The Patient Voice in Value:
The NHC Patient-Centered Value Model Rubric

March 28, 2016
Housekeeping Announcements

- Please submit questions to the moderator via the chat function on the screen
- Submitted questions will be answered at the end of the webinar
- Will record the presentation and make it available via the National Health Council website
- Problems during the presentation?
  - Contact us at sreid@nhcouncil.org or 202-785-3910
The Patient Voice in Value: The NHC Patient-Centered Value Model Rubric

March 28, 2016
Agenda

- Welcome and Introductions
- Value Models and their Impact on Patients
- Incorporating the Patient Voice in the Value Debate
- ICER Perspective
- Next Steps
- Q & A
Webinar Speakers

Moderator
Eleanor Perfetto, PhD, MS
Senior Vice President of Strategic Initiatives
National Health Council

Alan Balch, PhD
Chief Executive Officer
National Patient Advocate Foundation

Cary Sennett, MD, PhD
President & CEO
Asthma and Allergy Foundation of America

Steven D. Pearson, MD, MSc
President
Institute for Clinical and Economic Review
National Health Council’s Value Model Rubric

The rubric is intended to

- Help assess the patient centeredness of existing value models
- Ensure the patient community is engaged throughout the process

The rubric is *not* intended to

- Brand value models as “good” or “bad”
NHC View of Patient Centeredness

- Respectful of and responsive to individual patient preferences, needs, and values in context of their own social worlds
- Created by engaging, informing, and actively listening to people with chronic conditions at every point of contact from research to the bedside and everywhere in between
- Requires engagement with the patient community
NHC View of Meaningful Patient Engagement

- Interactions are based on a bidirectional, reciprocal, and continuous relationships and partnerships
- Communications are open, honest, clear
- Engagement goals, participants, methods, desired impacts, and actual impacts are clearly outlined and transparent
Value Models and Their Impact on Patients

Speaker:
Alan Balch, PhD
Chief Executive Officer
National Patient Advocate Foundation
Recent Value Models & Frameworks

ASCO®
American Society of Clinical Oncology

ICER
INSTITUTE FOR CLINICAL AND ECONOMIC REVIEW

Memorial Sloan Kettering Cancer Center

NCCN
National Comprehensive Cancer Network®
### 2015 – Year of Value Models/Frameworks

<table>
<thead>
<tr>
<th>Organization/Network</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memorial Sloan Kettering Cancer Center’s Drug Abacus</td>
<td>May 2015</td>
</tr>
<tr>
<td>National Comprehensive Cancer Network (NCCN)</td>
<td>June 2015</td>
</tr>
<tr>
<td>Institute for Clinical and Economic Review (ICER)</td>
<td>September 2015</td>
</tr>
<tr>
<td>American Society of Clinical Oncology (ASCO)</td>
<td>October 2015</td>
</tr>
</tbody>
</table>
Drug Abacus

An Interactive Website compares price to a value-based price based on user.

NCCN

Aims to inform physician-patient treatment decision-making; guidelines will be updated to include “evidence blocks” to indicate more affordable treatment.

ICER

A tool that releases a value-based benchmark price positioned to inform payers; PCSK9 class evaluation released; Plans for 15-20 drugs in 2 years.

ASCO

Aim is to support shared decision-making between physicians, patients.
Some Characteristics Noted

1. Significant focus on oncology
   • ICER model covers a broader range
2. Most evaluate “traditional” endpoints and evidence
3. Primary audience has been payers and physicians
4. All evolving, though process is unclear at this early stage
5. Scoring approach varies, can lead to a range in assessed “value” for same treatments
6. Most base evaluations on high-quality clinical trial data; though ICER states it uses all available trials
7. Methods can be unclear
Lack of Obvious Patient Centeredness

No apparent patient engagement throughout the process in

- Defining value
- Developing questions
- Formatting model
- Collecting data
- Dissemination

Costs to patients not consistently assessed and lack of clarity on how it’s done
Incorporating the Patient Voice in the Value Debate

Speaker:
Cary Sennett, MD, PhD
President and Chief Executive Officer
Asthma and Allergy Foundation of America
How Do We Know a Model Captures Value as Patients Perceive It?

