

Masterclass on the Conduct and Use of Patient-Oriented Research

Curriculum

(Last updated 11 April 2016)

Ivey Tangerine Leadership Centre, 130 King St. West, Toronto
18-20 April 2016

OVERVIEW OF THE MASTERCLASS

This masterclass is designed to prepare a cadre of key individuals drawn from four groups – 1) patients and families, 2) healthcare providers, 3) policymakers and managers, and 4) researchers and research trainees -- to champion and support the conduct and use of patient-oriented research in Ontario's health system. The masterclass includes a mix of plenary sessions involving all groups (black) and group-specific sessions (which are colour-coded for each of the four groups, and specifically green for patients and families, blue for healthcare providers, purple for policymakers and managers, and burgundy for researchers and research trainees.

OBJECTIVES OF THE MASTERCLASS

The objectives of the masterclass are:

- To develop the competencies needed to conduct and use patient-oriented research in Ontario
- To become familiar with the additional training and other supports available in Ontario to conduct and use patient-oriented research
- To identify ways that you, your organization and other organizations with whom you (could) work can better support the conduct and use of patient-oriented research in the future and monitor and evaluate your efforts

PRE-MASTERCLASS TASKS

Please complete the following two tasks by 7 April 2016:

1. complete the online survey about the competencies you're most interested in developing, as well as about three challenges you've experienced in conducting or using patient-oriented research;
2. prepare a single slide that contains your name, photograph, organization, and up to three points that describe how you or your organization are involved in conducting or using patient-oriented research (while only some participants will be called on to introduce themselves, please have your slide prepared in case it's needed).

MASTERCLASS READINGS

You will receive a link to a DropBox of relevant resources. You will note in this agenda, below, where those readings will be referred to during presentations and group activities.

MASTERCLASS FRAMEWORK

Please see table 1 for the competencies that will be addressed in the masterclass.

MASTERCLASS DEVELOPMENT

Please see table 2 for the names and affiliations of those who contributed to the design of the masterclass.

- All groups (black)
- Patients and families (green)
- Healthcare providers (blue)
- Policymakers and managers (purple)
- Researchers and research trainees (burgundy)

Day 1 – Monday 18 April 2016 – Plenary sessions

8:00–8:30 Breakfast

8:30–9:45 Day 1, Session 1

Title: Welcome, introductions and overview of the masterclass

Faculty: John Lavis

Format: – Masterclass introduction – John Lavis (5 minutes)
 – Brief presentations by select workshop participants (30 minutes)
 – Discussion (5 minutes)
 – Brief presentations by select workshop participants (30 minutes)
 – Discussion (5 minutes)

Objectives: – To be welcomed by and introduced to the OSSU leadership and lead masterclass faculty
 – To become familiar with the objectives, structure and mix of pedagogical approaches used in the masterclass and about the centrality of teams and support for team members in the masterclass
 – To meet some fellow masterclass participants and hear about how they or their organization are involved in conducting or using patient-oriented research

9:45–11:00 Day 1, Session 2

Title: What do those engaged in (supporting) the conduct and use of patient-oriented research need to know?

Faculty: Sara Wuite (for Moira Stewart), Western University and chair of the OSSU Working Group on Training and Capacity Building
 John Lavis, McMaster University

Format: – Presentation about the lessons learned by the working group, by Sara Wuite (15 minutes)
 – Presentation about health and the health system in Ontario, by John Lavis (15 minutes)
 – Small-group work on one thing that each group needs to know that wasn't covered in the presentation (30 minutes)
 – Reporting back by select groups (15 minutes)

Objectives: – To appreciate the key types of knowledge required by 3 or more of the participating groups (as articulated by the OSSU Working Group on Training and Capacity Building)
 – To inform the ongoing evolution of the list of key types of knowledge

Resources: – Duhigg C. What Google learned from its quest to build the perfect team. The New York Times Magazine, 25 January 2016. Web. Accessed 4 Apr. 2016.

11:00-11:15 Health break

11:15-12:30 Day 1, Session 3

- Title: What outlook do those engaged in (supporting) the conduct and use of patient-oriented research need to bring to the table?
- Faculty: Anne Lyddiatt, Patient Partners in Arthritis Program and member of the OSSU Working Group on Training and Capacity Building
- Format:
- Presentation (30 minutes)
 - Small-group work on one dimension of the outlook that each group needs to know that wasn't covered in the presentation (30 minutes)
 - Reporting back by select groups (15 minutes)
- Objectives:
- To appreciate the key dimensions of the outlook required by 3 or more of the participating groups (as articulated by the OSSU Working Group on Training and Capacity Building)
 - To inform the ongoing evolution of the list of key dimension of outlook
- Resource
- Gavin F. New Roles for Families in Research to Improve Child and Youth Health. Toronto, Canada: Canadian Family Advisory Network.

