Engaging with the public – aiming for collaborative care for deprescribing

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#deRx2018

Session resources available at deprescribing.org/TBD

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Learning Objectives

1. To be encouraged to be involved in research OR to encourage involvement of consumers in your research.
2. To gain background knowledge of theory and frameworks of consumer involvement in research.
3. To understand some of the barriers and facilitators to consumer involvement in research activities.
4. To gain a shared understanding of the benefits and expertise that different parties bring to the research process.

Public and consumer involvement in research: the why and the how (researcher perspective)

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Canada’s Strategy for Patient-Oriented Research (SPOR)

“[Patients] must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians.”

Patients bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness, as well as their experiences with treatments and the health care system.

http://www.cihr-irsc.gc.ca/e/45851.html

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Patient Engagement (PE)

"a continuum of research that engages patients as partners, focuses on patient identified priorities and improves patient outcomes" - SPOR Patient Engagement Framework, 2014

Guiding principles of PE

- inclusiveness
- support
- mutual respect
- co-building

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Why have consumers involved in your research?

Moral/ethical drive to empower lay participants in an otherwise expert-dominated endeavour and ensure civically responsible research.

- Increased transparency of research activities and accountability for research spending.
- Increased public trust in research and researchers.
- Increased public understanding of the research process.
- Demonstrates respect to patients and vulnerable populations.

Why have consumers involved in your research?

It creates a user-oriented research agenda.

- Expands beyond scientists' intellectual interests.
- Highlights problems identified by 'users' that may not be known in the 'literature'.
- Leads to more usable 'answers'.

James Lind Alliance

Priority Setting Partnerships

The JLA method, described in the JLA Guidebook, is designed to change the way research funding is granted, and to raise awareness of research questions which are of direct relevance and potential benefit to patients and the clinicians who treat them.

http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/

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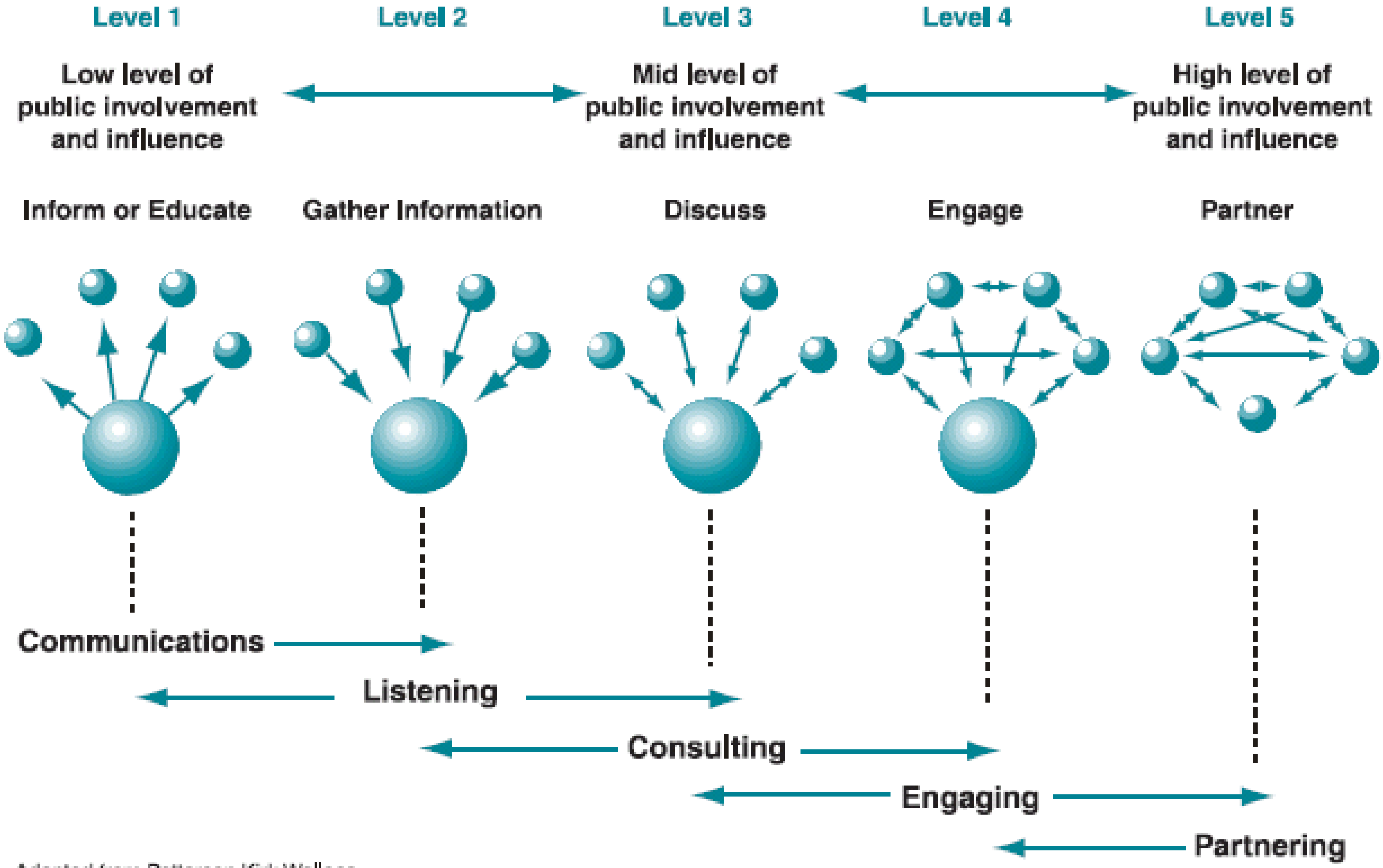
Why have consumers involved in your research?

