2020 LIVING DIABETES GUIDELINES CONSUMER/RESEARCHER FORUMS

FINAL REPORT AND PROPOSED OPTIMAL LIVING ENGAGEMENT MODEL

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1. About the forums

In this project, we aimed to explore how consumers could be **best** involved in the development of living clinical practice guidelines (living guidelines) for diabetes, and involved in living guidelines more broadly. Living guidelines use new technologies and new ways of working together to enable rapid, continual updating of recommendations in light of new research.

Consumers are currently engaged in the living guidelines being piloted by the Australian Living Evidence Consortium. Their engagement is evolving as guideline developers and health professionals also adapt to the new 'living' paradigm. As living guidelines present new and different opportunities for consumer involvement, this project sought to design an optimal, fit-for-purpose model of living engagement for the future.

In August 2020, we brought together 10 consumers with lived experience of diabetes and four researchers/guideline developers across two online discussion forums. Within the consumer group, one had been involved in the living guideline pilot. The other consumers brought lived experience of representing people with diabetes either within standard guideline processes or within the health system more broadly. During each forum, both consumers and researchers were invited to draw on their diverse experiences to propose an optimal consumer engagement model for living guidelines. The range of discussion topics included:

- At what stages of living guidelines should consumers be involved?
- What methods would be best for involving consumers at different stages (e.g. consumer panel, focus groups, inviting online submissions)?
- What are the best ways to reach and recruit a wide range of consumers to take part in the living guideline process?
- What resources would consumers need to support their involvement in living guidelines (including to access and understand MAGICapp)?

2. Draft report and feedback

This report describes the major themes arising during the discussion forums. Based on the themes, a model for optimal living engagement in living guidelines has been developed.

All consumers and researchers participating in the forums were invited to provide feedback on a draft of the report released in December 2020. We received feedback from two consumers and one researcher. The feedback was been integrated into version 1 of this report, published in February 2021.

Following publication of the first version, we received further consumer feedback. This feedback was integrated into version 2 of the report, published in March 2021.

3. Discussion forum themes

Theme 1: Consumer involvement should be empowering and encourage ownership of the guideline process

Consumers highlighted the importance of being involved meaningfully in guideline development. They provided examples of unacceptable token involvement including:

- Being asked to "rubber stamp" decisions already made
- Being asked to comment on documents after key aspects could not be changed
- Being the lone consumer voice in a much larger group of clinicians and researchers.

Consumers wanted the process of involvement to be empowering and encourage their ownership of the guideline. As one consumer participant stated:

> It is important not just to consult, but rather have an information exchange, to have consumers take ownership as much as they can of the living guideline as it relates to them. (C2)

The researcher participants agreed that consumers should be involved in more meaningful ways in the guideline process. As one researcher participant stated:

> We need to ensure that consumers are not just consulted, but actively involved so that they can own the process, to ensure better health for consumers. (R1)

Two ideas were presented to involve consumers more meaningfully in guidelines. These were:

- Skilled chairing of guideline panels to ensure consumer members are supported to participate
- Involving consumers in all stages of the guideline development process.

Theme 2: People with diabetes are a diverse population and need to be recruited in different ways

Several consumers raised the point that people with diabetes are a very diverse group. They felt guidelines would be more useful when they included the views of a wider range of consumers. Many consumers felt more diversity of the consumer population was needed in the living guideline development process.

Consumers suggested using a range of recruitment methods would help to encourage diversity in living guideline development. Some of the methods included:

- Using traditional print media, as well as social media and blog posts to recruit and promote living guidelines, and using internet forums for environment scanning for potential guideline topics

- Distributing materials through community organisations, GP and endocrinologists' offices, local newspapers, community radio, text messages and existing databases e.g. the National Diabetes Services Scheme (NDSS)
- Using celebrity champions and advertisements on diabetes-friendly food packaging
- Translating and broadly distributing key information into different languages and using pictorial representations rather than a lot of text
- Using consumers' personal online and offline networks and word-of-mouth.

Theme 3: A range of modes should be used to involve consumers in guideline development

Consumers suggested a combination of online and face-to-face modes should be used when involving people in living guideline development. Most consumers felt online methods were preferable for their wide reach. However, some participants felt traditional face-to-face formats were also valuable.

The most frequently proposed online method was the use of surveys using platforms such as SurveyMonkey. As one consumer said:

> SurveyMonkey is probably the best thing to use, it's pretty easy and simple […], as we need to capture as many people as we can to start with […], this helps [reaching] as many people as we can. (C8)

One consumer participant also emphasised the need for people to be able to participate in surveys anonymously. Zoom was also mentioned by consumers as a way of conducting online focus groups or forums.

Two consumers highlighted that the current public submission process for guidelines, whereby consumers can respond to draft guidelines via email, can be intimidating and inaccessible, especially for those with less knowledge of the guideline process. A suggested improvement to the current submission process was to use a survey with open questions instead.

