

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	At the Grassroots of Home and Community-based Aged Care: Strategies for Successful Consumer Engagement
AUTHORS	Brett, Lindsey; Siette, Joyce; Nguyen, A; Jorgensen, Mikaela; Miao, Melissa; Westbrook, Johanna; Lee, Winifred; Gow, Edwina; Hourihan, Fleur; Georgiou, A

VERSION 1 – REVIEW

REVIEWER	Johannes van Delden UMC Utrecht, NL
REVIEW RETURNED	03-May-2019

GENERAL COMMENTS	<p>The science of patient input is a relatively young discipline with only few established methods, let alone clear evidence of efficacy of these methods. Therefore reports such as this one are welcome as they clearly describe a process for consumer engagement from which others can learn.</p> <p>This is important because the need to listen well to consumers is clearly established. The authors clearly recognize this.</p> <p>That said I think the report could be much stronger. It now reads as one big success story in which all of the five principles were easily adhered to. That made me wonder whether there had been no challenges, no hurdles to overcome, no failures etcetera from which others can also learn. The main message of this report should not be that it is important to include consumers as we already know that. The main point should be to enable others to learn from the experience of these authors. And others can clearly also learn from failures and challenges.</p> <p>Some examples to support my view: Under the heading of inclusiveness the authors seem to say that everything went well and that they arrived at having a very inclusive group. Did they? How well did they reach hard-to-reach groups, such as the frail elderly themselves, ethnic minorities etc? How did they do that? Did they use any special strategies! Did the 23 people they spoke with belong to the usual suspects (e.g. higher education etc) or did they really represent a broad range of consumers? What was their criterion for being so satisfied? What was the composition of the sample?</p> <p>Under the heading of timely the authors again turn out to be rather satisfied with what they did. If I understand correctly they had forums halfway and end the end of the project. Why not at the beginning? Why not involve consumers in the planning of the project? What can we learn from this strategy? Would you do it again? If not what</p>
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	<p>would you change and why?</p> <p>Under the heading respectful again everything was great. Could the authors describe how they responded to opinions of consumers that in themselves were not respectful? What were challenging contributions to the debate? In what way was the project influenced? Did things really work out differently and how? What impact did the forums have?</p> <p>In short I welcome this report, but I think much more learnings could be derived from it.</p>
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REVIEWER	<p>Carolyn Steele Gray Lunenfeld Tanenbaum Research Institute, Sinai Health System, Toronto, Canada.</p> <p>University of Toronto, Toronto, Canada</p>
REVIEW RETURNED	16-May-2019

GENERAL COMMENTS	<p>This paper outlines a consumer engagement process used to guide development of the Aging Well program in Australia. Co-design methods like these are increasingly relevant and critical to support development of programs that meet the needs of older adults and complex patients. While an important topic there are a number of gaps in this communication paper that need to be addressed. Most importantly would be placing this in the broader literature around co-design to demonstrate what we can learn from this particular activity to advance broader thinking.</p> <p>See below a list of comments:</p> <ul style="list-style-type: none"> • In the background there is a bit of confusion regarding discussing consumer involvement in care delivery, versus consumer involvement in research. For example the first line of the second paragraph in the background takes about active consumers in care delivery, but later in the paragraph there is a switch to discussing consumers as active participants in research. These are two separate concepts and represent two types of engagement of consumers. Please clarify the distinction throughout the background where there is bouncing back and forth between these types of engagement • The background needs to better position this work as a contribution to the literature. There has been lots written on participatory research and co-designing models of care. What does this offer that those other papers do not? • There needs to be much more clarity on what the Ageing Well project is – I'm unclear whether this is about designing a new model of care or if it is a research project or both, and whether consumers were engaged to co-design the model of care or the research project or both • Key principles of consumer engagement developed by the Australian government are used to guide this work but there are many other frameworks available. Can this one be placed in the broader literature? What does it add, why is it useful, how was it created? The principles also need to be defined clearly so we can see the link to the work presented and later the outcomes linked to the principles. The terms alone are vague with lots of different definitions available in the literature – indeed a reference to the government document is given but clear definitions need to be part of this paper
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	<ul style="list-style-type: none"> • I'm not sure in the purposive section the forum was really designed with clients, rather focus groups were used to identify key themes. It's also unclear how this process supported assessment of availability and interest to engage. • Without additional details regarding some of the qualitative methods used it is difficult to assess their quality and rigour – is there perhaps another publication where this work is outlined in greater detail? Again, being distinct about the purpose of the participation will be helpful in determining the value of methodological detail here. • At the moment the sections outline activities related to the concepts of the engagement framework, but to make more of a contribution here I would anticipate this being couched in some additional literature around co-design or participatory research • I appreciate bringing in reflections on indicators of a successful model, but again how does this relate to other work in this field. What is the new learning here? Are the strategies and methods used here markedly different than what others have used, or are you further validating this approach. • Again at the end the distinction between research vs. co-designing a model of care must be made more clearly. It seems like the project was about co-designing care, however the paper discusses the value of participatory research methods. These may be related but this connection needs to be made here.
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VERSION 1 – AUTHOR RESPONSE

