(Re)defining legitimacy? Expertise and public and patient involvement in Canadian drug assessment

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Context

- 2006: add public or patient members to drug advisory committees
- 2010: accept submissions from patient advocacy groups

- Driven by patient demands and need to increase public legitimacy
- Experts see the process as already rigorous and effective

Research question

Have technical members' ideas about legitimacy changed since public and patient involvement was introduced?

Data

- Consultancy reports and parliamentary hearings
  - 2005: Ekos Research Associates, Common Drug Review
  - 2007: Standing Committee on Health, hearings and report
  - 2011/2012: SECOR, CADTH Evaluation phases I and II
  - 2012: SECOR, CADTH Patient Input Evaluation

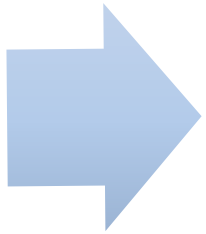
- 12 interviews with current or former technical members of CDEC, pERC, Ontario CED drug advisory committees (2014-2018)

Theoretical framework

- Describe two broad conceptions of legitimacy
  - Scientific: “good” (efficient, equitable, rigorous) decisions
  - Democratic: “fair” (inclusive, accountable, transparent) process

Describing ideational stability and change

Scientific legitimacy is paramount



Room for democratic legitimacy?

Before/during adoption of public and patient involvement, early 2000s

After experience with public and patient involvement, 2014-present

Findings: role of lay members

- Perception: having public and patient members on the committee enhances accountability and transparency

"If you don't have a [lay] member… there could always be a critic that says: how do I really know you're emphasizing patient values, there's no patient on your committee, there's no public member. And so I agree with that criticism, and I think that having someone there, from an optics point of view, makes a lot of sense." – *Tech member 2016*

"I think that the presence of [lay] members is essential to really make sure that when we go out with a recommendation, it is clear to the public why that recommendation was made" – *Tech member 2018*

Findings: role of patient submissions

- Consistent emphasis on standards of scientific evidence and concerns about bias
- Consensus that patient input could improve drug listing decisions

"For many conditions, the patient ultimately needs to be the person to advise: what are the outcomes that are important to them?"

– *Tech member 2016*

Findings: role of patient submissions

- Challenge: should patient input be more like scientific evidence?

"I certainly don't think there's any theory behind how that information [patient input] is presented, whereas there's a lot of theory behind how the clinical evidence and the economic evaluation stuff is presented."

– *Tech member 2018*

"I would like the patient groups to be a bit more critical of the evidence, if they can be." – *Tech member 2016*

Contributions

- Plausibility of concepts of scientific and democratic legitimacy as a way to understand participant views
- Most acceptance of democratic versions of legitimacy re: role of lay members
- Acceptability of patient submissions more likely to be framed in terms of approaching/contributing to scientific legitimacy

Questions and comments?

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