12:30-1:30 Lunch

4:40-4:55 Day 1, Session 7

- Title: Welcome and a brief history of and experiences with patient-oriented research in Ontario)
- Format:
- Welcome by the executive director of the Ontario SPOR Support Unit (including a brief history of and experiences with patient-oriented research in Ontario) - Vasanthi Srinivasan (5 minutes)
 - Welcome by the chair of the board of directors of the Ontario SPOR Support Unit - Michael Decker (10 minutes)

Day 1 – Monday 18 April 2016 – Sessions for patients and families/caregivers

1:30-2:45 Day 1, Session 4

- Title: What (else) do patients and families/caregivers need to know?
- Faculty: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network
- Format:
- Overview of session (5 minutes)
 - Small-group work on what patients and families/caregivers need to know to engage in the conduct and use of patient-oriented research, and where they'd go for support with this (25 minutes)
 - Small-group work on what one of three groups – providers, policymakers/managers and researchers – need to know, and where they'd go for support with this (25 minutes)
 - Reporting back by groups (20 minutes)
- Objectives:
- To hear from patients and families/caregivers about who needs to know what and how they and other groups can fill gaps in their knowledge
- Resources:
- For supplementary resources for this and later sessions, see:
 - Julia Abelson's resource guide for research teams and networks undertaking patient-engagement activities (<http://ossu.ca/wp-content/uploads/OSSU-Patient-Engagement-Resource-Document-May2015.pdf>)
 - Health Quality Ontario's webpages providing tools and resources to support patient engagement in improving Ontario's health systems (<http://www.hqontario.ca/Patient-Engagement/Health-Quality-Ontario-and-Patient-Engagement>)
 - The Health Foundation's person-centred care resource centre (<http://personcentredcare.health.org.uk/resources/person-centred-care-around-world>)

2:45-3:00 Working health break (please bring your refreshments back to your workspace)

2:45-4:00 Day 1, Session 5

- Title: What (other dimensions of) outlook do patients and families/caregivers need to bring to the table?
- Faculty: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network
- Format:
- Overview of session (5 minutes)
 - Small-group work on what outlook patients and families/caregivers need to bring to the table as they engage in the conduct and use of patient-oriented research, and where they'd go for support with this (25 minutes)
 - Small-group work on what one of three groups – providers, policymakers/managers and researchers – need to know and where they'd go for support with this (25 minutes)
 - Reporting back by groups (20 minutes)
- Objectives:
- To hear from patients and families/caregivers about who needs what type of outlook and how they and other groups can develop such an outlook

4:00-4:30

Day 1, Session 6

Title: Where are the shared ground and differences?

Moderator: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network

Format: Facilitated discussion (30 minutes)

Objectives: – To identify similarities and differences in the knowledge and outlook required of the groups engaged in the conduct and use of patient-oriented research

4:40-4:55

Reconvene in plenary

Day 1, Session 7

Title: Welcome and a brief history of and experiences with patient-oriented research in Ontario)

Format: – Welcome by the executive director of the Ontario SPOR Support Unit (including a brief history of and experiences with patient-oriented research in Ontario) – Vasanthi Srinivasan (5 minutes)
– Welcome by the chair of the board of directors of the Ontario SPOR Support Unit - Michael Decter (10 minutes)

Day 2 – Tuesday 19 April 2016 – Sessions for patients and families/caregivers

8:00–8:30 Breakfast

8:30–9:45 Day 2, Session 1

- Title: What to ask when trying to shape and use patient-oriented research, what to look for, and where to get it
- Faculty: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network
- Format:
- Presentation (30 minutes)
 - Cases (45 minutes)
- Objectives:
- To appreciate
 - Questions to ask about diagnostic tests, treatments, etc.
 - Types of research evidence needed to answer these questions (and related research terminology)
 - Appropriate sources of key types of pre-appraised research evidence

9:45–11:00 Day 2, Session 2

- Title: How to approach the shaping and use of patient-oriented research
- Faculty: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network
- Format:
- Presentation (30 minutes)
 - Cases (45 minutes)
- Objectives:
- To understand
 - Why science matters
 - Research can be high and low quality, and of greater or lesser applicability to patients' health and to research questions

11:00-11:15 Health break

11:15–12:30 Day 2, Session 3

- Title: How to shape and use patient-oriented research at the individual level
- Faculty: Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network
- Format:
- Presentation (10 minutes)
 - Small-group work (45 minutes)
 - Reporting back (20 minutes)
- Objectives:
- To develop skills in
 - Identifying and expressing needs for information, care and support in ways that are understandable to those seeking to understand or address their needs
 - Identify topics in research that are of concern to patients and families/caregivers
 - Search appropriate sources of pre-appraised research evidence

12:30-1:30

Lunch

1:30-2:45

Day 2, Session 4

Title:

How to shape and use patient-oriented research at the system level

Faculty:

Julia Abelson, McMaster University and Frank Gavin, Canadian Family Advisory Network

Format:

- Presentation (10 minutes)
- Small-group work (45 minutes)
- Reporting back (20 minutes)

Objectives:

- To develop skills in identifying changes in the health system that affect their experience and know who to contact to support the change or to explain how it negatively affects them and what could be done about it

2:45-3:15

Health break

Day 1 – Monday 18 April 2016 – Sessions for healthcare providers

1:30-2:45 Day 1, Session 4

- Title: What (else) do healthcare providers need to know?
- Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto
- Format:
- Introductions (15 minutes)
 - Presentation (40 minutes)
 - Discussion (20 minutes)
- Objectives:
- To develop an overview of patient engagement in research
 - To understand potential pros and cons of patient engagement in research
 - To develop knowledge of a model of patient engagement in research using the CAN experience

2:45-3:00 Working health break (please bring refreshments back to your workspace)

