HAD 5011: Patient Engagement Crash Course

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Friday September 6th, 2019
The lineup

3:00-5:20pm

3:00-3:15 Intro and Online Survey (Katie)
3:15-4:00 Lecture (Francine and Kerry)
4:00-4:30 Video and Discussion Questions (Susan)
4:30-5:15 Panel (Susan- Moderator)
5:15-5:20 Closing, Reflection Survey (Katie)
Lecture Outline

1. What is patient engagement?
   - A review of frameworks

2. What are the methods for engagement?

3. What things do you need to be mindful of?

4. How do you evaluate engagement?

5. Where can you go to find more information?
What is patient engagement?
In research...

“Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities.”

“….a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.”

Canadian Institutes of Health Research [http://www.cihr-irsc.gc.ca/e/48413.html#a4](http://www.cihr-irsc.gc.ca/e/48413.html#a4)
In policy and practice…

“Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.”
Carman et al (2013, p.224)
‘[Research] needs the best of what the best among us can give and the help of everybody’

Guiding Principles

Inclusivity – Be inclusive of both people and their ideas

Mutual Respect - Value each other's expertise and experiential knowledge. Respect use of partners time.

Partnership – Share decisions. Share ideas. Share work. Share power

Accountability – Maintain a safe environment that promotes honest interactions, cultural competence, training, and education.

Co-Learning - Provide a supportive environment to ask questions and be willing to learn from each others’ experiences.

Transparency - Information should be shared readily. Commit to being open and honest.

Compiled from guiding principles developed by PCORI and SPOR
Engagement capable environments

Enlisting and Preparing Patients

Asserting patient centered care and experience as a key goal

Ensuring leadership support and strategic focus

Communicating patient experiences to staff

Engaging Staff to Involve Patients

Supporting teams and removing barriers to engaging patients

Baker et al 2016; Baker & Denis 2011
Multidimensional Framework for Patient and Family Engagement in Health and Health Care
- Carman et al 2013

Levels of engagement:
- Direct Care
- Organizational design and governance
- Policy making

Continuum of engagement:
- Consultation
  - Patients receive information about a diagnosis
- Involvement
  - Patients are asked about their preferences in treatment plan
- Partnership and shared leadership
  - Treatment decisions are made based on patients’ preferences, medical evidence and clinical judgment

Factors influencing engagement:
- Patient (beliefs about patient role, health literacy, education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)


Note: Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.
LEVELS of PATIENT and RESEARCHER ENGAGEMENT in HEALTH RESEARCH

<table>
<thead>
<tr>
<th>GOALS</th>
<th>LEARN/INFORM</th>
<th>PARTICIPATE</th>
<th>CONSULT</th>
<th>INVOLVE</th>
<th>COLLABORATE</th>
<th>LEAD/SUPPORT</th>
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</thead>
<tbody>
<tr>
<td>PATIENT</td>
<td>To ask questions and learn about how to get more involved</td>
<td>To act as a subject or participant in a research study</td>
<td>To provide feedback and advice on specific research activities</td>
<td>To work directly with a research team throughout the project</td>
<td>To partner on equal footing with researchers in all aspects of research</td>
<td>To make decisions and lead research activities</td>
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<tr>
<td>RESEARCHER</td>
<td>To provide information, listen, and answer questions honestly</td>
<td>To act ethically and respectfully in the conduct of research</td>
<td>To seek your input on an ad hoc basis</td>
<td>To include you as standing members of an advisory group</td>
<td>To partner equally with you as team members</td>
<td>To follow your lead and support your decisions</td>
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HOW CAN THIS BE DONE

- Through orientation and information sessions, and media campaigns in an open atmosphere for sharing
- Through quantitative, qualitative, or mixed methods research
- Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels
- Patients as members of standing working groups and research advisory committees
- Patients as co-investigators and research partners, and as members of research steering committees
- Through patient or community steering committees and patients as principle investigators

