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# What matters most to patients about primary health care: Patient priority setting exercises within the PREFeR (PRioritiEs For Research) Project

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# Abstract

**Objectives:** To identify patient-generated priority topics for future primary care research in British Columbia (BC), Canada within a diverse patient population.

**Design:** Mixed methods priority setting exercises framed by the Dialogue Model, using the Nominal Group Technique (rank-ordered scoring).

**Setting:** BC, Canada

**Participants:** 10 patient partners (7 female, 3 male) from the BC Primary Health Care Research Network Patient Advisory.

**Results:** The 10 members recruited to the Patient Advisory provided over 80 experiences of what stood out for them in BC primary care, which were grouped thematically into 18 topics. Among the top 10 patient-ranked topics, *patient-centred care*, *information sharing (including electronic medical records)*, and *lack of regular primary care provider* scored highest.

**Conclusions:** The project activities to date demonstrate the feasibility of including patients in priority setting exercises for primary health care in general, rather than focusing on a condition-specific population or disease area. The Dialogue Model provided a useful framework in this context. Several patient-generated topics had not been previously identified by policymakers or researchers, underscoring the importance of including patients in research priority setting. The project activities that follow (online surveys, rapid literature reviews, and a multi-stakeholder dialogue discussion) will finalize the list of patient priority topics amongst a broader patient population, will indicate patient-primary care provider alignment in topic importance ratings, and highlight under-researched topic areas. Future projects will develop patient-identified priorities into specific research questions.

**Keywords:** patient engagement, priority setting, primary health care, Dialogue Model

# ARTICLE SUMMARY

## Strengths and limitations of this study

- This is the first-known patient priority setting project that addresses primary health care issues in general, rather than focusing on a particular health condition or issue.
- The project is framed within the Dialogue Model, which is a multi-stage, multi-stakeholder structured priority setting framework, and makes use of the Nominal Group Technique to foster idea generation and decision-making.
- The Patient Advisory members who generated the top 10 patient priorities are a socio-demographically diverse group with varied prior research experience. They identified unique priority topics that have not emerged from similar exercises among policymakers or researchers, further highlighting the importance of patient engagement in priority setting.
- Generalizability of the current priority topics might be limited to this patient group, but they provide the groundwork for establishing the importance of these key issues in primary care amongst a larger patient and primary care provider population (using online surveys, rapid literature reviews, and a multi-stakeholder dialogue discussion).

# INTRODUCTION

Primary care is the first point of contact with health care for most patients, and supports a wide variety of health needs. It is not surprising, therefore, that a host of primary care research focuses on studying patient needs and gaps in care. However, patients are not frequently included in prioritizing research ideas[1–3]. At a basic level, this is problematic because patient, clinician, and researcher priorities may differ significantly[4]. At an applied level, intervention uptake and, consequently, any impact on health outcomes may suffer if the problems studied and outcomes suggested have not considered patients' perspectives, leading to research 'waste'[5]. Patient prioritization of topics for research ultimately benefits the intended end-users of primary health care directly – patients themselves – and makes better use of scarce resources.

There is growing recognition of the importance of involving patients in research priority setting. In response, there has been a proliferation of patient priority setting studies in recent years, with 70 articles from the UK, US, Canada, the Netherlands and Australia identified between 2007-2017 in a rapid systematic review of public and patient engagement in prioritization[6]. Yet, most processes for engaging patients in research have focused on populations defined by a specific condition[6,7], rather than primary care more generally. While there have been exercises to identify primary care research priorities at clinical and academic conferences[8], these did not include patients. We have only identified two recent publications that examined primary care priorities more generally – i.e., in which the overall focus was not specific to a particular health condition – and that involved patients as one of the multi-stakeholder groups[9,10]. Even in these studies, the online survey[9] and World Café discussions[10] targeted a specific health topic – how to promote healthy behaviours through primary care – rather than allowing any issues relating to primary care experiences to emerge as priorities. In order to examine gaps in care that affect a large and diverse range of patients, it is important to enable patients to voice whatever primary health care priorities are most pressing for them.

There are a host of tools and techniques for priority setting. One recent methodological review found roughly equal numbers of studies that used specific, structured frameworks and those that used non-specific tools (e.g., surveys)[11]. In terms of structured approaches, there are several multi-stage priority setting frameworks, such as the James Lind Alliance Priority Setting Partnerships[12] and the Dialogue Model[1,13]. There does not appear to be a single, best method[14], nor is there clear agreement on whether using a combination of tools for priority setting is superior to using one technique alone[11]. However, use of a clearly defined approach is recommended[11,15], and the choice of which method(s) may be best guided by the research question[14]. The Cochrane Priority Setting Methods Group noted that researchers may adapt and implement the same methods in different ways depending on the context and research focus[16].

Recognizing 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 PREFeR (PRioritiEs For Research) Project was to identify patient-generated priorities for primary care research in British Columbia (BC), Canada. The project specifically sought to determine the top 10 primary health care topics that were most important to patients in the province, with a view to inform more focused research questions in the future. By focusing on topics that are of importance to patients, research is more likely to have positive impacts on policy and practice.

As noted in reviews[6,17], detail about methodology is often lacking in articles about priority setting, and this is essential to replicating approaches and understanding how and what works for patient engagement. The PREFeR Project is framed by the Dialogue Model, which is a multi-stage priority setting framework involving multiple stakeholders, but expressly incorporates patients' voices[1]. The main focus of this paper is on the methods and results from the initial priority identification activities of PREFeR. We also overview the other project activities that are couched within the later phases of the Dialogue Model, which correspond to secondary aims of PREFeR: to compare patient and primary care provider perspectives using online surveys, to assess whether research is already being conducted in BC on the key patient priorities through rapid literature reviews and 'horizon scanning' surveys with BC researchers, and to qualitatively explore where and why differences might occur in the survey results through a facilitated discussion ('dialogue') with patients and providers. Taken together, results from these activities are key considerations for setting future research questions.

# METHODS

## Participants and recruitment

The BC Primary Health Care Research Network (BC-PHCRN) Patient Advisory (hereafter, referred to as the Patient Advisory) was formed to engage patients in primary care research and gather their input into multiple studies supported by the BC-PHCRN. Patients living throughout BC were recruited to the Patient Advisory through expression of interest calls posted by the BC-PHCRN and Patient Voices Network, a network of patients and caregivers interested in engagement opportunities with health care partners in British Columbia, and through a patient engagement workshop at the Centre for Health Services and Policy Research annual conference (Vancouver, BC, March 2017). Effort was taken to recruit patients from each of the five regional health authorities, with a range of previous research experience and health care needs, and a diverse mix of socio-demographic backgrounds. Given that the Patient Advisory were research partners and the initial activities of PREFeR were considered community consultation, ethics approval was not required by the Simon Fraser University Research Ethics Board for the early phases of the project reported here.

## Patient and public involvement

The Patient Advisory were research partners in PREFeR and, therefore, contributed to planning and shaping the research activities, and also provided input as participants to the priority setting phase of this project, as described below.

## Overview of the Dialogue Model

Compared to the other structured priority setting frameworks, the five phases of the Dialogue Model – Exploration, Consultation, Prioritization, Integration, and Programming and Integration[1,13] – mapped most closely on to the overarching ethos of PREFeR (Figure 1). In particular, the Dialogue Model is based on participatory and interactive approaches, which advocate an equal partnership between patients and other stakeholders[1]. Through processes that encourage mutual learning, the Dialoge Model can lead to co-ownership of the priorities identified[1]. The model uses a variety of mixed methods (e.g., literature reviews, interviews, surveys) throughout the five phases, which we also identified as essential to the aims of PREFeR. Commonly, these methods are grounded in other structured techniques. For example, focus groups may be framed within the Nominal Group Technique (NGT)[18], which is a widely-used method of idea generation, based on four key stages: individual and silent idea generation in response to the nominal question, round-robin feedback to the group (i.e., each person sequentially shares one idea at a time), group discussion and clarification of ideas, individual voting (ranking or rating of ideas)[19].

The five phases of the Dialogue Model were modified slightly to match the aims of PREFeR. For example, we chose to carry out rapid literature reviews, which are typically conducted in the Exploration phase, after the Consultation phase, and have labelled this as part 2 of the Exploration phase. We wanted the rapid literature reviews to inform the scope of what has already been researched within BC and Canada, since this would impact future research questions and their funding potential. Within the Dialogue Model, literature reviews may be undertaken for scoping purposes, and to directly shape subsequent activities within the model. Another divergence from the traditional Dialogue Model is that we chiefly focused on patient views in the Consultation phase, since the aim of PREFeR was to generate patient priorities. However, priorities from our other stakeholder group, primary care providers, were gathered and compared to patient priorities later in the project. As noted in the introduction, we will briefly overview all activities in PREFeR that map on to the phases of the Dialogue Model, but the primary focus of this paper is on the initial prioritization activities.

## Data collection

### Exploration phase (part 1) – Brainstorming primary care experiences

In the first activity of the project (within the Exploration phase), the Patient Advisory was sent an email request to brainstorm their ideas in response to the following question, “Based on your experiences of primary care, what things really stand out for you?” Primary care was defined as where most people go first for medical help and advice when they have a health problem, and provided by health care professionals, like family doctors, nurses or nurse practitioners, pharmacists or emergency services staff. The question was neutrally framed by design, such that either positive or negative experiences of primary care might emerge. Patient Advisory members were asked to spend about 10 minutes on the task and write down as many things that came to mind in response to this question. They were invited to a teleconference to share their ideas with the group approximately two weeks later. For those unable to attend, an opportunity to provide their thoughts through individual telephone calls with the first author prior to the scheduled teleconference was offered. With permission, these members’ primary care experiences were shared with the rest of the Patient Advisory during the teleconference.

The teleconference was led by the first author and facilitated by the second author. Using the Nominal Group Technique[18], each Patient Advisory member was asked to provide one idea at a time, in round-robin fashion, until there were no more new ideas to share. In line with NGT, patients were asked to first briefly describe their primary care experiences, with further explanation and discussion by the entire group to follow after all ideas had been listed. The principal investigator (RL) took detailed notes throughout the teleconference, which were emailed to the Patient Advisory the following day for their review.

Based on the teleconference notes, the first author consolidated the raw list of brainstormed ideas. Common elements were grouped thematically into topics. A heading for each topic was constructed with a short phrase in lay language to reflect the underlying theme of the collection of examples and experiences raised by the patients. The specific patient examples and experiences were additionally provided in bullet form below each topic heading. After an initial discussion with the second and last author, the topic list was refined and then emailed to the Patient Advisory. The Patient Advisory was asked to review the list of topics ahead of an in-person priority setting workshop, to ensure it reflected the teleconference discussion accurately.

## Consultation and (Interim) Prioritization phases – Priority setting workshop

Three and a half weeks after the teleconference, a full-day priority setting workshop with the Patient Advisory was held in Vancouver, BC. The purpose of the workshop was, firstly, to review, discuss, revise, and agree on the list of the patient-generated primary care topics that emerged out of the teleconference (Consultation phase), and then to have the patients individually rank the top 10 most important topics ((Interim) Prioritization phase). Collectively, this constituted the remaining steps of the NGT process, which followed from the initial stages conducted during the teleconference.

To arrive at a final, agreed upon list of primary care topics, the Patient Advisory was asked to review the topics and consider: (1) the suitability of the topic label wording, (2) whether any topics were missed from the teleconference or new ideas had emerged since that discussion, and (3) whether any additional topics should be separated out from the patient examples and/or whether two or more topics could be grouped together. These points were discussed for each topic in turn, making revisions on a projected screen in real time during the workshop.

Once the list of primary care topics was finalized, the group moved on to the second task of the workshop – ranking the topics in terms of their importance. The final topic list was distributed to the Patient Advisory, who were then asked to privately choose the 10 topics that were most important to them personally. Personal importance could also include thinking about how the issues might affect other people they were close to (e.g., family, friends). A recording sheet was provided for patients to arrange their top 10 topics in terms of 1=*Most important* to 10=*Least important*. Ties were not permitted. In line with NGT methods, patients were asked to complete this task silently and on their own. The first author checked the ranking sheets for completeness as they were collected.

The first author entered the patient-ranked data into an Excel spreadsheet, and then reverse scored the data, such that 10=*Most important* and 1=*Least important*. Following the steps outlined in McMillan et al.[19], results were pooled by first creating a sum of scores for each topic, which indicated its ranked priority or strength of vote score[20]. Second, we computed the relative importance of each topic[21], or the proportion (%) of scores ranked within the top 10 topics. As in McMillan et al.[19], this was calculated as: (total summed score for the topic)/(maximum points for the group) x 100. The maximum number of points was given by the number of patients providing rankings multiplied by the sum of the 10 ranks available to each patient (i.e., 10 + 9 + 8 +…1 = 55 points). In order to resolve ties, a third method of tabulating the ranks involved counting the number of times each topic was ranked within the top 10 across patients, which is an indication of topic popularity[19,20]. The data were then sorted according to their ranked priority (proportion of scores within the top 10), and any ties were resolved by referring to the frequency of votes. In this way, if two topics had the same ranked priority, the topic with the higher number of votes was assigned the higher final ranked position. By the end of the workshop, patients were informed of the pooled results, which yielded the top 10 topics that the project would carry forward in a series of rapid literature reviews, online surveys, and a final dialogue event between patients and primary care providers (Figure 1). Methods for these activities will be briefly summarized next.

## Exploration phase (part 2) – Rapid literature reviews

Rapid literature reviews were carried out in MEDLINE for published research conducted within BC and Canada on each of the 10 patient-identified primary care topics. Protocols, commentaries, and reviews were excluded, but all types of study designs were included. Topic-specific search strategies using Medical Subject Heading terms and keywords were constructed for English language publications from 2008-2018. All searches included 'primary health care' and province or country keywords for the two respective searches. Two reviewers independently screened abstracts/titles for relevance to the topics, with guidance from the first and last authors. The total number of BC and Canadian papers included for each topic was tabulated. A reference library of provincial papers and all citations from the included papers in the two searches was compiled for use by the Patient Advisory.

## Prioritization phase – Topic importance and horizon scanning surveys

Online surveys were administered province-wide to capture BC patients' and primary care providers' importance ratings of the top 10 topics. Both stakeholder groups were asked to rate each topic individually from 1=*Not at all important* to 5=*Very important*. The topic heading, along with 2-4 bullet points of examples and experiences (from the Patient Advisory) to illustrate the topic, were included to mitigate misunderstanding and misinterpretation of the topic heading. Following the importance ratings, several socio-demographic questions were included in the surveys.

We recruited survey respondents using multiple online dissemination channels, such as social media (Twitter, Facebook), e-newsletters, emails, snowballing and notices posted on several websites. We also included a one-time classified ad in 31 local newspapers in small BC communities and offered telephone completion as an alternative to the online survey. Due to time and budget constraints, the surveys were only provided in English. The sole inclusion criterion was that patients and providers must be living in BC to complete the survey. Analyses will compare importance ratings within and between patients and providers, as well as explore socio-demographic differences in the ratings.

A third survey with BC researchers was included for horizon scanning purposes; namely, to capture any past, ongoing, or upcoming (in the next 12 months) research on the 10 primary care topics. This complements the rapid literature reviews, but enabled us to capture research that has not been published, completed or for which funding has recently been secured. This online survey presented each topic with the same 2-4 bullet point example statements. We collected information on study design and publications, as well as socio-demographics. The surveys were disseminated through similar online channels to the other surveys.

### Integration phase – Dialogue event

A final dialogue event is planned for the project, which will bring patients and primary care providers together to share the survey results, and to engage in a facilitated discussion about areas of concordance and dissimilarity in the results. Patients will include the Patient Advisory and others that we will recruit to enhance the representativeness of minority populations (e.g., those who are new to the province). We also intend to recruit a diverse mix of primary care providers, including GPs, nurses, nurse practitioners, and pharmacists.

The aim of the event is to gain a better qualitative understanding of the general perspectives of patients and primary care providers with respect to the quantitative survey results, rather than to achieve consensus on the top primary care topics for the two stakeholder groups, as in the Dialogue Model. We have chosen to modify the purpose of the PREFeR dialogue event in this way because it is more in line with the overall objective of the project; namely, to identify patient priorities for future primary care research. Comparing patient priorities to those of providers is an important secondary aim of PREFeR. Nevertheless, we think it is more imperative to understand where and how these might differ, rather than try to bring the views of a small subgroup of patients and primary care providers together.

In addition to the main patient and provider component, a parallel discussion will be held with researchers and policymakers at the dialogue event. These stakeholders will also discuss the survey findings, but the focus will be on how these results might be translated into future research and their policy implications. All groups will come together at the end of the event to share a summary of their discussions with the entire group of attendees.

# RESULTS

## Patient Advisory characteristics

In total, 11 members (8 female, 3 male) were recruited to the Patient Advisory between March and May 2017. However, one female patient resigned at the start of the PREFeR Project and did not provide any input to the project. The remaining 10 Patient Advisory members (7 female, 3 male) were characterized by a mix of socio-demographic characteristics, including ethnic minority backgrounds, speaking multiple languages, born outside of Canada or the province, and representation from all five health authorities (Table 1). Nevertheless, the group were predominantly employed (7/10, 70%), well educated (BSc, BA, teacher's college or higher university degree: 6/9, 67%), and were considered 'experienced' (e.g., members of one or more research committees/organizations, patient partners in other studies, research participant involvement, etc.) in terms of previous research involvement (6/9, 67%).

Table 1. Characteristics of British Columbia Primary Health Care Research Network Patient Advisory (n=10). All values reported are N(%), unless otherwise specified.

| | N (%) |
|---|---|
| Age in years (M, SD)[1] | 48.4 (13.9) |
| Sex | |
| Female | 7 (70) |
| Male | 3 (30) |
| Ethnicity[1] | |
| White only | 3 (33) |
| Mixed or any other background | 6 (67) |
| Language(s) spoken[1] | |
| English only | 5 (56) |
| Multiple languages | 4 (44) |
| Employed | |
| Yes | 7 (70) |
| Highest education level[1] | |
| Trade or non-University certificate/diploma, community college, University certificate below BA | 3 (33) |
| BA, teacher's college or higher | 6 (67) |
| Country of birth[1] | |
| Canada | 8 (89) |
| Years living in BC[1] | |
| 0-5 | 2 (22) |
| 6-15 | 1 (11) |
| More than 15 years | 6 (67) |
| Regional Health Authority | |
| Vancouver Coastal Health | 5 (50) |
| Vancouver Island Health | 2 (20) |
| Fraser Health | 1 (10) |
| Interior Health | 1 (10) |
| Northern Health | 1 (10) |
| Previous research involvement[1] | |
| None | 1 (11) |
| Moderate | 2 (22) |
| Experienced | 6 (67) |

[1] Data available for 9 of the 10 Patient Advisory members.

## Brainstorming primary care experiences

Two (1 male, 1 female) Patient Advisory members were unable to attend the primary care experiences teleconference in September 2017, and so their ideas were shared via a telephone call with the first author in advance. In total, these and the remaining eight Patient Advisory members (2 male, 6 female) provided 82 experiences and examples of what stood out for them in primary care in BC (data not shown). There was considerable overlap in these primary care experiences, which were initially grouped into 19 themes (Table 2, column 1). Frequently-mentioned topics across all patients included themes around patient-provider communication, accessibility difficulties, electronic medical records/information sharing, and diversifying care amongst healthcare professionals other than GPs.

