

Patient and community engagement in primary health care research:

What it is and why it matters

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Simone Dahrouge, PhD

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Workshop Outline

1. Outline & Introductions (10 min)
2. What is patient engagement & why does it matter? (15 min)
 - ▶ Engagement frameworks
 - ▶ Forms, benefits of engagement
 - ▶ Practical considerations
3. Researcher and patient perspectives (15 min)
4. Sharing experiences & plans for patient engagement (30 min)
5. Setting priorities for the Resource Centre (10 min)

Introductions

Danielle Rolfe, PhD

Co-Lead, Patient Engagement in Primary Health Care Resource Centre



Simone Dahrouge, PhD

Co-Lead, Patient Engagement in Primary Health Care Resource Centre



Karen James, BSc

Community member, IMPACT (Ontario) Project



Workshop Participants:

Primary professional role?

Engagement experience to date?

2:40-2:50pm

Resource Centre

Patient Engagement in Research

A Resource Centre for Primary Health Care Researchers

How do you meaningfully involve patients in primary health care research?



Involving patients as participants is not new to primary health care researchers, but asking patients to help decide *what* or *how* primary health care research is done, is.

With support from the INSPIRE-Primary Health Care Research Network, Danielle Rolfe, PhD and Simone Dahrouge, PhD, are leading the development of a Resource Centre for primary health care researchers

with an interest, but limited prior experience, in involving patients in research.

The Resource Centre will:

- Offer an online catalogue of key resources and a 'how-to manual' of strategies, methods and tools for patient engagement
- Provide direct support to researchers by responding to requests for information
- Connect primary health care researchers with experts in patient engagement for research
- Provide support and guidance about researchers' projects via a Patient Advisory Council

To learn more, please contact Danielle at drolfe@bruyere.org



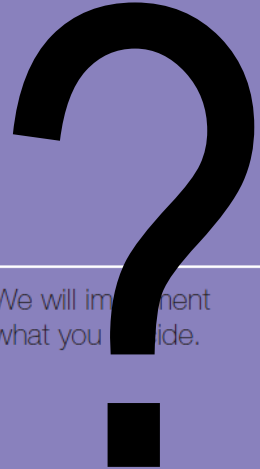
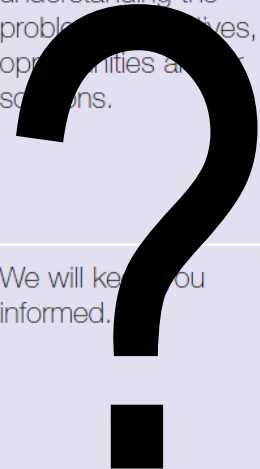
- How your input will be used
- Needs assessment



International Association of Public Participation (IAP2) – Spectrum of Participation

INCREASING IMPACT ON THE DECISION 

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.



CIHR Continuum of Engagement



Listening/Informing: Used primarily to explain or gather information, this level of engagement is employed when priorities and decisions are still being shaped. It allows CIHR to explain the issue to citizens, while (at the same time) it provides an opportunity for CIHR to gather information to understand the perspectives and ideas of citizens.

Promise to the public:
We will keep you informed and will provide you with an opportunity to ask questions.



Discussion: This level of engagement generally involves two-way information exchange in which the public discusses a policy, issue, or research priority. Discussion among and with different stakeholders is encouraged. This type of interaction allows CIHR to deepen its knowledge by exploring and responding to the ideas and concerns described by individual participants.

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Dialogue: This type of interaction involves thorough and in-depth deliberation about the policy, issue, or research priority. Different perspectives are shared and parties can influence each other. These dialogues allow CIHR and participants to explore and work through issues together, and gain a greater understanding of each other's perspectives and values. The closer relationships and greater interaction can lead to new ideas and consideration of complex tradeoffs.

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Collaboration: At this level of interaction, parties share responsibility for implementing decisions and a mutually beneficial relationship is usually established. With this pattern of communication, the goal is both to create CIHR-to-participant relationships and participant-to-participant relationships. The participants have a greater role in shaping the process as well as its outcomes.

