

Response ID ANON-Y3X3-JBJT-1

Submitted to Draft National Consumer Engagement Strategy for Health and Wellbeing
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Introduction

1 What is your name?

Name:
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2 What is your email address?

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3 Are you responding on behalf of an organisation, or as a consumer/individual?

On behalf of an organisation

4 Are you a policy-maker?

Yes

5 What is your organisation and/or field of expertise?

What is your organisation and/or field of expertise?:
Health genomics

6 If representing an organisation, which sector does your organisation belong to?

Other: Please specify

If representing an organisation, which sector does your organisation belong to?:

Australian Genomics supports the Involve Australia initiative, a community led project promoting effective and meaningful community involvement in genomics research. A founding goal of Involve Australia was to develop a set of guidelines for genomics researchers on community involvement. These have been developed over 3 years (2021- 2023) and will soon be released. The guidelines cover 5 key domains: Building relationships, Setting expectations, Valuing community members, Evaluating and reporting on community involvement and Real-world applications of research. Each domain contains a set of recommendations each with an evidence-based section and a section with practical "how-to" suggestions. We acknowledge that the work we have carried out is focused on genomic research however believe the overall principles for involvement are transferrable across health contexts. Our experience in creating these guidelines informs our response to this Strategy.

Consultation Questions

7 Purpose

Is it clear what this Strategy is for? - Is the purpose of the strategy and/or the target audience clear?:

Clear

If not, what would make it clearer?:

• The purpose statement nicely captures who is involved, what they are being involved in, and what the intended outcomes are. To make it shorter, consider removing the 'design, evaluation and implementation' part, limiting it to 'programs' which still captures design, evaluation and implementation in its scope. • Although the audience for this document is clear, given that Strategy is focused on consumer involvement we feel that it should be more consumer friendly. The language used is often complicated and the document itself is long. However, we do understand that it is eventually intended that the Toolkit will be presented as a separate document/resource, making each resource more digestible.

8 Objectives

Are the objectives for the Strategy clear and appropriate? - Are the objectives for the Strategy clear and appropriate?:

Clear

If not, what is missing?:

9 Fundamentals

Do the Fundamentals capture what you see as essential for consumer engagement? - Do the Fundamentals capture what you see as essential for consumer engagement?:

Clear

If not, what is missing?:

10 Good Practice Guidelines

Do you think the Guidelines describe what is needed to help policy-makers work effectively with consumers? - Do you think the Guidelines describe what is needed to help policy-makers work effectively with consumers?:

Well

Do you think the Guidelines describe what is needed to help policy-makers work effectively with consumers? - Are the Guidelines explained in a way that makes them useful?:

Unsure

Do you have anything to add about the Guidelines?:

- Case studies are a useful tool to show people how to involve consumers well. The Strategy and HELP Toolkit could benefit from some concrete examples of consumer involvement to better teach people how to carry out this work. Consumer quotes are a great way to make the document more engaging and provide evidence and while there are some within the document they could be used more frequently.

11 If you have been involved in policy-making before as a consumer, what made your engagement in that process

A positive and welcome experience :

A dissatisfying experience :

12 HELP Toolkit

HELP Toolkit - Do you think the Toolkit will be easy to use?:

Unsure

Do you think the Toolkit will help policy-makers better engage consumers in policy-making? - Do you think the Toolkit will help policy-makers better engage consumers in policy-making?:

Helpful

Do you have anything else to add? :

- The one-page summary (Strategy overview) is useful but is quite text heavy. This would be a good place to incorporate the Fundamentals icons and create a more engaging infographic.
- Some parts of the guidelines are repetitive, this adds to the length of the document. We would suggest that the repetitive sections are removed to make the documents more succinct.
- The figure 'Using a guideline throughout the policy cycle: an illustration' is a useful tool which Strategy implementers could readily adapt to their different policymaking contexts.

13 Are you supportive of the overall purpose and objectives of the Strategy?

Yes, with proposed changes

Please specify proposed changes:

- The vision and aim are not explicitly outlined in this document – should these have been inferred by the reader? Or this may indicate a closer linking of 'vision' to the 'fundamentals' and 'aim' to 'objectives' was intended.
- We believe the fundamentals of the strategy speak to the important elements of consumer involvement and align with the evidence-based guidelines that Involve Australia has developed.
- We note that the Strategy uses the term 'engagement'. We suggest changing to the term 'involvement' which is a more accurate representation of a consumer's role and is used broadly across government, health care and research and in a number of published documents eg Involve, ACTA, MRFF, NHMRC. The document should clearly differentiate between consumer engagement and involvement with the use of examples.
- Some of the language used such as 'hard to reach' and 'hard to engage' is deficit language and puts the onus on the consumer, suggesting that they are "difficult". The responsibility of engaging with these priority populations should fall to the policy makers. Using the term priority population is a good alternative. Additionally, the phrasing "Preventive health requires active participation from consumers and communities to affect behaviour change and create healthy environments" (pg.8, paragraph 5, lines 1-2) also puts the onus on communities. Considering rewording to "Consumers should be actively engaged by policy makers so more appropriate and relevant health environments are created."

