

Public and Patients in HTA Decision Making: A Decision Maker Perspective

Gerald Evans, MD FRCPC
Associate Professor of Medicine,
Queen's University
Past Chair, Committee to Evaluate Drugs
Ontario MOHLTC

COI Disclosure

- From 2006-2012, I received a monthly retainer from the Government of Ontario while serving as Chair of the CED
- No other intellectual, financial or pecuniary COI of a commercial type or with patient advocacy groups

Citizen Engagement in HTA

I'M BRINGING YOU INTO THE
DECISION-MAKING PROCESS, RUGGLES.
HERE - FLIP THIS COIN.



Citizen Engagement in Ontario

- Patients
 - Committee to Evaluate Drugs (CED)
 - CED-CCO Subcommittee
 - Two “patient as persons” members on each group
 - They joined the committees in 2007 as full voting members
- Public
 - Citizens’ Council
 - 25 Ontario citizens chosen to represent the diversity of the provincial population
 - Deliberate on societal issues in HTA

Patient Members on the CED

- All received a 2-day training & orientation program to understand the process of drug regulation and evaluation, and their role
 - Evidence-based medicine principles
 - Traditional drug evaluation metrics
 - Efficacy, safety and cost-effectiveness
 - Primer on pharmacoeconomics
 - Value considerations
 - Ethics and COI



What were the issues initially?

- Very steep learning curve
- Complexity of HTA was major stumbling block
- Role on the committee
 - Reluctant to ask questions or make comments
 - Overwhelmed by medical jargon & science
 - Pharmacoconomics – *Lost in Translation*
 - Voting “swayed” by persuasive CED members with particularly strong opinions

Other Issues

- Policy considerations
 - Discrepancy between recommendations and decisions
- Conflict of interest considerations when they had the illness under consideration
- Cancer drug evaluation particularly problematic due to:
 - Multiplicity of clinical outcomes and their “relevance”
 - Implicit “skew” of economic thresholds
 - Tendency toward more sympathy for cancer patients
 - Not overly persuaded by “rule of rescue”

Perspective



Value Added Contributions

- They do bring a new perspective to deliberations
- After a year or so, they were more likely to actively join in discussion
- Provided a mechanism to bring patient advocacy to the table
 - Patient members critique and present the patient submissions to the committee
- Professional members very respectful and appreciative of patient member contributions

Issues in Evolution

- Patient advocacy vs. patient participation
- Given that most PA groups are reliant on funding from other sources, often Pharma, there is an inherent COI in their positions on drug reimbursement
 - There has NEVER been a negative drug recommendation from a PA group
- PA-based submissions lack critical validity
 - They implicitly accept conjecture and speculation on drug effectiveness & safety
 - They often mimic pharmaceutical marketing
 - They typically negate or ignore economic considerations

Public Members - Citizens' Council

- An emerging success story
- Engaged, enthusiastic, eager and earnest
- 4/25 are writers



Citizens' Council Topics

1. Drugs for Rare Diseases
 - Validated the current DRD framework
2. Formulary modernization
 - A topic generated by the Council
3. Values in decision-making
 - Helped to frame the role of values for the Council
4. The role of private vs. public payers

Citizens' Council Issues

- Frustration on early lack of engagement
- Timeliness of responses to CC reports
- Are “they” making a difference?
- Did not want to be a “token” for public engagement

Citizen Engagement in Ontario

Summary

- Patient engagement
 - A work in progress; we are not there yet
 - Needs to evolve beyond simple patient advocacy
 - Need to significantly improve patient submissions
- Public engagement
 - Huge opportunity for bringing the public perspective to drug policy
 - In Ontario, it has begun to make important contributions, but there are more to come...

It's all in the perspective

