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Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: A Qualitative Descriptive study of Barriers and Priorities for Patient-oriented Research

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Title

Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: a Qualitative Descriptive study of Barriers and Priorities for Patient-oriented Research

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Abstract

Objectives: The involvement of patients as partners in research is important to ensure that health research is relevant to patients. The aim of this study was to identify priorities for cardiovascular (CV) health research when working together with patients and clinicians - researchers.

Design: This qualitative descriptive patient-oriented research (POR) used participatory health research approach to work with participants in eliciting their priorities. Data collection were collectively analyzed. Participants also developed a plan for continued engagement to support POR in CV health research.

Setting: Libin Cardiovascular Institute of Alberta, Calgary, Canada.

Participants: A total of 23 participants, including patients and family caregivers (n=12), and clinicians and researchers (n=11)

Results: Participants identified barriers to CV POR (lack of awareness of the existence of POR and poor understanding on the role of patients) and ten research priorities for improving CV health. The CV health research priorities co-developed by participants included: (1) CV disease prediction and prevention; (2) Access to CV care; (3) Communication with providers; (4) Use of eHealth technology; (5) Patient experiences in healthcare; (6) Patient engagement; (7) Transitions and continuity of CV care; (8) Integrated CV care; (9) Development of structures for patient-to-patient support; and, (10) Research on rare heart diseases.

Conclusions: In this study research priorities for improving CV health were identified by patients, and their caregivers working together with clinicians and researchers. Future research programs and projects will be developed to address these priorities.

Keywords: patient oriented research, cardiovascular health, priority setting, patient engagement, research priorities

Strengths

- Patients and their caregivers identified barriers and facilitators to work as partners in health research
- Patients and their caregivers worked together with clinicians and researchers to identify priorities for cardiovascular health research
- This patient-oriented research used participatory action research to work with participants

Limitations

- The identified priorities may not be relevant to other cardiovascular patients in other healthcare organisations

Introduction

The patient is the only constant in the journey of care, the person who experiences both the processes and the outcomes of care. As users of the healthcare system, patients hold information that is vital for the improvement of delivery of care, system functions and health policies. Patient experience provides insights into patient needs, preferences, and values, which are valuable for organizational design and improvements.¹ Patient-oriented research presents an important opportunity towards building a collaborative model that involves patients in research programs to improve health and healthcare. Specifically, Patient-oriented research is conducted in multidisciplinary teams, working in partnership with all relevant partners including patients, family members and clinicians-researchers. It focuses on identifying patient priorities and applying the learnings to improve health and healthcare.¹⁻⁵

Cardiovascular disease is a leading cause of death of men and women in Canada and is associated with significant morbidity, disability, and hospitalizations.⁶ The past three decades have seen the introduction and application of many therapies for the prevention and treatment of cardiovascular disease.⁶⁻⁹ However, the experiences and outcomes from the patients’ perspective with cardiovascular disease remain to be optimized. Patient-oriented research offers new promise to increase the relevance of research and ultimately improve cardiovascular health and care to patients. This opportunity to gain an understanding of what matters to patients and to learn how patients’ priorities align with clinician-researchers in cardiovascular care could result in research and outcomes that are more relevant to both patients and clinicians.²⁻⁴

The ultimate goal of the study was to identify research priorities to improve cardiovascular health. Our study focused on capacity building for Patient-oriented research and explored how patients and clinician-researchers can become involved in bidirectional Patient-oriented research teams.

Methods

Study context

This qualitative descriptive study used a participatory health research approach to work with participants to elicit their top ten priorities for cardiovascular health. This study was informed by the Canadian Institutes of Health Research framework on Patient-oriented research.¹ This patient engagement framework was developed to support the design and conduct of Patient-oriented research projects, while establishing the structures to build collaborations with patients, family members, clinicians and researchers, in the identification of health research priorities.

We conducted a two-day workshop (figure 1), co-designed and co-led by a Patient Research Partner (SZ), who is one of the trainers for the national Canadian Institutes of Health Research-Strategy for Patient-Oriented Research Foundational Curriculum.¹ This train the trainer module teaches patients and researchers the concepts of patient-oriented research, Health Research and Team Building so that they can model and train other multi-disciplinary research teams about patient-oriented research concepts and strategies. Based on a participatory health research approach,¹⁰ we used this patient engagement process to guide the discussions and rank priorities (Figure 1).

This workshop occurred at the *Libin Cardiovascular Institute of Alberta* in Calgary,¹¹ Alberta in December 2017. The Institute serves and coordinates cardiovascular patient care, research and education for all of Southern Alberta, and Southeastern British Columbia (population of about 2 million). This Institute is both affiliated with the University of Calgary for academic activities and *Alberta Health Services*, the single provincial healthcare organization.

Sampling and participants

Recruitment of patients: We strived for a maximum variation including a diverse group of patients and family caregivers (diversity by age, sex, ethnicity, occupation, working status, cardiovascular condition and disease stage, rural and urban residence). Recruitment flyers were

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shared with healthcare providers, clinic managers at outpatient clinics and tertiary healthcare centers in Alberta, and the provincial *Strategy for Patient Oriented Research Unit*. Patients who expressed interest in attending the workshop were then contacted by the lead patient research partner (SZ) to start the engagement process. The lead patient research partner (SZ) had no personal relationships with the participants. During this first encounter she discussed with potential participants their expectations and consent. Patients and family members received a small honorarium for their participation in the workshop.

Recruitment of clinicians and researchers: Clinicians and researchers from the *Person to Population Cardiovascular Research Collaborative* at the Libin Institute were invited to participate. This group was established with the Libin Institute with the goal of improving and optimizing cardiovascular health in Alberta. This multidisciplinary team of more than 20 researchers and clinician-scientists have expertise in patient and family centred care, health services research, and cardiovascular care to catalyze patient-oriented research priorities. A formal invitation to participate in this patient-oriented research capacity building process was provided to the clinician-researchers accompanied by a brief description of the purpose and process of the workshop.

Theoretical framework: The theoretical principles guiding the development of this workshop are based on participatory health research, which has as its aim the engagement of citizens, specifically patients and other stakeholders. The Canadian Institutes of Health Research-Strategy for Patient-Oriented Research provides a foundational framework in the development of the workshop by ensuring that patients are involved throughout the research process. The level of patient and researcher engagement as per the framework was also presented to workshop participants, in order to set the stage for patient-oriented research² and build the foundation for patient-oriented research.

Process: The workshop was co-chaired by a patient-oriented research expert (MS) and a patient research partner (SZ). Patients co-designed and co-facilitated the workshop to other participants; patients identified top priorities for research; and patients were engaged throughout the workshop days on the development of a patient-advisory group. A participatory health research approach was used for involving patients in topic generation for patient-oriented research¹²⁻¹⁷ and was used to guide the discussions, vote and rank priorities.

These discussions included diverse stakeholders and all participants contributed equally to the discussion. It included five steps:

- 1) introduction to patient-oriented research;
- 2) all members individually identified barriers and facilitators to conducting patient-oriented research;
- 3) all members' point of views were discussed and barriers identified and recorded;
- 4) participants brainstormed to identify their top ten priorities;
- 5) all members voted and consensus was reached on their top ten priorities.

To describe the process, we will refer to these five steps.

Step 1. On day one, participants were introduced to patient-oriented research using patient engagement and capacity building frameworks provided by the Canadian Institutes of Health Research.² The workshop started with the introductions of each participant using an ice-breaker to create a comfortable environment and encourage group cohesiveness. The patient research partner (SZ) the patient-oriented research expert (MS) provided a presentation introducing participants to patient-oriented research and the different levels of patient engagement using a modified version of the International Association for Public Participation's Spectrum framework.¹³ For instance, patients could be 'consulted' when the researcher seeks their input on ad-hoc basis, or patients could 'collaborate' in the research project as an equal partner and be a member of the research team.

Step 2. After the presentations, participants were grouped in tables of five and each presented their views on how to operationalize patient-oriented research. They identified barriers and facilitators to patient-oriented research in cardiovascular research. Then, each participant's individual views were discussed at each table and presented to the entire group.

Step 3. Discussions on how patient-oriented research could be operationalized from all stakeholders' (patients, clinicians-researchers) points of views were encouraged. This led to the final identification of barriers and facilitators to patient-oriented research in cardiovascular research. Next, participants were separated during the brainstorming activity, which allowed for each group to identify

what cardiovascular research priorities mattered most to them. Clinician-researchers and patients were placed in separate groups for the initial brainstorming activity to allow for participants to become comfortable in sharing their views and identifying their top priorities.

Step 4. After discussion, each group was invited to present their priorities for a larger group discussion. Patients and clinician-researchers then came together to co-create a short presentation justifying their chosen priority. Specifically, one patient and clinician-researcher from each group work co-presented the priority to the larger group. Presentations focused on the importance, relevance and feasibility of the priority. Day-one then wrapped-up by reviewing the research priorities and merging similar priorities.

