

What Matters Most to Patients About Primary Healthcare: Mixed-Methods Patient Priority Setting Exercises Within the PREFeR (PRioritiEs for Research) Project

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For which topic were research priorities identified?

primary healthcare

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Recognising that patient engagement early in the research process is important, but has been largely absent from priority setting exercises in primary care, the main aim of the PRioritiEs For Research (PREFeR) Project was to identify patient-generated priorities for primary care research in British Columbia (BC), Canada. This is consistent with Canada's Strategy for Patient-Oriented Research, which supports research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes.²⁰ This decision to focus on patient priorities was also shaped by the fact that research priorities for primary care had recently been identified in BC, but this process included policy-makers, clinicians and researchers, and not patients.²¹ By focusing on topics that are of importance to patients, research is more likely to have positive impacts on policy and practice.

What was the objective?

to identify patient-generated priority topics for future primary care research in British Columbia, Canada within a diverse patient population

What was the outcome?

a ranking list of 10 research topics

How long did the research prioritization take?

March 2017 - May 2018

Which methods were used to identify research priorities?

meeting; survey; workshop

How were the priorities for research identified exactly?

Step 1: exploration via survey 1: 10-member patient advisory asked to brainstorm the question: Based on your experiences of primary care, what things really stand out for you?, additionally followed by teleconference: to further share ideas, using nominal group technique. Step 2: data processing thematic analysis. Step 3: interim priority setting workshop: 10-member patient advisory asked to review the topics and consider the suitability of the topic label wording, whether any topics were missed from the teleconference or new ideas had emerged since that discussion and whether any additional topics should be separated out from the patient examples and/or whether two or more topics could be grouped together, participants then finalized list of topics, followed by ranking the topics in terms of their importance. Step 4: survey 2: participants were asked to rate each topic. Step 5: horizon scan via survey 3: researchers were asked to capture any past, ongoing or upcoming (in the next 12 months) research on the 10 primary care topics, additionally review of literature was conducted. Step 6: integration phase: dialogue meeting: group discussion

Which stakeholders took part?

General practitioners, nurses, nurse practitioners, and pharmacists. Survey 1: 10 patients. Workshop: 10 patients. Survey 2: 464 patients and 173 primary care providers. Survey 3: researchers. Meeting: general practitioners, nurses, nurse practitioners, and pharmacists.

How were stakeholders recruited?

Patients living throughout BC were recruited to the patient living advisory through expression of interest calls posted by the BC-PHCRN, through Patient Voices Network and through a patient engagement workshop at the Centre for Health Services and Policy Research annual conference. Patients were purposively recruited to maximise diversity with respect to healthcare needs, regional health authority, ethnicity (including First Nations), age and gender. Patients included people with both visible/congenital (one member) and invisible disabilities, experiences of long-standing chronic illness (including mental health disorders, chronic infectious disease, chronic pain). Survey respondents were recruited using multiple online dissemination channels, such as social media (Twitter, Facebook), newsletters, emails, snowballing and notices posted on general web sites. Also one-time classified ad in local newspapers in small BC communities was included and offered telephone completion as an alternative to the online survey. The sole inclusion criterion was that patients and providers must be living in BC to complete the survey. A diverse mix of primary care providers, including general practitioners, nurses, nurse practitioners, and pharmacists was recruited for the integration phase.