Increases quality of the research methods (optimising the design, validity, applicability or dissemination of the research).

- Increased recruitment and retention of study participants (appropriate approach, study materials, non-burdensome procedures, culturally appropriate)
- Accelerates adoption of evidence into practice (possibly by eliciting buy-in during the research, patients may become excited about implementation and dissemination).

Concannon TW, et al. J. Gen. Intern. Med. 2014;29:1692–701; Concannon TW, et al. J. Gen. Intern. Med. 2012;27:985–91; Oliver SR, et al. Heal. Expect. 2008;11:72–84; Esmail L, et al J. Comp. Eff. Res. 2015;4:133–45; Woolf SH, et al Health Aff. 2016;35:590–4; Shippee ND, et al Heal. Expect. 2015;18:1151–66; Sheridan S, et al Ann. Fam. Med. 2017;15:165–70.

The five levels of public involvement



Level 1	Level 2	Level 3	Level 4	Level 5
Low level of public involvement and influence	↔	Mid level of public involvement and influence	↔	High level of public involvement and influence
Inform or Educate	Gather Information	Discuss	Engage	Partner

Communications →

← Listening →

← Consulting →

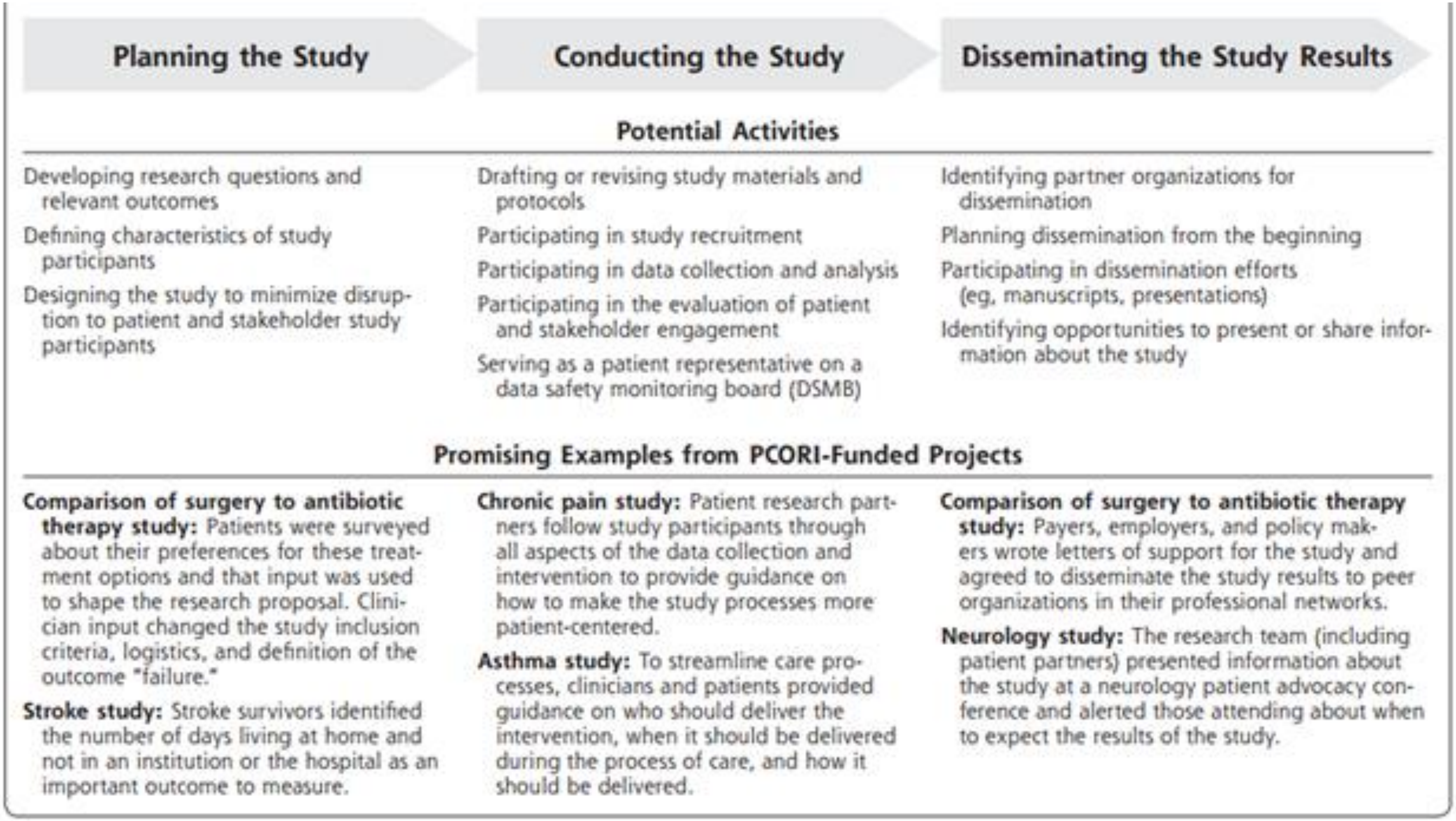
← Engaging →

← Partnering

Adapted from Patterson Kirk Wallace

Health Canada's "Policy Toolkit for Public Involvement in Decision Making" Prepared by the Corporate Consultation Secretariat, Health Policy and Communications Branch, 2000.

PCORI Engagement Rubric



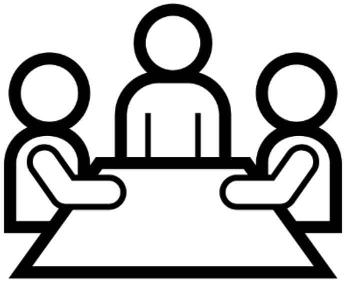
Planning the Study	Conducting the Study	Disseminating the Study Results
Potential Activities		