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Patient Engagement: “A rose by any other name would smell as sweet”

	HEALTH EXPERIENCE RESEARCH	PUBLIC AND PATIENT PARTICIPATION	PATIENT ORIENTED RESEARCH	INTEGRATED KNOWLEDGE TRANSLATION	PARTICIPATORY RESEARCH
GOAL	To elicit in-depth experiential knowledge about living with a health condition	To improve health care and services	To generate research that answers patient-focused questions	To increase uptake of research findings	To identify and act upon local priorities
POSSIBLE LEVELS	Consult	Inform, Consult, Involve, Collaborate, Empower	Inform, Consult, Involve, Collaborate	Involve, Collaborate	Collaborate, Empower
METHODS	Primarily qualitative methods	Deliberative processes: public forums, steering committees	Mixed (qualitative, quantitative) & deliberative processes	Mixed (qualitative, quantitative) & deliberative processes	Mixed (primarily qualitative) & deliberative processes
KEY PLAYERS (non-researchers)	Patients and caregivers	Members of the public, health planners, providers	Patients and caregivers	Knowledge users	Community members

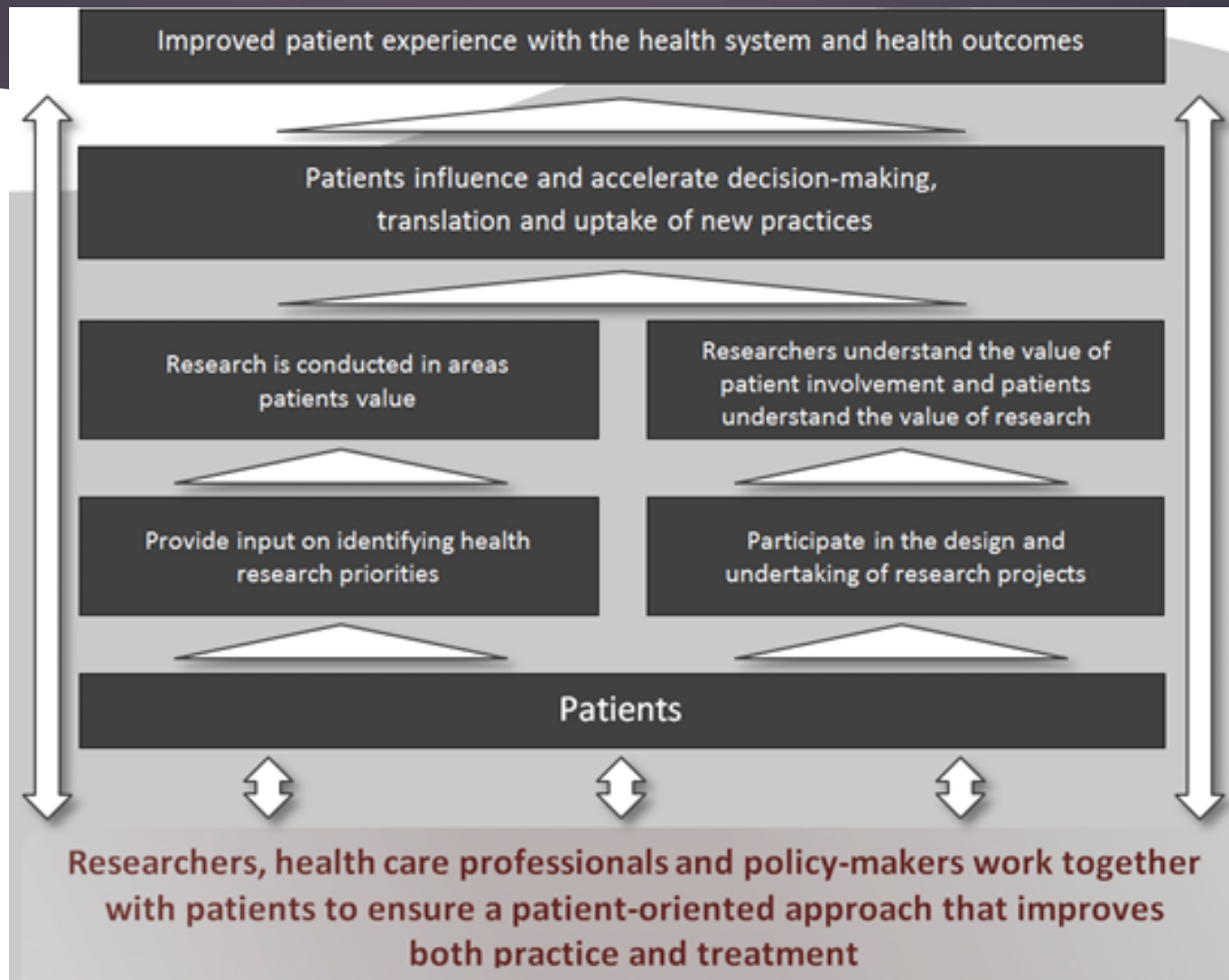
Forms of Engagement

- ▶ Planning, designing, guiding the research project
- ▶ Engaging other patients, bringing voice to table
- ▶ Identifying relevant research question, design, recruitment, data collection, analysis
- ▶ Improving access to hard-to-reach patients, groups

Benefits of Engagement

- ▶ Research goals aligned with patients' needs, priorities
- ▶ Research interventions acceptable to patients
- ▶ Participants facilitate recruitment
- ▶ Participants may feel empowered, valued
- ▶ Can lead to novel ideas, approaches
- ▶ Participants facilitate dissemination, may increase uptake
- ▶ Increased accountability to public, funders

CIHR Visual Value Model for Patient Engagement



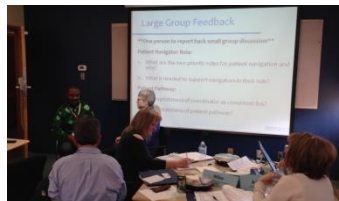
Practical Considerations

- ▶ Time & Cost