Step 5. On day two, the group proceeded with a ‘dotmocracy’ exercise to rank priorities.¹⁶⁻¹⁸ Dotmocracy is a participatory large group decision-making tool.¹⁶⁻¹⁸ This tool has been used in priority setting, particularly with large groups (20-30 participants) as a method to recognize points of agreement.¹⁶⁻¹⁸ Dotmocracy was chosen as a prioritization tool, as it has been used before with community members in other research projects of ours with success. This participatory tool engages patients in the research process, and as partners in research. Dotmocracy allows participants to be fully engaged in the research process, especially if they have not participated in research before.¹⁶⁻¹⁸ During this process, instructions were made clear to all participants to place one sticker per research priority, and each participant had a total of ten stickers. The priorities with the least number of stickers were considered of lower priority. After that, the top ten priorities were reviewed as a group and priorities that could be merged were discussed among participants.

To conclude day two of the workshop, the top ten priorities were presented back to the group for members to review. After this, then participants began to plan future steps, including developing a communication strategy (e.g., how to keep in contact), and establishing the degree of patient engagement and how it reflects on capacity building (following Canadian Institutes for Health Research-Strategy for Patient-Oriented Research Framework).¹ Finally, they determined a strategy to establish, evaluate progress, and assess the impact of an advisory panel on patient-oriented research for cardiovascular health.

Data collection

Materials for data collection included notes, flip charts, and videos. At the start of the workshop, barriers and facilitators to patient-oriented research were written on flip-charts and agreed upon by all participants. Throughout the workshop two note-takers observed and collected discussion points. Then, discussions around the top ten priorities were annotated onto the flip charts at each table, and later presented to the entire group. These presentations were also video-taped.

Data analysis

The notes were collectively analyzed by themes to identify the top areas of prioritization (SA, SZ, MS). Additionally, a summarized version of the top priorities was presented to the participants for members checking. We then reviewed the notes and flipcharts to ensure that no priorities were missed. Additionally, video-taped presentations and flip charts were reviewed by two members of the team (SA, SZ) to confirm results and describe the process in this paper. Comments made during the discussions were linked to the name of any individual participant. All notes and flipcharts were stored in the Principal Investigator's office, and on password protected computers.

Patient & Public Involvement: This is a patient-oriented research project, therefore patients and a patient research partner were involved throughout different stages of the project (design conception, data collection, data analysis, dissemination, etc).

Results

A total of 23 participants attended the workshop. There were 10 individuals (patients) with cardiovascular conditions. They ranged in age from 35 to 70 years old, and 50% were women. Their cardiovascular conditions included coronary artery disease, arrhythmias, heart transplants and congenital heart disease. Two spouses (ages 65 to 70 years) also participated. The seven clinicians (3/7 women) were physicians and nurses with specialties in cardiovascular care, endocrinology, nephrology, and internal medicine. Four participants were

health services researchers (3/4 women). Table 1 presents the barriers and solutions to patient-oriented research discussed by all participants.

Barriers to Patient-Oriented Research (POR)	Identified Solutions
Lack of awareness of the existence of POR	Building networks with patient and family advisors Reaching out to communities Connecting with healthcare providers Utilizing social media (e.g. Facebook®, Twitter®)
Lack of understanding of the role of patients – where do patients fit into health research?	Clear expectations and roles Including a protocol for conducting POR
Access/opportunities to participation in POR (distance, time)	Accommodating patient partners (i.e. using technology such as email, phone,

Table 1. Barriers and their associated solutions to patient-oriented research identified by patients, caregivers, and researchers.

	etc. to allow for virtual meetings)
Diverse backgrounds	Working together with a collaborative mindset Ensuring there is diversity (in education, ethnicity, age, working status, sex and gender) in your team to incorporate multiple perspectives

Identifying Research Priorities. Figure 2 presents the 13 preliminary priorities discussed by *patients and clinician-researchers*. Matched priorities emerged from discussions as common priorities to patients and clinician-researchers. These priorities were discussed and the top ten were selected.

The Top Ten Cardiovascular Research Priorities. Selected top priorities are presented in order of ranking in the following paragraphs; and summarized in Appendix 1 with selected quotes from participants that took place during the discussions. Furthermore, after the workshop clinician-researchers met and developed some questions to conduct future research based on these priorities, including “*How can we co-design tools with patients and caregivers to predict and communicate risk factors for cardiovascular disease?*” (see Appendix 1)

Prevention and Prediction – Patients discussed that despite adhering to recommendations they had preventing recurrent events, including heart attacks, they felt being provided with information on prevention was not enough. Participants identified research on prediction of future events important to better inform their conversations during clinical visits.

Access to Care- Accessing after regular hours care, waiting to see specialists, and access to care for patients living in rural communities were identified as patient priorities. Patients emphasized the importance of research focusing on providing care to underserved populations and improving quality of life and efficiency by addressing travel time for care.

Communication was highlighted as key to empowering patients to understand their condition, promote adherence to treatment, and ultimately improve health outcomes. Participants highlighted the importance on building trust through communication, not only providing information but also by ensuring that the patients understand the information.

e-Health Technology – the use of e-health technology was raised as a research priority by researchers, especially in the facilitation of communication between patients and healthcare providers.

Patient Experience – the focus was on understanding what was important to patients, the measurement of patient experiences and the development of strategies to address the needs of patients and caregivers.

Patient Engagement was identified as a pillar to support disease management and promote decision-making while improving care and patient outcomes. Participants discussed empowerment strategies to enhance engagement, including sharing information and opportunities to use information tools available to both patients and clinicians.

Transitions and Continuity of Care – Participants highlight the need for research on strategies to improve transitions and test interventions that will improve continuity of care.

Integrated Care – For patients, integrated care meant efficient and timely care, while for providers it implied safety and quality of care.

Patient to Patient Support – Peer support was identified as a priority and an opportunity to learn and find support from individuals that have common lived experiences.

Rare Heart Disease – Patients wanted to become their own advocates and particularly access specialists and knowledge when they had rare heart diseases.

At the end of the workshop, participants agreed on creating a patient advisory group to work together with clinician-researchers to improve cardiovascular health. The newly created group planned to meet quarterly during the year to further develop the projects based

on the identified priorities and to develop a plan to ensure future sustainability of the group, with the support of the Libin Institute¹¹ and through external funding sources (i.e., grants).

Discussion

This study described a Working Together workshop that included patients, clinicians and researchers. This group co-developed cardiovascular research priorities at a Canadian academic cardiovascular health research institute. These priorities are important to inform provincial programs for cardiovascular research, funding priorities, grant proposals and research projects to ultimately improve cardiovascular health of patients and communities.

The theoretical principles guiding the development of this workshop are of participatory health research,¹⁶⁻¹⁸ and our aim is to engage citizens, specifically patients and other stakeholders. The Canadian Institutes for Health Research-Strategy for Patient-Oriented Research¹ provides a foundational framework in the development of the workshop by ensuring patients are involved throughout the research process. The level of patient and researcher engagement framework was also presented to workshop participants, in order to set the stage for patient-oriented research² and build the foundation for patient-oriented research.

In cardiovascular health, Vandigo et al.¹⁹ examined a hypothetical example on how patients could be engaged in cardiovascular health research. However, in our study patients and clinician-researchers were engaged following a participatory health research approach, and supported by Canadian Institutes for Health Research frameworks, becoming one of the first studies conducted in cardiovascular health in Canada with patient engagement. Additionally, this study was led by a patient-partner trained by the recently developed Canadian Institutes for Health Research Foundational Curriculum, leveraging patient’s involvement and leadership in research activities. This research project will be useful to Canadian Institutes for Health Research as it contributes to the current knowledge on POR and provides an example of patient-oriented research for cardiovascular health.

We found that our identified priorities had a strong emphasis on patient-centred care, as depicted in Santana et al. framework²⁰ including access to care, communication, improving patient experiences, patient engagement, transitions and continuity of care, and integration of care. The impact of patient-centred care in priority setting has been noted in a few studies, for instance in developing research priorities for kidney disease.²¹ The findings of the kidney study²¹ were disease specific because the focus was on identifying priorities related to burden on symptoms and treatment, whereas in our study the focus was related to more general challenges of healthcare.

Prevention and prediction of cardiovascular disease was the top priority for both clinician researchers and patients/caregivers. Khan et al.²² found prevention and prediction to be a top research priority in their priority setting exercise. However, the rest of the priorities reported in Khan et al.²² placed more of an emphasis on prioritization of lifestyle interventions, which were not identified by our group. Perhaps this difference is due to the different focus of our study as we were identifying overall and general healthcare priorities of patients, rather than focusing on a specific condition. However, participants voiced their willingness to be involved in all aspects of their care and were interested in the development of e-health solutions that could help to predict cardiovascular disease.