2:45-3:35 Day 1, Session 5

- Title: What are the challenges to patient engagement in research that clinicians need to consider?
- Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto
- Format:
- Videos as background to discussion (10 minutes)
 - Small group discussion on what are the challenges to patient engagement that clinicians need to consider? (20 minutes)
 - Large group report back/discussion (20 minutes)
- Objectives:
- To gain knowledge about the challenges to patient engagement in research
- Resources:
- <http://www.pcori.org/funding-opportunities/what-we-mean-engagement>
 - <http://can.arthritisalliance.ca/en/video>

3:35-4:35 Day 1, Session 6

- Title: How can patients be engaged in research?
- Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto
- Format:
- Scenario: You are a physician seeing a patient who was just diagnosed with colon cancer. You have heard about a potential new treatment to consider and find there is a randomized trial that is testing this intervention.
 - o *How would you approach your patient to consider participating in this trial? What challenges to engaging them in research might you expect?*
 - o Think (2 minutes); Pair (10 minutes); Share as large group (10 minutes)
 - Illustrate some of the challenges and approaches with healthtalk videos – each video will be discussed as a large group
 - o Video 1: Setting the stage
 - Lester: comes down to trusting the physician to tell you they don't know which treatment is best (1.5 minutes)
 - o Video 2: Reasons why patients may want to participate (2.5 minutes)

- Video 3: Perceptions of randomization, what happens if don't get the intervention(2.3 minutes)
 - Video 4: Importance of blinding
 - Amanda: the research nurse wanted a particular result, the importance of blinding (3.3 minutes)
- Objectives:
- To gain knowledge and skills in engaging patients in research as study participants
 - To gain knowledge about the challenges and benefits to various approaches to patient engagement in research
- Resources:
- Video 1: <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/feelings-about-being-allocated-randomised-treatment-group>
 - Video 2: <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/reasons-wanting-take-part-personal-benefit>
 - Video 3: <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/feelings-about-being-allocated-randomised-treatment-group>
 - Video 4: <http://www.healthtalk.org/peoples-experiences/medical-research/clinical-trials/blinded-trials>

Reconvene in plenary

4:40-4:55

Day 1, Session 7

- Title: Welcome and a brief history of and experiences with patient-oriented research in Ontario)
- Format:
- Welcome by the executive director of the Ontario SPOR Support Unit (including a brief history of and experiences with patient-oriented research in Ontario) – Vasanthi Srinivasan (5 minutes)
 - Welcome by the chair of the board of directors of the Ontario SPOR Support Unit - Michael Decter (10 minutes)

Day 2 – Tuesday 19 April 2016 – Sessions for healthcare providers

**8:00–
8:30** **Breakfast**

**8:30–
9:25** **Day 2, Session 1**

Title: Moving from research participant to research collaborator – how can patients be engaged as research collaborators?

Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto

Format: – Overview of patient engagement in research from priority setting through to research completion (15 minutes)
 – Scenario: You are working with a team to establish research priorities for older adults (aged 65 years and older) with 2 or more chronic diseases (including the 10 commonest chronic diseases in Canada, namely cardiovascular disease, stroke, hypertension, diabetes, COPD/asthma, depression, arthritis, osteoporosis, cancer, dementia) and their caregivers. This is envisioned to be a national initiative and will include frail elderly and their caregivers, as well as those who speak English and French.
 ○ Small group discussion: How would you engage patients and caregivers in this? What are potential challenges to their recruitment and involvement in this exercise? (20 minutes)
 ○ Large group report back (20 minutes)

Objectives : – To gain knowledge and skills in engaging patients throughout the research enterprise
 – To gain knowledge and skills in engaging patients in research priority setting

**9:25–
10:30** **Day 2, Session 2**

Title: How can we come to consensus on research priorities

Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto

Format: – Establish ground rules for the process (5 minutes)
 – Small group discussion: discussion of priorities – using 25 questions that were previously identified (30 minutes)
 – Large group report back: on top 3 priorities, on perceptions of the process, pros/cons (30 minutes)

Objectives : – To develop skills in research priority setting with patients

**10:30–
11:15** **Day 2, Session 3**

Title: What is shared decision making?

Faculty: Linda Wilhelm, Canadian Arthritis Patient Alliance and Sharon Strauss, University of Toronto

- Format: – Presentation – overview of what it is and the evidence for it (15 minutes)
 – Video (5 minutes)
 – Large group discussion on challenges to shared decision-making (25 minutes)
- Objectives : – To gain knowledge about shared decision making in practice and the evidence for it
 – To gain knowledge about the importance of eliciting patient preferences
 – To develop knowledge about the challenges to shared decision making in practice
- Resources : – Gavin F. Tip Sheet for Medical Students and Residents. Toronto, Canada: Canadian Family Advisory Network
 – [https://www.dropbox.com/s/up2i2g8q0gifmr6/OMA_Scene3_\(2007\)_\(English\).wmv?dl=0](https://www.dropbox.com/s/up2i2g8q0gifmr6/OMA_Scene3_(2007)_(English).wmv?dl=0)

11:15-11:30 **Health break** (note that the other groups will be taking their health break from 11-11:15)

11:30-12:30 **Day 2, Session 4**

Title: How can we find evidence?

Faculty: Sharon Strauss, University of Toronto

- Format: – Presentation (40 minutes)
 – Discussion/questions (20 minutes)

- Objectives : – To gain knowledge about searching for evidence to inform decision making
 – To gain knowledge about pros/cons of different evidence resources
 – To gain knowledge about resources for appraising evidence

12:30-1:30 **Lunch**

1:30-2:30 **Day 2, Session 5**

Title: How else can patient oriented research be used?