Developing research questions and relevant outcomes Defining characteristics of study participants Designing the study to minimize disruption to patient and stakeholder study participants	Drafting or revising study materials and protocols Participating in study recruitment Participating in data collection and analysis Participating in the evaluation of patient and stakeholder engagement Serving as a patient representative on a data safety monitoring board (DSMB)	Identifying partner organizations for dissemination Planning dissemination from the beginning Participating in dissemination efforts (eg, manuscripts, presentations) Identifying opportunities to present or share information about the study
Promising Examples from PCORI-Funded Projects		
Comparison of surgery to antibiotic therapy study: Patients were surveyed about their preferences for these treatment options and that input was used to shape the research proposal. Clinician input changed the study inclusion criteria, logistics, and definition of the outcome "failure." **Stroke study:** Stroke survivors identified the number of days living at home and not in an institution or the hospital as an important outcome to measure.	**Chronic pain study:** Patient research partners follow study participants through all aspects of the data collection and intervention to provide guidance on how to make the study processes more patient-centered. **Asthma study:** To streamline care processes, clinicians and patients provided guidance on who should deliver the intervention, when it should be delivered during the process of care, and how it should be delivered.	**Comparison of surgery to antibiotic therapy study:** Payers, employers, and policy makers wrote letters of support for the study and agreed to disseminate the study results to peer organizations in their professional networks. **Neurology study:** The research team (including patient partners) presented information about the study at a neurology patient advocacy conference and alerted those attending about when to expect the results of the study.