Our findings of improved access to care for individuals in rural settings is in line with findings from other patient priorities exercises in health research.²³

Recently, several approaches have emerged in an attempt to guide patient engagement. However, to date, there is no one formula on how to conduct patient-oriented research.^{12,17,22-29} We framed the workshop according to the methods for engaging patients in topic generation for research, ranking priorities in a large group setting, and dotmocracy. Dotmocracy has been identified as one of the four methods for priority setting by Ontario Health.¹⁶ Past studies have identified research priorities using diverse methods including the James Lind Alliance approach,¹² specifically in developing research priorities for prostate cancer,²⁹ hypertension management,²² and gestational diabetes mellitus.²⁸ Other approaches include the Delphi²⁹ and the nominal group technique.³⁰ Selection of methods depends on purpose of the study and diversity and size of participants.

The study limitation in conducting POR is related to the fact that the two groups (patient-caregiver vs clinician-researcher) are not accustomed to working together, it is possible that they inhibited or censored themselves in contributing the ideas. However, we tried to allow for the participants to know each other, starting with an ‘ice-breaker’ exercise and providing time for patients to identify barriers and generate ideas in their own way. Also, by working together in groups, patients and clinician-researchers were able to learn from each other and hear different perspectives. Participants were able to get an idea of what POR looks like, and how future partnerships can be developed. This workshop paved the way for a patient-advisory panel at the Libin Institute, led by one of the patients who attended the workshop.

Conclusion

In this study, we have explored patient-oriented research needs in Alberta for cardiovascular health research by engaging patients and clinician-researchers to establish a multidisciplinary team with an array of expertise and backgrounds. We also identified barriers to conduct patient-oriented research and discussed solutions. This process can inform the design of other patient-oriented research projects and enlighten high priority areas for future cardiovascular health research that is relevant to patients.

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Author Contributions

MS is the principal investigator. SZ is the patient-partner. MS and SZ conceived the idea and work on the manuscript supported by SB, HQ and the rest of the authorship. SA and CD supported the workshop working through the data. All authors reviewed the draft of the final version of the manuscript.

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Competing interest statement

There are no competing interests

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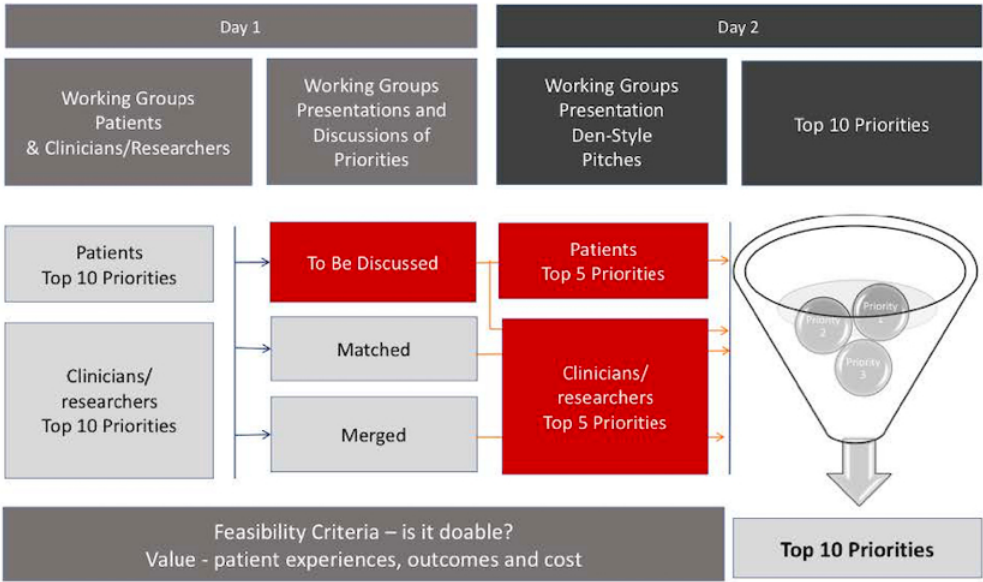


Figure 1. Overview of the Study: Identifying, Refining, and Ranking the Top Ten Priorities

Patient, Family Caregiver	Matched	Clinician-researchers
Access to Care	Continuity and Transitions of Care	Collecting and reporting of patient-reported outcome measures (PROMs) and patient reported experience measures (PREMs)
Integration of Care	Communication	Technology to predict and prevent cardiovascular disease
Experience of care	Tools to support shared decision making	Patient and caregivers' perceptions on the role of technology in patient engagement
Structure for patient-to-patient support and patient advocacy	Patient Engagement	
Rare heart disease	Prevention and Prediction	

Figure 2. Priorities for CVD research identified by patients, caregivers and clinicians and researchers.

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Appendix 1. Top research priorities, selected quotes from participants and identified research questions

Top Priorities (ranked from most important to least)	Selected Quotes	Research Questions
Prevention & Prediction	<p>"I have a family history of CVD, I know, and that's why I took care of it, why didn't work? The information I was given by the doctors was not enough, I followed it and I had another event...What else could I have done, I don't know, ... How do we find people that are at risk of having an event?"</p> <p>Patient</p>	<p>How can we prevent and predict CVD?</p> <p>What tools can be used to predict CVD?</p> <p>How can we co-design tools with patients and caregivers to predict and communicate risk factors for CVD?</p>
Access to Care	<p>"There is a way to make improvements to access to care in smaller communities... technology-like the choosing wisely Canada app - which is free and can help people become more educated about what they need" – Patient</p>	<p>How can we improve access to care?</p> <p>How can we access care in small rural communities?</p> <p>How can we create services in these rural underserved areas?</p>

		How can we improve access to specialist care for vulnerable populations?
Communication	<p>“My background is French and when I moved to Alberta, I was talking to people here in English... One thing that shocked me... People saying “I hear you”... but do you understand what I’m trying to share with you? ...”- Patient</p>	<p>How can we improve communication between patients and healthcare providers across healthcare sectors?</p> <p>How can we develop a trusting relationship with healthcare providers?</p> <p>How we can improve information sharing across healthcare sectors?</p> <p>How can we use healthcare information solutions to aid communication in a timely manner?</p>
E-Health technology	“Saving time, saving travel, can occur outside office hours-improved	Does the use of eHealth technology improve access to care and

	flexibility, and not location specific” – Patient	<p>delivery of information to patients and providers across healthcare sectors?</p> <p>Does the use of eHealth technology facilitate communication of risk reduction to patients?</p> <p>What software can we develop to meet individual needs?</p> <p>How can healthcare systems integrate eHealth solutions?</p>
Patient experiences	How can we improve experiences with CVD care? Can we learn from other models of care? What are the gaps, what is feasible and responsive to patient’s needs”- Researcher	<p>What is important to patients and caregivers?</p> <p>How to improve patients’ experiences</p> <p>What measures can be used to capture the patient experience?</p> <p>Strategies to report patient reported experience measures to</p>

		patients, caregivers, and healthcare professionals What strategies address the needs of the patients and families?
Patient Engagement	“My empowerment has come little by little every year from individuals who would take time to listen to me and my family”- Patient	How can we engage patients in self-management and decision making?
Transitions and continuity of care	“for us, follow up and transitions of care was not good. I tried getting in touch with a family doctor after discharge from the hospital. I could not get past the receptionist...I tried to get in touch with the cardiologist assigned to him - ‘no I’m sorry you can see him in 3 months’-”- Family caregiver	How can we improve transitions and continuity of care? How can we involve patients and caregivers? How do we co-design transition models of care with patients and caregivers? What are the gaps in current transition models, and how can they be addressed?

Integrated Care	“Can we learn from the pediatric model and transfer it over to the adult care model?”- Researcher	How do we ensure care is coordinated and located in one setting? What can we learn from pediatric care?
Patient to Patient Support	“What we hope the pairing will do is that questions and answers can be given from one patient to the other because we know that the biggest barrier to a successful outcome is the patient’s fear”- Patient	Does the creation of a network of patient support improve health and healthcare? Does the creation of support systems and advocacy improve patients’ experiences with CVD?
Rare Heart Diseases	“It was the scariest part of my life & my family’s life to entrust the specialist and rehab facilities with my life because we didn’t know, if tomorrow I would be here. So we entrust them - their knowledge and their power, but they don’t have access to the information - why can’t we find others out there who would be willing to find out information about rare heart diseases”- Patient	How can we improve the understanding of patients’ experiences with rare heart diseases? How can we individualize care for patients with rare heart diseases? How can we improve knowledge on rare heart diseases?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 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	1,2,5
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4 Purpose of the study and specific objectives or questions	4
Qualitative approach and research paradigm	#5 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	5

recommended; rationale. 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.