Faculty: Sharon Strauss, University of Toronto and Linda Wilhelm, Canadian Arthritis Patient Alliance

- Format: – Small group discussion (20 minutes) – Outline their experiences with patient engagement in research, what worked, what didn't work
 – Large group report back

- Objectives : – To gain knowledge and skills in eliciting patient questions and other steps in the research enterprise
 – To discuss outstanding challenges to patient engagement in research and ways to overcome these challenges

2:30-3:15 **Health break** (note that the other groups will be taking their health break from 2:45-3:15)

Day 1 – Monday 18 April 2016 – Sessions for policymakers/managers

1:30-2:45 Day 1, Session 4

- Title: What (else) do policymakers/managers need to know?
- Faculty: Anne Lyddiatt, Patient Partners in Arthritis Program, and John Lavis, McMaster University
- Format:
- Discussion about the good, the bad and the ugly of involving patients and families in the conduct and use of patient-oriented research (15 minutes)
 - Work in pairs to prepare a brief, informal presentation (maximum 3 minutes) on what policymakers/managers need to know and where to go for supports on one of the following topics (20 minutes)
 - o History of patients and families in research
 - o Broad understanding of patients' and families' experiences in relation to healthcare and research
 - o Health of the population (e.g., multimorbidity)
 - o Health systems - provincially, nationally and internationally
 - o How to engage and partner with patients and families in decision making
 - o One other topic
 - Brief presentations and discussion (40 minutes)
- Objectives:
- To hear from policymakers/managers about what they need to know and how they can fill gaps in their knowledge

2:45-3:00 Working health break (please bring your refreshments back to your workspace)

2:45-4:00 Day 1, Session 5

- Title: What (other dimensions of) outlook do policymakers/managers need to bring to the table?
- Faculty: Anne Lyddiatt, Patient Partners in Arthritis Program, and John Lavis, McMaster University
- Format:
- Work in pairs to prepare a brief, informal presentation (maximum 4 minutes) on what (other dimensions of) outlook policymakers/managers need to have and how they can develop such an outlook (20 minutes)
 - o Accepting patients' and families' experiences and diversity
 - o Understanding that patients' perspective are distinct from research, clinical, and policy perspectives
 - o Understanding that patients' and families' expressed needs are relevant to research questions
 - o Understanding that the types of questions that patients want to ask may not be part of traditional research
 - o Moving from consultation to partnerships with patient groups and other health-system stakeholders
 - o Understanding the perspectives of diverse stakeholder groups
 - o Understanding why science matters
 - o 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
 - o One other topic
 - Brief presentations and discussion (55 minutes)
- Objectives:
- To hear from policymakers/managers about what type of outlook they need to bring to the table and how they can develop such an outlook

4:00-4:30

Day 1, Session 6

Title: Where are the shared ground and differences?

Moderator: Anne Lyddiatt, Patient Partners in Arthritis Program, and John Lavis, McMaster University

Format: Facilitated discussion (30 minutes)

Objectives: – To identify similarities and differences in the knowledge and outlook expected of other groups (patients and families, healthcare providers, and researchers / trainee) engaged in the conduct and use of patient-oriented research

Reconvene in plenary

4:40-4:55

Day 1, Session 7

Title: Welcome and a brief history of and experiences with patient-oriented research in Ontario)

Format: – Welcome by the executive director of the Ontario SPOR Support Unit (including a brief history of and experiences with patient-oriented research in Ontario) – Vasanthi Srinivasan (5 minutes)
– Welcome by the chair of the board of directors of the Ontario SPOR Support Unit - Michael Decter (10 minutes)

Day 2 — Tuesday 19 April 2016 – Sessions for policymakers/managers

8:00–8:30 Breakfast

8:30–9:45 Day 2, Session 1

Title: Clarifying a policy or managerial problem using patient-oriented research

Faculty: John Lavis, McMaster University and Anne Lyddiatt, Patient Partners in Arthritis Program

Format:

- Presentation (5 minutes)
- Small-group work using task sheet #2 (20 minutes)
- Reporting back (20 minutes)
- Presentation (10 minutes)
- Small-group work using task sheet #3 (15 minutes)
- Reporting back (5 minutes)

Objectives:

- To appreciate
 - Questions to ask about a problem
 - Types of research evidence needed to answer these questions (and related research terminology)
 - Appropriate sources of key types of pre-appraised research evidence
- To understand the importance of
 - Working iteratively to understand a problem 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
 - Being systematic and transparent in finding and using research evidence as one input to the decision-making process
 - Looking first for a perfect match in the available research evidence (to support an instrumental use) and then looking more broadly (to support a conceptual use)
- To develop skills in
 - Clarifying a problem
 - Searching appropriate sources of pre-appraised research evidence

9:45–11:00 Day 2, Session 2

Title: Framing options to address a problem using patient-oriented research

Faculty: John Lavis, McMaster University and Anne Lyddiatt, Patient Partners in Arthritis Program

Format:

- Presentation (5 minutes)
- Small-group work using task sheet #4 (10 minutes)
- Reporting back (5 minutes)
- Presentation (10 minutes)
- Small-group work using task sheet #5 (20 minutes)
- Reporting back (10 minutes)
- Presentation (5 minutes)
- Small-group work using task sheet #8 (10 minutes)