No.	Reviewer	Comment/question	Response	Location
Overall				
1	1	It now reads as one big success story in which all of the five principles were easily adhered to. That made me wonder whether there had been no challenges, no hurdles to overcome, no failures etcetera from which others can also learn. The main message of this report should not be that it is important to include consumers as we already know that. The main point should be to enable others to learn from the experience of these authors. And others can clearly also learn from failures and challenges.	<p>We have now included further details about the research steps that lead up to the success of the day which included building a successful relationship with the aged care provider, and building rapport with staff and clients, over a long period of time.</p> <p>Where applicable we have also added detail about actual and potential challenges associated with consumer engagement in research.</p>	<p><i>Key Principles for Consumer Engagement</i> section, pages 4-8.</p> <p><i>Discussion</i> section, pages 8-9.</p>

No.	Reviewer	Comment/question	Response	Location
2	2	While an important topic there are a number of gaps in this communication paper that need to be addressed. Most importantly would be placing this in the broader literature around co-design to demonstrate what we can learn from this particular activity to advance broader thinking.	Please see response to comment 1 above.	<i>Key Principles for Consumer Engagement</i> section, pages 4-8. <i>Discussion</i> section, pages 8-9.
Background				
3	2	In the background there is a bit of confusion regarding discussing consumer involvement in care delivery, versus consumer involvement in research. For example the first line of the second paragraph in the background takes about active consumers in care delivery, but later in the paragraph there is a switch to discussing consumers as active participants in research. These are two separate concepts and represent two types of engagement of consumers. Please clarify the distinction throughout the background where there is bouncing back and forth between these types of engagement	We have now ensured that the purpose of the paper, providing lessons for involving consumers in research, is now clearer.	<i>Background</i> section, paragraphs 1-2, page 3.
4	2	The background needs to better position this work as a contribution to the literature. There has been lots written on participatory research and co-designing models of care. What does this offer that those other papers do not?	In the updated paper, we have now included more lessons to those who are conducting research involving consumers, generated from or lessons learned from the planning and conduct of this Stakeholder Forum. Please also see response to comment 1 above.	<i>Key Principles for Consumer Engagement</i> section, pages 4-8. <i>Discussion</i> section, pages 8-9.

No.	Reviewer	Comment/question	Response	Location
5	2	There needs to be much more clarity on what the Ageing Well project is – I'm unclear whether this is about designing a new model of care or if it is a research project or both, and whether consumers were engaged to co-design the model of care or the research project or both	<p>Further details about the Ageing Well project is now included in the updated paper.</p> <p>More clarity regarding the involvement of consumers in this project has been included throughout.</p>	<p><i>Background</i> section, paragraph 3, page 3.</p> <p>Reference for the Ageing Well protocol paper added (reference 12).</p> <p><i>Key Principles for Consumer Engagement</i>, pages 4-8.</p> <p><i>Discussion</i> sections, pages 8-9.</p>
6	2	Key principles of consumer engagement developed by the Australian government are used to guide this work but there are many other frameworks available. Can this one be placed in the broader literature? What does it add, why is it useful, how was it created?	We have now provided further information about the <i>Key Principles of Consumer Engagement</i> framework in a wider context and why we selected it for this element of the Ageing Well project.	<i>Background</i> section, paragraph 4, page 3 – paragraph 1, page 4.
7	2	The principles also need to be defined clearly so we can see the link to the work presented and later the outcomes linked to the principles. The terms alone are vague with lots of different definitions available in the literature – indeed a reference to the government document is given but clear definitions need to be part of this paper	The definitions of <i>Key Principles of Consumer Engagement</i> are now included.	As part of the subheading for each key principle within the <i>Key Principles for Consumer Engagement</i> section, pages 4-8.

