

Response ID ANON-9BTQ-P3CP-P

Submitted to Consultation on the revised PBS Post-market Review (PMR) Framework
Submitted on 2022-12-16 08:08:12

Section 1. Privacy and consent

1 Do you consent to the Department collecting the information requested in Citizen Space about you, including any sensitive information, for the purposes of this consultation?

Yes, I consent

2 Do you consent to the Department publishing your response to this consultation, on the Published responses page, after the consultation close date?

Yes, I consent to my full response being published

Section 2. Contact details

3 What is your name?

Name:
Nicole Millis

4 What is your email address?

Email address:
nicole.millis@rarevoices.org.au

5 Are you providing input as an individual or on behalf of an organisation?

Other

6 If you are providing input on behalf of an organisation, please provide the name of your organisation.

Organisation name:
Rare Voices Australia

7 What is your phone number?

Phone number:
+61459021204

Section 3. Proposed change no. 1 - Public consultation on the draft Terms of Reference

8 Please provide your comments.

Comments:

RVA strongly discourages any HTA process from reducing public consultation, which runs counter to the National Medicines Policy; other Departmental initiatives such as the Consumer Evidence and Engagement Unit; as well as the National Strategic Action Plan for Rare Diseases which has a foundation principle of "Person-centred", and "embed the voice of people living with a rare disease and the families and carers throughout structures and systems that impact rare diseases" as a key action.

Public consultation on the Draft ToRs is an important safeguard to help ensure the scope of the review is most appropriate. If the public consultation on the Draft ToRs in the current process has limited effectiveness, this is more likely reflective of other factors requiring urgent attention, such as ineffective community engagement, awareness and education. RVA encourages the Department to internally consult with its Consumer Evidence and Engagement Unit in the first instance to strengthen the PBS PMR review process. Rather than remove the current public consultation on the Draft ToRs, RVA recommends the provision of additional ways to capture consumer input. For instance, the process should also integrate those related questions into the public consultation form itself and allow the PBAC flexibility to consider areas outside of Terms of Reference as they are raised. eg Questions should be similar to 'Do the ToRs cover all the relevant issues? What is not covered? What do we need to know about this?'

Section 4. Proposed change no. 2 - Review Reference Group

9 Please provide your comments.

Comments:

While recognising the existing expertise on PBAC, it is important that relevant and informed consumers are involved in the decisions about the need for a Consumer Reference group in each instance. The involvement of the Department's Consumer Evidence and Engagement Unit would facilitate greater effectiveness and efficiency here.

Section 5. Proposed change no. 3 - Publication of Review Reference Group membership

10 Please provide your comments.

Comments:

Publishing information on the Reference Group Membership at the beginning of the PMR provides greater transparency and reassurance for stakeholders regarding members' experience and expertise.

Section 6. Proposed change no. 4 - Removal of references to internal working groups and other wording updates

11 Please provide your comments.

Comments:

Nil comment

Section 7. General comments

12 Please provide your comments.

Comments:

Rare Voices Australia supports the aim of more rapid post-market reviews, but this simply should not be done at the expense of public consultation. RVA encourages better internal collaboration with the Consumer and Evidence Engagement Unit, which would not only result in more effective consumer consultation, but also produce efficiencies due to the Unit's expertise, experience and established stakeholder relationships.

Thank you for the opportunity to provide input. RVA is happy to be contacted for any further information/ clarification as required.

Reference:

Australian Government, Department of Health (2020) National Strategic Action Plan for Rare Diseases

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