- We look to see that the model was developed with meaningful patient engagement.
- We look to see that the model and process considered patient centeredness to the extent possible.
Assessing a Value Model’s Patient Centeredness

PURPOSE:
- Tool to assess the level of patient centeredness of a given model
- Guide value model developers in meaningful patient engagement throughout the process

AUDIENCE:
- Health care stakeholders, including NHC members and other patient organizations

DESired OUTCOMES:
- As value models are developed and refined, they reflect the views of patients and their families
Value-Model Development Process

- Planning
- Drafting and Refinement
- Dissemination and Implementation
- Evaluation
- Update and Maintenance

- Patient partnership
- Transparency to patients
- Inclusiveness of patients
- Diversity of patients/populations
- Outcomes patients care about
- Patient-centered data sources
Characteristics of Patient Engagement and Patient Centeredness in Value Models

Meaningful Patient Engagement in Model Development Process:
- Illustrate efforts for incorporation of the patient voice
- Patient community is engaged directly in development processes

Patient-Centeredness Considerations in General:
- Enhance the patient centeredness of the model and the development processes, though patient engagement may not always be direct
## Value Model Rubric: Examples

<table>
<thead>
<tr>
<th>Characteristics of Meaningful Patient Engagement in Model Development</th>
<th>Other Characteristics of Patient-Centeredness in Model Development</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Partnership</strong></td>
<td></td>
</tr>
<tr>
<td>Patients are recognized as partners and are integrated in all aspects of model development phases</td>
<td>Patients are engaged in pilot testing and refinement of the model</td>
</tr>
<tr>
<td><strong>Transparency</strong></td>
<td></td>
</tr>
<tr>
<td>The process for selection of patient representatives is transparent</td>
<td>The methodology is made transparent to patients in a timely manner</td>
</tr>
<tr>
<td><strong>Inclusiveness</strong></td>
<td></td>
</tr>
<tr>
<td>The patient community is involved throughout the process</td>
<td>The draft model is vetted with a broad coalition of stakeholders, including patients</td>
</tr>
</tbody>
</table>
# Value Model Rubric: Examples

<table>
<thead>
<tr>
<th>Characteristics of Meaningful Patient Engagement in Model Development</th>
<th>Other Characteristics of Patient-Centeredness in Model Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diversity</td>
<td></td>
</tr>
<tr>
<td>Diversity of the patient population is acknowledged and considered</td>
<td>Processes are included for identifying/incorporating new knowledge regarding patient subpopulations and disease trajectory</td>
</tr>
<tr>
<td>Outcomes</td>
<td></td>
</tr>
<tr>
<td>Outcomes important to patients are identified and incorporated into the model</td>
<td>Economic inputs are considered in the context of a patient’s experience</td>
</tr>
<tr>
<td>Data Sources</td>
<td></td>
</tr>
<tr>
<td>Existing sources of patient-generated health data are identified and considered</td>
<td>Data beyond randomized controlled trials are considered (e.g., patient preferences)</td>
</tr>
</tbody>
</table>
ICER Perspective

Speaker:
Steven D. Pearson, MD, MSc
President
Institute for Clinical and Economic Review
Next Steps

Speaker:
Eleanor Perfetto, PhD, MS
Senior Vice President, Strategic Initiatives
National Health Council
Next Steps

- **IMPLEMENTATION AND EVALUATION**
  - How/where does the rubric work?
  - How/where is it not working?

- **UPDATE AND IMPROVE BASED ON EXPERIENCE**

- **DEVELOP OTHER NEEDED TOOLS**
  - “Get Ready” Checklist
  - Facilitated conversations
  - Patient/patient group training about economics and value models
Q & A

Moderator
Eleanor Perfetto, PhD, MS
Senior Vice President of Strategic Initiatives
National Health Council

Alan Balch, PhD
Chief Executive Officer
National Patient Advocate Foundation

Cary Sennett, MD, PhD
President & CEO
Asthma and Allergy Foundation of America

Steven D. Pearson, MD, MSc
President
Institute for Clinical and Economic Review
For more information, please contact

Eleanor Perfetto
eperfetto@nhcouncil.org

To download the Value Model Rubric or view a recording of this webinar, go to

www.nationalhealthcouncil.org/value