Patient Centricity in Healthcare Decision Making (including HTA)

Durhane Wong-Rieger, PhD
Canadian Organization for Rare Disorders

Patient Roles in Healthcare Decision Making Are Changing!
# Multiple Roles for Engaged Patients

<table>
<thead>
<tr>
<th>Inside Advisor, Reformer</th>
<th>Broker, Council Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Input: Council, Task Force,</td>
<td>- Input: Committee, Board, Council</td>
</tr>
<tr>
<td>- Collect Info: Survey, Focus Group</td>
<td>- Collect Info: Experts, Deliberation</td>
</tr>
<tr>
<td>- Form of Info: Consultation, Debate</td>
<td>- Form of Info: Analytical, Guidelines</td>
</tr>
<tr>
<td>- Impact: Advise, Discretionary</td>
<td>- Impact: Varied, Based on Guidelines</td>
</tr>
<tr>
<td>- Examples: NICE Citizens Council, IQWiG</td>
<td>- Examples: EMA, AU MASC, CADTH</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Individual Patients</th>
<th>Patient Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Input thru Clinical Trials, Testimony</td>
<td>- Input: Submission</td>
</tr>
<tr>
<td>- Collect Info: QoL, PROs, Impact Statement</td>
<td>- Collect Info: Written, Oral, Meetings</td>
</tr>
<tr>
<td>- Form of Info: Ratings, Qualitative</td>
<td>- Form of Info: Qualitative Statement</td>
</tr>
<tr>
<td>- Examples: FDA, SMC, IQWiG</td>
<td>- Examples: NICE, SMC AU MASC, CADTH</td>
</tr>
</tbody>
</table>

**External – Internal Engagement**

**Patient Representation**

**HTA Agencies All Introducing Patient Engagement Processes**
Patient Involvement in HTA: Country Differences

Patient Evidence From Published secondary, expert groups primary data

Patient Submission: By individuals, comments from experts, associations

Patient Submission: By patient groups, networks, consortiums

Patient Rep: Include Individuals, advocates, groups on committees; public forums

Patients/Public Attendance: HTA deliberation/decision-making

Denmark (regionalized)
Sweden SBU
Italy AGENAS

UK NICE
Brazil CONITEC
Colombia IETS
Taiwan NHIA

Australia PBAC
Germany IQWiG
Scotland SMC
Canada CADTH

England NICE
Germany G-BA
Sweden SBU & TLV
Australia PBAC & MSAC
Canada CADTH

UK NICE
Germany IQWiG
Scotland SMC

Do Patient Goals Align with Other Stakeholders’?

Sponsors: Constituency Approval & Sustainability

Industry: Broad access & Funding

HTA Agencies: Justify Budgets & Credibility

Users: Optimal therapy & Sustainable access

CRISIS
Patient-Based Evidence Supports Sustainable Access

Training Patients for Participation

Individual patients/caregivers; naïve or involved in clinical trials vs. Patient groups: Ad hoc or registered, representative feedback, trained

Timeframe for Input: Not Set: By invitation Posted for commentary vs. Standardized: 2 weeks 6 weeks

Structured submission following template with pre-defined fields vs. Open testimony In-person or written


Engagement Feedback on specific output or recommendations vs. Member of appraisal committee
Key Learning re: Patient Engagement

- Globally, patient centricity has evolved increasingly to patient engagement in all spheres of healthcare decision making, including HTA
- Emerging best practices for engaging patients in HTA process (and beyond) serve as useful tools but they must be customized to fit country-specific HTA process and country culture
- Benefits of patient engagement in healthcare decision making including HTA are real but need to be better documented to encourage more patient engagement
- Patients (including patient groups and advocates) require training and support to take full advantage of opportunities for engagement and adding value

Thank You!

Durhane Wong-Rieger
www.raredisorders.ca
416-969-7435
durhane@sympatico.ca