Table 2. Researcher-suggested primary care topic headings compared to patient-revised topic headings.

| Researcher-proposed topic headings | Patient-revised topic headings |
|---|---|
| 1) More patient-centred care needed | 1) Care guided by patient needs, values, preferences, and priorities |
| 2) Communication – Informing/empowering patients | 2) Informing and empowering patients |
| 3) Improving patient-provider communication | 3) Improve and strengthen communication between patients and primary health care providers |
| 4) Electronic Medical Records (EMR)/information sharing | 4) Information sharing, including electronic medical records |
| 5) Resources to better manage one's own health | 5) Resources to better manage one's own health |
| 6) Prevention/early intervention | 6) Prevention/early intervention |
| 7) Inability to access regular family doctors (GPs) | 7) Unable to find a regular family doctor or other primary health care provider |
| 8) Inadequacy of walk-in clinics | 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service) |

| | |
|---|---|
| 9) Accessing after-hours care | 9) Accessing care where and when patients need it |
| 10) Access to specialist knowledge | 10) Access to specialist knowledge |
| 11) Impact of a new diagnosis | 11) Support for living with chronic conditions |
| 12) Care of chronic conditions | |
| 13) Accessing mental health resources | 12) Mental health resources |
| 14) Challenges in small towns/cities | 13) Challenges in small towns/cities and remote areas |
| 15) Patient stigma | 14) Addressing stigma and bias |
| 16) Gaps in clinical evidence/information | 15) Knowledge gaps in clinical evidence and information |
| 17) Broaden roles for other health care professionals | 16) New models of primary care that include other health care professionals |
| 18) Inefficient practices put pressure on the system | 17) Improving continuity and coordination |
| 19) No universal drug plan | 18) No universal drug plan |

## Priority setting workshop

Nine (2 male, 7 female) of the 10 Patient Advisory members attended the in-person priority setting workshop in Vancouver, Canada in September 2017. The researcher-proposed 19 primary care themes were reviewed, discussed, and revised (Table 2, column 2; topic headings and full set of illustrative bullet points are provided in the Supplementary Material). No additional themes were added, but 14 of the topic headings were changed and two of the researcher-suggested topics (*Impact of a new diagnosis, Care of chronic conditions*) were combined to form a single patient-revised topic (*Support for living with chronic conditions*). In total, 18 final topics were retained from the first part of the workshop.

Table 3 shows the reverse-scored rankings of the 18 priorities evaluated by the nine Patient Advisory members attending the workshop. Patients selected and then ranked the 10 most important topics for themselves and in consideration of their social network. The raw rankings in Table 3 are followed by methods of tabulating the final ranked priority topics (via scores and votes), which included the sum of scores across patients, ranked priority via scores, relative importance, ranked priority via relative importance, and the number of votes. The top ranked priority for patient partners was *Care guided by patient needs, values, preferences and priorities*. There were some tied ranks, which were resolved by the number of votes. For example, *Accessing care when and where patients need it* and *Support for living with chronic conditions* were tied for fourth place, but the access-related topic received more votes overall, and so retained the higher priority position.

Table 3. Patient-ranked raw scores (n=9) for primary care topics and methods of tabulating final ranked priority topics.

| Topic[1] | Ranked scores by patients[2] | | | | | | | | | Sum of scores | Ranked priority (via scores) | Relative importance (%)[3] | Ranked priority (via %) | Number of votes | Final ranked priority (via scores & votes) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | | | | | | |
| Care guided by patient needs, values, preferences, priorities | 7 | | 9 | | 10 | | 10 | 8 | 7 | 51 | 1 | 10.3 | 1 | 6 | 1 |
| Information sharing, EMR | 5 | 1 | 8 | 6 | 5 | | 7 | 6 | 8 | 46 | 2 | 9.3 | 2 | 8 | 2 |
| Unable to find a doctor | | 10 | 3 | | | 10 | 4 | 5 | 10 | 42 | 3 | 8.5 | 3 | 6 | 3 |
| Accessing care when, where needed | 9 | 7 | 4 | 3 | 2 | 8 | 3 | | 5 | **41** | **4** | **8.3** | **4** | **8** | **4** |
| Support for chronic conditions | | 8 | 1 | 8 | | 6 | 2 | 10 | 6 | **41** | **4** | **8.3** | **4** | **7** | **5** |
| Mental health resources | 8 | 4 | | 4 | 8 | 1 | | 3 | 9 | 37 | 6 | 7.5 | 6 | 7 | 6 |
| New models of primary care | 10 | | 6 | 2 | 7 | 9 | | | | 34 | 7 | 6.9 | 7 | 5 | 7 |
| Improving continuity, coordination | | 6 | 5 | 9 | | 7 | | 2 | 4 | 33 | 8 | 6.7 | 8 | 6 | 8 |
| Challenges in small towns/cities | 2 | 5 | 7 | | | 5 | | 9 | 2 | 30 | 9 | 6.1 | 9 | 6 | 9 |

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Improve, strengthen patient-provider communication | 4 | | 2 | 7 | | 2 | 8 | 4 | | **27** | **10** | **5.5** | **10** | **6** | **10** |
| Informing, empowering patients | | | | 1 | 6 | 4 | 9 | 7 | | **27** | **10** | **5.5** | **10** | **5** | |
| Prevention/early intervention | 3 | | | | 9 | | 5 | | | 17 | | | | 3 | |
| Inadequacy of compensation model | | 3 | 10 | | 3 | | | | 1 | 17 | | | | 4 | |
| No universal drug plan | | | | 10 | 4 | | | | 3 | 17 | | | | 3 | |
| Resources to better manage health | | 9 | | | | | 6 | | | 15 | | | | 2 | |
| Knowledge gaps in clinical evidence | 6 | | | | 1 | | | 1 | | 8 | | | | 3 | |
| Access to specialist knowledge | | | | 5 | | | 1 | | | 6 | | | | 2 | |
| Addressing stigma and bias | 1 | 2 | | | | 3 | | | | 6 | | | | 3 | |

EMR = electronic medical record. Bold values indicate topics with ties.

[1] Topic headings have been shortened here for presentation ease. Refer to Table 2, column 2 for full topic headings.

[2] Ranked scores have been reverse scored, where 1=Least important and 10=Most important.

[3] Relative importance = [(topic score) / (maximum points for the group; i.e., number of patients (9) x 55 points) x 100].

# DISCUSSION

Involving patients in setting priorities for primary care research is feasible, fruitful and important to patients, but it is rare. This paper outlines the key activities of the PREFeR Project, which are framed within the Dialogue Model, and reports the processes and results from the initial priority setting exercises. A group of 10 socio-demographically diverse patients from all five regional health authorities in the province were recruited as patient partners to a Patient Advisory group. Using the Nominal Group Technique, over 80 experiences of what stood out for them in primary care were generated. These were first grouped according to common elements and themes into 19 topics by the researchers on the team. After reviewing, discussing and revising the original list, 18 patient-generated topics in lay language were then individually ranked by the Patient Advisory during a one-day priority setting workshop. Based on the pooled results, the top 10 topics were retained. The most highly ranked topics were about patient-centred care, information sharing (including electronic medical records), and finding a regular doctor/primary care provider.

This is the first-known study that has identified generic patient priorities for primary health care in a population not defined by having a specific health condition. The top priorities identified by the Patient Advisory align fairly well with some recent priority setting initiatives in BC. For example, the BC Ministry of Health identified eight service delivery priorities for the province's health system in 2014[22], which were re-confirmed at the primary care level by the BC-PHCRN research, clinical, and policy leads in 2015[23]. The four key primary care priorities from 2015 were 'optimizing community primary health care service delivery' (seven specific areas to optimize are subsumed under this parent topic), ‘improving patient experience and cultural appropriateness across the primary health care system’, ‘developing an adequate primary care workforce including determining future demand for a range of providers and optimal roles and scope, and supporting optimal provider experience,’ and ‘enhancing optimal access, utilization and continuity of patient information both across providers within the primary health care system and with other levels of care across the health system’. Although patients were not involved in this process, there is overlap between the BC-PHCRN first-listed priority and the following top topics identified in the current research: ‘new models of primary care that include other health care professionals’, ‘support for living with chronic conditions’, and ‘challenges in small towns/cities and remote areas’. The remaining three BC-PHCRN priorities all aligned to some degree with other priorities from the Patient Advisory. However, there were four uniquely-identified Patient Advisory priorities that were not advanced by either the BC Ministry of Health or BC-PHCRN: ‘mental health resources’ (albeit, access to specialist treatment, in general, was mentioned by both organizations, and reducing demand on hospitals by improving care for those with mental health and substance use issues was one of five strategic priorities for the BC Ministry of Health in 2017[24]), ‘unable to find a regular family doctor/other primary health care provider’, ‘improve and strengthen patient-provider communication’, and ‘information sharing, including electronic medical records’. This highlights the value of including patients directly in setting priorities for primary care, and is another demonstration of how the priorities of patients and providers/policymakers/researchers might differ.

The Dialogue Model, coupled with the Nominal Group Technique, was a useful framework for successfully identifying patient priorities for primary health care. This model has been used for agenda setting in many condition-specific populations, such as burns, diabetes, kidney disease, cystic fibrosis, dementia, bipolar disorder[1], but PREFeR is the first instance of primary care priority setting with a generic population that we are aware of. To aid future use of the Dialogue Model in primary care and other priority setting exercises, transparency of the methods used is essential. To this end, this paper details the initial prioritization activities of PREFeR, which map on to the Exploration, Consultation and (Interim) Prioritization phases of the Dialogue Model.

The 10 most important topics generated and selected by the Patient Advisory are broad, policy-level themes, rather than specific research questions. This is directly in line with PREFeR's original purpose. It is worth highlighting, however, that the Patient Advisory's rank order of importance of these 10 topics is not the finalized order. We acknowledge that generalizability of these priorities to the wider patient population might be a potential limitation of these findings, despite efforts to recruit a diverse Patient Advisory. For this reason, the next activity was to conduct province-wide online surveys of these top 10 primary care topics – to gather importance ratings from as many patients as possible – which will then form the final ranking of the topics. These will also be compared with BC primary care provider ratings of the 10 topics, to assess the degree of patient-provider alignment. Finally, results from rapid literature reviews of the 10 topics, along with results from the 'horizon scanning' survey with BC researchers relating to completed, current or upcoming research on the 10 topics, will provide valuable information about the nature and extent of research on the topics. The dialogue event between patients, providers, and researchers/policymakers will provide additional qualitative insights into the quantitative survey findings.

This project demonstrates the feasibility of including patients in priority setting exercises and offers an approach that is workable within the context of primary care, rather than a condition-specific population. Several patient-generated topics had not been previously identified by similar provincial policy and academic efforts, underscoring the importance of including patients in primary care priority setting. We recommend that future projects consider the topic importance ratings of patients, patient-provider alignment in these ratings, and under-researched areas to pursue when deciding which topics to develop into more specific research questions.

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# Footnotes

## Author Contributions

LE and MRL designed and led all phases of the project. Specific to the results reported in this paper, LE facilitated the priority setting exercises, thematically grouped the primary care experiences into topics, carried out the priority setting data entry and rankings, and drafted this paper. MRL is the PI for the PREFeR Project, oversaw all phases of the project, and contributed feedback to this paper. MRL and MM recruited the Patient Advisory members. MM led early engagement with the Patient Advisory, oversaw all administrative activities for and helped facilitate the priority setting exercises, and provided feedback on this paper. YB, RJ, KCL, HP are members of the BC Primary Health Care Research Network Patient Advisory and patient partners in PREFeR who provided feedback on this paper, as well as contributing to all aspects of the priority setting exercises reported herein. CMcG provided background information and training on research to the Patient Advisory, provided additional support at the priority setting workshop, and commented on this paper.

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## Competing interests

None declared.

## Ethical approval

Ethics approval advice was sought and was deemed not required by the Simon Fraser University Research Ethics Board for the phases of the project that are reported in this paper.

## Data sharing

No additional data available.

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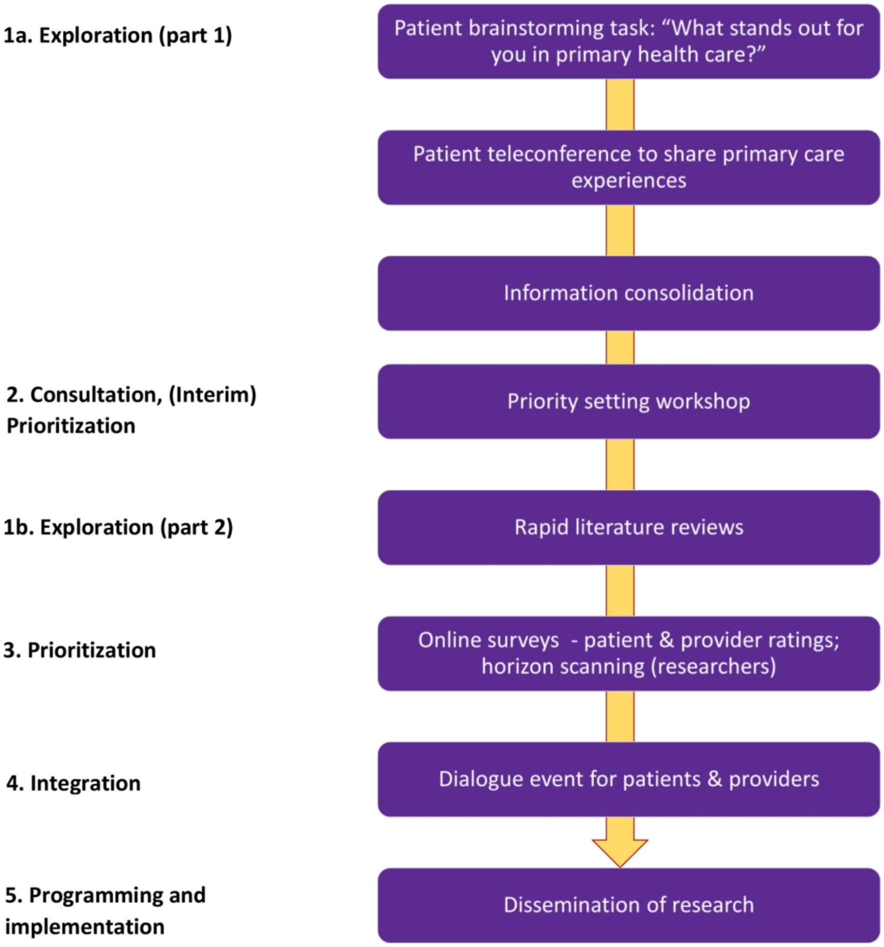

Figure 1. Key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

Key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

173x196mm (300 x 300 DPI)

## Patient-revised topics and full list of bullet point examples and experiences from the priority setting workshop

### 1) Care guided by patient needs, values, preferences, and priorities

- “Block and tackle” approach to protecting territory (i.e., using defensive/offensive tactics), rather than patient-centred care
- Care needs to keep pace with patients expectations for information, especially in the context of widespread access to online information
- Need to embark on a journey of discovery with the patient
- Role of primary care provider is to be a coordinator of care in a team-based setting
- More holistic approach needed, where the whole body is treated, not just whatever particular part/system is ‘ill’
- Consideration of non-pharmacological options for treatment

### 2) Informing and empowering patients

- Information not explained to patient adequately
- Not all treatment options explained/offered, especially around alternative medicine
- Advice needs to be targeted in a way that patients know how to take action (don’t just give diagnosis)
- Information not clearly communicated to patients about how/why something being prescribed
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Resources patients are directed to need to be appropriate and available based on needs of the community (including low-income)
- Guidance on red flags and when to seek care
- Strategies to address/accept ‘new normal’ after a new diagnosis
- Shock of new diagnosis may impair understanding/ability to ask questions during initial consultation
- Understanding individual patient priorities for their care and targeting care appropriately

### 3) Improve and strengthen communication between patients and primary health care providers

- Patients may not describe underlying issue/relevant symptoms, but questioning could identify it
- Patients may not have time/ability to process information to ask all questions during a consultation
- Enhancing decision-making shared between patients and providers

- Addressing language barriers in care
- Use recap strategy to check understanding

### 4) Information sharing, including electronic medical records

- Lack of coordinated information sharing between health care professionals (especially health authorities) means re-telling 'story' repeatedly & treatments/information given may never be known between health professionals and across settings including walk-in clinics, home-care, hospital
- Patients unable to access own EMR including clinical notes
- EMR often not reviewed before patient appointment, which leads to gaps in care
- Pharmanet works well in transferring prescription information between health authorities, but medical records don't similarly transfer
- Patient should not need to manage all of the communication within a care team
- Streamlined processes for patient-led consent and information sharing

### 5) Resources to better manage one's own health

- No access to EMR including clinical notes
- Should be ability to access information without seeing PHC physician (e.g., patient portal, patient-led chronic disease programming)
- No resources to help understand what patients can do to manage their own health (knowing schedule for check-ups, screening etc.)
- Lack of patient knowledge of clinical guidelines
- Patients need help interpreting what is and what isn't evidence-based
- Clarity needed around what to do when new to the province
- Need for centralized repositories with quality resources and programs available, including support groups

### 6) Prevention/early intervention

- Preventative medicine and lifestyle management not prioritized
- When, why and which health care professionals should do screening
- Lack of early interventions leads to poorer outcomes and higher cost down the road
- Roles for other professionals in preventative health care and lifestyle management

### 7) Unable to find a regular family doctor or other primary health care provider

- Weighing up convenience of walk-in over desire to see GP
- Places pressure on the emergency department
- Patients feel like a "product of the system"
- Hard to navigate healthcare system
- Receptionists act as gatekeepers (but without providing enough information)
- More students need to go into family practice

- Environmental/natural disasters impact patient health, which puts even further pressure on the system

## 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service)

- Often not possible to discuss multiple, interrelated issues (chronic conditions)
- Encourages walk-in clinic practice which does not meet patient needs
- Walk-in clinics –line ups for appointments are for long periods (not suitable for some patients/weather) & waiting space isn’t adequate
- Need research to understand how to most effectively compensate physician

## 9) Accessing care where and when patients need it

- Few options for after-hours care
- Need for care in home and long-term care
- Suitability of waiting space and physical design of clinics

## 10) Access to specialist knowledge

- Need for rapid access to specialist care for specific questions
- Processes to get specialist information that reduce need for face-to-face access to a specialist
- Need to keep patient in-the-loop on communication between primary care and specialists
- Direct access to specialists to answer a question

## 11) Support for living with chronic conditions

- No support for management of a chronic disease without a family doctor
- Family GPs refusing to accept patients with ‘complex’ conditions & ethics/implications of this
- Difficult to get repeat prescriptions filled without family GP
- Limited time with physician and nurse, especially with chronic conditions
- GPs could notify patients of support programs to help cope, including peer-to-peer support
- Some conditions cause cognitive difficulties (e.g., memory problems, difficulty processing or not correctly interpreting information)
- After a course of treatment, patient left somewhat alone dealing with side effects & feeling of being on own
- Can be long intervals between appointments & patient can ‘feel lost’ in this time interval
- Patient and doctor misconceptions likely with understanding condition/treatments
- Differentiation between chronic conditions and acquired conditions and recognition that there isn’t always a causal relationship between them

- Continuity of care is essential in the context of chronic disease
- Clear communication of prognosis and pathway of care going forward, including the spectrum of possibilities

### 12) Mental health resources

- Often limited or no availability of resources for mental health and substance use needs
- Gap between primary care and specialists services, particularly in the absence of a diagnosis
- Information needed on how to access mental health and substance use resources
- Primary care physicians (and Emergency doctors) not qualified to manage complex mental health needs, so patients access acute care more often
- Co-existence of mental health and physical conditions poorly managed

### 13) Challenges in small towns/cities and remote areas

- Primary care doctors need to do more, since there are fewer specialists in small towns/cities
- Transportation needs must be considered
- Improved access to specialists also needed
- Less access to diagnostic testing
- Less choice/availability for doctors/treatments, which has larger impact on 'complex' conditions
- Privacy/stigma issues in rural areas (e.g., prescription pick-up)

### 14) Addressing stigma and bias

- Cultural safety and competency
- Community sensitivities
- Care for LGBTQ communities
- Stigma particular to transgender community
- Assumptions made based on health condition/background/socioeconomic status
- Effects of terminology, diagnoses, etc.
- Impact of stigma and bias on patient outcomes

### 15) Knowledge gaps in clinical evidence and information

- Issues of consistency across doctors when seeing multiple providers and levels of expertise (of GPs)
- GPs appear uncertain of correct course of care, or reluctant to perform procedures (provide clinical 'judgement')
- Knowledge and application of clinical guidelines
- Continuing education for practicing professionals
- Need to study who responds, not just the treatments themselves

- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Speed of implementation of scientific research (17 years) needs to be improved
- Patients want new treatments now, even though full evidence base may not be there
- Patients aware of differences in treatments between provinces and countries and want access to full set of options
- Scientific/research models only useful insofar as they predict outcomes in the real world
    - Magnitude of effect needs to be considered

### 16) New models of primary care including other health care professionals

- Need for better collaboration and cooperation among health care professionals and health disciplines
- Expanded roles for other health care professionals
- Better support needed for caregivers and home support workers, including respite care

### 17) Improving continuity and coordination

- Care outside of office (long-term care, home care) and outside of office hours is needed to ensure continuity
- Reluctance to renew prescriptions for more than three months
- Unnecessary appointments required to access services (e.g. vaccinations, physiotherapists)
- New questions occur to patients after an appointment, but no one to ask/have to make a new appointment to have these questions answered
- Emergency respondents appear well-trained, but often involves 4-6 health professionals
- Patients discharged from secondary care without ensuring adequate services in place (transportation, clean/safe home, family pressure/stress)

### 18) No universal drug plan

- Patients' limitations, needs & affordability/financial issues must be taken into account
    - Some 'over-the-counter' products are cheaper
    - Patients may skip/halve medications (appear non-adherent, but can't afford 'as prescribed')
    - Lack of coverage for prescription drugs puts pressure on the system elsewhere
- Difficulties with pharmacies inputting out-of-province information (when new to BC)
- Education for primary care providers on cost of prescription drugs to guide prescribing decisions

BMJ Open

# What matters most to patients about primary health care: Mixed methods patient priority setting exercises within the PREFeR (PRioritiEs For Research) Project

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| | |

# What matters most to patients about primary health care: Mixed methods patient priority setting exercises within the PREFeR (PRioritiEs For Research) Project

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# Abstract

**Objectives:** To identify patient-generated priority topics for future primary care research in British Columbia (BC), Canada within a diverse patient population.