No.	Reviewer	Comment/question	Response	Location
Key Principles (overall)				
8	2	At the moment the sections outline activities related to the concepts of the engagement framework, but to make more of a contribution here I would anticipate this being couched in some additional literature around co-design or participatory research	Further literature linking our work to co-design and participatory research has now been included throughout (references 9, 11, 15, 17).	The <i>Background</i> section, paragraph 2, page 3 – paragraph 1, page 4. The <i>Key Principles for Consumer Engagement</i> section, pages 4-8.
9	2	I appreciate bringing in reflections on indicators of a successful model, but again how does this related to other work in this field. What is the new learning here? Are the strategies and methods used here markedly different than what others have used, or are you further validating this approach.	This paper offers insights from our experience of a coproduced research project in aged care. It further validates the use of the Key Principles of Consumer Engagement framework, and provides practical guidance about how this framework can be operationalised in practice. Throughout the paper reference to other literature has been added to support the approach we used and further validate the <i>Key Principles of Consumer Engagement</i> framework (references 11, 15). Please also see responses to comments 1 and 4 above which outline the practical guidance included in this paper.	Throughout whole paper.

No.	Reviewer	Comment/question	Response	Location
Purposeful				
10	2	I'm not sure in the purposive section the forum was really designed with clients, rather focus groups were used to identify key themes. It's also unclear how this process supported assessment of availability and interest to engage.	<p>The development of the forum included the following processes:</p> <ul style="list-style-type: none"> • Clients and staff were involved in the design of the forum during the development phase. • Focus groups were held to examine areas of interest of these groups. • Prior to the Stakeholder Forum, these areas were presented to clients and staff to indicate order of importance to them. • The top two areas were then selected to be discussed at the Stakeholder Forum. <p>Further information regarding the above processes, including how they were used to assess availability and interest, has now been included in the updated paper.</p>	<i>Purposeful</i> subsection, pages 4-5.
11	2	Without additional details regarding some of the qualitative methods used it is difficult to assess their quality and rigour – is there perhaps another publication where this work is outlined in greater detail?	<p>Further information about the qualitative analysis involved in the thematic analysis has now been added.</p> <p>A paper that specifically looks at the focus groups used to help develop the themes for the stakeholder forum is currently in preparation.</p>	<i>Purposeful</i> subsection, pages 4-5.
12	2	Again, being distinct about the purpose of the participation will be helpful in determining the value of methodological detail here.	See response to comment 11 above, and detail about consumer engagement in research included in the <i>Background</i> section.	<i>Purposeful</i> subsection, pages 4-5. <i>Background</i> section, paragraph 1, page 3.

No.	Reviewer	Comment/question	Response	Location
Inclusiveness				
13	1	Under the heading of inclusiveness the authors seem to say that everything went well and that they arrived at having a very inclusive group. Did they?	Further information regarding the inclusiveness of the group has been included in the updated paper.	<i>Inclusive</i> subsection, pages 5-6.
14	1	How well did they reach hard-to-reach groups, such as the frail elderly themselves, ethnic minorities etc? How did they do that? Did they use any special strategies!	<p>We worked with the aged care provider to reach minority and diverse groups during recruitment for the stakeholder forum.</p> <p>Other strategies included the use of a translator for CALD participants, bus for transport, video conference option for rural participants, and ensuring we used simple English throughout the forum.</p> <p>This information has been added to the updated paper.</p>	<i>Inclusive</i> subsection, pages 5-6.
15	1	Did the 23 people they spoke with belong to the usual suspects (e.g. higher education etc) or did they really represent a broad range of consumers?	<p>We were able to recruit a mixture of participants rather than just the 'usual suspects', and this included actual consumers rather than just group representatives.</p> <p>Further information on the type of stakeholders that attended the forum has been included.</p>	<i>Inclusive</i> subsection, paragraph 2, page 5.