Researcher characteristics and reflexivity	#6	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	5,6
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5,6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6,17
Data collection methods	#10	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	9
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	9
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	9

1	Data analysis	#14	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	9
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6	Techniques to enhance	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation);	9
7	trustworthiness		rationale	
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11	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and themes);	9-16
12	interpretation		might include development of a theory or model, or integration with prior research or theory	
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17	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	10-13
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21	Intergration with prior	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge	16
22	work, implications,		conclusions of earlier scholarship; discussion of scope of	
23	transferability and		application / generalizability; identification of unique	
24	contribution(s) to the field		contributions(s) to scholarship in a discipline or field	
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29	Limitations	#19	Trustworthiness and limitations of findings	16
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31	Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	17
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35	Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	17
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40 Medical Colleges. This checklist can be completed online using <https://www.goodreports.org/>, a tool made by
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Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: a Qualitative Descriptive study of Barriers and Priorities for Patient-oriented Research

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Title

Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: a Qualitative Descriptive study of Barriers and Priorities for Patient-oriented Research

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Abstract

Objectives: The overall goal of this study is to identify priorities for cardiovascular (CV) health research that are important to patients and clinician-researchers. To achieve this objective we brought together a group of cardiovascular patients and clinician-researchers new to Patient Oriented Research (POR), to build a multi-disciplinary POR team and form an advisory committee for the Libin Cardiovascular Institute of Alberta.

Design: This qualitative descriptive POR used a participatory health research paradigm to work with participants in eliciting their priorities. Data collection were collectively analyzed. Participants also developed a plan for continued engagement to support POR in CV health research.

Setting: Libin Cardiovascular Institute of Alberta, Cumming School of Medicine, University of Calgary, Canada.

Participants: A total of 23 participants, including patients and family caregivers (n=12) and clinician-researchers (n=11).

Results: Participants identified barriers and facilitators to POR in CV health (lack of awareness of POR and poor understanding on the role of patients) and ten research priorities for improving CV health. The CV health research priorities include: (1) CV disease prediction and prevention; (2) Access to CV care; (3) Communication with providers; (4) Use of eHealth technology; (5) Patient experiences in healthcare; (6) Patient engagement; (7) Transitions and continuity of CV care; (8) Integrated CV Care; (9) Development of structures for patient-to-patient support; and, (10) Research on rare heart diseases.

Conclusions: In this study, research priorities were identified by patients and clinician-researchers working together to improve CV health. Future research programs and projects will be developed to address these priorities.

Keywords: patient-oriented research, cardiovascular health, priority setting, patient engagement, research priorities

Strengths

- Patients and clinician-researchers identified barriers and facilitators to work as partners in health research
- Patients worked together with clinicians-researchers to identify priorities for health research
- This patient-oriented research used a participatory health research approach.
- The priorities will inform future research projects to improve cardiovascular health

Limitations

- The identified priorities may not be relevant to other cardiovascular patients in other healthcare organizations

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Introduction

The patient is the only constant in the journey of care, the person who experiences both the processes and the outcomes of care. As users of the healthcare system, patients hold information that is vital for the improvement of delivery of care, system functions and health policies. Patient experience provides insights into patient needs, preferences, and values, which are valuable for organizational design and improvements.¹ Patient-oriented research presents an important opportunity towards building a collaborative model that involves patients in research programs to improve health and healthcare. Specifically, Patient-oriented research is conducted in multidisciplinary teams, working in partnership with all relevant partners including patients, family members and clinicians-researchers. It focuses on identifying patient priorities and applying the learnings to improve health and healthcare.¹⁻⁵

In the last few years, efforts have been made to support patient and public engagement in health research to and within the healthcare system. In the United Kingdom, INVOLVE⁶ (involve.uk), is a charity that supports research that involves patients and public in health research with the vision to democratize research, while the American Patient-Centered Outcomes Research Institute (PCORI)⁷ is a non-governmental organisation (pcori.org) that supports and funds research to improve healthcare decisions for patients, caregivers, clinical specialists, employers, insurers and policymakers. In Canada, the Strategy for Patient-Oriented Research (SPOR)¹ a coalition of federal, provincial, and territorial partners focuses on including the patient voice into the research process and incorporated into healthcare policy and practice. In Canada, and in patient-oriented research, the term ‘patient’ refers to an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.¹

Cardiovascular disease is a leading cause of death of men and women in Canada and is associated with significant morbidity, disability, and hospitalizations.⁸ The past three decades have seen the introduction and application of many therapies for the prevention and treatment of cardiovascular disease.⁸⁻¹¹ However, the experiences and outcomes from the patients’ perspective with cardiovascular disease remain to be optimized.^{12,13} Patient-oriented research offers new promise to increase the relevance of research and ultimately improve cardiovascular health and care to patients.

This opportunity to gain an understanding of what matters to patients and to learn how patients' priorities align with clinician-researchers in cardiovascular care could result in research and outcomes that are more relevant to both patients and clinicians.²⁻⁴

The ultimate goal of the study was to identify CV health priorities while building bidirectional POR partnerships in cardiovascular health and form an advisory consul to support future POR at the Libin Cardiovascular Institute of Alberta.¹⁴

Methods

Study context

This qualitative descriptive study used participatory health research¹⁵ as the paradigm that guides the research process in eliciting the top ten research priorities for cardiovascular health. Participatory health research guides the approach to engage the participants in the study in working together, recognizing the value of each person's contribution to generation of knowledge in a process that is practical, collaborative and empowering.¹⁶⁻¹⁸ By working together in identifying priorities, we collected our data and analysed it in a collaborative manner. Additionally, during the final step of this study, these identified priorities will be disseminated, by all members of the working together study, to key stakeholders who could act on the research priorities and improving CV health.

This study was guided by the Canadian Institutes of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR) Patient Engagement framework.¹ The patient engagement framework was developed to support the design and conduct of patient-oriented research projects, while establishing the structures to build partnerships with patients, clinicians and researchers, to work together in research.

We conducted a two-day workshop (Figure 1), co-designed and co-led by a patient-research partner (SZ), who is one of the trainers for the national CIHR SPOR Foundational Curriculum.¹ The foundational curriculum teaches patients and researchers the concepts of patient-oriented research, health research and team building so that they can work better together in a respectful and collaborative environment with researchers and policy makers. The leadership of a patient-partner

1 emphasized the important role that patients played in the workshop ensuring their voices were
2 heard, addressing potential power differentials that may occur. Based on the SPOR foundational
3 curriculum and participatory health research approach,¹⁶⁻¹⁸ we used a patient engagement process to
4 guide the discussions and rank priorities (Figure 1).
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10 This workshop occurred at the *Libin Cardiovascular Institute of Alberta* in Calgary,¹⁴ Alberta in
11 December 2017. The Institute serves and coordinates cardiovascular patient care, research and
12 education for all of Southern Alberta, and Southeastern British Columbia (population of about 2
13 million). This Institute is both affiliated with the University of Calgary for academic activities and
14 *Alberta Health Services*, the single provincial healthcare organization.
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22 Sampling and participants

23 *Recruitment of patients:* We strived for a maximum variation including a diverse group of patients
24 (diversity by age, sex, ethnicity, occupation, working status, cardiovascular condition and disease
25 stage, rural and urban residence). Recruitment flyers were shared with healthcare providers, clinic
26 managers at outpatient clinics and tertiary healthcare centers in Alberta, and the patient engagement
27 team at the provincial SUPPORT Unit. Patients who expressed interest in attending the workshop
28 were then contacted by the lead patient research partner (SZ) to start the engagement process,
29 discuss expectations and acquire consent. Informed, written consent was also obtained for both
30 workshop days. The lead patient research partner (SZ) had no personal relationships with the
31 participants. Patients were fully supported by ensuring that all out of pocket expenses were covered
32 and an honorarium was provided as a recognition for their time and participation in the workshop.
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43 *Recruitment of clinicians and researchers:* Clinicians and researchers from the *Person to Population*
44 *Cardiovascular Research Collaborative* at the Libin Institute were invited to participate. This group was
45 established with the Libin Institute with the goal of improving and optimizing cardiovascular health in
46 Alberta. This multidisciplinary team of researchers and clinician-researchers have expertise in patient
47 and family centred care, health services research, and cardiovascular care to catalyze patient-oriented
48 research priorities. A formal invitation to participate in this patient-oriented research study was
49 provided to the clinician-researchers accompanied by a brief description of the purpose and process
50 of the workshop.
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Theoretical framework: The theoretical principles guiding the development of this workshop are based on participatory health research, which has as its aim the engagement of citizens, specifically patients and other stakeholders. The CIHR SPOR Patient Engagement framework¹ helped in the development of the workshop by ensuring that patients are involved as equal partners throughout the research process. This framework is underpinned by four guiding principles of engaging patient in health research, including: 1) Inclusiveness – relates to integrating a diversity of patient perspectives; 2) Support – needs to be provided to patients to ensure meaningful discussions, establish safe environment and compensate financially for their work; 3) Mutual Respect - as patients bring to the research their own experiences and expertise. When working together, strategies need to be developed to ensure that all partners value each other expertise; 4) Co-Build – partnership develops as all individuals work together from the beginning to identify barriers and facilitators, set priorities for research and develop knowledge translation plans. The framework was presented to workshop participants, to set the stage for POR¹ and build the foundation for working together.

