

Response ID ANON-UMZ8-J5E4-C

Submitted to Conversations for Change Consultation Survey
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Privacy Information

Further information about privacy

Consent to publish response (submission)

I consent to my submission being published including both my name and organisation's name (if relevant)

Acknowledgement

I acknowledge the above.

Your Details

What is your name?

Name:
Nicole Millis

What is your email address?

Email:
nicole.millis@rarevoices.org.au

What is your main area of interest?

Both

Please indicate the group that best represents you and/or your organisation:

Other (please specify)

Please comment if 'Other' ticked or further explanation is required:

National peak body for Australians living with a rare disease

If you are providing input on behalf of a group/organisation, please provide the name of your group/organisation:

Name of Organisation or Group:
Rare Voices Australia

The Survey

Please tell us what you like about the current opportunities for consumer input into the HTA process

Like about current consumer input opportunities:

Positives of the current HTA process are that there are clearly defined opportunities for consumers to provide input. In recent times, improvements to the website form as well as work done by and support from the Consumer Evidence and Engagement Unit, have made providing input less daunting for consumers. Quality education about HTA processes from external organisations such as Rare Voices Australia and Patient Voice Initiative also continues to be valuable for improving the quality of consumer engagement.

Please tell us where you consider consumer input could be increased in the process? Why do you think this will improve the current system?

Where to increase consumer input? Why will this improve it?:

As well as the current opportunities for consumer input, there should be additional opportunities to actively seek consumer input at earlier stages in the HTA process including:

1. consumer consultation ahead of a TGA assessment, and
2. consumer consultation at the initial stages of lodging an application.

Formal consumer consultation ahead of a TGA assessment will increase transparency and familiarity of consumers with the application which will improve the quality of their input later in the process. It will also ensure that the person-centred perspective is appropriately considered in the TGA Assessment in key areas such as indication/ population/ authority etc. This is particularly important as TGA approval provides the parameters for

PBAC/MSAC consideration.

Formal consumer consultation at the initial stages of lodging an application will enable greater transparency around potential uncertainties of the application and scoping of how to potentially address these, before PBAC/MSAC consideration. This may help reduce the over-reliance on multiple resubmissions to reduce uncertainty, and encourage a more timely outcome, particularly in the rare disease context.

Consumer consultation can be of particular value in the rare disease context where there is often limited data. Flagging the uncertainties/ challenges earlier provides consumers more time to provide information/ evidence/ data to address these.

The Survey continued

How should the consumer voice be included and supported?

Please tell us how you think the consumer can be better involved and supported in the HTA process.:

A distinction between individual submissions and consumer group led submissions would be helpful, with emphasis on building capacity of consumer led groups to provide informed, inclusive leadership to their communities and to provide submissions that are genuinely helpful to committees in their decision making.

1. Guidance and education for consumer led groups and peak bodies on the development of a group response to a submission. This should include:

- Feedback on what was helpful or not helpful in previous submissions
- Guidelines around what committees consider evidence in the context of HTA
- Guidelines around how consumer led groups can ethically and appropriately collect robust and valid data that can address limited evidence or uncertainty in complex submissions
- Ensuring that submissions from consumer led groups demonstrate evidence of community engagement in the development of submissions

What do you think is the most important? (from the above suggestions or other ideas):

Submission summary available

Education around HTA

Stakeholder meetings for complex submissions that are likely to have high levels of uncertainty.

Further comments and information

Please provide below any further comments you would like to make?

Further comments:

Thank you for the opportunity for Rare Voices Australia (RVA) to provide input. As the peak body RVA leads the way in experience and knowledge in rare disease HTA. We look forward to continuing this discussion.

UPLOAD A FILE: If you would like to upload a file with your responses to the above questions, please do so below.

File upload:

No file uploaded

All responses received will be summarised to inform further consultations during 2022

Yes I would like to be notified

Topics from the survey will be discussed at the HTA 'Conversations for Change' Consumer Symposium on the 18 and 19 October 2022.