**Design:** Mixed methods priority setting exercises framed by the Dialogue Model, using the Nominal Group Technique (rank-ordered scoring), and province-wide online surveys capturing importance ratings of the top 10 primary health care topics from patients and primary care providers.

**Setting:** BC, Canada

**Participants:** Topic identification was completed by 10 patient partners (7 female, 3 male) from the BC Primary Health Care Research Network Patient Advisory; online surveys were completed by 464 patients and 173 primary care providers.

**Results:** The 10 members recruited to the Patient Advisory provided over 80 experiences of what stood out for them in BC primary care, which were grouped thematically into 18 topics, 10 of which were retained in province-wide surveys. Top-rated survey topics for both patients (n=464) and providers (n=173) included being unable to find a regular family doctor/other primary health care provider, support for living with chronic conditions, mental health resources, and information sharing, including electronic medical records. However, all 10 topics were rated highly by both groups (patients: mean range=4.09-4.64, SDs=0.75-1.02; providers: mean range=3.95-4.59, SDs=0.76-1.07).

**Conclusions:** The current project activities demonstrate the feasibility of including patients in priority setting exercises for primary health care in general, rather than focusing on a condition-specific population or disease area. There was considerable overlap between patient-generated topics and topics previously identified by other stakeholders, but patients identified two additional topics (Mental health resources, Improve and strengthen patient-provider communication). More similarities than differences in topic importance between patients and providers emerged in the online surveys. The project activities that follow (rapid literature reviews, multi-stakeholder dialogue) will highlight under-researched topics and inform the development of specific research questions.

**Keywords:** patient engagement, priority setting, primary health care, Dialogue Model

# ARTICLE SUMMARY

## Strengths and limitations of this study

- This is the only published patient priority setting project that we are aware of that addresses primary health care topics in general, rather than focusing on a particular health condition or issue.
- The project was informed by the Dialogue Model, which is a multi-stage, multi-stakeholder structured priority setting framework, but explicitly focused on patient perspectives within the Exploration and Consultation Phases of primary health care topic generation.
- Patients identified new topics and added depth to topics previously identified in similar exercises among policymakers or researchers, further highlighting the importance of patient engagement in priority setting.
- Generalizability of the current priority topics might be limited, given the characteristics of the Patient Advisory and survey respondents.

# INTRODUCTION

Primary care is the first point of contact with health care for most patients, and supports a wide variety of health needs. It is not surprising, therefore, that a host of primary care research focuses on studying patient needs and gaps in care. However, patients are not frequently included in prioritizing research ideas[1–3]. At a basic level, this is problematic because patient, clinician, and researcher priorities may differ significantly[4]. At an applied level, intervention uptake and, consequently, any impact on health outcomes may suffer if the problems studied and outcomes suggested have not considered patients' perspectives, leading to research 'waste'[5]. Patient prioritization of topics for research ultimately benefits the intended end-users of primary health care directly – patients themselves – and makes better use of scarce resources.

There is growing recognition of the importance of involving patients in research priority setting. In response, there has been a proliferation of patient priority setting studies in recent years, with 70 articles from the UK, US, Canada, the Netherlands and Australia identified between 2007-2017 in a rapid systematic review of public and patient engagement in prioritization[6]. Yet, most processes for engaging patients in research have focused on populations defined by a specific condition[6,7], rather than primary care more generally. While there have been exercises to identify primary care research priorities at clinical and academic conferences[8], these did not include patients. We have only identified two recent publications that examined primary care priorities more generally – i.e., in which the overall focus was not specific to a particular health condition – and that involved patients as one of the multi-stakeholder groups[9–11]. Even so, these studies actually targeted more specific topics – how to promote healthy behaviours through primary care, and ensuring care is guided by patient goals and preferences – rather than allowing any topics relating to primary care experiences to emerge as priorities. In order to examine gaps in care that affect a large and diverse range of patients, it is important to enable patients to voice whatever primary health care priorities are most pressing for them.

There are a host of tools and techniques for priority setting. One recent methodological review found roughly equal numbers of studies that used published, structured frameworks and those that used newly-developed tools (e.g., surveys specific to the project)[12]. In terms of structured approaches, there are several multi-stage priority setting frameworks, such as the James Lind Alliance Priority Setting Partnerships[13] and the Dialogue Model[1,14]. The James Lind Alliance has developed important principles to guide priority setting for research with patients and caregivers [15], but this approach is anchored on treatment uncertainties and does not translate directly to questions related to primary care more generally. There does not appear to be a single, best method[16], nor is there clear agreement on whether using a combination of tools for priority setting is superior to using one technique alone[12]. However, use of a clearly defined approach is recommended[12,17], and the choice of which method(s) may be best guided by the research question[16]. The Cochrane Priority Setting Methods Group noted that researchers may adapt and implement the same methods in different ways depending on the context and research focus[18].

Recognizing 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 PREFeR

(PRioritiEs For Research) 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[19]. This decision was also shaped by the fact that research priorities for primary care had recently been identified in BC, but this process included policymakers, clinicians, and researchers, and not patients[20]. By focusing on topics that are of importance to patients, research is more likely to have positive impacts on policy and practice.

As noted in reviews[6,21], detail about methodology is often lacking in articles about priority setting, and this is essential to replicating approaches and understanding how and what works for patient engagement. The PREFeR Project was informed by the Dialogue Model, which is a multi-stage priority setting framework involving multiple stakeholders, but modified this model to focus solely on patient perspectives for initial topic generation[1]. Here we report the resulting patient-identified priorities and their importance for patients and primary care providers. We also overview the other project activities that are couched within the later phases of the Dialogue Model, which correspond to the secondary aims of PREFeR: to assess whether research is already being conducted on the patient priorities through rapid literature reviews and ‘horizon scanning’ surveys with BC researchers, and to explore where and why differences might occur in the survey results through a facilitated discussion (‘dialogue’) with patients, providers, researchers and policymakers. Taken together, results from these activities are key considerations for setting future research questions.

# METHODS

## Patient and public involvement

The BC Primary Health Care Research Network (BC-PHCRN) Patient Advisory (hereafter, referred to as the Patient Advisory) was formed to conduct this priority setting exercise, as well as gather their input into multiple studies supported by the BC-PHCRN. Patients living throughout BC were recruited to the Patient Advisory through expression of interest calls posted by the BC-PHCRN, through Patient Voices Network (a network of patients and caregivers interested in engagement opportunities with health care partners in British Columbia), and through a patient engagement workshop at the Centre for Health Services and Policy Research annual conference (Vancouver, BC, March 2017). We included the following text in the invitation: “Priority will be given to ensuring that patient partners are inclusive of the diverse communities and individuals who access primary health care services. Please let us know if and how your participation might add to diversity”. We used this information to purposively recruit patients, aiming to maximize diversity with respect to health care needs, health authority, ethnicity (including First Nations), age, and gender. We also sought to include both patients with and without previous research experience. As is consistent with Canada’s Strategy for Patient Oriented Research[19], the Patient Advisory members were research partners in PREFeR. They contributed to planning and shaping research activities other than priority setting, since they provided input as participants to the priority setting phase of this project, as described below.

## Overview of the Dialogue Model

Compared to the other structured priority setting frameworks, the five phases of the Dialogue Model – Exploration, Consultation, Prioritization, Integration, and Programming and Integration[1,14] – mapped most closely on to the overarching ethos of PREFeR (Figure 1). In particular, the Dialogue Model is based on participatory and interactive approaches, which advocate an equal partnership between patients and other stakeholders[1]. Through processes that encourage mutual learning, the Dialogue Model can lead to co-ownership of the priorities identified[1]. The model uses a variety of mixed methods (e.g., literature reviews, interviews, surveys) throughout the five phases, which we also identified as essential to the aims of PREFeR. Commonly, these methods are grounded in other structured techniques. For example, focus groups may be framed within the Nominal Group Technique (NGT)[22], which is a widely-used method of idea generation, based on four key stages: individual and silent idea generation in response to the nominal question, round-robin feedback to the group (i.e., each person sequentially shares one idea at a time), group discussion and clarification of ideas, individual voting (ranking or rating of ideas)[23].

The five phases of the Dialogue Model were modified to match the aims of PREFeR. Most notably, we chiefly focused on patient views in the Consultation phase, since the goal of PREFeR was to generate patient priorities. However, priorities from our other stakeholders were gathered and compared to patient priorities later in the project. Below, we overview all activities in PREFeR as they map on to the phases of the Dialogue Model, but the primary focus of this paper is on the Exploration, Consultation, and Prioritization phases. Research activities in these phases correspond to use of NGT to generate and prioritize patient-generated primary care topics, and province-wide online surveys to rate the importance of the top 10 patient-ranked topics amongst a wider group of patients and primary care providers.

## Data collection

### Exploration phase (part 1)

#### *Brainstorming primary care experiences*

In the first activity of the project (within the Exploration phase), the ten-member Patient Advisory was sent an email request to brainstorm their ideas in response to the following question, “Based on your experiences of primary care, what things really stand out for you?” Primary care was defined as where most people go first for medical help and advice when they have a health problem, and provided by health care professionals, like family doctors, nurses or nurse practitioners, pharmacists or emergency services staff. The question was neutrally framed by design, such that either positive or negative experiences of primary care might emerge. Patient Advisory members were asked to spend about 10 minutes on the task and write down as many things that came to mind in response to this question. They were invited to a teleconference to share their ideas with the group approximately two weeks later. For those unable to attend, an opportunity to provide their thoughts through individual telephone calls with the first author prior to the scheduled teleconference was offered. With permission, these members’ primary care experiences were shared with the rest of the Patient Advisory during the group teleconference.

The teleconference was led by the first author and facilitated by the second author. The first author has a PhD in psychology and over eight years' experience working within large, multi-stakeholder primary care research teams that all included patient and public involvement members. She joined the research team after the Patient Advisory had been recruited, did not know any of the members prior to working on the project, and the teleconference was her first interaction with the Patient Advisory. The first and second author worked together to ensure equal opportunity of patient voices throughout the teleconference.

Using the Nominal Group Technique[22] implemented with a teleconference platform[24], each Patient Advisory member was asked to provide one idea at a time, in round-robin fashion, until there were no more new ideas to share. In line with NGT, patients were asked to first briefly describe the ideas that they had in response to the question, "what things really stand out for you in primary care?". Further explanation and discussion by the entire group followed after all ideas had been listed. The principal investigator (RL) took detailed notes throughout the teleconference, which were emailed to the Patient Advisory the following day for their review. No identifiers were used in the notes, since the aim was to record the raw list of ideas from the entire group.

Based on the teleconference notes, the first author consolidated the raw list of brainstormed ideas. Common elements were grouped thematically into topics. A heading for each topic was constructed with a short phrase in lay language to reflect the underlying theme of the collection of examples and experiences raised by the patients. The specific patient examples and experiences were additionally provided in bullet form below each topic heading. After an initial discussion with the second and last author, the topic list was refined and then emailed to the

Patient Advisory. The Patient Advisory was asked to review the list of topics ahead of an in-person priority setting workshop, to ensure it reflected the teleconference discussion accurately.

## Consultation and (Interim) Prioritization phases

### *Interim priority setting workshop*

Three and a half weeks after the teleconference, a full-day, in-person priority setting workshop with the Patient Advisory was held in Vancouver, BC. The purpose of the workshop was, firstly, to review, discuss, revise, and agree on the list of the patient-generated primary care topics that emerged out of the teleconference (Consultation phase), and then to have the patients individually rank the top 10 most important topics ((Interim) Prioritization phase). Similar to the methods used by Broerse and colleagues [13], we decided in advance that 10 topics would be a manageable number to carry forward for patients and primary care providers to rate in an online survey. Collectively, this constituted the remaining steps of the NGT process, which followed from the initial stages conducted during the teleconference.

To arrive at a final, agreed upon list of primary care topics, the Patient Advisory was asked to review the topics and consider: (1) the suitability of the topic label wording, (2) whether any topics were missed from the teleconference or new ideas had emerged since that discussion, and (3) whether any additional topics should be separated out from the patient examples and/or whether two or more topics could be grouped together. These points were discussed for each topic in turn, making revisions on a projected screen in real time during the workshop.

Once the list of primary care topics was finalized, the group moved on to the second task of the workshop – ranking the topics in terms of their importance. The final topic list was distributed to the Patient Advisory, who were then asked to privately choose the 10 topics that were most important to them personally. Personal importance could also include thinking about how the issues might affect other people they were close to (e.g., family, friends). A recording sheet was provided for patients to arrange their top 10 topics in terms of 1=*Most important* to 10=*Least important*. Ties were not permitted. In line with NGT methods, patients were asked to complete this task silently and on their own, and they were given as much time as needed. The first author checked the ranking sheets for completeness as they were collected.

The first author entered the patient-ranked data into an Excel spreadsheet, and then reverse scored the data, such that 10=*Most important* and 1=*Least important*. Following the steps outlined in McMillan et al.[23], results were pooled by first creating a sum of scores for each topic, which indicated its ranked priority or strength of vote score[25], and then calculating the proportion (%) of scores ranked within the top 10 topics, which indicated relative importance [26]. In order to resolve ties, a third method of tabulating the ranks involved counting the number of times each topic was ranked within the top 10 across patients, which is an indication of topic popularity[23,25]. The data were then sorted according to their ranked priority, yielding the top 10 topics that the project would carry forward in the remaining project activities.

### *Exploration phase (part 2) - Rapid literature reviews*

Rapid literature reviews were carried out in MEDLINE for published research conducted within BC and Canada on each of the 10 patient-identified primary care topics. Topic-specific search strategies using Medical Subject Heading terms and keywords were constructed for English language publications from 2008-2018. Two reviewers independently screened abstracts/titles for relevance to the topics, with guidance from the first and last authors. The total number of BC and Canadian papers included for each topic was tabulated. This information was used to inform the Integration phase and future development of research questions, but we do not report results herein. This reflects a divergence from the Dialogue Model, in which we carried out rapid literature reviews after the Consultation phase, instead of within the Exploration phase.

## Prioritization phase

### *Topic importance surveys*

Online surveys were administered province-wide to capture BC patients' and primary care providers' importance ratings of the top 10 topics. Both stakeholder groups were asked to rate each topic individually from 1=*Not at all important* to 5=*Very important*. The topic heading, along with 2-4 bullet points of examples and experiences (from the Patient Advisory) to illustrate the topic, were included to mitigate misunderstanding and misinterpretation of the topic heading. Participants were asked to *rate* rather than *rank* the identified topics, so that we could understand which topics were closely clustered with respect to importance, and not just overall rank order. A freetext box was provided for any comments respondents wished to submit. Following the importance ratings, several socio-demographic questions were included in the surveys (Supplementary file 1). Completion of the online survey implied consent, which was outlined on the information landing page for the survey.

### Survey participants and recruitment

We recruited survey respondents using multiple online dissemination channels, such as social media (Twitter, Facebook), e-newsletters, emails, snowballing and notices posted on several websites. We also included a one-time classified ad in 31 local newspapers in small BC communities and offered telephone completion as an alternative to the online survey. Due to time and budget constraints, the surveys were only provided in English. The sole inclusion criterion was that patients and providers must be living in BC to complete the survey.

### Analysis of survey data

We report means and standard deviations of importance ratings among patients and providers. Future analyses will explore differences in the ratings by patient and provider characteristics.

### *Horizon scanning survey*

A third survey with BC researchers was included for horizon scanning purposes; namely, to capture any past, ongoing, or upcoming (in the next 12 months) research on the 10 primary care topics. This complements the rapid literature reviews, but it also enabled us to capture research that had not been published, completed or for which funding has recently been secured. This online survey presented each topic with the same 2-4 bullet point example statements. We collected information on study design and publications, as well as socio-demographics. The surveys were disseminated through similar online channels to the other surveys. As with the literature reviews, this information was used to inform the Integration phase and future development of research questions, but we do not report results herein.

## Integration phase

### *Patient, provider, researcher and policymaker dialogue event*

A final dialogue event brought patients and primary care providers together to share the survey results, and to engage in a facilitated discussion about areas of concordance and dissimilarity in the results. Patients included the Patient Advisory and others recruited to enhance the representativeness of minority populations (e.g., Indigenous peoples and newcomers to the province). We recruited a diverse mix of primary care providers, including GPs, nurses, nurse practitioners, and pharmacists.

The aim of the event was to gain a better qualitative understanding of the general perspectives of patients and primary care providers with respect to the quantitative survey results, rather than to achieve consensus on the top primary care topics for the two stakeholder groups, as in the Dialogue Model. We chose to modify the purpose of the PREFeR dialogue event in this way because it is more in line with the overall objective of the project; namely, to identify patient priorities for future primary care research. Comparing patient priorities to those of providers is an important secondary aim of PREFeR. Nevertheless, we think it is more imperative to understand where and how these might differ, rather than try to bring the views of a small subgroup of patients and primary care providers together.

In addition to the main patient and provider component, a parallel discussion was held with researchers and policymakers at the dialogue event. These stakeholders also discussed the survey findings, but the focus was on how these results might be translated into future research and their policy implications. All groups came together at the end of the event to share a summary of their discussions with the entire group of attendees. Findings from this event will be reported elsewhere.

# RESULTS

## Patient Advisory characteristics

In total, 11 members (8 female, 3 male) were recruited to the Patient Advisory between March and May 2017. Of these, 10 were recruited through recruitment advertisements placed with Patient Voices Network BC. A total of 3 males and 12 females replied to these ads, and we chose 3 males and 7 females. An eighth female member was recruited from another study to ensure equal representation across the five regional health authorities in the province. However, one female patient resigned at the start of the PREFeR Project and did not provide any input to the project. The final 10 Patient Advisory members (7 female, 3 male) were characterized by a mix of socio-demographic characteristics, including ethnic minority backgrounds, speaking multiple languages, born outside of Canada or the province, and representation from all five health authorities (Table 1). In line with the recruitment strategy, 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). Some had recovered from very severe, life-threatening health conditions (e.g., cancer), while others had only minor needs for episodic care. The group were predominantly employed (7/10, 70%), well educated (BSc, BA, teacher's college or higher university degree: 6/9, 67%), and were considered 'experienced' (e.g., members of three or more research committees/organizations, patient partners in other studies, research participant involvement, etc.) in terms of previous research involvement (6/9, 67%). The group did not know each other before joining the Patient Advisory, and the PREFeR project was the first task the Advisory worked on collectively.