- Objectives:
- To appreciate
 - Questions to ask about options to address a problem
 - Types of research evidence needed to answer these questions (and related research terminology)
 - Appropriate sources of key types of pre-appraised research evidence
 - What an AMSTAR score means
 - Questions to ask about local applicability considerations
 - To understand the importance of
 - Working iteratively to understand options
 - Using economic ways of thinking
 - Being systematic and transparent in finding and using research evidence as one input to the decision-making process
 - Finding and using the best available (i.e., highest quality, most locally applicable, synthesized) research evidence in the time you have available
 - Looking first for a perfect match in the available research evidence (to support an instrumental use) and then looking more broadly (to support a conceptual use)
 - To develop skills in
 - Framing options to address the problem
 - Searching appropriate sources of pre-appraised research evidence
 - Using AMSTAR to describe the quality of a systematic review
 - Conducting a local applicability assessment

11:00-11:15 Health break

11:15-12:30 Day 2, Session 3

Title: Identifying implementation considerations using patient-oriented research

Faculty: John Lavis, McMaster University and Anne Lyddiatt, Patient Partners in Arthritis Program

- Format:
- Presentation (5 minutes)
 - Small-group work using task sheet #6 (15 minutes)
 - Presentation (10 minutes)
 - Small-group work using the slide template (30 minutes)
 - Reporting back (10 minutes)
 - Recap (5 minutes)

- Objectives:
- To appreciate
 - Questions to ask about implementation considerations
 - Types of research evidence needed to answer these questions (and related research terminology)
 - Appropriate sources of key types of pre-appraised research evidence
 - To understand the importance of
 - Working iteratively to understand implementation considerations
 - Being systematic and transparent in finding and using research evidence as one input to the decision-making process
 - Looking first for a perfect match in the available research evidence (to support an instrumental use) and then looking more broadly (to support a conceptual use)
 - To develop skills in
 - Identifying implementation considerations
 - Commissioning research to fill gaps in research evidence
 - Sharing your current approach to a health-system challenge

12:30-1:30 Lunch

1:30-2:45 Day 2, Session 4

Title: Raising the bar for using patient-oriented research in your organization or system

Faculty: John Lavis, McMaster University and Anne Lyddiatt, Patient Partners in Arthritis Program

Format:

- Presentation (10 minutes)
- Discussion (15 minutes)
- Presentation (10 minutes)
- Discussion (15 minutes)
- Preparing for reporting back in plenary, using the slide template (25 minutes)

Objectives:

- To appreciate
 - Dimensions of capacity to use patient-oriented research
 - Range of possible efforts to support the use of patient-oriented research
- To develop skills in
 - Assessing capacity to find and use patient-oriented research
 - Identifying gaps in efforts to support the use of patient-oriented research

2:45-3:15 Health break

Day 1 – Monday 18 April 2016 – Sessions for researchers/trainees

1:30-2:45 Day 1, Session 4

Title: What (else) do researchers/trainees need to know?

Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative

Format:

- Overview of session (5 minutes)
- Small-group work on what researchers/trainees need to know to engage in the conduct and use of patient-oriented research, and where they'd go for support with this (25 minutes)
- Small-group work on what one of three groups – patients and families/caregivers, providers, and policymakers/managers – need to know, and where they'd go for support with this (25 minutes)
- Reporting back by groups (20 minutes)

Objectives:

- To hear from researchers/trainees about who needs to know what and how they and other groups can fill gaps in their knowledge

2:45-3:00 Working health break (please bring refreshments back to your workspace)

2:45-4:00 Day 1, Session 5

Title: What (other dimensions of) outlook do researchers/trainees need to bring to the table?

Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative

Format:

- Overview of session (5 minutes)
- Small-group work on what outlook researchers/trainees need to bring to the table as they engage in the conduct and use of patient-oriented research, and where they'd go for support with this (25 minutes)
- Small-group work on what one of three groups – patients and families/caregivers, providers, and policymakers/managers – need to know, and where they'd go for support with this (25 minutes)
- Reporting back by groups (20 minutes)

Objectives:

- To hear from patients and families/caregivers about who needs what type of outlook and how they and other groups can develop such an outlook

4:00-4:30 Day 1, Session 6

Title: Where are the shared ground and differences?

Moderator: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative

Format: Facilitated discussion (30 minutes)

Objectives:

- To identify similarities and differences in the knowledge and outlook required of the groups engaged in the conduct and use of patient-oriented research

Reconvene in plenary

4:40-4:55

Day 1, Session 7

Title: Welcome and a brief history of and experiences with patient-oriented research in Ontario)

Format:

- Welcome by the executive director of the Ontario SPOR Support Unit (including a brief history of and experiences with patient-oriented research in Ontario) – Vasanthi Srinivasan (5 minutes)
- Welcome by the chair of the board of directors of the Ontario SPOR Support Unit - Michael Decter (10 minutes)

Day 2 — Tuesday 19 April 2016 – Sessions for researchers/trainees

8:00–8:30

Breakfast

8:30–9:45

Day 2, Session 1

- Title: How to approach the conduct of patient oriented research
- Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative
- Format:
- Presentation (5 minutes)
 - Discussion (15 minutes)
 - Presentation (15 minutes)
 - Discussion (10 minutes)
 - Presentation (10 minutes)
 - Case presentations (10 minutes)
 - Case discussion (10 minutes)
- Objectives:
- To appreciate the components of patient-oriented research, including patient issues and patient engagement in interdisciplinary teams. How interdisciplinary research teams function
 - 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.

