

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

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# 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
  - Pharmacoeconomics – *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