**Table 1.** Characteristics of British Columbia Primary Health Care Research Network Patient Advisory (n=10). All values reported are N(%), unless otherwise specified.

| | N (%) |
|---|---|
| Age in years (M, SD)[1] | 48.4 (13.9) |
| Age range in years | 24-67 |
| Sex | |
| Female | 7 (70) |
| Male | 3 (30) |
| Ethnicity[1] | |
| White only | 3 (33) |
| Indigenous | 2 (20) |
| Any other background | 4 (40) |
| Language(s) spoken[1] | |
| English only | 5 (56) |
| Multiple languages | 4 (44) |
| Employed | |
| Yes | 7 (70) |
| Highest education level[1] | |
| Trade or non-University certificate/diploma, community college, University certificate below BA | 3 (33) |
| BA, teacher's college or higher | 6 (67) |

| | |
|---|---|
| Country of birth[1] | |
| Canada | 8 (89) |
| Years living in BC[1] | |
| 0-5 | 2 (22) |
| 6-15 | 1 (11) |
| More than 15 years | 6 (67) |
| Regional Health Authority | |
| Vancouver Coastal Health | 5 (50) |
| Vancouver Island Health | 2 (20) |
| Fraser Health | 1 (10) |
| Interior Health | 1 (10) |
| Northern Health | 1 (10) |
| Previous research involvement[1,2] | |
| None | 1 (11) |
| Moderate | 2 (22) |
| Experienced | 6 (67) |

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[1] Data available for 9 of the 10 Patient Advisory members.

[2] Moderate = 2-3 years of researcher/research participant experience and/or patient partner on >2 committees/studies; Experienced = >3 years of researcher/research participant experience and/or patient partner on >3 committees/studies.

## Brainstorming primary care experiences

Two (1 male, 1 female) Patient Advisory members were unable to attend the primary care experiences teleconference in September 2017, and so their ideas were shared via a telephone call with the first author in advance. In total, these and the remaining eight Patient Advisory members (2 male, 6 female) provided 82 experiences and examples of what stood out for them in primary care in BC. There was considerable overlap in these primary care experiences, which were initially grouped into 19 themes by LE, MM, and RL (Supplementary file 2 column 1).

## Interim priority setting workshop

Nine (2 male, 7 female) of the 10 Patient Advisory members attended the in-person priority setting workshop in Vancouver, Canada in September 2017. The researcher-proposed 19 primary care themes were reviewed, discussed, and revised (Supplementary file 2, column 2; topic headings and full set of illustrative bullet points are also provided in Supplementary file 2). No additional themes were added, but 14 of the topic headings were changed and two of the researcher-suggested topics (*Impact of a new diagnosis, Care of chronic conditions*) were combined to form a single patient-revised topic (*Support for living with chronic conditions*). In total, 18 final topics were retained from the first part of the workshop.

Patients selected and then ranked the 10 most important topics for themselves and in consideration of their social network. The raw rankings were followed by methods of tabulating the final ranked priority topics (via scores and votes), which included the sum of scores across patients, ranked priority via scores, relative importance, ranked priority via relative importance, and the number of votes (Supplementary file 3). There were some tied ranks, which were resolved by the number of votes. For example, *Accessing care when and where patients need it* and *Support for living with chronic conditions* were tied for fourth place, but the access-related topic received more votes overall, and so retained the higher priority position. There was consensus within the team that the top 10 topics captured the most important ideas.

## Survey participant characteristics

Between February and May 2018, 464 patients and 173 primary care providers living and working in BC completed the survey. As shown in Table 2, the majority of both patients and providers were female and of White ethnicity. Most patients lived in large metropolitan areas and were married or in a common-law relationship. The proportion of patient survey respondents from the five regional health authorities was closely aligned with 2017 provincial population estimates for Vancouver Coastal Health and Vancouver Island Health (provincial estimates: 24.6% and 16.5%, respectively), but there was over-representation from Interior and Northern Health (provincial estimates: 15.7% and 5.8%, respectively) and under-representation from Fraser Health (provincial estimate: 37.5%)[27].

Primary care providers from Interior Health authority were over-represented, constituting over half of all respondents. Providers were fairly evenly distributed between primary care physicians, nurses, and all other providers such as pharmacists, physical and occupational therapists, and social workers.

**Table 2.** Characteristics of patients and primary care providers completing the online survey. All values reported are N(%).

| | Patients (n=464) | Providers (n=173) |
|---|---|---|
| Age | | |
| Under 40 years | 123 (26.5) | - |
| 40-59 years | 158 (34.0) | - |
| 60+ years | 152 (32.7) | - |
| Sex | | |
| Female | 368 (79.3) | 130 (75.6) |
| Male | 77 (16.6) | 35 (20.4) |
| Ethnicity | | |
| White only | 366 (78.9) | 130 (75.1) |
| Mixed or any other background | 74 (15.9) | 22 (12.7) |
| Regional health authority | | |
| Vancouver Coastal Health | 108 (23.3) | 23 (13.3) |
| Fraser Health | 97 (20.9) | 19 (11.0) |
| Vancouver Island Health | 70 (15.1) | 16 (9.3) |
| Interior Health | 129 (27.8) | 99 (57.2) |
| Northern Health | 47 (10.1) | 5 (2.9) |
| Provincial Health Services Authority | | 9 (5.2) |
| Type of provider | | |
| Family doctor | - | 52 (30.1) |

| | | |
|---|---|---|
| Nurse | - | 52 (30.1) |
| Other primary care provider[2] | - | 10 (5.8) |
| Community-based/allied workers[3] | - | 38 (22.0) |
| Hospital-based only, including consultants | - | 21 (12.1) |

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[1] Figures do not always sum to 464 and 173 (100%), due to no response/system missing, 'prefer not to answer', 'don't know', or 'other' responses.

[2] Other primary care providers included pharmacists, midwives, or any other primary care provider other than family doctors and nurses.

[3] Community-based/allied workers included social workers, care aides, etc.

## Survey topic importance ratings

Comparing between patient and provider topic importance mean ratings, all 10 topics were rated highly by both groups (between 4="Important" and 5="Very important") (Table 3). Among both patients and providers, the top-ranked topic was *Unable to find a regular family doctor or other primary health care provider*. Among patients, the next six topics (*Support for chronic conditions*, *Information sharing (including EMR)*, *Mental health resources*, *Access to care when/where needed*, *New models of healthcare*, and *Improve continuity/coordination*) were all similarly rated (means 4.41 to 4.52). The same six mid-ranked topics were similarly clustered for providers, although there was a wider range of average ratings (means 4.27 to 4.53). The final three lower-ranked topics were still equivalent to the "Important" category, on average. Therefore, there were more similarities than differences between the rank ordering of topics for patients and providers.

**Table 3.** Mean (standard deviation) importance ratings of primary care topics listed in order of mean patient ratings

| Primary care topics | Patients (n=464) | Providers (n=173) |
|---|---|---|
| 1) Unable to find regular family doctor/other primary health care provider | 4.64 (0.76) | 4.59 (0.76) |
| 2) Support for living with chronic conditions | 4.52 (0.75) | 4.36 (0.88) |
| 3) Information sharing, including EMR | 4.52 (0.76) | 4.29 (0.91) |
| 4) Mental health resources | 4.51 (0.81) | 4.53 (0.77) |
| 5) Accessing care when and where patients need it | 4.46 (0.78) | 4.27 (0.85) |
| 6) New models of primary care that include other HCPs | 4.44 (0.83) | 4.30 (1.03) |
| 7) Improving continuity and coordination | 4.41 (0.81) | 4.31 (0.85) |
| 8) Improve and strengthen patient-provider communication | 4.21 (0.92) | 4.03 (1.05) |
| 9) Challenges in small towns/cities and remote areas | 4.18 (0.99) | 4.18 (0.92) |
| 10) Care guided by patient needs, values, preferences, and priorities | 4.09 (1.02) | 3.95 (1.07) |

VCH = Vancouver Coastal Health; FH = Fraser Health; VIH = Vancouver Island Health; IH = Interior Health; NH= Northern Health; EMR = electronic medical record; HCPs = health care professionals.

# DISCUSSION

Involving patients in setting priorities for primary care research is feasible, fruitful and important to patients, but it is rare. This paper outlines the key activities of the PREFeR Project, which are framed within the Dialogue Model, and reports the processes and results from the priority setting exercises. A group of 10 patients from all five regional health authorities in the province were recruited as patient partners to a Patient Advisory group. Using the Nominal Group Technique, over 80 experiences of what stood out for them in primary care were generated. After grouping these into 18 common themes, the top 10 ranked topics were retained for rating in a province-wide survey for patients and primary care providers. The most highly rated topics for both patients and providers were about being unable to find regular family doctor/other primary health care provider, support for living with chronic conditions, information sharing, including EMR, and mental health resources. In fact, the mean ratings and rank ordering of the topics were similar for both stakeholder groups.

The 10 priorities originally identified by the Patient Advisory align fairly well with some recent priority setting initiatives in the province. The BC Ministry of Health recently identified eight service delivery priorities for the province's health system in 2014[28]. These were re-confirmed at the primary care level by the BC-PHCRN research, clinical, and policy leads in 2015[20], but no patients were involved in this process. There is considerable overlap between the previous BC-PHCRN priorities and those reported herein, although there were two uniquely-identified Patient Advisory priorities that were not advanced by either the BC Ministry of Health or BC-PHCRN: *Mental health resources* (albeit, access to specialist treatment, in general, was mentioned by both organizations, and reducing demand on hospitals by improving care for those with mental health and substance use issues was one of five strategic priorities for the BC Ministry of Health in 2017[29]) and *Improve and strengthen patient-provider communication*. There were also examples where patient perspectives added depth and context. While both sets of priorities spoke to the need to address challenges specific to rural and remote settings, patients highlighted that transportation needs to be considered, and privacy and stigma may impact those in rural areas. The previous BC-PHCRN priorities included the need to enhance access, utilization, and continuity of patient information with other providers and levels of care, but patients spoke more directly to the need for electronic health records and the ability to access their medical records themselves. Finally, while the previous priorities noted issues around workforce planning, patients framed this as being unable to find a regular doctor or other primary health care provider. This highlights the value of including patients directly in setting priorities for primary care, and is another demonstration of how the priorities of patients and other stakeholders might differ.

The Dialogue Model, coupled with the Nominal Group Technique, was a useful framework for identifying patient priorities for primary health care research. This model has been used for agenda setting in many condition-specific populations, such as burns, diabetes, kidney disease, cystic fibrosis, dementia, bipolar disorder[1], but PREFeR is the first instance of primary care priority setting with a generic population that we are aware of. That said, the five phases of the Dialogue Model were modified substantially to address the aim of PREFeR, which explicitly focuses on patient priorities. Consistent with Canada's Strategy for Patient Oriented Research, the Patient Advisory members were research partners in PREFeR and contributed to planning and shaping the research activities. Their dual role as research participants and team members means that, to some degree, we shifted control and power to patients within the process, which is inconsistent with the Dialogue Model. This was implemented in a context where policymakers, clinicians, and researchers had previously worked to identify priorities in the absence of patients. Perspectives from these other stakeholder groups were, however, gathered and compared to patient priorities, albeit later in the project. In the end, these aligned quite closely, though patients identified some additional priorities and added additional context and depth to existing ones. In addition, the language used in the final topics was agreed on by patient team members, although different terminology may be more common among researchers.

Another notable divergence is that we identified *topics* for future research, rather than specific research questions. The top-rated topics are broad, and many reflect priorities for health system change that may be informed by research, but are not themselves research questions. Results from rapid literature reviews of the 10 topics, along with results from the 'horizon scanning' survey with BC researchers relating to completed, current or upcoming research on the 10 topics, will provide valuable information about the nature and extent of research on the topics. In some cases, the topics may suggest a need for strengthened knowledge translation or implementation science to inform changes to policies or service delivery rather than additional research. Also, as the searches covered broad topics, but were limited to BC and Canada, we recommend that more thorough reviews should be conducted that are specific to any future research objectives.

The main strengths of the current research are the contribution and partnership of patients in the priority setting exercises, using a structured framework to shape the research activities, and the volume of patients and providers completing the online surveys. However, there are several notable limitations to our approach. Although the initial priorities were developed by a group of patients purposively recruited to maximize diversity, we cannot claim to have reached saturation in possible topics, and we decided to limit the subsequent survey to 10 topics in order to make the online surveys more manageable. We did not directly solicit additional topics from survey respondents, and there are undoubtedly topics of high priority to patients missed in this process. Given the survey was conducted predominantly online and largely distributed within networks related to health care and health research, respondents are unlikely to be representative of the province as a whole. This might affect the generalizability of these results.

This project demonstrates the feasibility of including patients in priority setting exercises and offers an approach that is workable within the context of primary care, rather than a condition-specific population. The identified topics overlap with, but expand on, previously identified priorities, and the patient and primary care provider surveys highlighted more alignment than divergence between these two stakeholder groups in rating the topics. Nevertheless, two novel topics addressing mental health resources and patient-provider communication were identified here, underscoring the importance of including patients in primary care priority setting. These results, coupled with those of the remaining activities in this project, will jointly provide key considerations for setting future primary care research questions.

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# Footnotes

## Author Contributions

LE and MRL designed and led all phases of the project. Specific to the results reported in this paper, LE facilitated the priority setting exercises, thematically grouped the primary care experiences into topics, carried out the priority setting data entry and rankings, and drafted this paper. MRL is the PI for the PREFeR Project, oversaw all phases of the project, and contributed feedback to this paper. MRL and MM recruited the Patient Advisory members. MM led early engagement with the Patient Advisory, oversaw all administrative activities for and helped facilitate the priority setting exercises, and provided feedback on this paper. YB, RJ, KCL, HP are members of the BC Primary Health Care Research Network Patient Advisory and patient partners in PREFeR who provided feedback on this paper, as well as contributing to all aspects of the priority setting exercises reported herein. CMcG provided background information and training on research to the Patient Advisory, provided additional support at the priority setting workshop, and commented on this paper.

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## Competing interests

None declared.

## Ethical approval

Ethics approval advice was sought and was deemed not required by the Simon Fraser University Research Ethics Board for the Consultation and Exploration phases of the project involving the Patient Advisory. Harmonized ethical approval was granted by the Simon Fraser University and the University of British Columbia Research Ethics Boards (Reference number 20018s0051).

## Data sharing

Online survey data from 464 patients and 173 primary care providers, anonymously provided, which includes ratings of the importance of the top 10 patient-generated primary care topics. Data are available from Dr M Ruth Lavergne (Email: ruth_lavergne@sfu.ca).

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## Figure Legend

Figure 1. Key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

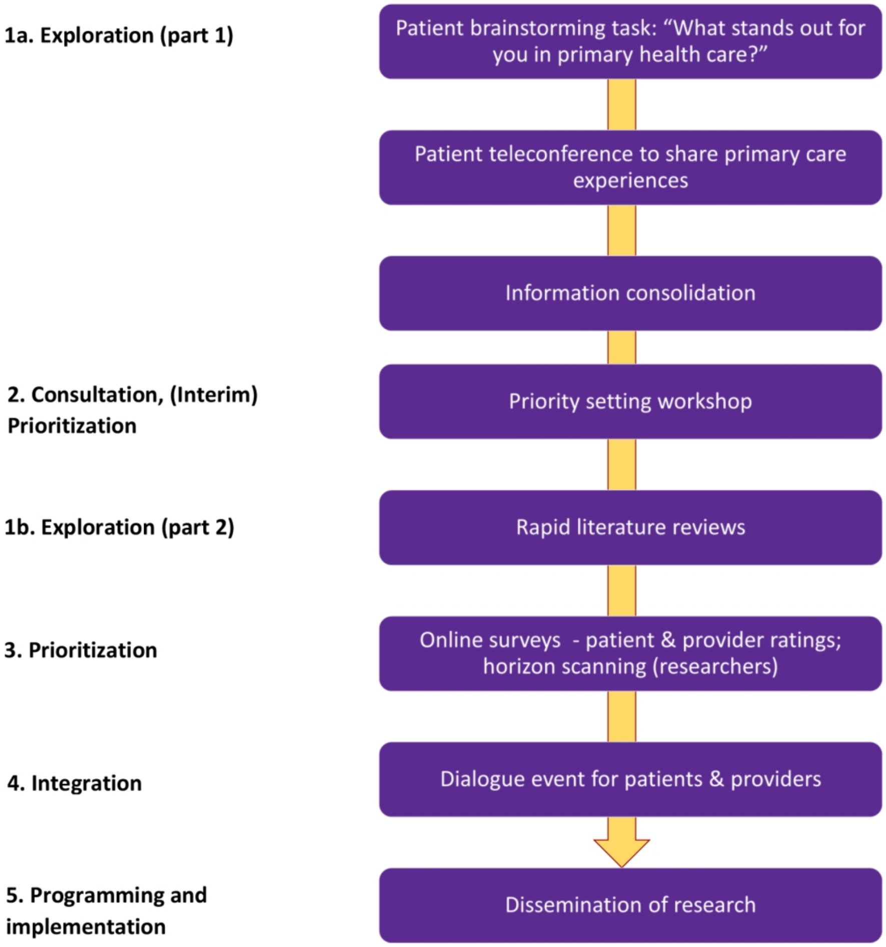

Figure 1. Key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

Key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

173x196mm (300 x 300 DPI)

# Online survey questions – Patient version

[Page 1 questions]

## How important are these topics to you?

Below are the 10 topics that have been identified by patients as primary health care priorities, which could be developed into more specific research questions.

It is important that everyone understands what each topic means in a similar way. For this reason, we include some statements or experiences from patients that help illustrate each topic. These examples are listed as bullet points under each topic.

When we use the term *primary health care provider*, we mean health care professionals, such as family doctors (GPs), nurses, and nurse practitioners.

- **After you have read all of the bullet points under each general topic, please rate EACH of the following 10 topics in terms of how important they are to you as a patient.**
- This may include how important they are to you personally, as well as how they affect people who are important to you (your friends and family members).
- Please rate each topic on its own. It is fine to use the same rating for more than one topic.

**How important are each of these topics to you on a scale from *Not at all important* to *Very important*?**

### 1) Unable to find a regular family doctor or other primary health care provider

*Example statements or experiences:*

- Not all patients are able to find a primary health care provider accepting patients
- Patients find it hard to get the care they need without a consistent primary health care provider (e.g., family doctor)

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

### 2) Improve and strengthen communication between patients and primary health care providers

*Example statements or experiences:*

- Identify strategies to help health care providers understand the concerns, priorities and/or symptoms that patients are trying to communicate

- Find ways to improve decision-making that is shared between patients and primary health care providers
- Find solutions to problems caused by language and communication barriers

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 3) Mental health resources

*Example statements or experiences:*

- Limited or no availability of resources for mental health, addictions and substance use needs through primary care
- Gap between primary care and specialist services
- It is common for people to experience mental health issues at the same time as they are also experiencing physical health conditions, and this situation is poorly managed

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 4) Support for living with chronic conditions

*Example statements or experiences:*

- Limited time in appointments to manage chronic conditions
- It can be difficult to find a family doctor if patients are perceived to have 'complex' conditions
- Without a family doctor, there is no support for management of a chronic disease (e.g., getting repeat prescriptions)
- Continuity of care is essential when living with a chronic disease
- Clear communication about what patients can expect and what should happen next is needed, especially because there can be long periods of time between appointments

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 5) Accessing care when and where patients need it

*Example statements or experiences:*

- Few options exist for after-hours care (outside of normal working hours, weekends)
- Patients weigh convenience of walk-in clinics and easier access to emergency departments over the desire to see a regular doctor
- There is a need for care in patients' homes and long-term care

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 6) Improving continuity and coordination

Example statements or experiences:

- Need for primary health care providers to coordinate care (i.e., communicate with specialists, organize care between hospital and community)
- Problems accessing primary health care providers make it difficult to maintain continuity with the same health care professional
- Lack of consistency when seeing multiple health care professionals with different levels of expertise

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 7) New models of primary care that include other health care professionals

*Example statements or experiences:*

- Need for a community of health care professionals (e.g., nurse practitioners, pharmacists, etc.) that takes advantage of their full expertise
- Need for better collaboration and cooperation among health care professionals and health disciplines
- Need for other options to access primary care services that do not require an in-person visit with a family doctor (e.g., prescription renewals)

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 8) Information sharing, including electronic medical records

*Example statements or experiences:*

- The lack of coordinated information sharing between health care professionals means re-telling health ‘story’ repeatedly
- Treatments/information given may not always be communicated between health professionals and across settings, including walk-in clinics, home-care, hospital
- Patients are unable to access their own medical records
- Patient should not need to manage communication among their health care providers

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don’t know/Not applicable |

## 9) Care guided by patient needs, values, preferences, and priorities

*Example statements or experiences:*

- A variety of treatment options should be explained and offered, including non-drug alternatives
- More holistic approach needed, where the whole person is treated, not just whatever particular body part/system is ‘ill’
- Find ways to meet individual patients’ expectations for information, especially in the context of widespread access to online information

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don’t know/Not applicable |

## 10) Challenges in small towns/cities and remote areas

*Example statements or experiences:*

- Less choice and availability of primary care providers, and less access to specialists and diagnostic testing
- Transportation needs before/after care must be considered
- Privacy/stigma issues may significantly impact those in rural areas (e.g., prescription pick-up)

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don’t know/Not applicable |

**Please use this space if you have any comments you'd like to share:**

[Page 2 questions]

# General information about you

In order for us to better understand possible differences between groups of people in ratings of primary health care topics, please complete the following anonymous information about yourself. It is important for us to have an accurate understanding of who is completing these surveys, but we will not be able to identify you from your answers.

