

Learning from patient- participants

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Patient Engagement as a Model

- For REB ethics review & oversight
- Law Commission of Canada Report 2000 on the *The Governance of Health Research Involving Human Subjects* identified research participants as
 - Experts on the impacts of participant protection; experts on their own lived experience
 - Important source of ethical legitimacy for research protection

Research participants

- Experience the impacts of what happens to them in research
- Multiple factors in determining impacts on participants
 - Context of participants' lives
 - Participants motives and reasons, ethical sensibilities
 - Activities of researchers, research institutions & REBs
- Whether to trust or not to trust

However

- REBs do NOT seek information from participants about their experiences in research
- Instead, REBs use **distal** learning strategies to predict participant experiences
 - Local precedents & checklists
 - Experts on the REB: lay, legal, scientific
 - Protective imagination
- Why don't REBs use more **proximal** learning strategies?

Engaging Patients as

- Active and engaged participants in patient oriented research
- Should be paralleled by engaging patients as partners in human research protection
- REBs should be asking about
 - Participants experiences in and after research
 - Their concerns, suggestions, and priorities

Specifically

- For Patient Oriented Research, REBs should learn from patient-partners about
 - Impacts of partnership on patients from start to finish
 - Whether there was a meaningful partnership?
- Need to think through the ethics of patient engagement
 - “Ethics is for human subjects, too” Cox & McDonald 2013
 - Collective as well individual dimension – research involving communities

Practical suggestions

- Ask investigators to detail plans for patient engagement
 - Communications with participants
 - Responsibilities & accountabilities
 - Publication of both negative and positive results
- Open lines of communication between patient-partners & the REB
 - Survey or debrief participants
- Development and sharing of best practices for REBs

Suggestions

1. Use surveys, questionnaires, interviews during and after research participation as a QI measure
 - <http://www.researchethicssurvey.ca/>
2. Ask researchers to explain their strategies for acquiring knowledge of participants before, during & at end
3. Use & encourage research on participants' experiences
4. Move from front-end review to virtuous learning loops
5. Scrutinize REB learning strategies with the same rigour as research proposals
6. Focus on impacts on participants, rather than the research methodology
7. Add the capacity to assess outcomes & build a strong knowledge base

Reorienting ourselves

REBS think in terms of

1. the application of rules and regulations
2. Research methodologies

But research participants think in terms of impacts on their lives

- Need to close the epistemic gap!
- Patient engagement offers an opportunity.

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Selected publications

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