No.	Reviewer	Comment/question	Response	Location
16	1	What was their criterion for being so satisfied?	We did not use or discuss specific criterion for being satisfied with the type of participants that attended the stakeholder forum in this paper. However, we do believe we achieved a good mix of people and varied insights. Please also see response to comment 13 above.	<i>Inclusive</i> subsection, pages 5-6.
17	1	What was the composition if the sample?	This information is now included.	<i>Inclusive</i> subsection, paragraph 2, page 5.
Timely				
18	1	If I understand correctly they had forums halfway and end the end of the project. Why not at the beginning?	The Stakeholder forums were held after results had been collected and not at the start as the focus was on: <ul style="list-style-type: none"> • Providing feedback to consumers on the Ageing Well project's progress • Gaining perspectives from staff and clients on the relevance and accuracy of the findings • Using the above information to guide the Ageing Well project in the final stages and future research in this field This information has been added to the updated paper.	<i>Timely</i> subsection, paragraph 3, page 6.
19	1	Why not involve consumers in the planning of the project?	Consumers were involved in an earlier research project that informed the planning of the Ageing Well project. This information has been added to the updated paper.	<i>Timely</i> subsection, paragraph 3, page 6.

No.	Reviewer	Comment/question	Response	Location
20	1	What can we learn from this strategy? Would you do it again? If not what would you change and why?	Learnings from our research have now been included throughout the paper.	<i>Key Principles for Consumer Engagement</i> section, pages 4-8. <i>Discussion</i> section, pages 8-9.
Respectful				
21	1	Could the authors describe how they responded to opinions of consumers that in themselves were not respectful?	We did not have this issue during the stakeholder forum, and this has now been acknowledged in the paper.	<i>Respectful</i> subsection, pages 7-8.
22	1	What were challenging contributions to the debate?	Please see response to comment 21 above.	<i>Respectful</i> subsection, pages 7-8.
23	1	In what way was the project influenced?	The project and those involved in the stakeholder forum were influenced in multiple ways by the coproduction process adopted (such as ideas for future research, the use of satisfaction surveys in the final stakeholder forum, development of relationships between the different stakeholders). Further clarification of how the project and those involved were influenced have been added throughout the updated paper.	<i>Key Principles for Consumer Engagement and Discussion</i> sections, pages 4-9.
24	1	Did things really work out differently and how?	Please see response to comment 23 above.	<i>Key Principles for Consumer Engagement and Discussion</i> sections, pages 4-9.

No.	Reviewer	Comment/question	Response	Location
25	1	What impact did the forums have?	Please see response to comment 23 above.	<i>Key Principles for Consumer Engagement and Discussion</i> sections, pages 4-9.
Discussion (previously titled: Impact of consumer engagement)				
26	2	Again at the end the distinction between research vs. co-designing a model of care must be made more clearly. It seems like the project was about co-designing care, however the paper discusses the value of participatory research methods. These may be related but this connection needs to be made here.	We have now ensured that the purpose of the paper, providing lessons for involving consumers in research, is now clearer. Please also see response to comment 3 above.	<i>Discussion</i> section, paragraphs 2-3, page 8 and paragraphs 2-3, page 9. <i>Background</i> section, paragraphs 1-2, page 3.

VERSION 2 – REVIEW

REVIEWER	Johannes JM van Delden Julius Center, UMC Utrecht, the NL chair of the Ethics and Compliance Advisory Board of PatientsLikeMe
REVIEW RETURNED	23-Aug-2019

GENERAL COMMENTS	Although I would have liked to see more of the failures and challenges the authors met with, I clearly see that they have made an effort to respond to my first review. I think the article contains enough interesting findings and advice to warrant publication.
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REVIEWER	Carolyn Steele Gray Bridgepoint Collaboratory for Research and Innovation, Canada
REVIEW RETURNED	16-Sep-2019