1. **How old are you?**

   ○ Under 20 years
   ○ 20-29 years
   ○ 30-39 years
   ○ 40-49 years
   ○ 50-59 years
   ○ 60-69 years
   ○ 70-79 years
   ○ 80-89 years
   ○ Over 90 years
   ○ Prefer not to say

2. **How do you describe yourself?**

   ○ Male
   ○ Female
   ○ Transgender
   ○ Do not identify as female, male, or transgender
   ○ Prefer not to say

3. **You may belong to one or more racial or cultural groups on the following list. Are you... ? (Check ALL that apply.)**

   ○ White

   ○ Chinese

   ○ Aboriginal (First Nations, Métis, or Inuit)

   ○ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)

   ○ Black

   ○ Filipino

   ○ Latin American

   ○ Southeast Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese, etc.)

   ○ Arab

   ○ West Asian (e.g., Afghan, Iranian)

   ○ Japanese

   ○ Korean

   ○ Other, please specify:_______________________________________________

   ○ Prefer not to say

4. **What is the name of the town or city you currently live in?** ______________________
   *NB: If you live in more than one place, please put the place you live the majority of the time.*

5. **What are the first 3 digits of your postal code?** ______________________
   *NB: We cannot identify where you live from this information, but it allows us to know roughly where people completing the survey live.*

   *NB: If you live in more than one place, please put the place you live the majority of the time.*

6. **How many years have you been living in BC?**
   If you moved away and came back to BC, we are interested in the number of years you have been living in BC since returning to BC most recently.

   ○ I live outside of BC

   ○ 0-2 years

   ○ 3-5 years

   ○ 6-10 years

   ○ 11-15 years

○ More than 15 years

**7. What is your marital status?**

○ Single/never legally married

○ Married

○ Living common-law

○ Separated, but still legally married

○ Divorced

○ Widowed

○ Prefer not to say

**8. What is your highest level of education?**

○ Some elementary/junior school, but not all grades completed

○ Completed elementary/junior school

○ High school (secondary school) diploma or certificate

○ Trade certificate or diploma from a vocational school or apprenticeship training

○ Non-university certificate or diploma from a community college, CEGEP, school of nursing, etc.

○ University certificate below bachelor's level

○ Bachelor's degree or teacher's college (e.g., B.A., B.A. (Hons.), B.Sc., B.Ed.)

○ University degree or certificate above bachelor's degree (e.g., M.A., M.Sc., M.B.A., M.D., Ph.D.)

○ Other, please specify:______________________________________

○ Prefer not to say

**9. Last week, was your main activity working at a paid job or business, looking for paid work, going to school, caring for children, household work, retired or something else?**

○ Working at a paid job or business

○ Vacation (from paid work)

○ Looking for paid work

○ Going to school (including vacation from school)

○ Caring for children

○ Household work

○ Retired

○ Maternity/paternity leave

○ Long-term illness

○ Volunteering

○ Care-giving other than for children

○ Other (please specify):___________________________________

○ Prefer not to say

**10. What kind of housing do you currently live in?**

○ Owned house, duplex or townhouse (not including motorhome)

○ Owned apartment or condominium

○ Owned motorhome

○ Rented house, duplex or townhouse

○ Rented apartment or condominium

○ Assisted-living (community group housing)

○ Other, please specify:___________________________________________

○ Prefer not to say

**11. Do you currently have any of the following long-term health conditions? We are interested in "long-term conditions" which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional. (Check ALL that apply.)**

○ Asthma

○ Chronic bronchitis, emphysema or chronic obstructive pulmonary disease or COPD

○ Arthritis (for example, osteoarthritis, rheumatoid arthritis, gout or any other type, excluding fibromyalgia)

○ Back problems, excluding scoliosis, fibromyalgia and arthritis

○ Mood disorder (such as depression, bipolar disorder, mania or dysthymia)

○ Anxiety disorder (such as a phobia, obsessive-compulsive disorder or a panic disorder)

○ Diabetes

○ Osteoporosis

○ High blood pressure

○ High blood cholesterol or lipids

○ Heart disease

○ Stroke

○ Cancer

○ Alzheimer's Disease or any other dementia

○ Other, please specify:_____________________________________________

○ None of these

○ Prefer not to say

**12. Do you have a regular health care provider in BC? By this, we mean one health professional that you regularly see or talk to when you need care or advice for your health.**

○ Yes ○ No

**a. What is the reason why you do not have a regular health care provider?**

○ Do not need one in particular, but you have a usual place of care

○ No one available in the area

○ No one in the area is taking new patients

○ I have not tried to find one

○ Had one who left or retired

○ Other (please specify):_________________________________________

## Researcher-suggested primary care topic headings compared to patient-revised topic headings

| Researcher-proposed topic headings | Patient-revised topic headings |
|---|---|
| 1) More patient-centred care needed | 1) Care guided by patient needs, values, preferences, and priorities |
| 2) Communication – Informing/empowering patients | 2) Informing and empowering patients |
| 3) Improving patient-provider communication | 3) Improve and strengthen communication between patients and primary health care providers |
| 4) Electronic Medical Records (EMR)/information sharing | 4) Information sharing, including electronic medical records |
| 5) Resources to better manage one's own health | 5) Resources to better manage one's own health |
| 6) Prevention/early intervention | 6) Prevention/early intervention |
| 7) Inability to access regular family doctors (GPs) | 7) Unable to find a regular family doctor or other primary health care provider |

| | |
|---|---|
| 8) Inadequacy of walk-in clinics | 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service) |
| 9) Accessing after-hours care | 9) Accessing care where and when patients need it |
| 10) Access to specialist knowledge | 10) Access to specialist knowledge |
| 11) Impact of a new diagnosis | 11) Support for living with chronic conditions |
| 12) Care of chronic conditions | |
| 13) Accessing mental health resources | 12) Mental health resources |
| 14) Challenges in small towns/cities | 13) Challenges in small towns/cities and remote areas |
| 15) Patient stigma | 14) Addressing stigma and bias |
| 16) Gaps in clinical evidence/information | 15) Knowledge gaps in clinical evidence and information |
| 17) Broaden roles for other health care professionals | 16) New models of primary care that include other health care professionals |
| 18) Inefficient practices put pressure on the system | 17) Improving continuity and coordination |

| | |
|---|---|
| 19) No universal drug plan | 18) No universal drug plan |

## Patient-revised topics and full list of bullet point examples and experiences from the interim priority setting workshop

### 1) Care guided by patient needs, values, preferences, and priorities

- "Block and tackle" approach to protecting territory (i.e., using defensive/offensive tactics), rather than patient-centred care
- Care needs to keep pace with patients' expectations for information, especially in the context of widespread access to online information
- Need to embark on a journey of discovery with the patient
- Role of primary care provider is to be a coordinator of care in a team-based setting
- More holistic approach needed, where the whole body is treated, not just whatever particular part/system is 'ill'
- Consideration of non-pharmacological options for treatment

### 2) Informing and empowering patients

- Information not explained to patient adequately
- Not all treatment options explained/offered, especially around alternative medicine
- Advice needs to be targeted in a way that patients know how to take action (don't just give diagnosis)
- Information not clearly communicated to patients about how/why something being prescribed
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Resources patients are directed to need to be appropriate and available based on needs of the community (including low-income)
- Guidance on red flags and when to seek care
- Strategies to address/accept 'new normal' after a new diagnosis
- Shock of new diagnosis may impair understanding/ability to ask questions during initial consultation
- Understanding individual patient priorities for their care and targeting care appropriately

### 3) Improve and strengthen communication between patients and primary health care providers

- Patients may not describe underlying issue/relevant symptoms, but questioning could identify it
- Patients may not have time/ability to process information to ask all questions during a consultation
- Enhancing decision-making shared between patients and providers
- Addressing language barriers in care
- Use recap strategy to check understanding

### 4) Information sharing, including electronic medical records

- Lack of coordinated information sharing between health care professionals (especially health authorities) means re-telling 'story' repeatedly & treatments/information given may never be known between health professionals and across settings including walk-in clinics, home-care, hospital
- Patients unable to access own EMR including clinical notes
- EMR often not reviewed before patient appointment, which leads to gaps in care
- Pharmanet works well in transferring prescription information between health authorities, but medical records don't similarly transfer
- Patient should not need to manage all of the communication within a care team
- Streamlined processes for patient-led consent and information sharing

### 5) Resources to better manage one's own health

- No access to EMR including clinical notes
- Should be ability to access information without seeing PHC physician (e.g., patient portal, patient-led chronic disease programming)
- No resources to help understand what patients can do to manage their own health (knowing schedule for check-ups, screening etc.)
- Lack of patient knowledge of clinical guidelines
- Patients need help interpreting what is and what isn't evidence-based
- Clarity needed around what to do when new to the province
- Need for centralized repositories with quality resources and programs available, including support groups

## 6) Prevention/early intervention

- Preventative medicine and lifestyle management not prioritized
- When, why and which health care professionals should do screening
- Lack of early interventions leads to poorer outcomes and higher cost down the road
- Roles for other professionals in preventative health care and lifestyle management

## 7) Unable to find a regular family doctor or other primary health care provider

- Weighing up convenience of walk-in over desire to see GP
- Places pressure on the emergency department
- Patients feel like a "product of the system"
- Hard to navigate healthcare system
- Receptionists act as gatekeepers (but without providing enough information)
- More students need to go into family practice
- Environmental/natural disasters impact patient health, which puts even further pressure on the system

## 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service)

- Often not possible to discuss multiple, interrelated issues (chronic conditions)
- Encourages walk-in clinic practice which does not meet patient needs
- Walk-in clinics –line ups for appointments are for long periods (not suitable for some patients/weather) & waiting space isn't adequate
- Need research to understand how to most effectively compensate physician

## 9) Accessing care where and when patients need it

- Few options for after-hours care
- Need for care in home and long-term care
- Suitability of waiting space and physical design of clinics

## 10) Access to specialist knowledge

- Need for rapid access to specialist care for specific questions
- Processes to get specialist information that reduce need for face-to-face access to a specialist

- Need to keep patient in-the-loop on communication between primary care and specialists
- Direct access to specialists to answer a question

### 11) Support for living with chronic conditions

- No support for management of a chronic disease without a family doctor
- Family GPs refusing to accept patients with ‘complex’ conditions & ethics/implications of this
- Difficult to get repeat prescriptions filled without family GP
- Limited time with physician and nurse, especially with chronic conditions
- GPs could notify patients of support programs to help cope, including peer-to-peer support
- Some conditions cause cognitive difficulties (e.g., memory problems, difficulty processing or not correctly interpreting information)
- After a course of treatment, patient left somewhat alone dealing with side effects & feeling of being on own
- Can be long intervals between appointments & patient can ‘feel lost’ in this time interval
- Patient and doctor misconceptions likely with understanding condition/treatments
- Differentiation between chronic conditions and acquired conditions and recognition that there isn’t always a causal relationship between them
- Continuity of care is essential in the context of chronic disease
- Clear communication of prognosis and pathway of care going forward, including the spectrum of possibilities

### 12) Mental health resources

- Often limited or no availability of resources for mental health and substance use needs
- Gap between primary care and specialists services, particularly in the absence of a diagnosis
- Information needed on how to access mental health and substance use resources
- Primary care physicians (and Emergency doctors) not qualified to manage complex mental health needs, so patients access acute care more often
- Co-existence of mental health and physical conditions poorly managed

### 13) Challenges in small towns/cities and remote areas

- Primary care doctors need to do more, since there are fewer specialists in small towns/cities
- Transportation needs must be considered
- Improved access to specialists also needed
- Less access to diagnostic testing
- Less choice/availability for doctors/treatments, which has larger impact on ‘complex’ conditions
- Privacy/stigma issues in rural areas (e.g., prescription pick-up)

### 14) Addressing stigma and bias

- Cultural safety and competency
- Community sensitivities
- Care for LGBTQ communities
- Stigma particular to transgender community
- Assumptions made based on health condition/background/socioeconomic status
- Effects of terminology, diagnoses, etc.
- Impact of stigma and bias on patient outcomes

### 15) Knowledge gaps in clinical evidence and information

- Issues of consistency across doctors when seeing multiple providers and levels of expertise (of GPs)
- GPs appear uncertain of correct course of care, or reluctant to perform procedures (provide clinical ‘judgement’)
- Knowledge and application of clinical guidelines
- Continuing education for practicing professionals
- Need to study who responds, not just the treatments themselves
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Speed of implementation of scientific research (17 years) needs to be improved
- Patients want new treatments now, even though full evidence base may not be there
- Patients aware of differences in treatments between provinces and countries and want access to full set of options
- Scientific/research models only useful insofar as they predict outcomes in the real world – Magnitude of effect needs to be considered

### 16) New models of primary care including other health care professionals

- Need for better collaboration and cooperation among health care professionals and health disciplines
- Expanded roles for other health care professionals
- Better support needed for caregivers and home support workers, including respite care

### 17) Improving continuity and coordination

- Care outside of office (long-term care, home care) and outside of office hours is needed to ensure continuity
- Reluctance to renew prescriptions for more than three months
- Unnecessary appointments required to access services (e.g. vaccinations, physiotherapists)
- New questions occur to patients after an appointment, but no one to ask/have to make a new appointment to have these questions answered
- Emergency respondents appear well-trained, but often involves 4-6 health professionals
- Patients discharged from secondary care without ensuring adequate services in place (transportation, clean/safe home, family pressure/stress)

### 18) No universal drug plan

- Patients' limitations, needs & affordability/financial issues must be taken into account
    – Some 'over-the-counter' products are cheaper
    – Patients may skip/halve medications (appear non-adherent, but can't afford 'as prescribed')
    – Lack of coverage for prescription drugs puts pressure on the system elsewhere
- Difficulties with pharmacies inputting out-of-province information (when new to BC)
- Education for primary care providers on cost of prescription drugs to guide prescribing decisions

## Patient-ranked raw scores (n=9) for primary care topics and methods of tabulating the top 10 priority topics

| Topic[1] | Ranked scores by patients[2] | | | | | | | | | Sum of scores | Ranked priority (via scores) | Relative importance (%)[3] | Ranked priority (via %) | Number of votes | Final ranked priority (via scores & votes) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | | | | | | |
| Care guided by patient needs, values, preferences, priorities | 7 | | 9 | | 10 | | 10 | 8 | 7 | 51 | 1 | 10.3 | 1 | 6 | 1 |
| Information sharing, EMR | 5 | 1 | 8 | 6 | 5 | | 7 | 6 | 8 | 46 | 2 | 9.3 | 2 | 8 | 2 |
| Unable to find a doctor | | 10 | 3 | | | 10 | 4 | 5 | 10 | 42 | 3 | 8.5 | 3 | 6 | 3 |
| Accessing care when, where needed | 9 | 7 | 4 | 3 | 2 | 8 | 3 | | 5 | **41** | **4** | **8.3** | **4** | **8** | **4** |
| Support for chronic conditions | | 8 | 1 | 8 | | 6 | 2 | 10 | 6 | **41** | **4** | **8.3** | **4** | **7** | **5** |
| Mental health resources | 8 | 4 | | 4 | 8 | 1 | | 3 | 9 | 37 | 6 | 7.5 | 6 | 7 | 6 |
| New models of primary care | 10 | | 6 | 2 | 7 | 9 | | | | 34 | 7 | 6.9 | 7 | 5 | 7 |

| | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Improving continuity, coordination | | 6 | 5 | 9 | | 7 | | 2 | 4 | 33 | 8 | 6.7 | 8 | 6 | 8 |
| Challenges in small towns/cities | 2 | 5 | 7 | | | 5 | | 9 | 2 | 30 | 9 | 6.1 | 9 | 6 | 9 |
| Improve, strengthen patient-provider communication | 4 | | 2 | 7 | | 2 | 8 | 4 | | **27** | **10** | **5.5** | **10** | **6** | **10** |
| Informing, empowering patients | | | | 1 | 6 | 4 | 9 | 7 | | **27** | **10** | **5.5** | **10** | **5** | |
| Prevention/early intervention | 3 | | | | 9 | | 5 | | | 17 | | | | 3 | |
| Inadequacy of compensation model | | 3 | 10 | | 3 | | | | 1 | 17 | | | | 4 | |
| No universal drug plan | | | | 10 | 4 | | | | 3 | 17 | | | | 3 | |
| Resources to better manage health | | 9 | | | | | 6 | | | 15 | | | | 2 | |
| Knowledge gaps in clinical evidence | 6 | | | | 1 | | | 1 | | 8 | | | | 3 | |
| Access to specialist knowledge | | | | 5 | | | 1 | | | 6 | | | | 2 | |
| Addressing stigma and bias | 1 | 2 | | | | 3 | | | | 6 | | | | 3 | |

EMR = electronic medical record. Bold values indicate topics with ties.

[1] Topic headings have been shortened here for presentation ease. Refer to Supplementary file 2, column 2 for full topic headings.

[2] Ranked scores have been reverse scored, where 1=Least important and 10=Most important.

[3] Relative importance = [(topic score) / (maximum points for the group; i.e., number of patients (9) x 55 points) x 100].

# Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

## Title and abstract

| | Page/line no(s). |
|---|---|
| **Title** - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| **Abstract** - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 3-4 |

## Introduction

| | |
|---|---|
| **Problem formulation** - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 6-8 |
| **Purpose or research question** - Purpose of the study and specific objectives or questions | 7-8 |

## Methods

| | |
|---|---|
| **Qualitative approach and research paradigm** - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale** | 11-13 |
| **Researcher characteristics and reflexivity** - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 11-12 |
| **Context** - Setting/site and salient contextual factors; rationale** | 11-13 |
| **Sampling strategy** - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale** | 9, 18 |
| **Ethical issues pertaining to human subjects** - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 32 |
| **Data collection methods** - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale** | 11-14, 21-22 |

| | |
|---|---|
| **Data collection instruments and technologies** - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 11-14 |
| **Units of study** - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 18-21 |
| **Data processing** - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 11-14, 21-22 |
| **Data analysis** - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 11-14 |
| **Techniques to enhance trustworthiness** - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 12-13 |

**Results/findings**

| | |
|---|---|
| **Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | N/A |
| **Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | Supp File 2 |

**Discussion**

| | |
|---|---|
| **Integration with prior work, implications, transferability, and contribution(s) to the field -** Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 26-29 |
| **Limitations** - Trustworthiness and limitations of findings | 29 |

**Other**

| | |
|---|---|
| **Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 13-14, 27-28 |
| **Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 31 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

BMJ Open

# What matters most to patients about primary health care: Mixed methods patient priority setting exercises within the PREFeR (PRioritiEs For Research) Project

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| Secondary Subject Heading: | Research methods |
| Keywords: | patient engagement, priority setting, primary health care, Dialogue Model |
| | |

# What matters most to patients about primary health care: Mixed methods patient priority setting exercises within the PREFeR (PRioritiEs For Research) Project

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# Abstract

Objectives: To identify patient-generated priority topics for future primary care research in British Columbia (BC), Canada within a diverse patient population.

