



What (else) do patients and families/caregivers need to know?

Masterclass on the Conduct and Use of Patient-Oriented Research
Day 1 (Session 4) - April 18, 2016
Toronto, ON

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Citation: Abelson J, Gavin F. What (else) do patients and families/caregivers need to know? Masterclass on the Conduct and Use of Patient-Oriented Research, McMaster University, April 2016.



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Session objectives

- To hear from patients and families/caregivers about who needs to know what and how they and other groups can fill these knowledge gaps

Resources:

- OSSU resource guide for research teams and networks undertaking patient-engagement activities <http://ossu.ca/wp-content/uploads/OSSUPatient-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/Engaging-Patients>)
- Health Foundation's person-centred care resource centre (<http://personcentredcare.health.org.uk/resources/person-centred-care-around-world>)
 - Others [to be added by participants]



But first...short introductions and ice breaking activity

- Name, relevant affiliations
- What does patient-oriented research mean to you?
- What do you most want to learn about in this course?



Proposed session structure (1:30-2:45)

- What patients and families/caregivers need to know – all (20 minutes)
- Sources of support and guidance – all (20 minutes)
- What other groups need to know + supports for this (15 minutes)
 - Researchers (Group A)
 - Providers or policymakers/managers (Group B)
- Report back and wrap up (20 minutes)



Suggested topics to cover (from curriculum competencies table)

- 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 and research
- Types of research evidence to answer questions
- Appropriate sources of key types of pre-appraised research evidence
- How to engage and partner with researchers in decision making
- Other topics?





What (other dimensions of outlook) do patients and families/caregivers need to bring to the table?

Masterclass on the Conduct and Use of Patient-Oriented Research
Day 1 (Session 5) - April 18, 2016
Toronto, ON

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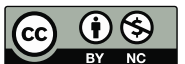


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Session objectives

- 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
- Resources: faculty and participants to identify



Proposed session structure (2:45-4:00)

- What outlook (attitudes?) do patients and families/caregivers need to bring to the table – all (20 minutes)
- Sources of support and guidance for this (20 mins)
- What outlook (attitudes?) do other groups need to bring to the table + supports (15 minutes)
 - Researchers (group A)
 - Providers or policymakers/managers (group B)
- Report back and wrap up (20 minutes)



Suggested topics to cover (from competencies table)

- 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
- Accepting patients' and families' experiences and diversity
- 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 patients' health and to research questions
- 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
- Other topics





Where are the shared ground and differences?

Masterclass on the Conduct and Use of Patient-Oriented Research
Day 1 (Session 6) - April 18, 2016
Toronto, ON

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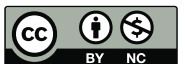


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Session objectives

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



Session structure (4:00-4:30)

- Facilitated discussion
- Note taking (flip charts, etc.)
- Use reporting template



Similarities and differences in knowledge expected of patients and families/caregivers & other groups

- Patients and families/caregivers
- Researchers
- Providers
- Policymakers/managers



Similarities and differences in outlook expected of patients and families/caregivers & other groups

- Patients and families/caregivers
- Researchers
- Providers
- Policymakers/managers