9:45–11:00

Day 2, Session 2

- Title: What to ask when trying to conduct patient-oriented research, what to look for, and where to get it
- Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University, Wanrudee Isaranuwatjai, Centre of Excellence for Economic Analysis Research (CLEAR), and Lorraine Bayliss, patient/family representative
- Format:
- Presentation (10 minutes)
 - Interactive workshop (50 minutes)
 - Presentation (10 minutes)
- Objectives:
- 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.
 - To understand the importance of using economic ways of thinking.
 - To appreciate the resources in Ontario for data access, methodological and analytical support, and knowledge translation support (i.e. OSSU Member Centres), as well as sources of pre-appraised, synthesized research evidence

11:00–11:15

Health break

11:15–12:30**Day 2, Session 3**

- Title: How to conduct patient-oriented research
- Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative
- Format:
- Presentation (20 minutes)
 - Small group discussion (20 minutes)
 - Report back (15 minutes)
 - Panel response (10 minutes)
 - Presentation (10 minutes)
- Objectives:
- To develop skills in engaging patients in shaping a research study

12:30-1:30**Lunch****1:30-2:45****Day 2, Session 4**

- Title: How to support the use of patient-oriented research: setting research priorities
- Faculty: Sandra Regan and Amanda Terry (for Moira Stewart), Western University and Lorraine Bayliss, patient/family representative
- Format:
- Presentation (15 minutes)
 - Interactive activity (30 minutes)
 - Discussion (10 minutes)
 - Activity (5 minutes)
 - Discussion (5 minutes)
 - Wrap up for reporting back (10 minutes)
- Objectives:
- To develop skills in engaging patients in setting priorities for a research program

2:45-3:15**Health break**

Day 2 – Tuesday 19 April 2016 – Plenary sessions

3:15–4:00 Day 2, Session 5

Title: Hearing back from the groups

Faculty: Steini Brown

Format:

- Facilitated discussion (45 minutes)
 - o Presentation by patient/family group using slide template provided (5 minutes)
 - o Presentation by provider group using slide template provided (5 minutes)
 - o Discussion (10 minutes)
 - o Presentation by policymaker/manager group using slide template provided (5 minutes)
 - o Presentation by researcher/research trainee group using slide template provided (5 minutes)
 - o Discussion (25 minutes)

Objectives:

- To hear back from participants in each of the groups about the key insights that they took away from the group-specific sessions

4:00–4:45 Day 2, Session 6

Title: Supporting the conduct and use of patient-oriented research among Ontario's aboriginal populations

Faculty:

- Michael Green, Queen's University
- (introduced by Steini Brown)

Format:

- Lecture (25 minutes)
- Questions and answers (20 minutes)

Objectives:

- To appreciate the historical and cultural reasons why the conduct and use of patient-oriented research may take different forms among Ontario's aboriginal populations

4:45–5:30 Day 2, Session 7

Title: Research ethics

Faculty:

- Charles Weijer, Western University
- (introduced by Steini Brown)

Format:

- Lecture (25 minutes)
- Questions and answers (20 minutes)

Objectives:

- To appreciate the principles underlying ethics and their application to research questions

Day 3 – Wednesday 20 April 2016 – Plenary sessions

7:00–7:30 **Breakfast**

7:30–8:00 **Day 3, Session 1**

Title: Welcome

Speaker: Bob Bell, Deputy Minister, Ministry of Health and Long-Term Care
(introduced by Vasanthi Srinivasan)

Format: Presentation

Objectives: – To hear from the province’s deputy minister about the government’s efforts to
 ‘put patients first’ and to base decision-making on the best available research
 evidence

8:00 – 8:30 **Breakfast continued**

8:30–9:45 **Day 3, Session 2**

Title: Patients (and families/caregivers) as shared decision-makers about the care they
(or their family member) receive and as contributors to setting direction for broad
system change

Faculty: – France Légaré, Université Laval
 – Mike Wilson on engaging patients in setting direction for broad system change,
 McMaster University
 – (introduced by Jeremy Grimshaw)

Format: – Presentations (15 minutes each) and Q&A (15 minutes each)
 – Plenary discussion (35 minutes)

Objectives: – To appreciate the lessons learned from the Quebec and Ontario experiences
 with engaging patients (and families/caregivers) in shared decision-making and
 setting direction for broad system change
 – To identify the types of patient-oriented research and supports for using
 patient-oriented research that are needed to facilitate the broader uptake of
 patient (and family/caregiver) involvement in shared decision-making and
 setting direction for broad system change in Ontario

9:45–10:00 **Health break**

10:00–11:15 **Day 3, Session 3**

Title: Role play: Working together (part 1)

Faculty: – Jeremy Grimshaw, University of Ottawa
 – Andreas Laupacis, University of Toronto
 – John Lavis, McMaster University
 – Michael Wilson, McMaster University

- Format:**
- Introduction by Jeremy Grimshaw (25 minutes)
 - Orientation to exercises (10 minutes)
 - Role play of first meeting (40 minutes)
- Objectives:**
- To appreciate the dynamics of small-group behaviour, particularly when groups are diverse with respect to the types of expertise they bring to the table, the hierarchies that can operate in the health sector, etc.
 - To identify practical tips for the chairs of and participants in small groups seeking to facilitate the broader engagement of patients and families/caregivers in setting direction for the conduct and use of patient-oriented research
 - To begin to experience one method of group process that includes and values all members of the team
- Resources**
- Scenario and instructions for role play of first meeting

