

Building Patient Engagement in your Research Proposal:

The role of the patient partner
across the research cycle

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Introductions

Researchers?

Patient partners?

**Experiences with
patient partners?**

Learning objectives

At the end of the workshop participants will...

1. Have a better understanding of patient engagement in research
2. Be able to build meaningful patient engagement into their research proposals
3. Be aware of patient engagement resources available to them

Workshop outline

1. What is patient engagement (PE) in research?
2. Ways of engaging patients in research
3. Building PE into research projects
4. Criteria for funding applications
5. Wrap up

What is patient engagement in patient-oriented research?

What is patient
engagement in
research?

DISCUSS

What is patient engagement in research?

Patient engagement occurs when patients **meaningfully** and actively **collaborate** in the **governance, priority setting, and conduct of research**, as well as in summarizing, distributing, sharing, and applying its resulting **knowledge**

CIHR 2014

Patient engagement is...

NOT using patients or their patient information as data for the research



SPOR

- Strategy for Patient-Oriented Research (SPOR)

POR is “a continuum of research that engages **patients as partners**, focusses on patient-identified priorities and improves patient outcomes.”

SPOR PE Framework, 2014

- Ontario SPOR SUPPORT Unit (OSSU)

One of the provincial/territorial SUPPORT units

Collaborates with

- 12 leading health Research Centres in Ontario
- 7 funded pan-Canadian SPOR Networks

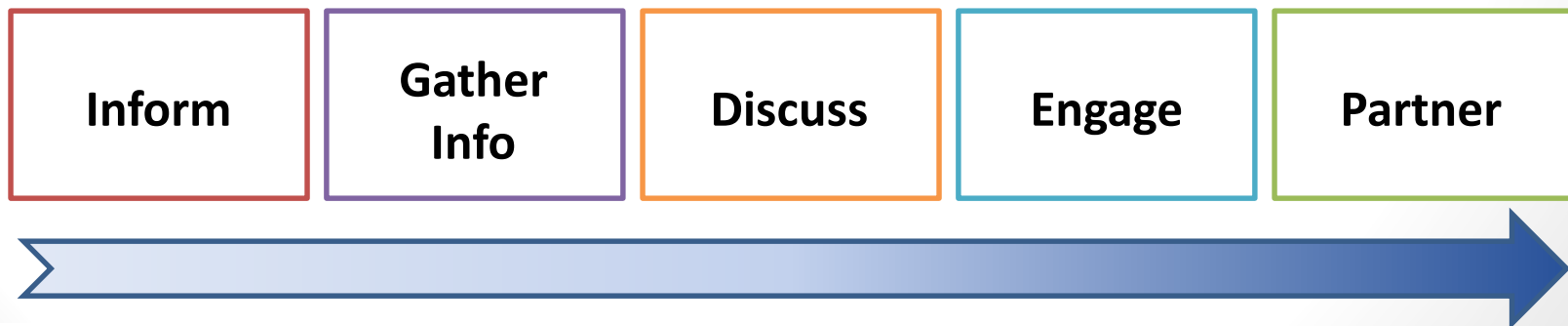
Ways of engaging patients in research

Ways of engaging patients

IAP₂: Public Participation Spectrum:



CIHR: Citizen Engagement Framework:



Thinking about the
spectrum of engagement...

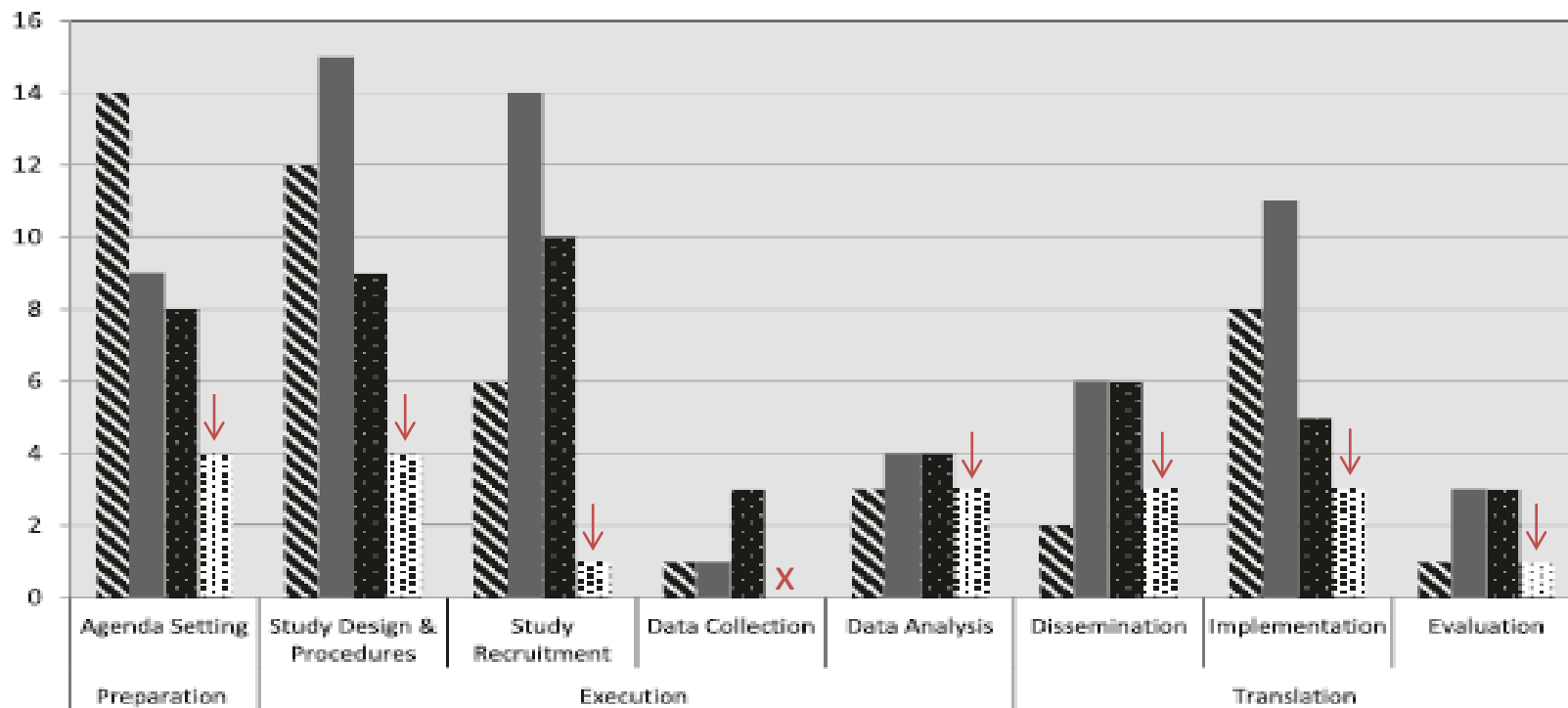
What is
appropriate
engagement?

