (Time)</b>	<b>Purpose (consumer engagement principle[s] addressed)</b>	<b>Outcome</b>
Morning tea (30min)	Opportunity for participants to meet. ( <i>inclusive</i> )	Provided a supportive environment to get to know each other and facilitate forum discussions.
Welcome to the research institute and overview of the forum agenda (15min)	Welcome participants and provide a clear understanding of how the forum would run. ( <i>purposeful, timely, transparent, respectful</i> )	Participants understood what activities would occur during the forum and how they could actively engage.
Ice-breaker activity (15min)	Participants got to know the other members in their smaller discussion groups, and then feed this information back to all participants. ( <i>inclusive, respectful</i> )	Provided insight into each participant's background, fostering a collaborative and supportive environment for the forum discussions.
Overview of the Ageing Well project (15min)	Inform participants about the purpose of the project, how it was progressing, and give them an opportunity to ask questions. ( <i>purposeful, transparent</i> )	Participants had an understanding of the Ageing Well project and how it related to the forum.
Discussion topic 1: Access and barriers to community aged care services and social participation activities (50min)	Participants discussed this topic, which was ranked as the most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss potential solutions and future directions to improve access. An example was issues related to transport, and current and potential strategies to overcome this barrier.
Lunch (50min)	An opportunity for participants to refuel and prevent mental fatigue. During this time a video booth was set up for participants to provide feedback on the Ageing Well project, the forum, and/or community aged care services. ( <i>inclusive, respectful</i> )	Participants were able to stay actively engaged throughout the forum and had a further opportunity to network with other participants.
Discussion topic 2: Needs of community aged care clients to help them maintain social participation in their community (50min)	Participants discussed this topic, which was ranked as the second most important and relevant by community aged care clients and care coordinators during the development of the stakeholder forum. ( <i>purposeful, inclusive, transparent, respectful</i> )	Participants provided their individual opinions and experiences, and came together to discuss the needs and preferences of aged care clients. An example was the provision of a safe environment for lesbian, gay, bisexual, transgender and intersex older adults to participate in social participation activities.
Concluding remarks (15min)	The research team summarised the forum activities and how the discussion topics would guide future research and policies of the involved aged care provider. ( <i>transparent, respectful</i> )	Participants felt empowered and were able to understand how their input would be used to benefit aged care clients and services.