In addition to online methods, two participants highlighted the use of traditional, offline, ways of involving consumers. One consumer participant proposed that face to face focus groups may enhance participation:

> We shouldn't lose sight of good old-fashioned methods such as face to face focus groups. Whilst they are very labor-intensive for the researchers, they often present some really good outcomes. (C4)

The researcher participants confirmed the need to reach out to those who are not online. As one stated:

> It is very internet-centric today. We recently released […] living guidelines for public consultation where we had to email a lot of people. Traditionally, we had to advertise in newspapers. [Public submissions] to guidelines currently is also via email, and there is probably a lot of people that want to submit but don't have access to the internet." (R2)

Theme 4: Consumers have different preferences about when they are involved in the guideline process

Across the two forums, there were differing views about which stages of guideline development should involve consumers. There was widespread agreement that consumers should be involved at least at the beginning of the process, including topic selection. Beyond this, some consumers wanted to be involved in all stages and others at more specific stages.

Consumers said it was more empowering to be involved from the beginning of the process and helped to ensure the guideline would be helpful. As one consumer described:

> I did a survey once that was about pre-existing diabetes in pregnancy. This guideline enraged people with diabetes as it said avoid hypo's, but there was no advice on how to avoid hypo's and no acknowledgement about how difficult it is to avoid them. (C5)

A couple of consumers also confirmed consumer involvement avoided waste:

> The sooner consumers are involved the better the outcomes. I've seen far too many projects that involved consumers at the second last step, only for the consumer to then ask have you thought about X, which could have been considered at the beginning, and would have saved months' worth of work. (C4)

This view was supported by researcher participants, one of whom stated: "Consumer input at later stages may go towards the wrong question." (R2)

Some consumers highlighted the need to involve consumers at the dissemination stage to ensure the guideline was easy to understand and less medically-driven. Three consumers stated that guidelines should be presented in an engaging way for consumers as it is already a challenge to persuade some consumers to read information. As one consumer stated:

> The biggest challenge is having people read the information, guidelines. People who are not reading these guidelines are those that need to read them most. (C9)

One participant stated that consumer summaries of the guidelines may useful. In addition, having a multi-pronged approach may also promote use:

> I think it's about targeting people living with diabetes at the right time points, when they actually need that information, and having very strategic marketing tools and resources that are easy to access, easy to read and understand. And this is where I think we have to work closely with Diabetes Australia, NDSS [National Diabetes Services Scheme], the research groups, and people living with diabetes. Even use health marketing strategies [to understand] how we actually get this information in the hands of people who need to use information at the right time points they will use them. (C10)

One consumer stated that ensuring the information is presented in as many places, languages and formats as possible may help informing consumers:

> You can increase the likelihood that people will be exposed to information through […] networking channels, so there can be a bunch of people doing that […] making it more accessible to people. (C7)

One consumer, who had been involved with living guideline development perceived that the dissemination phase was a key difference between living and standard guidelines. He felt the key advantage of living guidelines was their frequent updates, but that these updates were only useful if health practitioners and consumers were actually using them.

Theme 5: A think tank with outreach could ensure a wide range of consumers' views, using different methods, are represented

Participants in one forum suggested a model for optimising the number and diversity of consumers involved in the guideline process. This would involve a small 'think tank' of consumers with the same type of diabetes but at different stages in their illness and at different stages of life. As one participant expressed:

> When you get to the stage of putting people into smaller groups, you need to put [them] into buckets so that you know that you are covering the main areas that you want opinions on. […] As you want to cover the whole spectrum, you can probably put 10 buckets there to cover all areas. (C9)

Several consumers said that these "representative" consumers should ideally be connected to the wider diabetes community. One participant stated that:

> Having a range of consumers involved in guidelines who are linked into different parts of the diabetes community can help to ensure that as many views are represented as possible. (C8)

The think tank would then come up with key points that required further consultation with the wider diabetes community (e.g. via a widely disseminated survey etc.). Members of this group could also go back and consult with their own networks or communities to get consensus on consumers' views about different issues.

Several consumer participants were keen to begin the priority setting process in a think tank style and then reach out for broader consultation**.** Advantages of this approach included less likelihood of skewing the data (e.g. if more people with T1 than T2 responded to a survey) and avoiding the challenges of going "too broad too early", such as difficulties refining topics.

The researcher participants were supportive of the concept of a think tank. In terms of living guidelines, a think tank could allow a small group to be involved at frequent intervals (e.g. weekly) in reviewing the evidence but this group could be refreshed over time. Then, at relevant stages in the guideline process, as also suggested by the consumers, the think tank could reach out to a broader consumer base through online surveys or other methods.

Theme 6: Consumers require support to be involved in developing living guidelines

Consumers stated that different types of support were needed to facilitate consumers' involvement in living guidelines. Support included:

- Training for consumers to participate in living guidelines
- Paying consumers for their expertise
- Better education resources about living guidelines (e.g. what are they? How are they different?)