Design: Mixed methods priority setting exercises framed by the Dialogue Model, using the Nominal Group Technique (rank-ordered scoring), and province-wide online surveys capturing importance ratings of the top 10 primary health care topics from patients and primary care providers.

Setting: BC, Canada

Participants: Topic identification was completed by 10 patient partners (7 female, 3 male) from the BC Primary Health Care Research Network Patient Advisory; online surveys were completed by 464 patients and 173 primary care providers.

Results: The 10 members recruited to the Patient Advisory provided over 80 experiences of what stood out for them in BC primary care, which were grouped thematically into 18 topics, 10 of which were retained in province-wide surveys. Top-rated survey topics for both patients (n=464) and providers (n=173) included being unable to find a regular family doctor/other primary health care provider, support for living with chronic conditions, mental health resources, and information sharing, including electronic medical records. However, all 10 topics were rated important, on average, by both groups.

**Conclusions:** The current project activities demonstrate the feasibility of including patients in priority setting exercises for primary health care in general, rather than focusing on a condition-specific population or disease area. There was considerable overlap between patient-generated topics and topics previously identified by other stakeholders, but patients identified two additional topics (Mental health resources, Improve and strengthen patient-provider communication). More similarities than differences in topic importance between patients and providers emerged in the online surveys. The project activities that follow (rapid literature reviews, multi-stakeholder dialogue) will highlight under-researched topics and inform the development of specific research questions.

**Keywords:** patient engagement, priority setting, primary health care, Dialogue Model

# ARTICLE SUMMARY

## Strengths and limitations of this study

- This is the only published patient priority setting project that we are aware of that addresses primary health care topics in general, rather than focusing on a particular health condition or issue.
- The project was informed by the Dialogue Model, which is a multi-stage, multi-stakeholder structured priority setting framework, but explicitly focused on patient perspectives within the Exploration and Consultation Phases of primary health care topic generation.
- Patients identified new topics and added depth to topics previously identified in similar exercises among policymakers or researchers, further highlighting the importance of patient engagement in priority setting.
- Generalizability of the current priority topics might be limited, given the characteristics of the Patient Advisory (e.g., well educated, previous experience with research) and survey respondents (e.g., predominantly female, White).

# INTRODUCTION

Primary care is the first point of contact with health care for most patients, and supports a wide variety of health needs. It is not surprising, therefore, that a host of primary care research focuses on studying patient needs and gaps in care. However, patients are not frequently included in prioritizing research ideas[1–3]. At a basic level, this is problematic because patient, clinician, and researcher priorities may differ significantly[4]. At an applied level, intervention uptake and, consequently, any impact on health outcomes may suffer if the problems studied and outcomes suggested have not considered patients' perspectives, leading to research 'waste'[5]. Patient prioritization of topics for research ultimately benefits the intended end-users of primary health care directly – patients themselves – and makes better use of scarce resources.

There is growing recognition of the importance of involving patients in research priority setting. In response, there has been a proliferation of patient priority setting studies in recent years, with 70 articles from the UK, US, Canada, the Netherlands and Australia identified between 2007-2017 in a rapid systematic review of public and patient engagement in prioritization[6]. Yet, most processes for engaging patients in research have focused on populations defined by a specific condition[6,7], rather than primary care more generally. While there have been exercises to identify primary care research priorities at clinical and academic conferences[8], these did not include patients. We have only identified a few recent publications that examined primary care priorities more generally – i.e., in which the overall focus was not specific to a particular health condition – and that involved patients as one of the multi-stakeholder groups[9–12]. Even so, these studies actually targeted more specific topics – how to promote healthy behaviours through primary care, ensuring care is guided by patient goals and preferences, and patient safety concerns – rather than allowing any topics relating to primary care experiences to emerge as priorities. In order to examine gaps in care that affect a large and diverse range of patients, it is important to enable patients to voice whatever primary health care priorities are most pressing for them.

There are a host of tools and techniques for priority setting. One recent methodological review found roughly equal numbers of studies that used published, structured frameworks and those that used newly-developed tools (e.g., surveys specific to the project)[13]. In terms of structured approaches, there are several multi-stage priority setting frameworks, such as the James Lind Alliance Priority Setting Partnerships[14] and the Dialogue Model[1,15]. The James Lind Alliance has developed important principles to guide priority setting for research with patients and caregivers [16], but this approach is anchored on treatment uncertainties and does not translate directly to questions related to primary care more generally. There does not appear to be a single, best method[17], nor is there clear agreement on whether using a combination of tools for priority setting is superior to using one technique alone[13]. However, use of a clearly defined approach is recommended[13,18], and the choice of which method(s) may be best guided by the research question[17]. The Cochrane Priority Setting Methods Group noted that researchers may adapt and implement the same methods in different ways depending on the context and research focus[19].

Recognizing 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 PREFeR

(PRioritiEs For Research) 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 was also shaped by the fact that research priorities for primary care had recently been identified in BC, but this process included policymakers, 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.

As noted in reviews[6,22], detail about methodology is often lacking in articles about priority setting, and this is essential to replicating approaches and understanding how and what works for patient engagement. The PREFeR Project was informed by the Dialogue Model, which is a multi-stage priority setting framework involving multiple stakeholders, but modified this model to focus solely on patient perspectives for initial topic generation[1]. Here we report the resulting patient-identified priorities and their importance for patients and primary care providers. We also overview the other project activities that are couched within the later phases of the Dialogue Model, which correspond to the secondary aims of PREFeR: to assess whether research is already being conducted on the patient priorities through rapid literature reviews and 'horizon scanning' surveys with BC researchers, and to explore where and why differences might occur in the survey results through a facilitated discussion ('dialogue') with patients, providers, researchers and policymakers. Taken together, results from these activities are key considerations for setting future research questions.

# METHODS

## Patient and public involvement

The BC Primary Health Care Research Network (BC-PHCRN) Patient Advisory (hereafter, referred to as the Patient Advisory) was formed to conduct this priority setting exercise, as well as gather their input into multiple studies supported by the BC-PHCRN. Patients living throughout BC were recruited to the Patient Advisory through expression of interest calls posted by the BC-PHCRN, through Patient Voices Network (a network of patients and caregivers interested in engagement opportunities with health care partners in British Columbia), and through a patient engagement workshop at the Centre for Health Services and Policy Research annual conference (Vancouver, BC, March 2017). We included the following text in the invitation: “Priority will be given to ensuring that patient partners are inclusive of the diverse communities and individuals who access primary health care services. Please let us know if and how your participation might add to diversity.” We used this information to purposively recruit patients, aiming to maximize diversity with respect to health care needs, health authority, ethnicity (including First Nations), age, and gender. We also sought to include both patients with and without previous research experience. As is consistent with Canada’s Strategy for Patient Oriented Research[20], the Patient Advisory members were research partners in PREFeR. They contributed to planning and shaping research activities other than priority setting, since they provided input as participants to the priority setting phase of this project, as described below.

## Overview of the Dialogue Model

Compared to the other structured priority setting frameworks, the five phases of the Dialogue Model – Exploration, Consultation, Prioritization, Integration, and Programming and Integration[1,15] – mapped most closely on to the overarching ethos of PREFeR (Figure 1). In particular, the Dialogue Model is based on participatory and interactive approaches, which advocate an equal partnership between patients and other stakeholders[1]. Through processes that encourage mutual learning, the Dialogue Model can lead to co-ownership of the priorities identified[1]. The model uses a variety of mixed methods (e.g., literature reviews, interviews, surveys) throughout the five phases, which we also identified as essential to the aims of PREFeR. Commonly, these methods are grounded in other structured techniques. For example, focus groups may be framed within the Nominal Group Technique (NGT)[23], which is a widely-used method of idea generation, based on four key stages: individual and silent idea generation in response to the nominal question, round-robin feedback to the group (i.e., each person sequentially shares one idea at a time), group discussion and clarification of ideas, individual voting (ranking or rating of ideas)[24].

The five phases of the Dialogue Model were modified to match the aims of PREFeR. Most notably, we chiefly focused on patient views in the Consultation phase, since the goal of PREFeR was to generate patient priorities. However, priorities from our other stakeholders were gathered and compared to patient priorities later in the project. Below, we overview all activities in PREFeR as they map on to the phases of the Dialogue Model, but the primary focus of this paper is on the Exploration, Consultation, and Prioritization phases. Research activities in these phases correspond to use of NGT to generate and prioritize patient-generated primary care topics, and province-wide online surveys to rate the importance of the top 10 patient-ranked topics amongst a wider group of patients and primary care providers.

## Data collection

### Exploration phase (part 1)

#### *Brainstorming primary care experiences*

In the first activity of the project (within the Exploration phase), the ten-member Patient Advisory was sent an email request to brainstorm their ideas in response to the following question, “Based on your experiences of primary care, what things really stand out for you?” Primary care was defined as where most people go first for medical help and advice when they have a health problem, and provided by health care professionals, like family doctors, nurses or nurse practitioners, pharmacists or emergency services staff. The question was neutrally framed by design, such that either positive or negative experiences of primary care might emerge. Patient Advisory members were asked to spend about 10 minutes on the task and write down as many things that came to mind in response to this question. They were invited to a teleconference to share their ideas with the group approximately two weeks later. For those unable to attend, an opportunity to provide their thoughts through individual telephone calls with the first author prior to the scheduled teleconference was offered. With permission, these members’ primary care experiences were shared with the rest of the Patient Advisory during the group teleconference.

The teleconference was led by the first author and facilitated by the second author. The first author has a PhD in psychology and over eight years' experience working within large, multi-stakeholder primary care research teams that all included patient and public involvement members. She joined the research team after the Patient Advisory had been recruited, did not know any of the members prior to working on the project, and the teleconference was her first interaction with the Patient Advisory. The first and second author worked together to ensure equal opportunity of patient voices throughout the teleconference.

Using the Nominal Group Technique[23] implemented with a teleconference platform[25], each Patient Advisory member was asked to provide one idea at a time, in round-robin fashion, until there were no more new ideas to share. In line with NGT, patients were asked to first briefly describe the ideas that they had in response to the question, "what things really stand out for you in primary care?" Further explanation and discussion by the entire group followed after all ideas had been listed. The principal investigator (RL) took detailed notes throughout the teleconference, which were emailed to the Patient Advisory the following day for their review. No identifiers were used in the notes, since the aim was to record the raw list of ideas from the entire group.

Based on the teleconference notes, the first author consolidated the raw list of brainstormed ideas. Common elements were grouped thematically into topics. A heading for each topic was constructed with a short phrase in lay language to reflect the underlying theme of the collection of examples and experiences raised by the patients. The specific patient examples and experiences were additionally provided in bullet form below each topic heading. After an initial discussion with the second and last author, the topic list was refined and then emailed to the

Patient Advisory. The Patient Advisory was asked to review the list of topics ahead of an in-person priority setting workshop, to ensure it reflected the teleconference discussion accurately.

## Consultation and (Interim) Prioritization phases

### *Interim priority setting workshop*

Three and a half weeks after the teleconference, a full-day, in-person priority setting workshop with the Patient Advisory was held in Vancouver, BC. The purpose of the workshop was, firstly, to review, discuss, revise, and agree on the list of the patient-generated primary care topics that emerged out of the teleconference (Consultation phase), and then to have the patients individually rank the top 10 most important topics ((Interim) Prioritization phase). Similar to the methods used by Broerse and colleagues [13], we decided in advance that 10 topics would be a manageable number to carry forward for patients and primary care providers to rate in an online survey. Collectively, this constituted the remaining steps of the NGT process, which followed from the initial stages conducted during the teleconference.

To arrive at a final, agreed upon list of primary care topics, the Patient Advisory was asked to review the topics and consider: (1) the suitability of the topic label wording, (2) whether any topics were missed from the teleconference or new ideas had emerged since that discussion, and (3) whether any additional topics should be separated out from the patient examples and/or whether two or more topics could be grouped together. These points were discussed for each topic in turn, making revisions on a projected screen in real time during the workshop.

Once the list of primary care topics was finalized, the group moved on to the second task of the workshop – ranking the topics in terms of their importance. The final topic list was distributed to the Patient Advisory, who were then asked to privately choose the 10 topics that were most important to them personally. Personal importance could also include thinking about how the issues might affect other people they were close to (e.g., family, friends). A recording sheet was provided for patients to arrange their top 10 topics in terms of 1=*Most important* to 10=*Least important*. Ties were not permitted. In line with NGT methods, patients were asked to complete this task silently and on their own, and they were given as much time as needed. The first author checked the ranking sheets for completeness as they were collected.

The first author entered the patient-ranked data into an Excel spreadsheet, and then reverse scored the data, such that 10=*Most important* and 1=*Least important*. Following the steps outlined in McMillan et al.[24], results were pooled by first creating a sum of scores for each topic, which indicated its ranked priority or strength of vote score[26], and then calculating the proportion (%) of scores ranked within the top 10 topics, which indicated relative importance [27]. In order to resolve ties, a third method of tabulating the ranks involved counting the number of times each topic was ranked within the top 10 across patients, which is an indication of topic popularity[24,26]. The data were then sorted according to their ranked priority, yielding the top 10 topics that the project would carry forward in the remaining project activities.

### *Exploration phase (part 2) - Rapid literature reviews*

Rapid literature reviews were carried out for English language publications from 2008-2018, reporting research conducted within BC and Canada on each of the 10 patient-identified primary care topics. This information was used to inform the Integration phase and future development of research questions, but we do not report results herein. This reflects a divergence from the Dialogue Model, in which we carried out rapid literature reviews after the Consultation phase, instead of within the Exploration phase. This modification was made to provide input to contextualize what research had already been conducted within Canada. Within the Dialogue Model, literature reviews may be undertaken for scoping purposes, and to directly shape subsequent activities within the model, such as we chose to do.

## Prioritization phase

### *Topic importance surveys*

Online surveys were administered province-wide to capture BC patients' and primary care providers' importance ratings of the top 10 topics. Both stakeholder groups were asked to rate each topic individually from 1=*Not at all important* to 5=*Very important*. The topic heading, along with 2-4 bullet points of examples and experiences (from the Patient Advisory) to illustrate the topic, were included to mitigate misunderstanding and misinterpretation of the topic heading. Participants were asked to *rate* rather than *rank* the identified topics, so that we could understand which topics were closely clustered with respect to importance, and not just overall rank order. A freetext box was provided for any comments respondents wished to submit. Following the importance ratings, several socio-demographic questions were included in the surveys (Supplementary file 1). Completion of the online survey implied consent, which was outlined on the information landing page for the survey.

### Survey participants and recruitment

We recruited survey respondents using multiple online dissemination channels, such as social media (Twitter, Facebook), e-newsletters, emails, snowballing and notices posted on several websites. We also included a one-time classified ad in 31 local newspapers in small BC communities and offered telephone completion as an alternative to the online survey. Due to time and budget constraints, the surveys were only provided in English. The sole inclusion criterion was that patients and providers must be living in BC to complete the survey.

### Analysis of survey data

We report means and standard deviations of importance ratings among patients and providers. Future analyses will explore differences in the ratings by patient and provider characteristics.

### *Horizon scanning survey*

A third survey with BC researchers was included for horizon scanning purposes; namely, to capture any past, ongoing, or upcoming (in the next 12 months) research on the 10 primary care topics. This complements the rapid literature reviews, but it also enabled us to capture research that had not been published, completed or for which funding has recently been secured. As with the literature reviews, this information was used to inform the Integration phase and future development of research questions, but we do not report results herein.

## Integration phase

### *Patient, provider, researcher and policymaker dialogue event*

A final dialogue event brought patients and primary care providers together to share the survey results, and to engage in a facilitated discussion about areas of concordance and dissimilarity in the results. Patients included the Patient Advisory and others recruited to enhance the representativeness of minority populations (e.g., Indigenous peoples and newcomers to the province). We recruited a diverse mix of primary care providers, including GPs, nurses, nurse practitioners, and pharmacists.

The aim of the event was to gain a better qualitative understanding of the general perspectives of patients and primary care providers with respect to the quantitative survey results, rather than to achieve consensus on the top primary care topics for the two stakeholder groups, as in the Dialogue Model. We think it is more imperative to understand where and how patient and provider perspectives might differ, rather than try to bring the views of a small subgroup of patients and primary care providers together.

A parallel discussion was additionally held with researchers and policymakers at the dialogue event. These stakeholders also discussed the survey findings, but the focus was on how these results might be translated into future research and their policy implications. Findings from this event will be reported elsewhere.

# RESULTS

## Patient Advisory characteristics

In total, 11 members (8 female, 3 male) were recruited to the Patient Advisory between March and May 2017. Of these, 10 were recruited through recruitment advertisements placed with Patient Voices Network BC. A total of 3 males and 12 females replied to these ads, and we chose 3 males and 7 females. An eighth female member was recruited from another study to ensure equal representation across the five regional health authorities in the province. However, one female patient resigned at the start of the PREFeR Project and did not provide any input to the project. The final 10 Patient Advisory members (7 female, 3 male) were characterized by a mix of socio-demographic characteristics, including ethnic minority backgrounds, speaking multiple languages, born outside of Canada or the province, and representation from all five health authorities (Table 1). In line with the recruitment strategy, 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). Some had recovered from very severe, life-threatening health conditions (e.g., cancer), while others had only minor needs for episodic care. The group were predominantly employed (7/10, 70%), well educated (BSc, BA, teacher's college or higher university degree: 6/9, 67%), and were considered 'experienced' (e.g., members of three or more research committees/organizations, patient partners in other studies, research participant involvement, etc.) in terms of previous research involvement (6/9, 67%). The group did not know each other before joining the Patient Advisory, and the PREFeR project was the first task the Advisory worked on collectively.

**Table 1.** Characteristics of British Columbia Primary Health Care Research Network Patient Advisory (n=10). All values reported are N(%), unless otherwise specified.

| | N (%) |
|---|---|
| Age in years (M, SD)[1] | 48.4 (13.9) |
| Age range in years | 24-67 |
| Sex | |
| Female | 7 (70) |
| Male | 3 (30) |
| Ethnicity[1] | |
| White only | 3 (33) |
| Indigenous | 2 (20) |
| Any other background | 4 (40) |
| Language(s) spoken[1] | |
| English only | 5 (56) |
| Multiple languages | 4 (44) |
| Employed | |
| Yes | 7 (70) |
| No | 3 (30) |
| Highest education level[1] | |
| Trade or non-University certificate/diploma, community college, University certificate below BA | 3 (33) |

| | |
|---|---|
| BA, teacher's college or higher | 6 (67) |
| Country of birth[1] | |
| Canada | 8 (89) |
| Outside Canada | 1 (11) |
| Years living in BC[1] | |
| 0-5 | 2 (22) |
| 6-15 | 1 (11) |
| More than 15 years | 6 (67) |
| Regional Health Authority[2] | |
| Vancouver Coastal Health | 5 (50) |
| Vancouver Island Health | 2 (20) |
| Fraser Health | 1 (10) |
| Interior Health | 1 (10) |
| Northern Health | 1 (10) |
| Previous research involvement[1,3] | |
| None | 1 (11) |
| Moderate | 2 (22) |
| Experienced | 6 (67) |

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[1] Data available for 9 of the 10 Patient Advisory members.

[2] There are five regional Health Authorities in British Columbia.

[3] Moderate = 2-3 years of researcher/research participant experience and/or patient partner on >2 committees/studies; Experienced = >3 years of researcher/research participant experience and/or patient partner on >3 committees/studies.

## Brainstorming primary care experiences

Two (1 male, 1 female) Patient Advisory members were unable to attend the primary care experiences teleconference in September 2017, and so their ideas were shared via a telephone call with the first author in advance. In total, these and the remaining eight Patient Advisory members (2 male, 6 female) provided 82 experiences and examples of what stood out for them in primary care in BC. There was considerable overlap in these primary care experiences, which were initially grouped into 19 themes by LE, MM, and RL (Supplementary file 2 column 1).