DISCUSS

Building PE in Research

Literature Examples (Methods and Research Phases of PE in Domecq et al, 2014 - Review)

No. studies



Focus Group
 Interview
 Survey
 Deliberation/Organizational participation

Partnership & options

At the governance/steering committee level

- 2+ patient partners to help steer the project & determine what tasks require additional patient advisor support

At the task-based level

- Multiple patient advisors to help with specific tasks
 - Communication materials for study participants
 - Questionnaire design for study participants

Building patient engagement into research projects

What is the benefit
of patient
engagement in
research?

DISCUSS

Some benefits

- Research is targeted to what is important for patients
- Intervention/communication more acceptable/appropriate
- Greater ability to transfer research into action

What aspects of PE
should be
evaluated?

DISCUSS

Evaluating PE

- Process – how and what and when
- Participation -- who
- Outcome -- impact

Evaluating PE

There is not much in the literature evaluating patient engagement in any area.

Funders are starting to pay attention to this.

There are some tools available – see the references.

Small Group Activity

How will you
build PE in the
proposal?

What activities?

- Planning the study
- Conducting the study
- Spreading study results

Results?

DISCUSS

Patient Contribution

1. PLANNING THE STUDY:

- Developing the research question
- Minimize disruption to patients
- Aligning study activities to be consistent with ongoing care

2. CONDUCTING THE STUDY:

- Drafting or revising study materials and protocols
- Assisting with the recruitment of study participants
- Assisting with data collection and data analysis
- Participating in the evaluation of patient and stakeholder engagement
- Serving as a patient representative on a data safety monitoring board

3. DISSEMINATING THE STUDY RESULTS

- Identifying partner organizations for dissemination
- Planning and participating in dissemination efforts, such as presenting study findings
- Identifying opportunities to present or share information about the study

Building PE into the proposal

PE can impact on the following sections:

- Time investment
- Timelines
- Budget

Criteria for funding applications

Funding criteria for PE

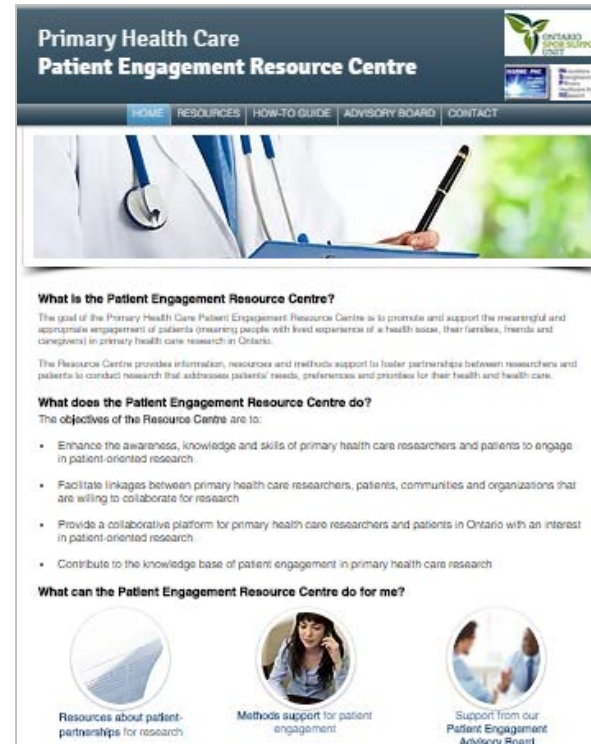
See handout

CIHR (Canada)	PCORI (US)	NHS-NIHR (UK)
Patients need to be involved in <u>all</u> aspects of the research to ensure questions and results are relevant	All applications funding <u>must include</u> an Engagement Plan	Ensure patients are <u>aware of opportunities</u> to participate in high quality research
SPOR is outcome driven and incorporates <u>performance measurement and evaluation</u> as integral components of the initiative	Encourage applicants to bring their most <u>creative engagement ideas</u> forward	Enable patients, carers and the public to <ul style="list-style-type: none">➤ <u>contribute</u> to the work of the Clinical Research Network➤ have <u>access to learning and development opportunities</u> to support their involvement and participation

Wrap up

Resources

- Primary Health Care Patient Engagement Resource Centre website
- **PERC** - the Patient Engagement Resource Committee
- Today's handouts



<https://www.patientengagement-nt-phcresearch.com/>

What do you see
now as the benefits
of PE in research?

FINAL QUESTIONS

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