11:15–12:30 Day 3, Session 4

- Title:** Role play: Working together (part 2)
- Faculty:**
- Jeremy Grimshaw, University of Ottawa
 - Andreas Laupacis, University of Toronto
 - John Lavis, McMaster University
 - Michael Wilson, McMaster University
- Format:**
- Role play of second meeting (40 minutes)
 - De-brief (35 minutes)
- Objectives:**
- To continue experiencing one method of group process that includes and values all members of the team
 - To appreciate the structures and skills required for inclusive team member participation
- Resources**
- Scenario and instructions for role play of second meeting

12:30-1:30 Lunch

1:30-2:45 Day 3, Session 5

- Title:** Patients as contributors to setting direction for the conduct and use of patient-oriented research
- Faculty:** Andreas Laupacis, University of Toronto (introduced by John Lavis)
- Format:**
- Presentation (10 minutes)
 - Simulation of a research priority-setting group (45 minutes)
 - Plenary discussion (20 minutes)
- Objectives:**
- To appreciate the lessons learned from the Ontario experience with engaging patients and families/caregivers in research advisory groups to set direction for the conduct and use of patient-oriented research
 - To identify the steps that groups need to take to facilitate the broader engagement of patients and families/caregivers in setting direction for the conduct and use of patient-oriented research

2:45-3:00 **Working health break** (please bring refreshments back to the meeting room)

2:45-3:45 **Day 3, Session 7**

Title: Where to from here

Faculty: John Lavis, McMaster University (for Steini Brown, University of Toronto)

Format: – Small-group work (30 minutes)
 – Presentations by small groups (30 minutes)

Objectives: – To identify three next steps that each group would prioritize for themselves or others to advance the conduct and use of patient-oriented research in Ontario

3:45-4:15 **Day 3, Session 8**

Title: Wrap-up

Moderator: – John Lavis, McMaster University
 – Vasanthi Srinivasan, Ontario SPOR Support Unit

Format: – Presentation (10 minutes)
 – Closing by Ontario SPOR Support Unit (5 minutes)
 – Evaluation of the masterclass (15 minutes)

Objectives: – To appreciate the additional opportunities available in Ontario to build capacity in the conduct and use of patient-oriented research
 – To evaluate the masterclass

Resource: – OSSU Working Group on Training and Capacity Building (2015). Ontario SPOR Support Unit Capacity Building Compendium. Toronto, Canada: OSSU.

Table 1: Competencies identified as salient by the OSSU Working Group on Training and Capacity Building, by group

	Patients and families	Healthcare providers	Policymakers/managers	Researchers/trainees
Knowledge shared by ≥ 3 groups	<ul style="list-style-type: none"> • The history of patients and families in research • Broad understanding of other patients' and families' experiences in relation to healthcare and research • Health of the population (e.g., multimorbidity) • Health systems - provincially, nationally and internationally • Research terminology • Types of research evidence needed to answer questions about their health • Appropriate sources of key types of pre-appraised research evidence 	<ul style="list-style-type: none"> • The history of patients and families in research • Broad understanding of patients' and families' experiences in relation to healthcare and research • Health of the population, (e.g., multimorbidity) • Health systems - provincially, nationally and internationally • Research terminology • Questions to ask about a problem, options, and implementation considerations • Types of research evidence needed to answer health and healthcare-related questions • Appropriate sources of key types of pre-appraised research evidence • Research ethics 	<ul style="list-style-type: none"> • The history of patients and families in research • Broad understanding of patients' and families' experiences in relation to healthcare and research • Health of the population, (e.g., multimorbidity) • Health systems - provincially, nationally and internationally • Research terminology • Questions to ask about a problem, options and implementation considerations • Types of research evidence needed to answer health and healthcare-related questions • Appropriate sources of key types of pre-appraised research evidence • Research ethics 	<ul style="list-style-type: none"> • The history of patients and families in research • Broad understanding of patients' and families' experiences in relation to healthcare and research • Health of the population, (e.g., multimorbidity) • Health systems - provincially, nationally and internationally • Research ethics

