Response
2
The Department may, at its discretion, publish part or all of the information provided in your submission on the Department's website or in related documents. If information from your submission is published, the Department may identify you and/or your organisation as the author of the submission. All personal contact details will be removed prior to publishing.
Yes, I consent to my identified submission being published
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What is your name?
Janelle Bowden
7
Please select the type of individual(s) or organisation(s) you represent. Please select all that apply. - Selected Choice
Patient or consumer (or representative organisation),Consulting
8.1
What is the name of your organisation? - My organisation is called: - Text
AccessCR Pty Ltd
9
Are you making feedback on behalf of your organisation?
Your organisation
13
Please select which chapter/s you would like to provide feedback on. You may provide feedback on as many or few chapters as you wish.
1. Transparency, communication, and stakeholder involvement in HTA
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Please select the topics within the chapter(s) you would like to provide feedback on. 1. Transparency, communication and stakeholder involvement in HTA
1.2. Consumer, clinician and other stakeholder engagement and consideration in HTA
27
Taking all Options within this section: 1.2. Consumer, clinician and other stakeholder engagement and consideration in HTA into account. **Overall, to what extent could the options (if implemented) address the issues that relate to them?**
Don't know
28
If you would like to expand on your answer above you can do so below:
AccessCR acknowledges that the scope of the HTA review does not encompass the research and development of therapeutic products which may one day end up in seeking public reimbursement. However HTA processes do take into account the evidence generated during clinical trials. For that reason we support the development of a framework which promotes consumer input into clinical trials and reduces duplication by asking sponsors to report any patient input/patient experience data. With respect to strengthening that consumer evidence however, we would suggest a stronger mandate is needed to involve patients up front. This could be achieved, as has been done in other jurisdictions, by a requirement to explicitly outline the involvement of patients during the clinical trial phases, as well as their experiences of the product during clinical trials (beyond clinical outcomes) when applying for registration and reimbursement of their products. Requiring such evidence would also increase certainty for the HTA review committees, should they be considering provisional funding arrangements at the time of registration, that a product indeed is desirable, safe, effective and addresses patient needs, from the patient and families perspectives. With support increased transparency in HTA committee meeting deliberations, but advise care will necessary to ensure that diverse consumers are able to represent their experiences and needs, not just the single loudest voice.
29.1
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Develop an engagement framework
Positive
29.2
If implemented, overall would these Options have a positive or negative impact on you (/your organisation)? - Strengthen consumer evidence
Neutral
167
In summary, considering all the draft reform options together: **How confident are you that the reform options (if implemented) will make health technology assessments better overall?**
Don't know
168
If you would like to expand on your answer above you can do so below:
AccessCR's expertise exists in the clinical trials domain, rather than in latter Health Technology Assessment processes. We refrain therefore from making conclusions about the likely impact of the full suite of options presented. Our submission has purposefully been limited to where the Options Paper makes reference to consumer input into, and experiences in clinical trials (section 1.2). In our view, mandating greater consumer input into clinical trials, and requiring the collection and reporting of more data on the experience patients in clinical trials have with those products can only strengthen the certainty and confidence of regulators and HTA bodies to approve and fund (or not) the products before them.
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Finally, do you have any further comments about the draft Options Paper or consultation you would like to make before submitting your feedback?
Thankyou for the opportunity to make a submission. We acknowledge the enormous work of many in undertaking this review. AccessCR is hopeful that while the entire product lifecycle is out of scope for this review, that the committee will structure recommendations in a way that will support greater consumer engagement, input and consumer evidence generation at all stages of product development.