4. Proposed optimal model for living engagement in living guidelines

In the following section, we have taken the themes and ideas arising during the forums and turned them into a draft optimal model for engagement in living guidelines. The aims of the model are to:

- Encourage consumer ownership of living guidelines
- Encourage a diverse range of people to be involved in different ways
- Accommodate different preferences about how and when to be involved in guidelines
- Use a consumer think tank
- Provide support for people to participate in the engagement process.

The model seeks to address researchers' concerns about consumer fatigue given the work of a guideline panel member on a living guideline does not stop. However, the model also seeks to balance consumers' needs for continuity in consumer involvement by retaining some consumers in ongoing roles.

Under the proposed model, consumers could be involved in a living guideline via three different modes:

1. As a member of a consumer think tank
2. As a rotating member of the guideline panel
3. As a member of the consumer crowd.

These three modes would be interlinked to allow consumers to transition into different roles according to their preference. The key characteristics of the different modes are summarised in Table 1 with more detailed explanations provided below.

Table 1: Characteristics of the three modes of involvement in the proposed living engagement model

Mode of involvement	Methods	Face to face or online	Timing	Training and support
As a member of a consumer think tank	Think tank meetings and email discussions	Online	Multi-stage – regular meetings at key stages of guideline development plus email feedback on guideline meeting proposals	• Online training in living guideline methods • Peer mentors for new members • Consumer liaison officer • Consumer stipend
As a member of the guideline panel	Guideline panel meetings	Face to face or online	Continuous	• Training in living guideline methods • Peer mentors for new members • Consumer liaison officer • Consumer stipend

Mode of involvement	Methods	Face to face or online	Timing	Training and support
As a member of the consumer crowd	Range of consultation methods including surveys, discussion forums, feedback on documents	Mainly online but some face to face when needed	One or two key stages requiring broad consumer involvement (e.g. topic setting, feedback on draft guidelines)	• Online training in living guideline methods • Consumer liaison officer

Consumer think tank (ongoing advisory role)

Similar to the suggestions in the forums, we anticipate the consumer think tank would comprise around 8 to 10 people representing a range of lived experience with diabetes. The group would be chosen to represent a range of views, within a particular diabetes diagnosis, including the following: time since diagnosis (newly diagnosed to living with diabetes for many years), different culturally and linguistically diverse backgrounds and range of ages.

All members of the consumer think tank would receive online training and support about participating in the living guideline process. Also, as consumer guideline panel members would be drawn from the think tank, all think tank members would receive training about being a guideline panel member (see below). Consistent with the intensity of consumer think tank input, consumers would be compensated for their time in meetings and preparation. Think tank meetings would be supported by a consumer liaison officer.

The think tank would be convened online at key stages in the guideline process. The role of the think tank would be to provide consumer expertise to the guideline panel about:

- The scope, questions and recommendations for the guideline
- Whether the proposed outcome measures are important to consumers
- How a recommendation might be viewed by different consumers
- Consumer issues arising from public consultations (including from the crowd)
- Guideline implementation issues for consumers.

The consumer think tank would also decide when specific issues needed a broader range of input through referral to the consumer crowd. The think tank would also be asked to provide feedback to consumer guideline panel members prior to guideline panel meetings when needed.

Consistent with being a “living” model, if a think tank member decides to step down, a new member representing a similar population will be sought via the consumer crowd (see below).

Consumer think tank members could participate in different guidelines relevant to the population they are representing.

Consumer guideline panel members (rotating advisory role)

This role is most similar to the current role for consumers in standard guidelines. At any one time, there would be two consumer members on the multidisciplinary guideline panel (who rotate at

staggered intervals). The guideline panel would be involved in all stages of guideline development. As living guidelines are continuously updated, the work of the guideline panel is ongoing. Therefore, to prevent consumer fatigue, pairs of think tank members would rotate on and off the guideline panel at staggered intervals according to a roster with each attending for a period of six to twelve months before being replaced by a new member from the think tank.

All think tank members would be trained and supported to undertake the role of a consumer guideline panel member. However, only think tank members wanting to participate on the guideline panel would be asked to fulfil this role. Consumer guideline panel members would consult with the think tank via email prior to panel meetings on any items requiring consumer input. This would help consumer guideline panel members to represent a range of consumer views and also feel their panel participation was supported by a larger group of consumers.

Consumer crowd (consultancy role, could be one-off or ongoing)

The consumer crowd would be a large group consisting of a diverse range of consumers both online and offline. The crowd would play a consultancy role in guideline development. Crowd members would receive regular updates on the development of the guideline. They would also be consulted when a broader range of consumers views would be pert at key stages, such as topic selection and review of draft guidelines (through online or phone surveys and discussion forums).

Crowd members will be recruited through social media, the networks of think tank members and targeted approaches to community agencies, community media etc. People would be able to join the think tank at any time across the course of the guideline.

Vacancies on the think tank would be advertised through the crowd to promote the role to a wider range of people.

5. Acknowledgements

The authors would like to thank the consumers and researchers involved in the forums.