14 If you are a consumer and haven't been involved in policy making, would you like to be? Why/Why not?

Not Answered

If you have wanted to be involved, what has stopped you from doing so?:

15 Are there any other engagement approaches that you have found helpful and effective?

Are there any other engagement approaches that you have found helpful and effective?:

- An important aspect of consumer involvement is appropriate acknowledgement of consumers. We feel that further information on this aspect could be added to the document. For example, more information on remuneration. Our evidence shows that consumers are motivated by being paid. We acknowledge that our evidence has possibly been acquired through a biased sample as data was gathered through a market research sample, however, evidence has also been found through our other data collection methods. Other ways to acknowledge consumers that could be highlighted include

naming them on official reports/ documents/websites, inviting them to co-present and acknowledging them in presentations, and to be involved in other dissemination activities.

- Further to highlighting the provision remuneration, the importance of reimbursement for costs incurred as part of consumers' involvement as well as provisions being made for the impact of their involvement should be discussed within the Strategy. For example, parking costs should be covered or lunch should be provided for all day meetings.

16 Do you have any other comments or suggestions?

Do you have any other comments or suggestions? :

- Overall, we are supportive of these guidelines, they are thorough and cover most key aspects of consumer involvement. The relationship building section articulates well the importance of building trusting relationships and highlighting the mismatch in policy timelines and the time it takes to develop good trusting relationships. We also feel the graphics capture the content well, especially the policy cycle.

- We are concerned that using a "now" statement such as "Don't let perfect be the enemy of good" will date the document quickly. We are also concerned that this statement infers that consumers aren't experts so they couldn't contribute to a "perfect" policy in the way that policymakers could if working alone. We do not think this sets the right tone for the Strategy.

- We think that this document could benefit from more information on how consumers were engaged to develop this Strategy, including what tasks they undertook, whether they were remunerated and who the consumers were (e.g. part of a consumer organisation, individual patient advocates etc). This adds to the authenticity of the Strategy, as well as providing a case study for involvement.

- Another key aspect of consumer involvement that is omitted from the Strategy is the reporting of consumer involvement. This is important to build an evidence base for policy makers and consumers on the 'how-to', benefits and challenges of consumer involvement. We suggest additional information on this topic should be added to the Strategy. This could include what specific co-design principles or frameworks were used.

- We note that the Strategy states that a checklist is to be developed as part of good practice guidelines. Checklists can be too prescriptive and can make consumer involvement feel overwhelming if you cannot check all the boxes. We would suggest a set of guiding questions might be more suitable and user friendly.

- Young people are a group that are often unheard in these contexts. We believe that information about this should be included in the Strategy to encourage policy makers to reach this important group.

- Preventive health strategies are often delivered as health promotion or public health programs. Examples might include the addition of fluoride to drinking water, or strategies to stop the spread of COVID. These types of actions might not always be popular with the public but are founded in evidence-based policy making. Has the Strategy considered how consumer and community involvement will be approached in cases like these, and whether there will need to be modifications to how the community is involved? In depth discussion might not be needed in this document, but acknowledgement that there might be different approaches to involvement for different contexts (including more divisive topics) might be warranted.

- Expanded Reproductive Carrier Screening and genomic Newborn Bloodspot Screening are two preventive health strategies which use genomic technologies and may be implemented into the Australian health system. Public education and awareness programs co-designed utilising consumer and community involvement will be central to public trust and uptake of these programs and so adopting successful strategies such as those outlined in the document will be critical.

- The HELP Toolkit Factsheet outlines one Tip for success to "Digitise (with caution)". Reconsideration for the need to include "with caution" is advised. Throughout the document there is acknowledgement that digital tools are already in use and that they can be very successful, so framing this Tip in a negative way is not necessary, especially since the concept of the digital divide has been acknowledged. As mentioned elsewhere in the document, digital strategies, including the use of social media, can be very effective tools and the Strategy will not want to discourage policymakers from exploring their use by using such wording in the document.