Roles of the consumer

- stakeholders leading the research
- stakeholders as co-investigators – member of the research team (collaboration)
- stakeholders as consultants
- stakeholders as staff on the project
- stakeholders as subjects/participants of the research or program

Methods of engagement

- surveys/quantitative questionnaires
- written consultation
- key informant interviews/one-on-one in-depth discussions/face to face meetings
- focus groups
- town meetings
- citizens' juries
- panels/advisory committees
- formal partner meetings
- teleconferences
- combined partner and stakeholder feedback sessions (formal presentations)
- social media and printed media (newsletters)
- emails, online sharing



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from Noun Project

Methods of synthesis of consumer views

- Qualitative synthesis of written notes or transcripts
- Engagement in joint decision making (consider power imbalance)
- Delphi process
- Quantitative questionnaires for ranking or rating (more appropriate for priority setting)

Monitoring and evaluating engagement

- Structure for reporting engagement: Concannon TW, Fuster M, Saunders T, Patel K, Wong JB, Leslie LK, et al. A Systematic Review of Stakeholder Engagement in Comparative Effectiveness and Patient-Centered Outcomes Research. J. Gen. Intern. Med. 2014;29:1692–701.
- Measures to evaluate engagement: Esmail L, Moore E, Rein A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. J. Comp. Eff. Res. 2015;4:133–45.
- A conceptual framework: Oliver SR, Rees RW, Clarke-Jones L, Milne R, Oakley AR, Gabbay J, et al. A multidimensional conceptual framework for analysing public involvement in health services research. Heal. Expect. 2008;11:72–84.
- Surveys: https://www.patientscanada.ca/index.cfm?pagepath=Make_an_Impact/Strategy_for_Patient_Oriented_Research/Tools_for_Patient_Partnership_in_Research&id=76578
- Public and Patient Engagement Evaluation Tool (PPEET): http://fhs.mcmaster.ca/publicandpatientengagement/ppeet.html

Consumer experience of involvement in research

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Why I am involved patient-oriented research?

- Almost all patients become involved as patient partners because something bad has happened to them or a loved one.
- This is a common human response:

  I want to make sure this doesn't happen to anyone else.

Project: TaperMD

Patient identified barriers to reducing medications

Frequently would like to take less medication but do not initiate conversations about reducing because they:

- fear their doctor’s response
- fear relapsing and being denied the ability to resume medication
- fear abandonment by their physician if they discontinue their prescriptions

TaperMD cont’d

Family doctor identified barriers

- Hesitate to engage patients in discussing quality of life and life expectancy issues
- The lack of a ***framework / guidance for discontinuation***
- Anxiety about not following single disease guidelines
- Doubts about their ability to manage discontinuation

TaperMD cont’d

TAPER framework

- A trial medication ‘pause’ with monitoring
- Prioritizes treatments not by disease but according to patient preferences, informed by evidence

TaperMD cont'd

Effective Care

- Recognition of the patients needs
- Consideration by professional and patient of the best medical science has to offer
- Context: A **relationship** that will maximize the therapeutic effect of using (or not using) treatments

What works well?

- When there is a match between the passion of the researchers and the passion of the patient -- the right patient for the right project
- When the patient partners feels heard and respected
- Many professionals will be surprised to see their public partners’ expertise
- This wisdom is gained by having “skin in the game”– experts by experience
- By partnering, the patient makes meaning of their painful experience
- Instead of being seen as a random tragedy in a broken system – it becomes healing for the patient to be part of the change and a chance to regain trust

Project: ActionADE

- ADE:
  - Unintended & harmful events associated with medication use/misuse, includeding ADRs, drug interactions, supra-/sub- therapeutic dose, nonadherence, ineffective drug, untreated indication, errors & drug withdrawals.
- Repeat ADE:
  - ADE due to same drug or drug-class re-exposure that previously caused an ADE or repeat inappropriate withdrawal causing a similar ADE.
- Ascertainment:
  - Clinical pharmacist and physician **independently** reviewed research record & **ONE** volume of the patient's hospital chart.
  - Discussion until consensus reached, if unable adjudication.
  - Exclusion of any cases for which alternative causes identified.

