Patients as Partners in Clinical Research
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Disclosure
- I have no conflicts of interest related to this presentation.

Objectives
- Identify and discuss benefits of engaging patients in clinical research
- Identify and discuss questions about which patients to engage and how patients are defined
- Identify and discuss some obstacles to engagement and some ways to overcome them
- Identify and discuss ways to sustain partnerships with patients
Where I’m Coming From

- Thirty years as an English teacher at Centennial College
- Periodic experiences as a patient
- Thirty years as the father of a son with health needs, sometimes acute
- Twenty years as a volunteer, mostly related to child health
- Five years as a public member of the Canadian Drug Expert Committee (part of the Common Drug Review at CADTH)
- A few years as a member of a research advisory committee for a CIHR-funded project
- Two years occasionally reviewing applications for funding by the Ontario SPOR Support Unit (I am an OSSU Board Member)
- Precious little experience in clinical research.

Bad Reasons to Engage Patients in Clinical Research

- The granting agency requires evidence of or a plan for patient engagement (in cases where you would not otherwise be engaging patients).
- You think having patients on the research team or as advisors will make it easier to recruit patients as research subjects. (They may be helpful in doing just this, but patients don’t join teams to be recruiters, and they may not be the best people to help recruit the most appropriate subjects.)
- You want patients to “keep the rest of the team honest” or to act as “critics.”
- You’ve heard or you expect that it will make the rest of the team feel good.

Good Reasons to Engage Patients in Clinical Research

- Patients are the best source of information about what matters most to patients—though clinicians often assume they know best.
  2. Michael J. Fox Foundation’s work on what matters to Parkinson’s patients
  3. Psoriasis patients’ emphasis on location of plaques rather than amount of surface area covered in plaques.
  4. Cancer patients’ desire to measure whether a non-constipating opioid allows more patients to die at home
Some Other Good Reasons

- Patients can identify ways to make the surveying and interviewing process easier for research subjects and more useful for researchers, e.g. our experience in Parenting Matters doing dry-runs and noting what subjects should/need to be told about purpose of questions, use of responses, etc.
- Patient engagement almost always means translation and dissemination are embedded in every stage of the work
- Good experiences and lessons learned can “spill over” into clinical and policy settings (Cf. What has happened with patient safety)
- Engaging patients can help to prevent researchers avoid falling victim to the focusing illusion (Daniel Kahneman: “Nothing in life is as important as you think it is when you are thinking about it.”)

Acknowledgement

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Deciding Whom to Engage: Patients, Patients Everywhere ...

- "Patient" is becoming a more broadly-used and more widely—and sometimes fiercely—contested term.

1. CIHR's SPOR framework says it is an "overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends."

2. PCORI says "patient partners" can be inclusive of all those CIHR identifies as well as "organizations that are representative of the population of interest."

3. Many mental health groups and other communities (e.g. those related to developmental conditions, people who are deaf, etc.) reject or are uneasy with the term / label.

4. Involve (UK) refers as much to public as patient involvement in research.

More about “Whom”

- Some questions to consider:
  1. Do you want caregivers as well as patients? Do you want them to assume distinct roles, to work mostly together or apart?
  2. Do you want “experiencing” patients or “remembering” patients? (Kahneman’s distinction between the experiencing self and the remembering self) Do you want pts. at a particular point on the trajectory?
  3. Does age, SES, ethnicity, sex, education, occupation, language, severity of condition, previous experience as a research partner, membership in a patient group, or temperament matter?
  4. Do you want people with expertise? In what? (CIHR stresses the “expertise” patients have.)
  5. Do you want patients with experience as research partners but little or no experience of the disease or condition in question?
Some Obstacles and Ways to Overcome Them

- Patients’ lack of clarity about purpose and role: “Why am I here?”
  - Be specific and candid. Allow for negotiation. Identify appropriate peer mentors and “contact person.” Schedule “check in” meetings.

- Patients’ investment in a project that may never be funded
  - Be candid and realistic. Look for future possibilities if not funded.

- Patients’ experience with and attachment to advocacy
  - Ask about patients’ motives/expectations. Explain/discuss advocacy’s place—and where it has no place—in research.

- Patients’ unfamiliarity with the language of research
  - Be clear and specific about what language pts. need to know. Provide glossaries, suggest they create their own, take an incremental approach, don’t make pts. language police, enlist their help in translation, dissemination, etc.

- Patients and researchers at sea about expenses and compensation
  - Distinguish between expenses and payment; find out if there are guidelines, precedents. Allow pts. to choose to volunteer; make payments promptly; distinguish payments from “honoraria” to “fees.”

- Patients’ and researchers’ confusion about the distinction between lived experience and patient stories and the place of each
  - Discuss whether pts. are expected to tell their stories/share their experience and if so why. Discuss relation between stories and evidence.

- Researchers’ and patients’ fear of conflict/disagreement
  - Make clear from start that these are inevitable and helpful in research. Don’t exempt pts. from assessments, difficult discussions. Have regular “check-ins.”

- Researchers’ assumption that good intentions are enough—or almost enough
  - This is new, hard, time-consuming, and sometimes frustrating—but potentially very good for everyone.

Sustaining Engagement: Some Suggestions

- Make training iterative; avoid frontloading too much of it.

- Include experienced patient partners in the training of new partners and in the training of researchers new to such research.

- Evaluate (most important, formatively) all patient partners, the patient engagement process, and its results.

- Have patients evaluate themselves, others, and the process.

- Recognize that patients likely are working/living with different time frames from those of researchers on career paths and so plan for possible exit points or periods of unavailability.

- Remember to thank and praise all to whom thanks and praise are due.
Some Resources

- Involve, National Institute for Health Research (UK): http://www.invo.org.uk/ (Website includes very useful documents about compensation and adversarial principles and values as well as a helpful briefing notes for researchers)
- Patient-Centered Outcomes Research Institute (USA): http://www.pcori.org/
- CIHR’s Strategy for Patient-Oriented Research: http://www.cihr-irsc.gc.ca/e/41204.html
- Ontario’s SPOR Support Unit: http://ossu.ca/

Questions and Discussion

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