Process: The workshop was co-designed and co-facilitated by POR experts; an academic researcher (MS) and patient research partner (SZ). This partnership helped to model and set the stage for participants to learn about POR, discuss potential barriers and facilitators to POR, identify top priorities for CV research, and work together on the development of a CV advisory committee. A participatory health research approach was used for involving all stakeholder partners in topic generation for POR¹⁶⁻¹⁸ and was used to guide the discussions, vote and rank priorities. Plan to address disagreement was in place - any disagreements were discussed by the group until consensus was reached.

These discussions included diverse stakeholders and all participants contributed equally to the discussion. It included five steps:

- 1) Introduction to patient-oriented research
- 2) Identify barriers and facilitators to conducting POR
- 3) Identify patient and clinician-researcher cardiovascular and vote on priorities
- 4) Presentations and discussions of top 10 priorities
- 5) Next steps

To describe the process, we will refer to these five steps.

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2 Step 1 - On day one, the workshop started with the introductions of each participant using an ice-
3 breaker to create a comfortable environment and encourage group cohesiveness. In addition, a set of
4 rules on mutual respect and collaboration were presented to the group and displayed on the white
5 board throughout the workshop. The co-facilitators (MS, SZ) provided a presentation introducing the
6 group to POR using the CIHR framework on Patient Engagement.¹ Specifically, there was an emphasis
7 on the four guiding principals and the importance of everyone bringing valuable expertise to the
8 working group. Additionally, the different levels of patient engagement using a modified version of
9 the International Association for Public Participation’s Spectrum framework¹⁸ were presented. For
10 instance, patients could be ‘consulted’ when the researcher seeks their input on ad-hoc basis, or
11 patients could ‘collaborate’ in the research project as an equal partner and be a member of the
12 research team. After the presentation, questions addressed points on power differentials, reinforcing
13 the notion of co-building and mutual respect.
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26 Step 2 - Then participants were grouped in tables of five to discuss and document on flip chart papers
27 the potential barriers and facilitators to conducting POR. This step was crucial in setting the stage for
28 partnership building, as participants reflected on their concerns for POR, and how they could address
29 those concerns. At each table a volunteer served as chair to monitor discussions, ensuring everyone
30 was heard, and another individual annotated the topics discussed and presented to the entire group
31 for final discussions. Participants discussed how POR could be operationalized. As the discussions
32 progressed, data was collected in large flip charts stuck to the walls. Then, after all the barriers and
33 facilitators were identified by the group, the data collected were presented & discussed together to
34 reach the final group of barriers and facilitators. Participants were encouraged to deal with
35 disagreement while working in groups. In case of disagreement, discussion continued until agreement
36 was achieved. This step led to the final identification of barriers and facilitators to patient-oriented
37 research in cardiovascular research.
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50 Step 3 - Participants were separated for a brainstorming activity to identify what cardiovascular
51 research priorities mattered most to them. Clinician-researchers and patients were placed in separate
52 groups for the initial brainstorming activity to allow participants to be comfortable in sharing their
53 views and perspectives while identifying CV priorities. This allowed for each group to freely discuss
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and decide on CV priorities based on their expertise and experiences. Each table had a volunteer that chaired the discussions and another individual that presented the priorities to the larger group. Flip charts were used to collect this data, and all together the priorities were analyzed. In order to reach consensus from the 23 attendees, dotmocracy was used to narrow down to 10 priorities.¹⁹⁻²¹

Dotmocracy is a participatory large group decision-making tool.¹⁸⁻²⁰ This tool has been used in priority setting, particularly with large groups (20-30 participants) as a method to recognize points of agreement.¹⁹⁻²¹ Dotmocracy was chosen as a prioritization tool, as it has been used before with community members in other research projects of ours with success. This participatory tool engages patients in the research process, as partners in research. Dotmocracy allows participants to be fully engaged in the research process, especially if they have not participated in research before.¹⁹⁻²¹ During this process, instructions were made clear to all participants to place one sticker per research priority, and each participant had a total of ten stickers. The priorities with the least number of stickers were considered of lower priority. Then, the top ten priorities were reviewed ensuring that the group felt that what was important to them, was addressed in the top ten priorities. Before adjourning the meeting, a brief introduction to Day-2 was provided.

Step 4 - On day 2, patients and clinician-researchers worked together to co-create a short presentation focusing on the importance, relevance and feasibility of the chosen priorities. Ten teams including patient and clinician-researchers co-presented one of the top 10 priorities as a 'pitch' that follow the "Dragon's Den" format and these presentations were video recorded with their consent. This exercise enabled patients and clinician-researchers to work in partnership, co-designing and learning from one another. For example, some patients had difficulties in knowing the feasibility of conducting research for a specific priority, this provided the researcher an opportunity to help build their capacity by explaining the feasibility criteria and the steps that would need to be taken in order to conduct the research.

Step 5 - To conclude day-two of the workshop, the top ten priorities were presented back to the group for members checking. Then, the participants began to plan future steps, including the establishment of the advisory council to support future POR for CV health at the Libin Cardiovascular Institute of Alberta.¹⁴ The team worked also together in developing a communication strategy (e.g.,

1 how to keep in contact), and establishing the degree of patient engagement. Finally, the team worked
2 together in establishing a strategy to disseminate the findings of the study, evaluate progress and
3 assess the impact of the advisory council on POR for cardiovascular health.
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9 *Data collection*

10 Materials for data collection included notes, flip charts, and videos. At the start of the workshop,
11 barriers and facilitators to POR were written on flip charts and agreed upon by all participants.
12 Throughout the workshop two note-takers observed and collected discussion points to support
13 discussions when needed. Then, discussions around the top ten priorities were annotated onto the
14 flip charts at each table, and later presented to the entire group. Dragon-style presentations (i.e
15 pitches on priorities) were also video-taped.
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23 *Data analysis*

24 The notes were collectively analyzed by themes to identify the top areas of prioritization (SA, SZ, MS).
25 Additionally, a summarized version of the top priorities was presented to the participants for
26 members checking. We then reviewed the notes and flipcharts to ensure that no priorities were
27 missed. Additionally, after the workshop video-taped presentations and flip charts were reviewed by
28 two members of the team (SA, SZ) to confirm results and describe the process in this paper and in
29 other documents arising from this workshop. All notes and flipcharts were stored in the Principal
30 Investigator's office, and on password protected computers.
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40 Patient and Public Involvement: This is a POR project; as such patients and a patient-research partner
41 were involved throughout different stages of the project (design conception, data collection, data
42 analysis, dissemination).
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47 **Results**

48 A total of 23 participants attended the workshop. There were 10 individuals (patients) with
49 cardiovascular conditions. They ranged in age from 35 to 70 years old, and 50% were women. Their
50 cardiovascular conditions included coronary artery disease, arrhythmias, heart transplants and
51 congenital heart disease. Two spouses (ages 65 to 70 years) also participated. The seven clinicians
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(3/7 women) were physicians and nurses with specialties in cardiovascular care, endocrinology, nephrology, and internal medicine. Four participants were health services researchers (3/4 women). Table 1 presents the barriers and solutions to patient-oriented research discussed by all participants.

Table 1. Barriers and their associated solutions to patient-oriented research identified by patients & clinician-researchers.

Barriers to Patient-Oriented Research (POR)	Identified Solutions
Lack of awareness of the existence of POR	Building networks with patient and family advisors Reaching out to communities Connecting with healthcare providers Utilizing social media (e.g. Facebook®, Twitter®)
Lack of understanding of the role of patients – where do patients fit into health research?	Clear expectations and roles Including a protocol for conducting POR
Access/opportunities to participation in POR (distance, time)	Accommodating patient partners (i.e. using technology such as email, phone, etc. to allow for virtual meetings)
Diverse backgrounds	Working together with a collaborative mindset Ensuring there is diversity (in education, ethnicity, age, working status, sex and gender) in your team to incorporate multiple perspectives

Identifying Research Priorities

1 As depicted in Figure 1, participants worked independently in groups by patients and clinician-
2 researchers to identify their top 10 priorities. Then all of these priorities were discussed and classified
3 into three groups (displayed in Figure 2), including 5 priorities from patients, 5 common priorities to
4 both groups (matched) and 3 priorities unique to clinician-researchers. Then out of the other 8
5 priorities, three were merged. Merged priorities included: patient experiences (from patients) merged
6 with patient-reported experiences and outcomes (from clinician-researchers) and three priorities
7 (tool to support decision-making, technology to predict and prevent cardiovascular disease, and
8 patient and caregivers' perceptions on the role of technology in patient engagement) merged into
9 priority 4 – e-health technology. *Matched priorities* emerged from discussions as common priorities to
10 patients and clinician-researchers. These priorities were discussed and the top ten were selected.
11 No disagreement were encountered throughout the workshop, as each priority was discussed among
12 the group.