## Interim priority setting workshop

Nine (2 male, 7 female) of the 10 Patient Advisory members attended the in-person priority setting workshop in Vancouver, Canada in September 2017. The researcher-proposed 19 primary care themes were reviewed, discussed, and revised (Supplementary file 2, column 2; topic headings and full set of illustrative bullet points are also provided in Supplementary file 2). No additional themes were added, but 14 of the topic headings were changed and two of the researcher-suggested topics (*Impact of a new diagnosis, Care of chronic conditions*) were combined to form a single patient-revised topic (*Support for living with chronic conditions*). In total, 18 final topics were retained from the first part of the workshop.

Patients selected and then ranked the 10 most important topics for themselves and in consideration of their social network. The raw rankings were followed by methods of tabulating the final ranked priority topics (via scores and votes), which included the sum of scores across patients, ranked priority via scores, relative importance, ranked priority via relative importance, and the number of votes (Supplementary file 3). There were some tied ranks, which were resolved by the number of votes. For example, *Accessing care when and where patients need it* and *Support for living with chronic conditions* were tied for fourth place, but the access-related topic received more votes overall, and so retained the higher priority position. There was consensus within the team that the top 10 topics captured the most important ideas.

## Survey participant characteristics

Between February and May 2018, 464 patients and 173 primary care providers living and working in BC completed the survey. As shown in Table 2, the majority of both patients and providers were female and of White ethnicity. The proportion of patient survey respondents from the five regional health authorities was closely aligned with 2017 provincial population estimates for Vancouver Coastal Health and Vancouver Island Health (provincial estimates: 24.6% and 16.5%, respectively), but there was over-representation from Interior and Northern Health (provincial estimates: 15.7% and 5.8%, respectively) and under-representation from Fraser Health (provincial estimate: 37.5%)[28].

Primary care providers from Interior Health authority were over-represented, constituting over half of all respondents. Providers were fairly evenly distributed between primary care physicians, nurses, and all other providers such as pharmacists, physical and occupational therapists, and social workers.

**Table 2.** Characteristics of patients and primary care providers completing the online survey. All values reported are N(%).

| | Patients (n=464) | Providers (n=173) |
|---|---|---|
| Age | | |
| Under 40 years | 123 (26.5) | - |
| 40-59 years | 158 (34.0) | - |
| 60+ years | 152 (32.7) | - |
| Sex | | |
| Female | 368 (79.3) | 130 (75.6) |
| Male | 77 (16.6) | 35 (20.4) |
| Ethnicity | | |
| White only | 366 (78.9) | 130 (75.1) |
| Mixed or any other background | 74 (15.9) | 22 (12.7) |
| Regional health authority[2] | | |
| Vancouver Coastal Health | 108 (23.3) | 23 (13.3) |
| Fraser Health | 97 (20.9) | 19 (11.0) |
| Vancouver Island Health | 70 (15.1) | 16 (9.3) |
| Interior Health | 129 (27.8) | 99 (57.2) |
| Northern Health | 47 (10.1) | 5 (2.9) |
| Provincial Health Services Authority | | 9 (5.2) |
| Type of provider | | |
| Family doctor | - | 52 (30.1) |

| | | |
|---|---|---|
| Nurse | - | 52 (30.1) |
| Other primary care provider[3] | - | 10 (5.8) |
| Community-based/allied workers[4] | - | 38 (22.0) |
| Hospital-based only, including consultants | - | 21 (12.1) |

---

[1] Figures do not always sum to 464 and 173 (100%), due to no response/system missing, 'prefer not to answer', 'don't know', or 'other' responses.

[2] There are five regional Health Authorities in British Columbia.

[3] Other primary care providers included pharmacists, midwives, or any other primary care provider other than family doctors and nurses.

[4] Community-based/allied workers included social workers, care aides, etc.

## Survey topic importance ratings

Comparing between patient and provider topic importance mean ratings, all 10 topics were rated highly by both groups (between 4="Important" and 5="Very important") (Table 3). Among both patients and providers, the top-ranked topic was *Unable to find a regular family doctor or other primary health care provider*. Among patients, the next six topics (*Support for chronic conditions*, *Information sharing (including EMR)*, *Mental health resources*, *Access to care when/where needed*, *New models of healthcare*, and *Improve continuity/coordination*) were all similarly rated (means 4.41 to 4.52). The same six mid-ranked topics were similarly clustered for providers, although there was a wider range of average ratings (means 4.27 to 4.53). The final three lower-ranked topics were still equivalent to the "Important" category, on average. Therefore, there were more similarities than differences between the rank ordering of topics for patients and providers.

**Table 3.** Mean (standard deviation) importance ratings of primary care topics listed in order of mean patient ratings

| Primary care topics | Patients (n=464) | Providers (n=173) |
|---|---|---|
| 1) Unable to find regular family doctor/other primary health care provider | 4.64 (0.76) | 4.59 (0.76) |
| 2) Support for living with chronic conditions | 4.52 (0.75) | 4.36 (0.88) |
| 3) Information sharing, including EMR | 4.52 (0.76) | 4.29 (0.91) |
| 4) Mental health resources | 4.51 (0.81) | 4.53 (0.77) |
| 5) Accessing care when and where patients need it | 4.46 (0.78) | 4.27 (0.85) |
| 6) New models of primary care that include other HCPs | 4.44 (0.83) | 4.30 (1.03) |
| 7) Improving continuity and coordination | 4.41 (0.81) | 4.31 (0.85) |
| 8) Improve and strengthen patient-provider communication | 4.21 (0.92) | 4.03 (1.05) |
| 9) Challenges in small towns/cities and remote areas | 4.18 (0.99) | 4.18 (0.92) |
| 10) Care guided by patient needs, values, preferences, and priorities | 4.09 (1.02) | 3.95 (1.07) |

EMR = electronic medical record; HCPs = health care professionals. The 10 topics were each rated on a scale from 1 (*Not at all important)* to 5 (*Very important)*.

# DISCUSSION

Involving patients in setting priorities for primary care research is feasible, fruitful and important to patients, but it is rare. This paper outlines the key activities of the PREFeR Project, which are framed within the Dialogue Model, and reports the processes and results from the priority setting exercises. A group of 10 patients from all five regional health authorities in the province were recruited as patient partners to a Patient Advisory group. Using the Nominal Group Technique, over 80 experiences of what stood out for them in primary care were generated. After grouping these into 18 common themes, the top 10 ranked topics were retained for rating in a province-wide survey for patients and primary care providers. The most highly rated topics for both patients and providers were about being unable to find regular family doctor/other primary health care provider, support for living with chronic conditions, information sharing, including EMR, and mental health resources. In fact, the mean ratings and rank ordering of the topics were similar for both stakeholder groups.

The 10 priorities originally identified by the Patient Advisory align fairly well with some recent priority setting initiatives in the province. The BC Ministry of Health recently identified eight service delivery priorities for the province’s health system in 2014[29]. These were re-confirmed at the primary care level by the BC-PHCRN research, clinical, and policy leads in 2015[21], but no patients were involved in this process. There is considerable overlap between the previous BC-PHCRN priorities and those reported herein, although there were two uniquely-identified Patient Advisory priorities that were not advanced by either the BC Ministry of Health or BC-PHCRN: *Mental health resources* (albeit, access to specialist treatment, in general, was mentioned by both organizations, and reducing demand on hospitals by improving care for those with mental health and substance use issues was one of five strategic priorities for the BC Ministry of Health in 2017[30]) and *Improve and strengthen patient-provider communication*. There were also examples where patient perspectives added depth and context. While both sets of priorities spoke to the need to address challenges specific to rural and remote settings, patients highlighted that transportation needs to be considered, and privacy and stigma may impact those in rural areas. The previous BC-PHCRN priorities included the need to enhance access, utilization, and continuity of patient information with other providers and levels of care, but patients spoke more directly to the need for electronic health records and the ability to access their medical records themselves. Finally, while the previous priorities noted issues around workforce planning, patients framed this as being unable to find a regular doctor or other primary health care provider. This highlights the value of including patients directly in setting priorities for primary care, and is another demonstration of how the priorities of patients and other stakeholders might differ.

The Dialogue Model, coupled with the Nominal Group Technique, was a useful framework for identifying patient priorities for primary health care research. This model has been used for agenda setting in many condition-specific populations, such as burns, diabetes, kidney disease, cystic fibrosis, dementia, bipolar disorder[1], but PREFeR is the first instance of primary care priority setting with a generic population that we are aware of. That said, the five phases of the Dialogue Model were modified substantially to address the aim of PREFeR, which explicitly focuses on patient priorities. Consistent with Canada's Strategy for Patient Oriented Research, the Patient Advisory members were research partners in PREFeR and contributed to planning and shaping the research activities. Their dual role as research participants and team members means that, to some degree, we shifted control and power to patients within the process, which is inconsistent with the Dialogue Model. This was implemented in a context where policymakers, clinicians, and researchers had previously worked to identify priorities in the absence of patients. Perspectives from these other stakeholder groups were, however, gathered and compared to patient priorities, albeit later in the project. In the end, these aligned quite closely, though patients identified some additional priorities and added additional context and depth to existing ones. In addition, the language used in the final topics was agreed on by patient team members, although different terminology may be more common among researchers.

Another notable divergence is that we identified *topics* for future research, rather than specific research questions. The top-rated topics are broad, and many reflect priorities for health system change that may be informed by research, but are not themselves research questions. Results from rapid literature reviews of the 10 topics, along with results from the 'horizon scanning' survey with BC researchers relating to completed, current or upcoming research on the 10 topics, will provide valuable information about the nature and extent of research on the topics. In some cases, the topics may suggest a need for strengthened knowledge translation or implementation science to inform changes to policies or service delivery rather than additional research. Also, as the searches covered broad topics, but were limited to BC and Canada, we recommend that more thorough reviews should be conducted that are specific to any future research objectives.

The main strengths of the current research are the contribution and partnership of patients in the priority setting exercises, using a structured framework to shape the research activities, and the volume of patients and providers completing the online surveys. However, there are several notable limitations to our approach. Although the initial priorities were developed by a group of patients purposively recruited to maximize diversity with regard to gender, ethnicity, prior research experience, health region and health issues, they were mostly well educated and had previous experience with research, and we cannot claim to have reached saturation in possible topics. We also decided to limit the subsequent survey to 10 topics in order to make the online surveys more manageable. We did not directly solicit additional topics from survey respondents, and there are undoubtedly topics of high priority to patients missed in this process. Given the survey was conducted predominantly online and largely distributed within networks related to health care and health research, respondents are unlikely to be representative of the province as a whole. This might affect the generalizability of these results.

This project demonstrates the feasibility of including patients in priority setting exercises and offers an approach that is workable within the context of primary care, rather than a condition-specific population. The identified topics overlap with, but expand on, previously identified priorities, and the patient and primary care provider surveys highlighted more alignment than divergence between these two stakeholder groups in rating the topics. Nevertheless, two novel topics addressing mental health resources and patient-provider communication were identified here, underscoring the importance of including patients in primary care priority setting. These results, coupled with those of the remaining activities in this project, will jointly provide key considerations for setting future primary care research questions.

## Acknowledgements

We are grateful to the 10 BC-PHCRN Patient Advisory members (Yaron Butterfield, Regina Cid, Chad Dickie, Penny Henderson, Brenda Jagroop, Ravin Johl, Kent Cadogan Loftsgard, Marilyn Parker, Hayley Pelletier, and one other who wished to remain anonymous) for volunteering their time, openly sharing their experiences, and contributing so valuably to PREFeR. We thank the BC SUPPORT Unit for in-kind support and helping to publicize this study. The Patient Voices Network assisted with recruiting the Patient Advisory. The BC-PHCRN generously provided support to PREFeR, both administratively and through engagement with the Patient Advisory. The Centre for Health Services and Policy Research provided in-kind support through salary for a project coordinator. Additional co-investigators who contributed to this project: Dr Sabrina T. Wong, Dr Kim McGrail, Dr Rita McCracken, Dr Vanessa Brcic, and Victoria Schuckel.

# Footnotes

## Author Contributions

LE and MRL designed and led all phases of the project. Specific to the results reported in this paper, LE facilitated the priority setting exercises, thematically grouped the primary care experiences into topics, carried out the priority setting data entry and rankings, and drafted this paper. MRL is the PI for the PREFeR Project, oversaw all phases of the project, and contributed feedback to this paper. MRL and MM recruited the Patient Advisory members. MM led early engagement with the Patient Advisory, oversaw all administrative activities for and helped facilitate the priority setting exercises, and provided feedback on this paper. YB, RJ, KCL, HP are members of the BC Primary Health Care Research Network Patient Advisory and patient partners in PREFeR who provided feedback on this paper, as well as contributing to all aspects of the priority setting exercises reported herein. CMcG provided background information and training on research to the Patient Advisory, provided additional support at the priority setting workshop, and commented on this paper.

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## Competing interests

None declared.

## Ethical approval

Ethics approval advice was sought and was deemed not required by the Simon Fraser University Research Ethics Board for the Consultation and Exploration phases of the project involving the Patient Advisory. Since research team members belonged to two different institutions, harmonized ethical approval was jointly granted by the Simon Fraser University and the University of British Columbia Research Ethics Boards for the topic importance surveys (Reference number 20018s0051).

## Data sharing

Online survey data from 464 patients and 173 primary care providers, anonymously provided, which includes ratings of the importance of the top 10 patient-generated primary care topics. Data are available from Ruth Lavergne (Email: ruth_lavergne@sfu.ca).

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## Figure Legend

Figure 1. Flowchart of key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

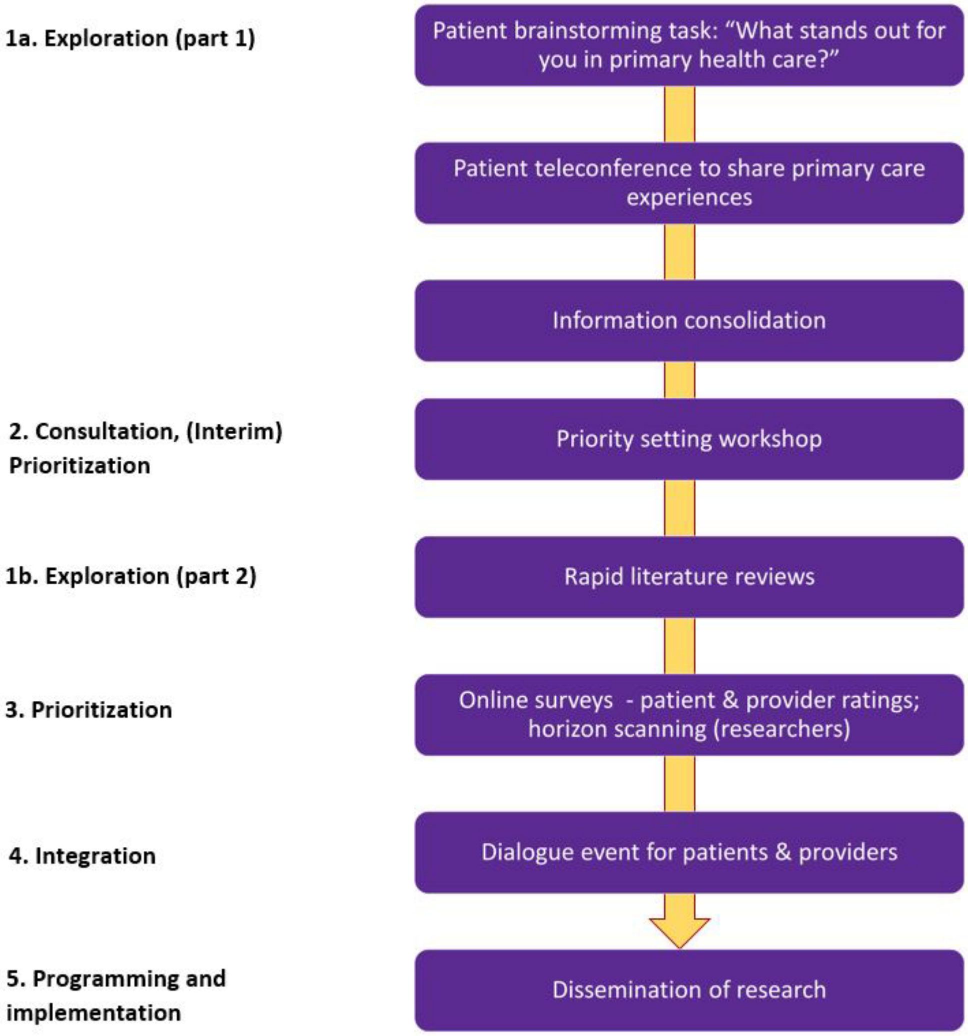

Figure 1. Flowchart of key activities of the PREFeR Project, framed within the five phases of a modified Dialogue Model

## Online survey questions – Patient version

[Page 1 questions] **How important are these topics to you?**

Below are the 10 topics that have been identified by patients as primary health care priorities, which could be developed into more specific research questions.

It is important that everyone understands what each topic means in a similar way. For this reason, we include some statements or experiences from patients that help illustrate each topic. These examples are listed as bullet points under each topic.

When we use the term *primary health care provider*, we mean health care professionals, such as family doctors (GPs), nurses, and nurse practitioners.

- **After you have read all of the bullet points under each general topic, please rate EACH of the following 10 topics in terms of how important they are to you as a patient.**
- This may include how important they are to you personally, as well as how they affect people who are important to you (your friends and family members).
- Please rate each topic on its own. It is fine to use the same rating for more than one topic.

**How important are each of these topics to you on a scale from *Not at all important* to *Very important*?**

### 1) Unable to find a regular family doctor or other primary health care provider

*Example statements or experiences:*

- Not all patients are able to find a primary health care provider accepting patients
- Patients find it hard to get the care they need without a consistent primary health care provider (e.g., family doctor)

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

### 2) Improve and strengthen communication between patients and primary health care providers

*Example statements or experiences:*

- Identify strategies to help health care providers understand the concerns, priorities and/or symptoms that patients are trying to communicate

- Find ways to improve decision-making that is shared between patients and primary health care providers
- Find solutions to problems caused by language and communication barriers

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

### 3) Mental health resources

*Example statements or experiences:*

- Limited or no availability of resources for mental health, addictions and substance use needs through primary care
- Gap between primary care and specialist services
- It is common for people to experience mental health issues at the same time as they are also experiencing physical health conditions, and this situation is poorly managed

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

### 4) Support for living with chronic conditions

*Example statements or experiences:*

- Limited time in appointments to manage chronic conditions
- It can be difficult to find a family doctor if patients are perceived to have 'complex' conditions
- Without a family doctor, there is no support for management of a chronic disease (e.g., getting repeat prescriptions)
- Continuity of care is essential when living with a chronic disease
- Clear communication about what patients can expect and what should happen next is needed, especially because there can be long periods of time between appointments

| 1 | 2 | 3 | 4 | 5 | 6 |
|---|---|---|---|---|---|
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 5) Accessing care when and where patients need it

*Example statements or experiences:*

- Few options exist for after-hours care (outside of normal working hours, weekends)
- Patients weigh convenience of walk-in clinics and easier access to emergency departments over the desire to see a regular doctor
- There is a need for care in patients' homes and long-term care

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 6) Improving continuity and coordination

Example statements or experiences:

- Need for primary health care providers to coordinate care (i.e., communicate with specialists, organize care between hospital and community)
- Problems accessing primary health care providers make it difficult to maintain continuity with the same health care professional
- Lack of consistency when seeing multiple health care professionals with different levels of expertise

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 7) New models of primary care that include other health care professionals

*Example statements or experiences:*

- Need for a community of health care professionals (e.g., nurse practitioners, pharmacists, etc.) that takes advantage of their full expertise
- Need for better collaboration and cooperation among health care professionals and health disciplines
- Need for other options to access primary care services that do not require an in-person visit with a family doctor (e.g., prescription renewals)

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 8) Information sharing, including electronic medical records

*Example statements or experiences:*

- The lack of coordinated information sharing between health care professionals means re-telling health 'story' repeatedly
- Treatments/information given may not always be communicated between health professionals and across settings, including walk-in clinics, home-care, hospital
- Patients are unable to access their own medical records
- Patient should not need to manage communication among their health care providers

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 9) Care guided by patient needs, values, preferences, and priorities

*Example statements or experiences:*

- A variety of treatment options should be explained and offered, including non-drug alternatives
- More holistic approach needed, where the whole person is treated, not just whatever particular body part/system is 'ill'
- Find ways to meet individual patients' expectations for information, especially in the context of widespread access to online information

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## 10) Challenges in small towns/cities and remote areas

*Example statements or experiences:*

- Less choice and availability of primary care providers, and less access to specialists and diagnostic testing
- Transportation needs before/after care must be considered
- Privacy/stigma issues may significantly impact those in rural areas (e.g., prescription pick-up)

| | | | | | |
|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 |
| ○ | ○ | ○ | ○ | ○ | ○ |
| Not at all important | Slightly important | Moderately important | Important | Very important | Don't know/Not applicable |

## Please use this space if you have any comments you'd like to share:

[Page 2 questions]

# General information about you

In order for us to better understand possible differences between groups of people in ratings of primary health care topics, please complete the following anonymous information about yourself. It is important for us to have an accurate understanding of who is completing these surveys, but we will not be able to identify you from your answers.