- ▶ Establishing and maintaining trust
- ▶ Recruiting the “right” patients
- ▶ Training participants (researchers and patients)
- ▶ Evaluating engagement

PHC Researcher Perspective

IMPACT

Innovative **M**odels **P**romoting
Access-to-**C**are **T**ransformation



- ▶ Goal
- ▶ Engagement by design
- ▶ Engagement methods
- ▶ Lessons learned

Community Member Perspective

- ▶ Past projects
- ▶ Reasons for participation
- ▶ Expectations
- ▶ Experiences
- ▶ Benefits
- ▶ Challenges



Sharing experiences & plans for patient engagement

- ▶ **Consider a relevant completed, in progress, or planned research project that could involve engagement**
- ▶ **Self-reflection** (5 minutes), then discuss in **small groups** (15 mins)
 - ▶ How engagement could be useful
 - ▶ What approach/strategy you propose (who, how, when)?
 - ▶ Potential challenges and how would you overcome these?
- ▶ Report back to **large group** (10 mins)
 - ▶ Common, divergent ideas about how engagement could be useful
 - ▶ Common, novel strategies for engagement
 - ▶ Lessons learned from experience to address potential challenges

Resource Centre for Patient Engagement in Primary Health Care Research

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- ▶ Resources, tools
- ▶ Network/Advisory Board
- ▶ Support for researchers
- ▶ Promote patient engagement
- ▶ Contribute new knowledge

The “How-to” Guide for Engagement

- ▶ Who to involve?
- ▶ When to involve?
- ▶ How to approach?
- ▶ How to recruit patients that can engage?
- ▶ How to sustain engagement?
- ▶ Is partnership right for you?
- ▶ How to end engagement?

Tools for community and patient engagement

- ▶ Online guides, resources
- ▶ Recruiting and screening patients
- ▶ Communication plan
- ▶ Evaluation tools
- ▶ Patient advisory board

Please complete Needs Assessment



Thank you!

▶ Danielle Rolfe

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613-562-6262 x 2924

Please complete feedback survey