

# What (else) do researchers need to know what outlook do they need to bring to the table?

Day 1, Sessions 4, 5, & 6: Researchers  
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OSSU Masterclass on the Conduct and Use of Patient-Oriented Research  
Toronto, ON  
April 18-20, 2016



# Lorraine Bayliss

- B.A. University of Toronto, H.B.A. York University, M.Ed University of Toronto
- Lived with Type 1 diabetes for going on 45 years
- Engaged in many volunteer activities supporting those living with Type 1 Diabetes
  - facilitated the establishment of a support group now in its fourteenth year that meets monthly at the Toronto General Hospital which seeks to provide support through shared experiences and understanding
  - member of the Canadian Diabetic advocacy team
  - works with Type 1 Diabetes Think Tank as a Patient Opinion Leader
  - Type 1 Diabetes Think Tank Network is a model for change whose approach is collaboration and partnership between HCP and patients, as equals, emphasizing communication, learning and respect.

# Amanda Terry

- Assistant Professor, PhD in Epidemiology
- Department of Family Medicine, Department of Epidemiology & Biostatistics, Schulich Interfaculty Program in Public Health, Western University
- Health services researcher focused on electronic medical record implementation and use in primary health care
- Previous work – ten years health system planning Ontario's District Health Council system

# Sandra Regan, RN, PhD

- Registered Nurse and Associate Professor
- Arthur Labatt Family School of Nursing, Western University
- Research Program focuses on health policy, health human resources & models of care in primary health care, public health and home care.
- Research incorporates decision-maker, provider, patient and caregiver experiences of health care
- Previous positions – clinician, clinical educator, policy consultant

# Roundtable Introductions

- Name
- Discipline
- University/organization
- Level of experience in patient-oriented research (POR) (none, some, lots)

# Objectives

1. To hear from researchers about who needs to know what (i.e. knowledge), and how they and other groups can fill gaps in their knowledge.
2. To hear from researchers about who needs what kind of outlook (attitude, approach) and how they and other groups can develop this.
3. To identify similarities and differences in the knowledge and outlook required of the groups engaged in the conduct and use of patient-oriented research.

# Overview Sessions 4,5,6

1. What else do researchers need to know?
  - Small group work and reporting back
2. Break
3. What outlook do researchers need to bring to the table?
  - Small group work and reporting back
4. What are the shared ground and differences?
  - Facilitated full group discussion

# Art of Listening

- Handout: The Art of Listening, L. Bayliss



# Art of Listening

## REMEMBER

- The illness is only a small part of the larger person
- Remember this is a person not a disease
- Body language is powerful - think before you speak
- Care about you - care about the patient
- Listening can be time efficient
- Empathy can be time efficient
- Think globally - build locally - one person at a time

# Session 4: What else do researchers need to know?

1. What do researchers need to know to engage in the conduct and use of patient oriented research? Where could they go for support on this? (15 mins)
2. What does your assigned stakeholder group need to know to engage in the conduct and use of patient oriented research? Where could they go for support on this? (15 mins)
3. Reporting back (15 mins)

# Session 4: What else do researchers need to know?

## Key Resources:

- Health Quality Ontario's webpages providing tools and resources to support patient engagement in improving Ontario's health systems (<http://www.hqontario.ca/Engaging-Patients>)
- Health Foundation's person-centred care resource centre (<http://personcentredcare.health.org.uk/resources/person-centred-care-around-world>)
- Others to be identified by participants (and supplemented as needed)

# Session 4: What else do researchers need to know?

- History of patients and families in research
- Broad understanding of patients' and families' experiences in relation to healthcare and research
- Health systems - provincially, nationally and internationally
- Health of the population (e.g. multimorbidity)
- How to engage and partner with patients and families in decision making
- How interdisciplinary research teams function
- Methods and methodologies

# Session 5: What outlook do researchers need to bring to the table?

1. What outlook (attitudes, approaches) do researchers need to bring to the table as they engage in the conduct and use of patient oriented research? Where could they go for support on this? (15 mins)
2. What outlook (attitudes, approaches) does your assigned stakeholder group need to bring to the table to engage in the conduct and use of patient oriented research? Where could they go for support on this? (15 mins)
3. Reporting back (15 mins)

# Session 5: What outlook do researchers need to bring to the table?

- Accepting patients' and families' experiences and diversity
- Understanding that patients' perspective are distinct from research, clinical, and policy perspectives
- Understanding that patients' and families' expressed needs are relevant to research questions
- Understanding that the types of questions that patients want to ask may not be part of traditional research
- Moving from consultation to partnerships with patient groups and other health-system stakeholders
- Understanding the perspectives of diverse stakeholder groups
- Considering that the health system needs to be guided by patients' systematically elicited needs and inviting them to comment on the system and how it can meet their needs

# Session 6: What are the similarities and differences?

1. What are the similarities and differences in the knowledge and outlook required of the groups engaged in the conduct and use of patient oriented research? (30 mins)

# Next Steps

<b>8:30 – 9:45</b>	<b>Day 2 Session 1</b>
<b>Title:</b>	<b>How to approach the conduct of patient oriented research</b>
<b>Faculty:</b>	<b>Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative</b>
<b>Objectives:</b>	<ul style="list-style-type: none"> <li>• To appreciate the components of patient-oriented research, including patient issues and patient engagement in interdisciplinary teams.</li> <li>• To understand the importance of considering that the health system needs to be guided by patients' systematically elicited needs; inviting them to comment on the system and how it can meet their needs.</li> </ul>
<b>9:45 – 11:00</b>	<b>Day 2 Session 2</b>
<b>Title:</b>	<b>What to ask when trying to conduct patient-oriented research, what to look for, and where to get it</b>
<b>Faculty:</b>	<b>Sandra Regan and Amanda Terry (for Moira Stewart), Western University, Wanrudee Isaranuwatthai, Centre of Excellence for Economic Analysis Research (CLEAR), and Lorraine Bayliss, patient/family representative</b>
<b>Objectives:</b>	<ul style="list-style-type: none"> <li>• To understand the importance of working iteratively as partners to understand a problem; options and implementation considerations in light of institutional constraints; interest group pressure, values and many other types of information; as well as 'external' factors such as the state of the economy.</li> <li>• To understand the importance of using economic ways of thinking.</li> <li>• To appreciate the resources in Ontario for data access, methodological and analytical support, and knowledge translation support (i.e. OSSU Member Centres).</li> </ul>
<b>11:15 – 12:30</b>	<b>Day 2 Session 3</b>
<b>Title:</b>	<b>How to conduct patient-oriented research</b>
<b>Faculty:</b>	<b>Sandra Regan and Amanda Terry (for Moira Stewart), Western University, and Lorraine Bayliss, patient/family representative</b>
<b>Objectives:</b>	<ul style="list-style-type: none"> <li>• To develop skills in engaging patients in shaping a research study</li> </ul>
<b>1:30 – 2:45</b>	<b>Day 2 Session 4</b>
<b>Title:</b>	<b>How to support the use of patient-oriented research: setting research priorities</b>
<b>Faculty:</b>	<b>Sandra Regan and Amanda Terry (for Moira Stewart), Western University, and Lorraine Bayliss, patient/family representative</b>
<b>Objectives:</b>	<ul style="list-style-type: none"> <li>• To develop skills in engaging patients in setting priorities for a research program</li> </ul>