



What to ask for when trying to shape and use patient-oriented research, what to look for, and where to get it?

Masterclass on the Conduct and Use of Patient-Oriented Research
Day 2 (Session 1) - April 19, 2016
Toronto, ON

Julia Abelson, PhD

Professor, Department of Clinical Epidemiology & Biostatistics
McMaster University

Frank Gavin

National Liason, Canadian Family Advisory Network

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Session objectives

- To appreciate:
 - different types of research studies and their purposes
 - where to go to understand key research terminology
 - different ways of thinking about evidence from different perspectives
 - the role of pre-appraised research evidence in addressing health research questions and health system problems
- To develop skills in:
 - entering into and navigating partnerships with researchers, providers, policymakers and managers
- Resources: CIHR jargon buster; hand outs in dropbox folder (F. Gavin's 2-pager on patient stories and health research; Dohan article)



Proposed session structure (8:30-9:45)

- Interactive presentations
- Warm-up and scenario exercises



Conceptual warm-up

Knowledge, research and evidence

- How would you define each of these terms?
- What are their...
 - distinguishing features?
 - similarities and differences?
 - relationships to each other?



Knowledge

“Familiarity, awareness, or understanding gained through *experience* or *study*.”

“The sum or range of what has been *perceived*, *discovered*, or *learned*.”

(American Heritage Dictionary of the English language, 2009)



Research

“the systematic investigation into and study of materials, sources, etc., in order to establish facts and reach new conclusions.”

“an endeavour to discover *new* or collate *old* facts by the *scientific study* of a subject or by a course of *critical investigation*.”

(COD, 1998, p.1226)



Evidence

“The available facts, circumstances, supporting or otherwise a belief, proposition, etc. or indicating whether or not a thing is true or valid.”

“Information given personally or drawn from a document and tending to prove a fact or proposition.”

(COD, 1998)



Research methods primer



Research topics and questions are driven by different interests and roles

- Clinical and patient care interests
 - to inform and improve longevity, quality of life and care of patients
- Service delivery, system monitoring and quality improvement interests
 - to ensure that programs and services are delivered appropriately and satisfactorily
- Organizational and policy level interests
 - to ensure that health system programs and policies achieve their goals



Review CIHR jargon buster

- Types of research
 - Clinical research – studies of the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens intended for human use (may be used for prevention, treatment, diagnosis or for relieving symptoms of a disease)
 - Epidemiological research - studies of health in populations to understand the causes and patterns of health and illness
 - Health services, health systems and health policy research – studies of the governance, financing, funding and delivery arrangements for health services and health systems



CIHR Jargon buster (2)

- Single research studies
 - Randomized controlled trials
 - Observational studies
 - Qualitative studies
 - Mixed method studies
- Systematic reviews and research syntheses
 - increasingly used to support evidence-informed decision making
 - aims to increase the confidence in what can be expected from an intervention (bias is reduced)
 - may allow patients to engage with research evidence more readily because it is presented in a more systematic and transparent way
 - can be used to synthesize many different types of studies (quantitative and qualitative, trials and observational studies)



Key features of quantitative research studies

- measuring the scope or prevalence of a problem
- evaluating the (cost) effectiveness of interventions
- eliciting preferences for different things
- testing causative or correlative hypotheses
- producing universally generalizable information



Key features of qualitative research studies

- studying things (e.g., decisions, people, relationships) in their natural settings,
- attempting to make sense of and interpret things in terms of the meaning, concepts, definitions, and characteristics that people bring to them
- exploratory, collecting and analyzing data by observing what people do and say

Common data sources/methods: interviews, focus group discussions, document analysis, observation



For reflection

- What counts as evidence?
- According to whom?



Scenario exercise 1 (work in groups of 4)

A researcher approaches you (or your organization) to participate in a study he is leading. He has given you a lot of information about the study but your role is vaguely defined.

- What questions would you ask the researcher to better understand the role that he envisions for you and how would you negotiate your or your organization's role in the study?
- What kinds of resources would be helpful to you in this discussion?





How to approach the shaping and use of patient-oriented research?

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Professor, Department of Clinical Epidemiology & Biostatistics
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Session objectives

- To consider the concepts of rigour and relevance in the context of patient-oriented research
- Resources
 - covered in previous session + Boivin et al. 2014 article in dropbox



Session structure (9:45-11:00)

- short presentation followed by discussion and scenario exercise



Rigour in research

- Research that applies the appropriate research tools to meet the stated objectives of the investigation
 - Was the appropriate design chosen to answer the question
 - Were the appropriate data collection methods and analytical techniques employed to address the research question?
- Associated with trustworthiness and integrity



Tools for assessing the quality of evidence

- Why are they needed?
 - research is of mixed quality
 - need critical appraisal tools to ensure that decisions are being made using high-quality evidence (where available)
- Different types for different purposes:
 - some assess quality of evidence only; some focus on quality and relevance
 - focus on appraising quality of study design; others focused on guidelines and evidence produced to support recommendations
- Commonly used tools:
 - AMSTAR (A Measurement Tool to Assess Systematic Reviews) - used by Canadian Agency for Drugs and Technologies in Health
 - AGREE (I and II) (Appraisal of Guidelines Research and Evaluation) – focuses on assessing the quality and reporting of practice guidelines
 - GRADE (Grading of Recommendations Assessment, Development and Evaluation) – used by many organizations to assess the quality of evidence supporting a recommendation



Assessing research relevance

- research relevance tools are mostly oriented to researchers seeking to ensure that research they are reviewing is relevant to their question(s) or problem
- assessing the relevance to patients' questions or concerns is much less common
- patient-oriented research movement provides opportunities for achieving a greater balance between researcher and patient priorities for research



Discussion questions

Think of 1 or 2 examples of studies or processes you are aware of that have involved patients in identifying their priorities for research questions.

How do you know about these examples?

How would you find other examples?

How would you know if they were 'good' examples?



Scenario exercise 2 (work in groups of 4)

You or your organization has become aware of a research priority setting process that is being undertaken that involves researchers, patients, and other relevant stakeholders. You are concerned that the organizers of this exercise have not included the perspectives of your particular patient population in their planning.

- How will you approach the organizers of this initiative to express your interest in participating?
- How will you explain the need for the perspectives of this patient population to be included in this process?
- How will you approach a question that may be put to you about how well your organization is able to represent the diversity of patient perspectives and experiences that you are claiming to represent?