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Why Patient Involvement was Essential!

- Meeting with the MOH to show pubic concern for this problem in order to secure their involvement
- Attending the CIHR funding “pitch” for Rewarding Success Funding when the adjudicators required a better sense of the extent of patient involvement and interest in this Strategy for Patient Oriented Research (SPOR) research

(Funding obtained for our ActionADE project Feb 2018)

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When partnering doesn’t work well for the patient

- When it becomes painfully obvious that the research will not improve care at the bedside anytime soon
- When patient engagement doesn’t result in a good “marriage” -- i.e. a mismatch, wrong patient/wrong study
- When the patient feels they are a token or checkbox
- When providers feel they know what patients think or want though those perspectives are completely different
- Use of the phrase “we’re all patients” by professionals
- When the patient is brought in late in the game to comment on a “done deal”
- There is no opportunity for co-design or even asking the right research questions

Case example 1: Guideline development

A research team is developing a new deprescribing guideline on opioids. The team has been able to secure funding for the development – a postdoctoral researcher (early career researcher) has obtained a fellowship from the government. This fellowship covers their salary for 2 years and provides a small amount of money for research expenses (such as hiring a professional copy editor and attending a conference).

The fellowship has a tight timeline (2 years) and much of the development needs to be completed in the first year to allow time for public consultation, endorsements and publishing.

About 6 months into the fellowship (the scope of the guideline has been set and literature review started) the research team realises that they would like to have a consumer on their research team.

Questions for reflection:

1. What should the research team do?
2. What are some of the barriers to consumer involvement in research and how can these be overcome?
3. How would you recruit and engage a consumer on a research project that is already in progress?

Case example 2: Real engagement?

Mr X is a 90-year-old male living in a residential care facility. He takes multiple medications and has had several hospitalisations recently for falls. His daughter Mrs Y is asked by staff at the care facility if she is interested in being involved in research about 'polypharmacy and deprescribing' – she says yes and the next day receives a call from a researcher from University A. The researcher explains all about the study that they are planning about deprescribing and asks whether she would be willing to be a 'consumer representative' for the study. Mrs Y agrees but after she gets off the phone she doesn't really know what she has agreed to and doesn't feel that she knows enough to really contribute to the research.

Two weeks later Mrs Y gets invited to an in-person meeting where she meets the researchers who are having a planning meeting about the study. She is interested by their conversation, but despite being a generally intelligent person she gets lost in much of the discussion. The researchers invite her to comment during this meeting but she feels rather intimidated and doesn't want to admit that she didn't understand what they wanted from her. At the end of the meeting she tells them that email is the best way to get in touch with her and she is happy to read documents sent to her via email. Over the next few months she receives emails with documents attached and many 'reply all' discussions that she doesn't understand. She does not reply to them.

One year later she receives an email from the research team to say that they have finished the study and give her a summary of what they did. The email says that they will be writing a publication and presenting the results at research conferences and invite her to be an author on the publication.

The research team feels like they have done 'all the right things' – they had a consumer on their research team, they met with her in person and asked her opinion, they even invited her to be a co-author on a publication. But they know that perhaps it wasn't quite right.

Questions for reflection:

1. Do you think this represents real consumer engagement in research?
2. What could have the researchers done differently?

Case example 3: Different priorities

A research team has obtained a program grant which gives them money to conduct several research studies over the next 5 years. The specific studies have not been decided but must be relevant to the areas of polypharmacy and deprescribing.

The research team has recruited and assembled an advisory committee of consumers (patients and family of patients with polypharmacy) to be involved with the program of research. In their first meeting, via a facilitated discussion, the advisory committee decides that an area of research that they think is important is making sure people take their medicines correctly (medication adherence).

But, the research team has a particular interest in implementing a deprescribing guideline – they think that based on the literature, this is what is most important and will have the most benefits for patients. They do not have a particular interest or experience in the field of adherence and also think that there has already been substantial research in this area.

Questions for reflection:

1. How should the research team and advisory committee proceed?