Knowledge shared by ≤2 groups	<ul style="list-style-type: none"> • Questions to ask about diagnostic tests, treatments, etc. - <i>added</i> 	<ul style="list-style-type: none"> • Questions to ask about diagnostic tests, treatments, etc. 	<ul style="list-style-type: none"> • How to engage and partner with patients and families, health care providers, policy makers and managers, and communities in decision making • What an AMSTAR score means • Questions to ask about local applicability considerations • Dimensions of capacity to find and use research evidence • Range of possible efforts to support the use of research evidence 	<ul style="list-style-type: none"> • How to engage and partner with patients and families, health care providers, policy makers and managers, and communities in research • How interdisciplinary research teams function <ul style="list-style-type: none"> ○ Theories of collaboration ○ Results of studies of collaboration • Methods and methodologies • Statistical techniques • Qualitative analytic techniques • Knowledge translation • Resources in Ontario (e.g. ICES) for data and analytic processes • Why, what, and how to study multimorbidity
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Dimensions of outlook (attitudes) shared by ≥ 3 groups	<ul style="list-style-type: none"> • Understanding that patients' perspective are distinct from research, clinical, and policy perspectives • Understanding that patients' needs for research and care are important and relevant to research questions • Understanding that the types of questions that patients want to ask may not be part of traditional research <ul style="list-style-type: none"> • Understanding why science matters • Understanding that research can be high and low quality, and of greater or lesser applicability to patients' health and to research questions 	<ul style="list-style-type: none"> • Accepting patients' and families' experiences and diversity • Understanding that patients' perspectives 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 and systematically eliciting their needs • Understanding the perspectives of diverse stakeholder groups • Understanding why science matters • Understanding that research can be high and low quality, and of greater or lesser applicability to research questions 	<ul style="list-style-type: none"> • 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 • Understanding why science matters • Understanding that research can be high and low quality, and of greater or lesser applicability to research questions 	<ul style="list-style-type: none"> • Accepting patients' and families' experiences and diversity • Understanding that patients' perspectives 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
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Dimensions of outlook (attitudes) shared by ≤2 groups		<ul style="list-style-type: none"> • Considering that care and support needs to be guided by the patient’s clinical condition, their values and preferences, and the research evidence • Finding and using the best available (i.e., highest quality, most locally applicable, synthesized) research evidence 	<ul style="list-style-type: none"> • 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 • 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 • Using economic ways of thinking • Being systematic and transparent in finding and using research evidence as one input to the decision-making process • Finding and using the best available (i.e., highest quality, most locally applicable, synthesized) research evidence in the time you have available • Looking first for a perfect match in the available research evidence (to support an instrumental use) and then looking more broadly (to support a conceptual use) • Setting clear expectations for others about what to ask and where to go for research evidence, and encouraging their use of related tools 	<ul style="list-style-type: none"> • 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 • Using economic ways of thinking
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Skills shared by ≥ 3 groups	<ul style="list-style-type: none"> • Communicate with all stakeholder groups using active listening • Work as partners with health care professionals, policy makers and managers, and researchers • Participate in research studies, research advisory committees, research ethics boards, research priority setting processes, and in the design of patient-oriented research and decisions support systems 	<ul style="list-style-type: none"> • Communicate with all stakeholder groups using active listening • Seek to identify and understand patients' needs for information, care, and support • Work as partners with patients and families, researchers, and policy makers and managers • Identify gaps where research evidence is needed • Clarify a problem (and its causes), framing options to address the problem, and identifying implementation considerations • Participate in research studies, research advisory committees, research ethics boards, research priority setting processes, and in the design of patient-oriented research and decision-support systems 	<ul style="list-style-type: none"> • Communicate with all stakeholder groups using active listening • Seek to identify and understand patients' needs for information, care, and support • Work as partners with patients and families, health care professionals, and researchers • Identify gaps where research evidence is needed • Clarify a problem (and its causes), framing options to address the problem, and identifying implementation considerations • Participate in research studies, research advisory committees, research ethics boards, research priority setting processes, and in the design of patient-oriented research and decision-support systems 	<ul style="list-style-type: none"> • Communicate with all stakeholder groups using active listening • Seek to identify and understand patients' needs for information, care, and support • Work as partners with patients and families, health care professionals, and policy makers and managers • Identify gaps where research evidence is needed • Clarify a problem (and its causes), framing options to address the problem, and identifying implementation considerations
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Skills shared by ≤2 groups	<ul style="list-style-type: none"> • Search appropriate sources of pre-appraised research evidence - <i>added</i> • Identify and express their needs for information, care and support in ways that are understandable to those seeking to understand or address their needs • Identify topics in research that are of concern to patients and families • Identify changes in the health system that affect their experience and know who to contact to support the change or to explain how it negatively affects them and what could be done about it 	<ul style="list-style-type: none"> • Search appropriate sources of pre-appraised research evidence • Elicit needs for information, care and support - <i>added</i> • Identify topics in research that are of concern to patients and families – <i>added - added</i> • Participate in shared decision making with patients and families, to the extent that patients and families care to 	<ul style="list-style-type: none"> • Search appropriate sources of pre-appraised research evidence • Use AMSTAR to describe the quality of a systematic review • Conduct a local applicability assessment • Commission research to fill gaps in research evidence • Share your current approach to a health system challenge • Assess capacity to find and use research evidence • Identify gaps in efforts to support the use of research evidence 	<ul style="list-style-type: none"> • Employ a range of methods and methodologies • Conduct interdisciplinary research • Conduct research in the full breadth of environments that Ontario patients and families experience • Employ appropriate and effective knowledge translation techniques • Lead research studies, research advisory committees, research ethics boards, research priority setting processes
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Table 2: Names and affiliations of those who contributed to the design of the masterclass

Role	Name	Affiliation
Development team members	John Lavis	McMaster University
	Jeremy Grimshaw	University of Ottawa
	Adalsteinn Brown	University of Toronto
Advisory group members		
• Patients and families/caregivers	Anne Lyddiatt	Patient Partners in Arthritis Program
	Crystal Chin	Patients Canada
• Healthcare providers	Frank Sullivan	North York General Hospital
	Nancy Lefebvre	Saint Elizabeth Health Care
• Policymakers and managers	Lee Fairclough	Health Quality Ontario
• Researchers and research trainees	Moir Stewart	Western University
	Colin Macarthur	Hospital for Sick Children
• OSSU staff	Vasanthi Srinivasan	Ontario SPOR Support Unit
	Eddy Nason	Ontario SPOR Support Unit
	Carolyn Genautis	Ontario SPOR Support Unit