GENERAL COMMENTS	Thank you for the careful revisions of this manuscript. The background on the framework as well as additional details regarding how activities at the forum speak to components of the framework for engagement provide structure and clarity in his version. It is much more evident how the activities address components of the framework. Comments/questions: - will the same themes used to drive conversations at the interim and be used in the final forum? If not, how will you use what was learned here to influence the structure of the final forum? What will you do
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	<p>differently now after conducting this one (beyond a satisfaction survey)?</p> <p>- could you provide an example of how the forums influenced the project in a meaningful way? please provide an illustrative example as this would help the readers see how this type of work can advance and ameliorate research work</p> <p>- another illustrative example that would help strengthen the paper would be on how research and stakeholder aims were aligned (maybe one particular aim that resonated across all and how they got there). This is a big challenge for folks working in this space so an example would be helpful.</p> <p>Minor issues: - some typos and editorial issues here and there (page 18 of 27 line 3 I believe has an extra "and", and a few others, copy editing should catch much of this)</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer Comment	Authors' response	Page
Will the same themes used to drive conversations at the interim and be used in the final forum? If not, how will you use what was learned here to influence the structure of the final forum?	<p>To clarify, the principles of consumer engagement (purposeful, inclusive, timely, transparent and respectful) will be used to drive conversations for all forums.</p> <p>For the reviewer's interest, the final forum will be designed in a similar way, taking into account the successful factors from this initial forum. This includes coproducing themes and questions from clients and aged care staff, being inclusive, having feedback opportunities and being respectful. The final forum's purpose is to guide future research activities. This is discussed under <i>Timely Principle</i> paragraph 2.</p>	P6
What will you do differently now after conducting this one (beyond a satisfaction survey)?	We have included alternative suggestions for future forums in the <i>Discussion</i> paragraph 3.	P9
Could you provide an example of how the forums influenced the project in a meaningful way? Please provide an illustrative example as this would help the readers see how this type of work can advance and ameliorate research work	<p>This was the first of two forums for the project. The purpose of this manuscript was to generate a sound theoretical basis on how to conduct future forums involving diverse stakeholders.</p> <p>There are several ways in which this forum influenced the project in meaningful ways:</p> <ol style="list-style-type: none"> 1. Having one forum half-way in the project ensured that consumer voices are heard by both researchers and the aged care organisation. It also confirmed that our research aims are still relevant in this context. This point is emphasised in the <i>Timely Principle</i> paragraph 2. 2. Driving the conversation forward with relevant stakeholders. This is highlighted in 	P6/7, P9

	the <i>Discussion</i> section paragraph 4.	
Another illustrative example that would help strengthen the paper would be on how research and stakeholder aims were aligned (maybe one particular aim that resonated across all and how they got there). This is a big challenge for folks working in this space so an example would be helpful.	<p>This is an excellent point. We have attempted to clarify this point through two parts: focus groups and discussions post focus group.</p> <p>Our project’s research aims were initially conceptualised through discussions with staff members prior to the project’s commencement date. We set out to develop these aims through multiple focus groups with relevant stakeholders prior to the stakeholder forum. The focus groups identified that barriers to social participation was a key concern of aged care clients. Following discussions with the Working Group and further feedback from clients and aged care staff, this discussion topic was incorporated into the stakeholder forum.</p> <p>We have described this in the <i>Purposeful Principle</i> paragraphs 2 and 3: “In order to ensure that the aims of the stakeholder forum of both researchers and consumers were aligned, focus groups with both community aged care clients (n=21) and care coordinators (n=21) were conducted prior to the stakeholder forum. This ensured the generation of aims that were reflective of participants’ needs and concerns in aged care and further establishing the core stakeholder forum themes. This initial coproduction confirmed their relevance for all stakeholders including researchers.”</p> <p>“As another stage of consumer engagement of the research and to further ensure alignment of researcher and stakeholder aims for the stakeholder forum, the themes identified in the focus groups were presented to the community aged care clients and care coordinators prior to the stakeholder forum.”</p>	P4, P5
Some typos and editorial issues here and there (page 18 of 27 line 3 I believe has an extra "and", and a few others, copy editing should catch much of this)	This has been reviewed and revised throughout.	All pages