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Title

Activities and impacts of patient engagement in research: A pan-Canadian online survey

Priority 1 (Research Category)

Patient engagement

Presenters

Anna Chudyk, PhD, BHSc, MSc, Annette Schultz, PhD, RN, Nicola McCleary, Roger Stoddard, Todd Duhamel, PhD

Abstract

Context: Patients and caregivers possess experiential knowledge of living with a health condition and/or accessing the healthcare system. This value-added knowledge complements the scientific and clinical insights gained from primary care researchers' and clinicians' perspectives. While emerging evidence demonstrates that patients and caregivers are valuable research team members, uncertainty about the practicalities of how to engage, and the associated impacts of engagement, are documented barriers to their research engagement.

Objective: To describe activities used to engage patients and caregivers as co-researchers, and the perceived impacts of their engagement across the research cycle.

Study Design and Analysis: A national cross-sectional online survey conducted in partnership with patients. Descriptive statistics and thematic analysis of data addressed the research objective.

Setting: Pan-Canadian.

Population Studied: Patients, caregivers, and researchers involved in a Canadian Institute of Health Research project funded through one of 13 Strategy for Patient-Oriented Research (SPOR) funding calls.

Intervention/Instrument: We developed a survey that included modified items drawing from Patient-Centered Outcomes Research Institute's WE-ENACT tool and newly created items measuring SPOR Patient Engagement Framework elements. Survey items also assessed sociodemographic characteristics and characteristics of participants' SPOR-funded projects.

Outcome Measures: Types of engagement activities and perceived impacts of engagement activities across the research cycle.

Results: Survey responses were collected from 66/551 contacted researchers and 20/28 patients and caregivers. Seven activities were used to engage patients and caregivers across the research cycle: (a) sharing experiences/giving advice, (b) identifying the research focus/methods, (c) developing/revising aspects of the project, (d) conducting research activities, (e) study participation, (f) presenting on behalf of the project, and (g) other grant development or knowledge translation activities. Impacts of engagement resided within six categories and related to knowledge, outputs, or direction taken.

Conclusions: Our study provides primary care researchers with practical evidence for engaging patients and caregivers in research. Findings are also important for primary care physicians, as they are often the first point of contact for patients and caregivers interested in engaging in research.