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Inclusion of Patient Input in Value and Health Technology Assessment

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Outline

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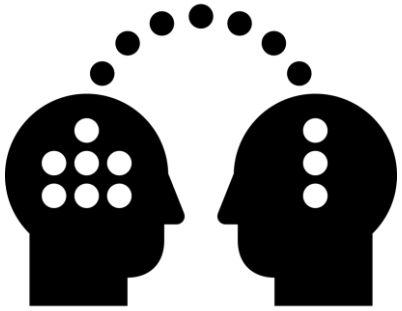

Background

- Evolution in recognizing the importance of patient-provided information (PPIn) in health care decision-making
  - Research, regulatory, clinical, etc.
- PPIn in value and health technology assessment (V/HTA)

Objective

To evaluate V/HTA organizations' requirements for and use of patient input, comparing practices across U.S. value assessment organizations and ex-U.S. health technology assessment bodies

Methods

- 11 V/HTA organizations
  - Europe
    - France – HAS
    - Germany – IQWiG
    - UK – NICE
  - North America
    - Canada – CADTH
    - U.S. – ACC/AHA, ASCO, A/FC, ICER, IVI, MSKCC, NCCN

Methods

- V/HTA methodology document(s) and up to 3 recent report document(s) per organization
- Systematic abstraction of PPIn recommendations and/or requirements
- 2 data abstractors, 1 tie-breaker

Results

Organization	Abbreviation	Country	Organization Type	Methods Document Title	Publish or Last Updated Date	Inclusion of PPIn	Accepted Patient Stakeholders	PPIn Solicitation Methods	PPIn Text
American College of Cardiology / American Heart Association	ACC / AHA	United States	Non-Profit	ACC/AHA Statement on Cost/Value Methodology in Clinical Practice Guidelines and Performance Measures	[CV] June 2014	Cannot determine if methods apply to cost/value assessment	N/A	N/A	[CV] "Moreover, the ACC and AHA remain committed to engaging patient representatives who now serve on the Task Force on Practice Guidelines and guideline writing committees in the discussion and dissemination of these concepts."
American Society of Clinical Oncology	ASCO	United States	Non-Profit	American Society of Clinical Oncology Statement: A Conceptual Framework to Assess the Value of Cancer Treatment Options	[CF] August 2015	No	N/A	N/A	[CF] "There is additional information that is important to patients that cannot easily be incorporated into the framework because of the lack of complete and easily accessible data, such as quality of life or patient-reported outcomes. Developing the framework illuminated how important it is that these variables be more consistently
Avalere/FasterCures	A/FC	USA	Non-Profit	[PPVF] Patient Perspective Value Framework	[PPVF] May 2017	Yes	Patients	Not described	[PPVF] "The incorporation of patient preferences into the process of assessing the value of a set of healthcare options is central to the PPVF" "The PPVF methodology is driven by the Patient Preferences domain. A PPVF assessment will measure patient preferences and then will use those preferences to weight
Canadian Agency for Drugs and Technologies in Health	CADTH	Canada	Government	[CDR] Procedure and Guidelines for CADTH CDR	[CDR] August 2018	Yes	Patients	Not described	[CDR] "Patient input provides patients' experiences and perspectives of living with a medical condition for which a drug under review is indicated, their experiences with currently available treatments, and their expectations for the drug under review. This information is used by CADTH in the review of submissions, resubmissions based on new
Canadian Agency for Drugs and Technologies in Health	CADTH	Canada	Government	[EE] Guidelines for the Economic Evaluation of Health Technologies: Canada	[EE] July 2017	No	N/A	N/A	Not mentioned
Canadian Agency for Drugs and Technologies in Health	CADTH	Canada	Government	[PI] Instructions for providing patient input	[PI] February 2018	Yes	Patient groups	Calls for patient input on website	[PI] "Any interested patient group can provide input. We seek input from patient groups, rather than from individuals, to encourage diversity of voices and experiences."; Calls for patient input, uses a CDR patient input template; patient groups receive a feedback letter after review is completed, highlights areas from the input

Results

- Methodologies
  - European and Canadian V/HTA bodies accept PPIn
  - U.S. V/HTA acceptance of PPIn is limited (ICER, A/FC)
  - Methods of PPIn solicitation are frequently unclear
- Reports
  - Use of collected PPIn is generally not well-documented

Results

- Examples of PPIn use
  - CADTH:
    - Comments on manufacturer-submitted economic model
    - Critique of pivotal clinical trial outcomes
  - NICE
    - PPIn is used to inform NICE-appraisal-committee members of disease impact to patients and careers in pre-meeting briefings

Key Limitations

- Limited details provided in publicly available documents
- Small sample of reports evaluated
- Could not assess PPIn in reports for organizations that do not publish assessments (A/FC, ASCO, MSKCC)

Conclusion

- U.S. V/HTA organizations lag behind Canadian and European counterparts in soliciting and incorporating patient input
- Potential for greater leveraging of PPIn in V/HTA processes
- Increased transparency and improved reporting are needed
- Good practices on including patient input should be identified and shared among V/HTA organizations

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