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25 *The Top Ten Cardiovascular Research Priorities*

26 Selected top priorities are presented in order of ranking in the following paragraphs; and summarized
27 in Appendix 1 with selected quotes from participants to further illustrate the discussions that took
28 place during the priority setting exercise. Furthermore, after the workshop clinician-researchers met
29 and developed some questions to conduct future research based on these priorities, including “*How*
30 *can we co-design tools with patients and caregivers to predict and communicate risk factors for*
31 *cardiovascular disease?*” (see Appendix 1) These questions were presented to the patient advisory
32 council and have been used as research questions for grant proposals.

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42 **Prevention and Prediction** – Patients discussed that despite adhering to recommendations they had
43 preventing recurrent events, including heart attacks, they felt being provided with information on
44 prevention was not enough. Participants identified research on prediction of future events important
45 to better inform their conversations during clinical visits.

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51 **Access to Care**- Accessing after regular hours care, waiting to see specialists, and access to care for
52 patients living in rural communities were identified as patient priorities. Patients emphasized the
53 importance of research focusing on providing care to underserved populations and improving
54 quality of life and efficiency by addressing travel time for care.

Communication was highlighted as key to empowering patients to understand their condition, promote adherence to treatment, and ultimately improve health outcomes. Participants highlighted the importance on building trust through communication, not only providing information but also by ensuring that the patients understand the information.

e-Health Technology – the use of e-health technology was raised as a research priority by researchers, especially in the facilitation of communication between patients and healthcare providers.

Patient Experience – the focus was on understanding what was important to patients, the measurement of patient experiences and the development of strategies to address the needs of patients and caregivers.

Patient Engagement was identified as a pillar to support disease management and promote decision-making while improving care and patient outcomes. Participants discussed empowerment strategies to enhance engagement, including sharing information and opportunities to use information tools available to both patients and clinicians.

Transitions and Continuity of Care – Participants highlight the need for research on strategies to improve transitions and test interventions that will improve continuity of care.

Integrated Care – For patients, integrated care meant efficient and timely care, while for providers it implied safety and quality of care.

Patient to Patient Support – Peer support was identified as a priority and an opportunity to learn and find support from individuals that have common lived experiences.

Rare Heart Disease – Patients wanted to become their own advocates and particularly access specialists and knowledge when they had rare heart diseases.

At the end of the workshop, participants agreed on creating a patient advisory council to work together with clinician-researchers to improve cardiovascular health. The newly created group

1
2 planned to meet quarterly during the year to further develop the projects based on the identified
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4 priorities and to develop a plan to ensure future sustainability of the group, with the support of the
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6 Libin Institute¹⁴ and through external funding sources (i.e., grants).
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9 **Discussion**

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13 This study described a Working Together workshop that included patients and clinician- researchers.
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15 This group co-developed cardiovascular research priorities at a Canadian academic cardiovascular
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17 health research institute. These priorities are important to inform provincial programs for
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19 cardiovascular research, funding priorities, grant proposals and research projects to ultimately
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21 improve cardiovascular health of patients and communities.
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24 The theoretical principles guiding of this workshop are of participatory health research,¹⁵⁻¹⁷ and
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26 underpinned in the four pillars of engaging patient in health research.¹ Inclusiveness was addressed
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28 by recruiting participants with diverse backgrounds, including patients with different cardiovascular
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30 conditions and clinician-researchers with different specialties. This diverse group allows that the
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32 priorities identified could be used in generic CV research projects (from hypertension, diabetes, heart
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34 failure to kidney failure and congenital heart disease). Support was offered to patients from the
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36 beginning of the project through discussions on their expectations, establishing a safe environment
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38 and compensating them financially for their time working together. While establishing a safe
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40 environment, a set of rules were presented at the start of the workshop, emphasizing mutual respect
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42 and ensuring that patients were equal partners in the process and all partners value each other
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44 expertise. Without creating the safe and collaborative environment, partnership will be difficult.
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46 Partnership is a key aspect of working together that was developed from the beginning throughout
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48 the workshop to identify barriers and facilitators, set priorities for research and co-build knowledge
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50 translation plans.

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52 In cardiovascular health, Vandigo et al.²² examined a hypothetical example on how patients could be
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54 engaged in cardiovascular health research. In contrast, in our study patients and clinician-researchers
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56 worked together during two-day workshop. A patient-partner and an academic led the workshop. This
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58 leadership was strategic to ensure that patients felt represented and heard throughout the process. In
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60 addition, the leadership of a trained patient-partner reflected the high level of engagement described

by the IAP2,¹⁸ leveraging patient's involvement and leadership in research activities.

We found that our identified priorities had a strong emphasis on patient-centred care, as depicted in Santana et al. framework²³ including access to care, communication, improving patient experiences, patient engagement, transitions and continuity of care, and integration of care. The impact of patient-centred care in priority setting has been noted in previous studies.²⁴⁻³⁷ However, most of these studies identified priorities related to burden on symptoms and treatment, whereas in our study the priorities were related to more general challenges of healthcare. Our findings addressed healthcare system issues such as patient-provider communication, while patients in dialysis prioritized itchiness as a burdensome symptom.

In a hypertension management project, Khan et al.²⁷ found alignment with our results, as prevention and prediction was a top research priority. However, while Khan et al's emphasized lifestyle interventions, our focus was on providing information to patients on how prevention strategies could predict another CV event. For instance, when patients follow all the prevention advice (lifestyle changes) that will predict the risk of preventing another heart attack. Moreover, Etchegar H et al.²⁸ in a Canadian setting conducted public consultations revealing priorities that aligned with our findings, including access to care in rural areas and prevention and health promotion.

Recently, several approaches have emerged in an attempt to guide patient engagement. However, to date, there is no one formula on how to conduct POR.^{2-4,17,22-38} The evidence is scarce on the process, best practices and evaluation of the engagement.^{2,4,33} Recent reviews revealed that patients are not meaningfully engaged.³¹⁻³³ We framed the workshop according to the methods for engaging patients in topic generation for research, ranking priorities in a large group setting, and dotmocracy. Dotmocracy has been identified as one of the four methods for priority setting by Ontario Health.²⁰ Other research priorities approaches includes the James Lind Alliance approach,³⁷ specifically in developing research priorities for prostate cancer³⁵, hypertension management,²⁷ and gestational diabetes mellitus.³⁴ Other approaches include the Delphi³⁰ and the nominal group technique³⁶. Selection of methods depends on the purpose of the study, diversity and size of participants. A recent review by Manafo et al.³⁸ described the levels of patient engagement in priority settings as tier 1 and 2, and highlight several ways to identify priorities emphasizing that 'one-size doesn't fit all.'

1 The study limitation in conducting POR is related to the fact that the two groups (patient and clinician-
2 researcher) are not accustomed to working together, it is possible that they inhibited or censored
3 themselves in contributing the ideas. However, we tried to allow for the participants to know each
4 other, starting with an 'ice-breaker' exercise, emphasizing respect, partnership and providing time for
5 patients to identify barriers and generate ideas in their own way. Also, by working together in groups,
6 patients and clinician-researchers were able to learn from each other, valuing their different
7 perspectives. Participants were able to get an idea of what POR looks like, and how future
8 partnerships can be developed. This workshop paved the way for a patient-advisory council at the
9 Libin Institute, led by one of the patients who attended the workshop.

19 **Conclusion**

22 This research project is one of the first Canadian studies identifying priorities in cardiovascular health.
23 In this study, first, we have explored POR needs in Alberta for cardiovascular health research by
24 engaging patients and clinician-researchers to establish a multidisciplinary team with an array of
25 expertise and backgrounds. Then, it identified barriers to conduct POR and discussed solutions. A key
26 output of this study is the creation of the patient advisory council that will provide support and will
27 work with clinician-researchers to improve CV health. Finally, this study can inform the design of
28 other POR projects and enlighten high priority areas for future cardiovascular health research that is
29 relevant to patients.