1. **How old are you?**
   - ○ Under 20 years
   - ○ 20-29 years
   - ○ 30-39 years
   - ○ 40-49 years
   - ○ 50-59 years
   - ○ 60-69 years
   - ○ 70-79 years
   - ○ 80-89 years
   - ○ Over 90 years
   - ○ Prefer not to say
2. **How do you describe yourself?**
   - ○ Male
   - ○ Female
   - ○ Transgender
   - ○ Do not identify as female, male, or transgender
   - ○ Prefer not to say

3. **You may belong to one or more racial or cultural groups on the following list. Are you... ? (Check ALL that apply.)**

   ○ White

   ○ Chinese

   ○ Aboriginal (First Nations, Métis, or Inuit)

   ○ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)

   ○ Black

   ○ Filipino

   ○ Latin American

   ○ Southeast Asian (e.g., Cambodian, Indonesian, Laotian, Vietnamese, etc.)

   ○ Arab

   ○ West Asian (e.g., Afghan, Iranian)

   ○ Japanese

   ○ Korean

   ○ Other, please specify:_______________________________________________

   ○ Prefer not to say

4. **What is the name of the town or city you currently live in?** ______________________
   *NB: If you live in more than one place, please put the place you live the majority of the time.*

5. **What are the first 3 digits of your postal code?** ______________________
   *NB: We cannot identify where you live from this information, but it allows us to know roughly where people completing the survey live.*

   *NB: If you live in more than one place, please put the place you live the majority of the time.*

6. **How many years have you been living in BC?**
   If you moved away and came back to BC, we are interested in the number of years you have been living in BC since returning to BC most recently.

   ○ I live outside of BC

   ○ 0-2 years

   ○ 3-5 years

   ○ 6-10 years

   ○ 11-15 years

○ More than 15 years

**7. What is your marital status?**

○ Single/never legally married

○ Married

○ Living common-law

○ Separated, but still legally married

○ Divorced

○ Widowed

○ Prefer not to say

**8. What is your highest level of education?**

○ Some elementary/junior school, but not all grades completed

○ Completed elementary/junior school

○ High school (secondary school) diploma or certificate

○ Trade certificate or diploma from a vocational school or apprenticeship training

○ Non-university certificate or diploma from a community college, CEGEP, school of nursing, etc.

○ University certificate below bachelor's level

○ Bachelor's degree or teacher's college (e.g., B.A., B.A. (Hons.), B.Sc., B.Ed.)

○ University degree or certificate above bachelor's degree (e.g., M.A., M.Sc., M.B.A., M.D., Ph.D.)

○ Other, please specify:_______________________________________

○ Prefer not to say

**9. Last week, was your main activity working at a paid job or business, looking for paid work, going to school, caring for children, household work, retired or something else?**

○ Working at a paid job or business

○ Vacation (from paid work)

○ Looking for paid work

○ Going to school (including vacation from school)

○ Caring for children

○ Household work

○ Retired

○ Maternity/paternity leave

○ Long-term illness

○ Volunteering

○ Care-giving other than for children

○ Other (please specify):____________________________________

○ Prefer not to say

**10. What kind of housing do you currently live in?**

○ Owned house, duplex or townhouse (not including motorhome)

○ Owned apartment or condominium

○ Owned motorhome

○ Rented house, duplex or townhouse

○ Rented apartment or condominium

○ Assisted-living (community group housing)

○ Other, please specify:_____________________________________________

○ Prefer not to say

**11. Do you currently have any of the following long-term health conditions? We are interested in "long-term conditions" which are expected to last or have already lasted 6 months or more and that have been diagnosed by a health professional. (Check ALL that apply.)**

○ Asthma

○ Chronic bronchitis, emphysema or chronic obstructive pulmonary disease or COPD

○ Arthritis (for example, osteoarthritis, rheumatoid arthritis, gout or any other type, excluding fibromyalgia)

○ Back problems, excluding scoliosis, fibromyalgia and arthritis

○ Mood disorder (such as depression, bipolar disorder, mania or dysthymia)

○ Anxiety disorder (such as a phobia, obsessive-compulsive disorder or a panic disorder)

○ Diabetes

○ Osteoporosis

○ High blood pressure

○ High blood cholesterol or lipids

○ Heart disease

○ Stroke

○ Cancer

○ Alzheimer's Disease or any other dementia

○ Other, please specify:_____________________________________________

○ None of these

○ Prefer not to say

**12. Do you have a regular health care provider in BC? By this, we mean one health professional that you regularly see or talk to when you need care or advice for your health.**

○ Yes ○ No

**a. What is the reason why you do not have a regular health care provider?**

○ Do not need one in particular, but you have a usual place of care

○ No one available in the area

○ No one in the area is taking new patients

○ I have not tried to find one

○ Had one who left or retired

○ Other (please specify):__________________________________________

## Researcher-suggested primary care topic headings compared to patient-revised topic headings

| Researcher-proposed topic headings | Patient-revised topic headings |
|---|---|
| 1) More patient-centred care needed | 1) Care guided by patient needs, values, preferences, and priorities |
| 2) Communication – Informing/empowering patients | 2) Informing and empowering patients |
| 3) Improving patient-provider communication | 3) Improve and strengthen communication between patients and primary health care providers |
| 4) Electronic Medical Records (EMR)/information sharing | 4) Information sharing, including electronic medical records |
| 5) Resources to better manage one's own health | 5) Resources to better manage one's own health |
| 6) Prevention/early intervention | 6) Prevention/early intervention |
| 7) Inability to access regular family doctors (GPs) | 7) Unable to find a regular family doctor or other primary health care provider |

| | |
|---|---|
| 8) Inadequacy of walk-in clinics | 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service) |
| 9) Accessing after-hours care | 9) Accessing care where and when patients need it |
| 10) Access to specialist knowledge | 10) Access to specialist knowledge |
| 11) Impact of a new diagnosis | 11) Support for living with chronic conditions |
| 12) Care of chronic conditions | |
| 13) Accessing mental health resources | 12) Mental health resources |
| 14) Challenges in small towns/cities | 13) Challenges in small towns/cities and remote areas |
| 15) Patient stigma | 14) Addressing stigma and bias |
| 16) Gaps in clinical evidence/information | 15) Knowledge gaps in clinical evidence and information |
| 17) Broaden roles for other health care professionals | 16) New models of primary care that include other health care professionals |
| 18) Inefficient practices put pressure on the system | 17) Improving continuity and coordination |

| | |
|---|---|
| 19) No universal drug plan | 18) No universal drug plan |

## Patient-revised topics and full list of bullet point examples and experiences from the interim priority setting workshop

### 1) Care guided by patient needs, values, preferences, and priorities

- “Block and tackle” approach to protecting territory (i.e., using defensive/offensive tactics), rather than patient-centred care
- Care needs to keep pace with patients’ expectations for information, especially in the context of widespread access to online information
- Need to embark on a journey of discovery with the patient
- Role of primary care provider is to be a coordinator of care in a team-based setting
- More holistic approach needed, where the whole body is treated, not just whatever particular part/system is ‘ill’
- Consideration of non-pharmacological options for treatment

### 2) Informing and empowering patients

- Information not explained to patient adequately
- Not all treatment options explained/offered, especially around alternative medicine
- Advice needs to be targeted in a way that patients know how to take action (don’t just give diagnosis)
- Information not clearly communicated to patients about how/why something being prescribed
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Resources patients are directed to need to be appropriate and available based on needs of the community (including low-income)
- Guidance on red flags and when to seek care
- Strategies to address/accept ‘new normal’ after a new diagnosis
- Shock of new diagnosis may impair understanding/ability to ask questions during initial consultation
- Understanding individual patient priorities for their care and targeting care appropriately

### 3) Improve and strengthen communication between patients and primary health care providers

- Patients may not describe underlying issue/relevant symptoms, but questioning could identify it
- Patients may not have time/ability to process information to ask all questions during a consultation
- Enhancing decision-making shared between patients and providers
- Addressing language barriers in care
- Use recap strategy to check understanding

### 4) Information sharing, including electronic medical records

- Lack of coordinated information sharing between health care professionals (especially health authorities) means re-telling ‘story’ repeatedly & treatments/information given may never be known between health professionals and across settings including walk-in clinics, home-care, hospital
- Patients unable to access own EMR including clinical notes
- EMR often not reviewed before patient appointment, which leads to gaps in care
- Pharmanet works well in transferring prescription information between health authorities, but medical records don’t similarly transfer
- Patient should not need to manage all of the communication within a care team
- Streamlined processes for patient-led consent and information sharing

### 5) Resources to better manage one’s own health

- No access to EMR including clinical notes
- Should be ability to access information without seeing PHC physician (e.g., patient portal, patient-led chronic disease programming)
- No resources to help understand what patients can do to manage their own health (knowing schedule for check-ups, screening etc.)
- Lack of patient knowledge of clinical guidelines
- Patients need help interpreting what is and what isn’t evidence-based
- Clarity needed around what to do when new to the province
- Need for centralized repositories with quality resources and programs available, including support groups

### 6) Prevention/early intervention

- Preventative medicine and lifestyle management not prioritized
- When, why and which health care professionals should do screening
- Lack of early interventions leads to poorer outcomes and higher cost down the road
- Roles for other professionals in preventative health care and lifestyle management

### 7) Unable to find a regular family doctor or other primary health care provider

- Weighing up convenience of walk-in over desire to see GP
- Places pressure on the emergency department
- Patients feel like a "product of the system"
- Hard to navigate healthcare system
- Receptionists act as gatekeepers (but without providing enough information)
- More students need to go into family practice
- Environmental/natural disasters impact patient health, which puts even further pressure on the system

### 8) Inadequacy of compensation model where doctors receive a set amount of money per visit (fee-for-service)

- Often not possible to discuss multiple, interrelated issues (chronic conditions)
- Encourages walk-in clinic practice which does not meet patient needs
- Walk-in clinics –line ups for appointments are for long periods (not suitable for some patients/weather) & waiting space isn't adequate
- Need research to understand how to most effectively compensate physician

### 9) Accessing care where and when patients need it

- Few options for after-hours care
- Need for care in home and long-term care
- Suitability of waiting space and physical design of clinics

### 10) Access to specialist knowledge

- Need for rapid access to specialist care for specific questions
- Processes to get specialist information that reduce need for face-to-face access to a specialist

- Need to keep patient in-the-loop on communication between primary care and specialists
- Direct access to specialists to answer a question

## 11) Support for living with chronic conditions

- No support for management of a chronic disease without a family doctor
- Family GPs refusing to accept patients with ‘complex’ conditions & ethics/implications of this
- Difficult to get repeat prescriptions filled without family GP
- Limited time with physician and nurse, especially with chronic conditions
- GPs could notify patients of support programs to help cope, including peer-to-peer support
- Some conditions cause cognitive difficulties (e.g., memory problems, difficulty processing or not correctly interpreting information)
- After a course of treatment, patient left somewhat alone dealing with side effects & feeling of being on own
- Can be long intervals between appointments & patient can ‘feel lost’ in this time interval
- Patient and doctor misconceptions likely with understanding condition/treatments
- Differentiation between chronic conditions and acquired conditions and recognition that there isn’t always a causal relationship between them
- Continuity of care is essential in the context of chronic disease
- Clear communication of prognosis and pathway of care going forward, including the spectrum of possibilities

## 12) Mental health resources

- Often limited or no availability of resources for mental health and substance use needs
- Gap between primary care and specialists services, particularly in the absence of a diagnosis
- Information needed on how to access mental health and substance use resources
- Primary care physicians (and Emergency doctors) not qualified to manage complex mental health needs, so patients access acute care more often
- Co-existence of mental health and physical conditions poorly managed

### 13) Challenges in small towns/cities and remote areas

- Primary care doctors need to do more, since there are fewer specialists in small towns/cities
- Transportation needs must be considered
- Improved access to specialists also needed
- Less access to diagnostic testing
- Less choice/availability for doctors/treatments, which has larger impact on ‘complex’ conditions
- Privacy/stigma issues in rural areas (e.g., prescription pick-up)

### 14) Addressing stigma and bias

- Cultural safety and competency
- Community sensitivities
- Care for LGBTQ communities
- Stigma particular to transgender community
- Assumptions made based on health condition/background/socioeconomic status
- Effects of terminology, diagnoses, etc.
- Impact of stigma and bias on patient outcomes

### 15) Knowledge gaps in clinical evidence and information

- Issues of consistency across doctors when seeing multiple providers and levels of expertise (of GPs)
- GPs appear uncertain of correct course of care, or reluctant to perform procedures (provide clinical ‘judgement’)
- Knowledge and application of clinical guidelines
- Continuing education for practicing professionals
- Need to study who responds, not just the treatments themselves
- Treatment recommendations need to be appropriate for/tailored to the needs of the community (including low-income)
- Speed of implementation of scientific research (17 years) needs to be improved
- Patients want new treatments now, even though full evidence base may not be there
- Patients aware of differences in treatments between provinces and countries and want access to full set of options
- Scientific/research models only useful insofar as they predict outcomes in the real world – Magnitude of effect needs to be considered

### 16) New models of primary care including other health care professionals

- Need for better collaboration and cooperation among health care professionals and health disciplines
- Expanded roles for other health care professionals
- Better support needed for caregivers and home support workers, including respite care

### 17) Improving continuity and coordination

- Care outside of office (long-term care, home care) and outside of office hours is needed to ensure continuity
- Reluctance to renew prescriptions for more than three months
- Unnecessary appointments required to access services (e.g. vaccinations, physiotherapists)
- New questions occur to patients after an appointment, but no one to ask/have to make a new appointment to have these questions answered
- Emergency respondents appear well-trained, but often involves 4-6 health professionals
- Patients discharged from secondary care without ensuring adequate services in place (transportation, clean/safe home, family pressure/stress)

### 18) No universal drug plan

- Patients' limitations, needs & affordability/financial issues must be taken into account
    – Some 'over-the-counter' products are cheaper
    – Patients may skip/halve medications (appear non-adherent, but can't afford 'as prescribed')
    – Lack of coverage for prescription drugs puts pressure on the system elsewhere
- Difficulties with pharmacies inputting out-of-province information (when new to BC)
- Education for primary care providers on cost of prescription drugs to guide prescribing decisions

## Patient-ranked raw scores (n=9) for primary care topics and methods of tabulating the top 10 priority topics

| Topic[1] | Ranked scores by patients[2] | | | | | | | | | Sum of scores | Ranked priority (via scores) | Relative importance (%)[3] | Number of votes | Final ranked priority (via scores & votes) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | | | | | |
| Care guided by patient needs, values, preferences, priorities | 7 | | 9 | | 10 | | 10 | 8 | 7 | 51 | 1 | 10.3 | 6 | 1 |
| Information sharing, EMR | 5 | 1 | 8 | 6 | 5 | | 7 | 6 | 8 | 46 | 2 | 9.3 | 8 | 2 |
| Unable to find a doctor | | 10 | 3 | | | 10 | 4 | 5 | 10 | 42 | 3 | 8.5 | 6 | 3 |
| Accessing care when, where needed | 9 | 7 | 4 | 3 | 2 | 8 | 3 | | 5 | **41** | **4** | **8.3** | **8** | **4** |
| Support for chronic conditions | | 8 | 1 | 8 | | 6 | 2 | 10 | 6 | **41** | **4** | **8.3** | **7** | **5** |
| Mental health resources | 8 | 4 | | 4 | 8 | 1 | | 3 | 9 | 37 | 6 | 7.5 | 7 | 6 |
| New models of primary care | 10 | | 6 | 2 | 7 | 9 | | | | 34 | 7 | 6.9 | 5 | 7 |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Improving continuity, coordination | | 6 | 5 | 9 | | 7 | | 2 | 4 | 33 | 8 | 6.7 | 6 | 8 |
| Challenges in small towns/cities | 2 | 5 | 7 | | | 5 | | 9 | 2 | 30 | 9 | 6.1 | 6 | 9 |
| Improve, strengthen patient-provider communication | 4 | | 2 | 7 | | 2 | 8 | 4 | | **27** | **10** | **5.5** | **6** | **10** |
| Informing, empowering patients | | | | 1 | 6 | 4 | 9 | 7 | | **27** | **10** | **5.5** | **5** | |
| Prevention/early intervention | 3 | | | | 9 | | 5 | | | 17 | | | 3 | |
| Inadequacy of compensation model | | 3 | 10 | | 3 | | | | 1 | 17 | | | 4 | |
| No universal drug plan | | | | 10 | 4 | | | | 3 | 17 | | | 3 | |
| Resources to better manage health | | 9 | | | | | 6 | | | 15 | | | 2 | |
| Knowledge gaps in clinical evidence | 6 | | | | 1 | | | 1 | | 8 | | | 3 | |
| Access to specialist knowledge | | | | 5 | | | 1 | | | 6 | | | 2 | |
| Addressing stigma and bias | 1 | 2 | | | | 3 | | | | 6 | | | 3 | |

EMR = electronic medical record. Bold values indicate topics with ties.

[1] Topic headings have been shortened here for presentation ease. Refer to Supplementary file 2, column 2 for full topic headings.

[2] Ranked scores have been reverse scored, where 1=Least important and 10=Most important.

[3] Relative importance = [(topic score) / (maximum points for the group; i.e., number of patients (9) x 55 points) x 100]. The total of 55 points is derived from the sum of the 10 ranks (1+2+3+4+5+6+7+8+9+10).

# Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

**Page/line no(s).**

## Title and abstract

| | |
|---|---|
| **Title** - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended | 1 |
| **Abstract** - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions | 3-4 |

## Introduction

| | |
|---|---|
| **Problem formulation** - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement | 6-8 |
| **Purpose or research questio**n - Purpose of the study and specific objectives or questions | 7-8 |

## Methods

| | |
|---|---|
| **Qualitative approach and research paradigm** - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale** | 11-13 |
| **Researcher characteristics and reflexivity** - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability | 11-12 |
| **Context** - Setting/site and salient contextual factors; rationale** | 11-13 |
| **Sampling strategy** - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale** | 9, 18 |
| **Ethical issues pertaining to human subjects** - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues | 32 |
| **Data collection methods** - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale** | 11-14, 21-22 |

| | |
|---|---|
| **Data collection instruments and technologies** - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study | 11-14 |
| **Units of study** - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results) | 18-21 |
| **Data processing** - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts | 11-14, 21-22 |
| **Data analysis** - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale** | 11-14 |
| **Techniques to enhance trustworthiness** - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale** | 12-13 |

**Results/findings**

| | |
|---|---|
| **Synthesis and interpretation** - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory | N/A |
| **Links to empirical data** - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings | Supp File 2 |

**Discussion**

| | |
|---|---|
| **Integration with prior work, implications, transferability, and contribution(s) to the field -** Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field | 26-29 |
| **Limitations** - Trustworthiness and limitations of findings | 29 |

**Other**

| | |
|---|---|
| **Conflicts of interest** - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed | 13-14, 27-28 |
| **Funding** - Sources of funding and other support; role of funders in data collection, interpretation, and reporting | 31 |

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388