Improving The Patient Centricity Of Value Assessments: A Rubric

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HTAi, June 19, 2017

Background

- Value is individualized and disease-dependent, and can evolve with the disease trajectory or a patient's stage of life

- Patient perspectives on value can differ significantly from that of physicians and payers

Objective

- Develop a Patient-Centeredness Rubric for Value Frameworks and Assessments
  - Guide for value framework developers on meaningful incorporation of patient engagement
  - Evaluate the patient-centeredness of value frameworks and assessments
  - "Rubric" or tool with criteria and levels of achievement in patient-centeredness and patient engagement

Methods

Roundtable Discussion	• Review existing patient engagement rubrics • Hallmark characteristics of patient-centeredness • Illustrative examples of high versus low engagement
Rubric Draft 1	• Reviewed by Roundtable participants • Rubric draft 1 edited based on feedback
Rubric Draft 2	• Circulated to a larger review group" (33 organizations) • Rubric draft 2 edited based on feedback
Rubric V1	• Rubric released alongside Webinar in March 2016

Participation

Roundtable Discussion	Review Group
28 organizations invited • 12 patient organizations • 3 payers • 6 professional or policy organizations • 5 biopharmaceutical organizations, and • 2 not-for-profit research organizations	**37 organizations invited** • 12 patient organizations, • 3 payers • 7 professional or policy organizations • 9 biopharmaceutical organizations • 2 not-for-profit research organizations • 4 value framework developers
14 organizations participated • 7 patient organizations • 1 consumer organization • 3 biopharmaceutical organizations • 2 professional organizations • 1 not-for-profit research organization	**14 organizations provided comment** • 1 payer • 3 professional or policy organizations • 7 biopharmaceutical organizations • 3 value framework developers

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Domains of a patient-centered value model

Planning	Drafting and Refinement	Dissemination and Implementation	Evaluation	Update and Maintenance

Patient partnership

Transparency to patients

Inclusiveness of patients

Diversity of patients/populations

Patient-centered outcomes

Patient-centered data sources

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Value Model Rubric

	Characteristics of Meaningful Patient Engagement in Model Development High ← → Low	Characteristics of Patient Centeredness in Model Development High ← → Low
Patient Partnership **Transparency** **Inclusiveness** **Diversity** **Outcomes** **Data Sources**	▪ Direct relationships and partnerships are bidirectional, reciprocal, and continuous. ▪ Communications are open, honest, and clear. Engagement goals, participants, methods, desired impacts, and actual impacts are clearly outlined and transparent.	▪ Created by engaging, informing, and actively listening to people with chronic conditions. ▪ Respectful of and responsive to patient preferences, needs, and values in context of their own social worlds.

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Patient Partnership: Patients should be involved in every step of the development and dissemination processes

Characteristic	High Engagement	Low Engagement
Direct input is collected from a wide range of patients as suited to the disease, population, and context	Patient survey, interviews of disease-specific patient advocacy group staff, and/or use of a disease-specific registry	Only include use of data from randomized controlled trials reporting clinical outcomes.

Consideration	High Patient-Centeredness	Low Patient-Centeredness
Rationale to substantiate the adequacy of the ratio of patient to non-patient participants is provided	Of a 10-member advisory committee, 2 members were patients and 1 was a family caregiver, and rationale was provided for stakeholder composition	No patients served on an advisory committee and no rationale was provided for stakeholder composition

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Transparency to Patients - Assumptions and inputs – and each step in the process – should be disclosed in an understandable way and in a timely fashion

Characteristic	High Engagement	Low Engagement
The process for selection of patient representatives is transparent	The specific criteria used to identify, select, and invite patient representatives were disclosed, along with a rationale	No systematic process and/or criteria for selecting patient representatives was provided

Inclusiveness of Patients - Perspectives drawn from a broad range of stakeholders, including the patient community, should be reflected

Consideration	High Patient-Centeredness	Low Patient-Centeredness
The draft framwork/model is vetted with a broad coalition of stakeholders, including patients	A broad coalition of patient organizations was given appropriate time to vet the framework/model	Notification of public comment period(s) was not widely distributed

Diversity of Patients/ Populations - Differences across patient subpopulations, trajectory of disease, and stage of a patient's life should be accounted for

Characteristic	High Engagement	Low Engagement
Diversity of the patient population is acknowledged and considered	Thoughtful consideration was given to differences in patient perceptions of value across relevant patient subpopulations, including populations at-risk and those with early- and late-stage disease	The model assumed the patient population is homogenous and takes a 'one-size-fits-all' approach

Outcomes Patients Care About - The outcomes integrated should include those patients have identified as important and consistent with their goals, aspirations, and experiences

Consideration	High Patient-Centeredness	Low Patient-Centeredness
Economic inputs are considered in the context of a patient's experience	The model incorporated costs from a variety of stakeholder perspectives, including patient out-of-pocket costs	Only cost issues from the payer perspective were included without rationale for exclusion of patient costs

Patient-Centered Data Sources – Variety of credible data sources are used allowing for incorporation of new information and account for the diversity of patient populations and patient-centered outcomes, especially those from real-world settings and reported by patients directly

Characteristic	High Engagement	Low Engagement
Existing sources of patient-generated health data (e.g., patient registries or patent-reported outcomes) are identified and considered	Data on patient-reported outcomes were used, and the sources well described	No effort was made to identify sources of patient-reported data on physical function, though this was identified by patients as the outcome of highest priority

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Discussion

- Participants support the intent behind value assessments and they do not wish to waste money or other resources on unnecessary procedures and/or prescriptions
  - But, patients want information to make informed decisions on the basis of what is or is not valuable to them

Limitations

- Rubric content was based on a convenience sample of NHC members, colleagues, collaborators, and others who had been recommended by roundtable participants

- Not formally tested and needs to be used by various stakeholders to fully capture its utility, validity, and impact

- Developed in the context of the US health care system

Conclusion

- Intended to assist all stakeholders and support developers in conceptualizing plans for meaningfully engaging patients
- Rubric should be considered a guide for patient-centeredness good practices
- Living document, to be refined over time on the basis of feedback from patient, patient group, framework developer, and other stakeholder-use experiences

Resources

- **Rubric:** The National Health Council. Patient-centered value model rubric released: National Health Council shares guidance for assessing the value of new treatments. Available from: http://www.nationalhealthcouncil.org/patient-centered-value-model-rubric-released

- **Webinar:** Perfetto EM, Balch A, Sennet C, Pearson S. The patient voice in value: the NHC patient-centeredness value model rubric. 2016. Available from: https://nhcouncil.adobeconnect.com/p2tfj2nr9e4/?launcher=false&fcsContent=true&pbMode=normal

- **Manuscript**: Perfetto EM, Oehrlein EM, Boutin M, Reid S, Gascho E. Value to Whom? The Patient Voice in the Value Discussion. Value Health. 2017 Feb; 20(2):286-291. doi: 10.1016/j.jval.2016.11.014.

- Acknowledgement: the National Health Council receives membership dues and sponsorship support from various organizations listed on its Web site (http://www.nationalhealthcouncil.org/about-nhc/sponsors)

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