39 **Acknowledgements**

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46 **Author Contributions**

49 MS is the principal investigator. SZ is the patient research partner. MS and SZ conceived the idea and
50 drafted the initial manuscript. SA, CD, MTJ, SW, HQ, NF, TA, SB provided input on various drafts of the
51 manuscript. All authors provided important intellectual contribution and guidance throughout the

development of the manuscript. All of the authors (MS, SZ, SA, CD, MTJ, SW, HQ, NF, TA, SB) contributed to critical review and revisions to the manuscript, agreeing on the final version.

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Competing interest statement

There are no competing interests

Ethics approval: The study was approved by the University of Calgary Conjoint Health Research Ethics Board, REB17-0864

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

Patient consent for publication Not required.

Figure 1. Overview of the Study: Identifying, Refining, and Ranking the Top Ten Priorities
Figure 2. Priorities for CVD research identified by patients, caregivers and clinicians and researchers.

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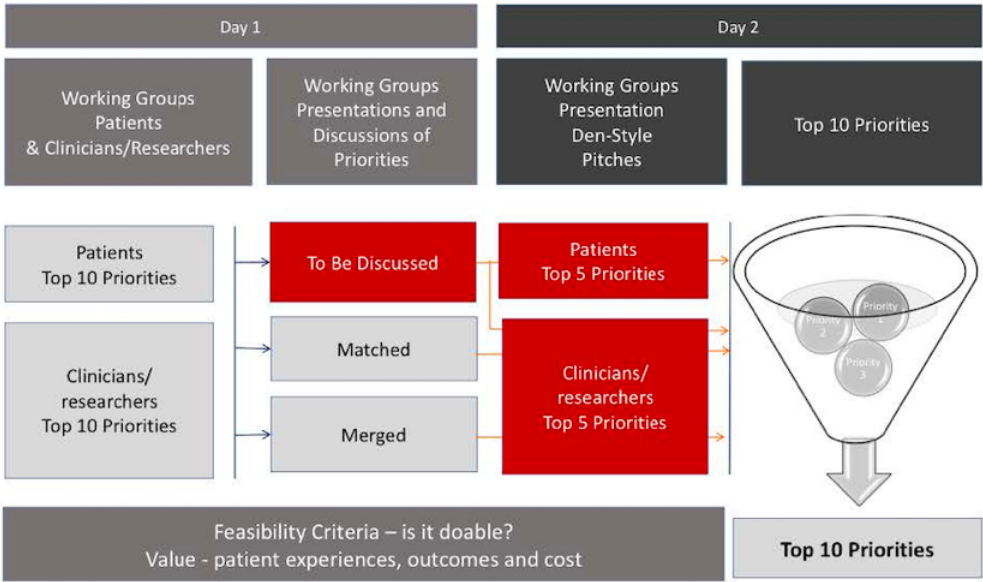


Figure 1. Overview of the Study: Identifying, Refining, and Ranking the Top Ten Priorities

Patient, Family Caregiver	Matched	Clinician-researchers
Access to Care	Continuity and Transitions of Care	Collecting and reporting of patient-reported outcome measures (PROMs) and patient reported experience measures (PREMs)
Integration of Care	Communication	Technology to predict and prevent cardiovascular disease
Experience of care	Tools to support shared decision making	Patient and caregivers' perceptions on the role of technology in patient engagement
Structure for patient-to-patient support and patient advocacy	Patient Engagement	
Rare heart disease	Prevention and Prediction	

Figure 2. Priorities for CVD research identified by patients, caregivers and clinicians and researchers.

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For peer review only

Appendix 1. Top research priorities, selected quotes from participants and identified research questions

Top Priorities (ranked from most important to least)	Selected Quotes	Research Questions
Prevention & Prediction	<p>"I have a family history of CVD, I know, and that's why I took care of it, why didn't work? The information I was given by the doctors was not enough, I followed it and I had another event...What else could I have done, I don't know, ... How do we find people that are at risk of having an event?" Patient</p>	<p>How can we prevent and predict CVD?</p> <p>What tools can be used to predict CVD?</p> <p>How can we co-design tools with patients and caregivers to predict and communicate risk factors for CVD?</p>
Access to Care	<p>"There is a way to make improvements to access to care in smaller communities... technology- like the choosing wisely Canada app - which is free and can help people become more educated about what they need" – Patient</p>	<p>How can we improve access to care?</p> <p>How can we access care in small rural communities?</p> <p>How can we create services in these rural underserved areas?</p> <p>How can we improve access to specialist care for vulnerable populations?</p>
Communication	<p>"My background is French and when I moved to Alberta, I was talking to people here in English... One thing that shocked me... People saying "I hear you"... but do you understand what I'm trying to share with you? ..." - Patient</p>	<p>How can we improve communication between patients and healthcare providers across healthcare sectors?</p> <p>How can we develop a trusting relationship with healthcare providers?</p>

		<p>How we can improve information sharing across healthcare sectors?</p> <p>How can we use healthcare information solutions to aid communication in a timely manner?</p>
E-Health technology	<p>“Saving time, saving travel, can occur outside office hours-improved flexibility, and not location specific” –Patient</p>	<p>Does the use of eHealth technology improve access to care and delivery of information to patients and providers across healthcare sectors?</p> <p>Does the use of eHealth technology facilitate communication of risk reduction to patients? What software can we develop to meet individual needs?</p> <p>How can healthcare systems integrate eHealth solutions?</p>
Patient experiences	<p>How can we improve experiences with CVD care? Can we learn from other models of care? What are the gaps, what is feasible and responsive to patient’s needs”- Researcher</p>	<p>What is important to patients and caregivers?</p> <p>How to improve patients’ experiences</p> <p>What measures can be used to capture the patient experience?</p> <p>Strategies to report patient reported experience measures to patients, caregivers, and healthcare professionals</p>

		What strategies address the needs of the patients and families?
Patient Engagement	"My empowerment has come little by little every year from individuals who would take time to listen to me and my family"- Patient	How can we engage patients in self-management and decision making?
Transitions and continuity of care	"for us, follow up and transitions of care was not good. I tried getting in touch with a family doctor after discharge from the hospital. I could not get past the receptionist...I tried to get in touch with the cardiologist assigned to him - 'no I'm sorry you can see him in 3 months' "- Family caregiver	<p>How can we improve transitions and continuity of care?</p> <p>How can we involve patients and caregivers?</p> <p>How do we co-design transition models of care with patients and caregivers?</p> <p>What are the gaps in current transition models, and how can they be addressed?</p>
Integrated Care	"Can we learn from the pediatric model and transfer it over to the adult care model?"- Researcher	<p>How do we ensure care is coordinated and located in one setting?</p> <p>What can we learn from pediatric care?</p>

Patient to Patient Support	“What we hope the pairing will do is that questions and answers can be given from one patient to the other because we know that the biggest barrier to a successful outcome is the patient’s fear”- Patient	Does the creation of a network of patient support improve health and healthcare? Does the creation of support systems and advocacy improve patients’ experiences with CVD?
Rare Heart Diseases	“It was the scariest part of my life & my family’s life to entrust the specialist and rehab facilities with my life because we didn’t know, if tomorrow I would be here. So we entrust them - their knowledge and their power, but they don’t have access to the information - why can’t we find others out there who would be willing to find out information about rare heart diseases”- Patient	How can we improve the understanding of patients’ experiences with rare heart diseases? How can we individualize care for patients with rare heart diseases? How can we improve knowledge on rare heart diseases?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

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	Reporting Item	Page Number
	#1 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	1,2,5
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4 Purpose of the study and specific objectives or questions	4
Qualitative approach and research paradigm	#5 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	5

recommended; rationale. 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.

Researcher characteristics and reflexivity	#6	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	5,6
Context	#7	Setting / site and salient contextual factors; rationale	5
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Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6,17
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Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
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Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	9-16
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	10-13
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	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 contributions(s) to scholarship in a discipline or field	16
Limitations	#19	Trustworthiness and limitations of findings	16
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	17
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	17

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BMJ Open

Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: a Qualitative study of Barriers and Priorities for Patient-oriented Research

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Title

Patients, Clinicians and Researchers Working Together to Improve Cardiovascular Health: a Qualitative study of Barriers and Priorities for Patient-oriented Research

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Abstract

Objectives: The overall goal of this study is to identify priorities for cardiovascular (CV) health research that are important to patients and clinician-researchers. We brought together a group of cardiovascular patients and clinician-researchers new to Patient Oriented Research (POR), to build a multi-disciplinary POR team and form an advisory committee for the Libin Cardiovascular Institute of Alberta.

Design: This qualitative POR used a participatory health research paradigm to work with participants in eliciting their priorities. Therefore, participants were involved in priority setting, and analysis of findings. Participants also developed a plan for continued engagement to support POR in CV health research.

