Cancer Patients’ Role in HTA

An International Perspective
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Key Messages

• To HTA Agencies: “If you’re not engaging patients, you’re not doing HTA!”

• To Industry: “If you are not improving patient relevant outcomes, your chances for successful reimbursement are diminished!”

Source: Dr. Brian O’Rouke, CADTH President and CEO; CTO Conference, October 2016
<table>
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<tr>
<th>LIFE</th>
<th>Kidney Cancer</th>
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What Patient Input is NOT:

• Mediated via clinicians, other health system “experts”

• Public/citizen/taxpayer representation
  – Bias of the well vs. reality of those directly affected

• Tokenism... single patient representation on committees.
What Patient Input IS:

Based upon HTAi Value Standards:

• **Relevance**
  – Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.

• **Fairness**
  – Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.

• **Equity**
  – Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.

• **Legitimacy**
  – Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.

• **Capacity building**
  – Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.

Source: HTAi.org Patient & Citizen Involvement Working Group
Integrated (pCODR - Canada)
Recent: Request for Advice (RFA)

- pCODR issued RFA to registered stakeholders
- New data on “drug A” vs “drug B” in 2\textsuperscript{nd} line
- Patient group response:
  - Accessed RWE database of 9,000+ patients
  - Data extract demonstrated equivalency of outcomes
  - Led to change in listing/criteria.
Best Practices Internationally

• SMC – patient representatives at the deliberation table
• NICE – patient reps involved in early scientific advice
• CADTH – feedback to patient groups
• PBAC – consumer representation; managed entry; RWE
Where are we going?

Experienced patient groups:
• From “template submission” to interactive dialogue
• From end of process to beginning of discussions
  • Early scientific dialogue; clinical trial design
  • Design of relevant PRO measures

• Patient groups: “Be careful what you ask for…”
  • Significant work involved
  • Resource/ funding for this work?
  • Can all patient groups equally participate?
Experience with ‘Patient Experience’

- **pCODR Patient Evidence Process**
  - **Significant** amount of work for patient orgs
    - Online survey, then 100+ hours per submission
  - pCODR expects input to be:
    - **Current, Canadian**, **Specific** to new molecule
    - Also: rural/urban, pan-Canadian, online/offline, representative of socio-economic spectrum, indigenous/northern, balanced +ve/-ve, ...
  - Techniques suggested:
    - Online surveys, but also: focus groups, IDIs (one on one interviews), telephone interviews, outreach to HCPs.

- Reality...
Issues: what keeps us up at night?

• Are we wasting our time on “low level evidence”
  – Ethical dilemma of surveying patients
• Funding from industry / COI
  – Can we say “not this drug, not yet...”?
• What if we just stopped participating?
  – Would recommendations/decisions be any different?
Can we be smarter about this?

• Global collaboration:
  • Collaborate with other organizations nationally?
    – Same mutation/same drug/issues
  • Collaborate with HTA agencies at national/regional level
    – What is our Opinion?
    – How can we work together?
  • Collaborate internationally
    – Towards a “Global Patient Evidence Submission”
Radical thoughts

1. Given limited patient advocate resources:
   • Where would you spend YOUR time?
     - Working with trial data after the fact?
       - Poorly designed trials; wastage; duplication
       - Lack of PROs, QoL data, value
       - Historical control arm; no longer relevant
     - OR
       – Early involvement in drug development process?
Radical thoughts

2. What if we agreed: “No data collection = no drug”. Period.

Outcomes matter
- Clinical trial and/or
- Registry
- Managed entry program

- With:
  – Patient-reported outcomes beyond “EQ-5D”...
Radical thoughts

3. How do we measure success together? Do we value?
- Cost containment
- Transparency
- Patient & public engagement
- Acceptance if not agreement?

“What kind of society do we want to live in?”
Thank you

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