Enhancing the Patient-Centricity of Value Assessment: Pearls of Wisdom from Other Members of the Patient Community

Patient Input in Value Assessment is Necessary
The patient community is a critical voice that should be included in the value assessment conversation. Despite this, it's a voice that often goes unheard. Including the perspectives of patient groups can help to ensure that economic models and final reports reflect patients' true lived experience. In order to be meaningfully engaged in value assessment, patient advocacy groups should explore the various ways their voices can be heard beyond public comment.

Five Pearls of Wisdom: Ways to Make an Impact Beyond Public Comment

PEARL: BE PROACTIVE AND TAKE ADVANTAGE OF OPPORTUNITIES
Many value assessment bodies are interested in engaging members of the patient community, but do not always know which organizations to reach out to. If a new product is expected to be approved in your therapeutic area, there is a good chance that a value assessment is coming. Reach out to value assessors proactively and express your organization's interest in contributing to their work. Ask if opportunities to engage exist and about the timeframe.

Be prepared: Engaging in value assessment will require staff time and resources, such as travel costs to participate in in-person meetings. If you are a small organization, you might need to rethink short-term goals to accommodate meaningful participation.

PEARL: CONSIDER ENGAGING VALUE-ASSESSMENT EXPERTS
Consider partnering with or contracting health economic and/or outcome researchers. The language and analyses included in a value assessment are often very complex. These experts can provide support to you in reviewing proposed economic models, epidemiologic estimates, and preparing comments.

PEARL: PROVIDE SUGGESTIONS ON DELIBERATIVE QUESTIONS
Some value-assessment bodies have a public meeting to deliberate or vote on specific questions. Review the questions in advance and provide suggestions, even if there is not a formal call for comments on those questions. Consider alignment between the questions, your organization’s comments, and anticipated public testimony.

PEARL: USE VALUE ASSESSMENT AS AN OPPORTUNITY TO RAISE AWARENESS ABOUT YOUR COMMUNITY
You may be able to piggyback on press coverage about a value assessment to raise awareness about challenges faced by patients in your community. Consider developing op-eds or other articles highlighting patient experiences, even articles not directly related to value assessment.

PEARL: ENCOURAGE INVOLVEMENT OF KEY EXPERTS
Clinical experts and methodologists are often included as advisors in value assessments. It is essential that those individuals have the most up-to-date knowledge about standards of care, ongoing research, and understanding of the patient community. As part of your early engagement with value assessors, you should recommend that they reach out to specific experts, including:

- Clinical experts
- Professional societies
- Methodologist with expertise in the specific disease area
- Patients or family caregivers

Ensure that recommended participants understand the purpose of value assessment and how it differs from regulatory review and clinical research.

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This list was developed by members of the patient community who have already gone through a value assessment. It is intended to be a resource for patient groups who are participating in a value assessment for the first time. It was developed as part of Breakout Session #2 during “Back to School with the National Health Council: Patient Community Training on Value Assessment” held on September 6, 2019. The training was funded through a Patient-Centered Outcomes Research Institute (PCORI) Engagement Award (8620-NHC). The views presented in this resource are solely those of Breakout group #2 participants and does not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, or Methodology Committee. Acknowledgements: Annie Kennedy and T. Rosie Love for facilitating the breakout session.