Time, Knowledge, and Funds Needed

Vandall-Walker, 2017

Shaded area indicates the levels that the AbSPORU Patient Engagement Platform focuses on

IAP2 framework adapted for patient engagement research
What are the methods for engagement?
Flexibility of methodology is really important.
Engagement Methods

The Centre for Health Care Innovation

Interactive Methods Map
https://chimb.ca/

Appreciative Inquiry Process

An Appreciative Inquiry Process takes a strengths-based approach to collaboratively making a research decision – focusing on what’s working rather than what’s not working. An Appreciative Inquiry Process is also known as the A4I cycle, as it involves four stages: Discovery, Dream, Design, and Destiny.

The process begins by choosing a research decision that the group wants to explore (e.g., “What outcome measures should we use?” “How will we evaluate success in this project?” “What research questions should we focus on?”), and then discovering what people appreciate and like about the topic. The next steps are to dream and envision as a group what could be, and then design what should be. The last stage is an active phase that considers what needs to be done to make it a reality.

The Appreciative Inquiry Process takes a positive spin and can be useful for:

- Generating new research priorities, questions, outcomes, and areas of evaluation.
- Creating a shared vision for both researchers and patient/public partners.
- Deciding on and committing to research decisions that will be actionable with accountability to patient/public partners.
A Pragmatic Clinical Trial

A research study proposes to evaluate the effectiveness of a home monitoring program for children who require home mechanical ventilation. Two groups of children are compared to usual care on a variety of outcomes.

A one-day **focus group** may be an effective way to engage patients to validate outcomes.

A patient or family member added to the study **steering committee** that is responsible for overseeing the research project.

A patient or caregiver could be invited to be a member of the **research team** as a SME.

A patient or caregiver could become a **co-Principal Investigator**, with equal decision-making power to direct the research project.
What things do you need to be mindful of?
Things to be mindful of

• Think of the patient
  • How do they want to engage?
  • How can they engage?
  • How do I acknowledge limitations & discover strengths
  • Treat others as you would want to be treated

• Start early and plan effectively
  • Build engagement into timeline
  • Plan for costs
  • Plan ways to support & amplify each others’ voices
Things to be mindful of

• Be mindful of dynamics

• Remove your assumptions

• You start on an equal playing field – you both don’t have the answer

• Manage expectations

• Plan for contingencies – but don’t make patients disposable

• Engagement is a relationship – not a project
How do you evaluate engagement?
Evaluation

• Growing body of research connecting patient engagement with positive system level outcomes
  • can inform patient and provider education and policies
  • enhance service delivery and governance
    Bombard et al 2018

• Less research on the impact of engagement on
  • people who are being engaged
  • quality of services from patient and caregiver perspectives
    Manafo et al, 2018

• Tools available to evaluate PE
  • Public and Patient Engagement Evaluation Tool
    Consists of 3 questionnaires (participant level, project level, and organization level)
  • Centre for Excellence on Partnership with Patients and the Public Tool-Kit
Evaluation

• Team evaluation/reflective practice-iterative, periodic check-ins, open communication as a mechanism for ongoing evaluation.
Where do I go to find more information?
Resources

• Ontario SPOR SUPPORT Unit [https://ossu.ca/](https://ossu.ca/) (resources for patients, researchers and policy makers)

• CIHR [http://www.cihr-irsc.gc.ca/e/45851.html](http://www.cihr-irsc.gc.ca/e/45851.html)
Patient Engagement Framework
[http://www.cihr-irsc.gc.ca/e/48413.html](http://www.cihr-irsc.gc.ca/e/48413.html)

• The Public and Patient Engagement (PPE) Research-Practice Collaborative @ McMaster led by Julia Abelson)
[https://healthsci.mcmaster.ca/ppe](https://healthsci.mcmaster.ca/ppe)
Resources

- Canadian Foundation for Healthcare Improvement
  https://www.cfhi-fcass.ca/WhatWeDo/on-call/PatientEngagementSeries.aspx
References