Setting: Libin Cardiovascular Institute of Alberta, Cumming School of Medicine, University of Calgary, Canada.

Participants: A total of 23 participants, including patients and family caregivers (n=12) and clinician-researchers (n=11).

Results: Participants identified barriers and facilitators to POR in CV health (lack of awareness of POR and poor understanding on the role of patients) and ten research priorities for improving CV health. The CV health research priorities include: (1) CV disease prediction and prevention; (2) Access to CV care; (3) Communication with providers; (4) Use of eHealth technology; (5) Patient experiences in healthcare; (6) Patient engagement; (7) Transitions and continuity of CV care; (8) Integrated CV Care; (9) Development of structures for patient-to-patient support; and, (10) Research on rare heart diseases.

Conclusions: In this study, research priorities were identified by patients and clinician-researchers working together to improve CV health. Future research programs and projects will be developed to address these priorities. A key output of this study is the creation of the patient advisory council that will provide support and will work with clinician-researchers to improve CV health

Keywords: patient-oriented research, cardiovascular health, priority setting, patient engagement, research priorities

Strengths & Limitation

- Patients and clinician-researchers identified barriers and facilitators to work as partners in health research
- Patients worked together with clinicians-researchers to identify priorities for health research
- This patient-oriented research used a participatory health research approach.
- Participant demographics (other than age, gender, cardiovascular condition) were not collected which may be a limitation

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Introduction

The patient is the only constant in the journey of care, the person who experiences both the processes and the outcomes of care. As users of the healthcare system, patients hold information that is vital for the improvement of delivery of care, system functions and health policies. Patient experience provides insights into patient needs, preferences, and values, which are valuable for organizational design and improvements.¹ Patient-oriented research presents an important opportunity towards building a collaborative model that involves patients in research programs to improve health and healthcare. Specifically, Patient-oriented research is conducted in multidisciplinary teams, working in partnership with all relevant partners including patients, family members and clinicians-researchers. It focuses on identifying patient priorities and applying the learnings to improve health and healthcare.¹⁻⁵

In the last few years, efforts have been made to support patient and public engagement in health research to and within the healthcare system. In the United Kingdom there are two organizations, INVOLVE⁶ (involve.uk), a charity that supports research that involves patients and public in health research with the vision to democratize research, as well as (invo.org.uk), a government funded program to support active public involvement in NHS, public health, and social care research. In the USA, the Patient-Centered Outcomes Research Institute (PCORI)⁷ is a non-governmental organisation (pcori.org) that supports and funds research to improve healthcare decisions for patients, caregivers, clinical specialists, employers, insurers and policymakers. In Canada, the Strategy for Patient-Oriented Research (SPOR)¹ a coalition of federal, provincial, and territorial partners focuses on including the patient voice into the research process and incorporated into healthcare policy and practice. In Canada, and in patient-oriented research, the term ‘patient’ refers to an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.¹

Cardiovascular disease is a leading cause of death of men and women in Canada and is associated with significant morbidity, disability, and hospitalizations.⁸ The past three decades have seen the introduction and application of many therapies for the prevention and treatment of cardiovascular disease.⁸⁻¹¹ However, the experiences and outcomes from the patients’ perspective with

cardiovascular disease remain to be optimized.^{12,13} Patient-oriented research offers new promise to increase the relevance of research and ultimately improve cardiovascular health and care to patients. This opportunity to gain an understanding of what matters to patients and to learn how patients' priorities align with clinician-researchers in cardiovascular care could result in research and outcomes that are more relevant to both patients and clinicians.²⁻⁴

The ultimate goal of the study was to identify CV health priorities while building bidirectional POR partnerships in cardiovascular health and form an advisory council to support future POR at the Libin Cardiovascular Institute of Alberta.¹⁴

Methods

Study context

This qualitative descriptive study used participatory health research¹⁵ as the paradigm that guides the research process in eliciting the top ten research priorities for cardiovascular health. Participatory health research guides the approach to engage the participants in the study in working together, recognizing the value of each person's contribution to generation of knowledge in a process that is practical, collaborative and empowering.¹⁶⁻¹⁸ By working together in identifying priorities, we collected our data and analysed it in a collaborative manner. Additionally, during the final step of this study, these identified priorities will be disseminated, by all members of the working together study, to key stakeholders who could act on the research priorities and improving CV health.

This study was guided by the Canadian Institutes of Health Research (CIHR) Strategy for Patient Oriented Research (SPOR) Patient Engagement framework.¹ The patient engagement framework was developed to support the design and conduct of patient-oriented research projects, while establishing the structures to build partnerships with patients, clinicians and researchers, to work together in research.

We conducted a two-day workshop (Figure 1), co-designed and co-led by a patient-research partner (SZ), who is one of the trainers for the national CIHR SPOR Foundational Curriculum.¹ The foundational curriculum teaches patients and researchers the concepts of patient-oriented research,

1 health research and team building so that they can work better together in a respectful and
2 collaborative environment with researchers and policy makers. The leadership of a patient-partner
3 emphasized the important role that patients played in the workshop ensuring their voices were
4 heard, addressing potential power differentials that may occur. Based on the SPOR foundational
5 curriculum and participatory health research approach,¹⁶⁻¹⁸ we used a patient engagement process to
6 guide the discussions and rank priorities (Figure 1).

14 This workshop occurred at the *Libin Cardiovascular Institute of Alberta* in Calgary,¹⁴ Alberta in
15 December 2017. The Institute serves and coordinates cardiovascular patient care, research and
16 education for all of Southern Alberta, and Southeastern British Columbia (population of about 2
17 million). This Institute is both affiliated with the University of Calgary for academic activities and
18 *Alberta Health Services*, the single provincial healthcare organization.

25 Sampling and participants

26 *Recruitment of patients:* We strived for a maximum variation including a diverse group of patients
27 (diversity by age, sex, ethnicity, cardiovascular condition and disease stage, rural and urban
28 residence). Recruitment flyers were shared with healthcare providers, clinic managers at outpatient
29 clinics and tertiary healthcare centers in Alberta, and the patient engagement team at the provincial
30 SPOR SUPPORT Unit. Patients who expressed interest in attending the workshop were then contacted
31 by the lead patient research partner (SZ) to start the engagement process, discuss expectations and
32 acquire consent. Informed, written consent was also obtained for both workshop days. The lead
33 patient research partner (SZ) had no personal relationships with the participants. Patients were fully
34 supported by ensuring that all out of pocket expenses were covered and an honorarium was provided
35 as a recognition for their time and participation in the workshop.

46 *Recruitment of clinicians and researchers:* Clinicians and researchers from the *Person to Population*
47 *Cardiovascular Research Collaborative* at the Libin Institute were invited to participate. This group was
48 established with the Libin Institute with the goal of improving and optimizing cardiovascular health in
49 Alberta. This multidisciplinary team of researchers and clinician-researchers have expertise in patient
50 and family centred care, health services research, and cardiovascular care to catalyze patient-oriented
51 research priorities. A formal invitation to participate in this patient-oriented research study was

provided to the clinician-researchers accompanied by a brief description of the purpose and process of the workshop.

Theoretical framework: The theoretical principles guiding the development of this workshop are based on participatory health research, which aims to have the engagement of citizens, specifically patients and other stakeholders. The CIHR SPOR Patient Engagement framework¹ helped in the development of the workshop by ensuring that patients are involved as equal partners throughout the research process. This framework is underpinned by four guiding principles of engaging patient in health research, including: 1) Inclusiveness – relates to integrating a diversity of patient perspectives; 2) Support – needs to be provided to patients to ensure meaningful discussions, establish safe environment and compensate financially for their work; 3) Mutual Respect - as patients bring to the research their own experiences and expertise. When working together, strategies need to be developed to ensure that all partners value each other expertise; 4) Co-Build – partnership develops as all individuals work together from the beginning to identify barriers and facilitators, set priorities for research and develop knowledge translation plans. The framework was presented to workshop participants, to set the stage for POR¹ and build the foundation for working together.

Process: The workshop was co-designed and co-facilitated by POR experts; an academic researcher (MS) and patient research partner (SZ). This partnership helped to model and set the stage for participants to learn about POR, discuss potential barriers and facilitators to POR, identify top priorities for CV research, and work together on the development of a CV advisory committee. A participatory health research approach was used for involving all stakeholder partners in topic generation for POR¹⁶⁻¹⁸ and was used to guide the discussions, vote and rank priorities. A plan to address disagreement was in place - any disagreements were discussed by the group until consensus was reached.

These discussions included diverse stakeholders and all participants contributed equally to the discussion. It included five steps:

- 1) Introduction to patient-oriented research
- 2) Identify barriers and facilitators to conducting POR
- 3) Identify patient and clinician-researcher cardiovascular research priorities and vote on those priorities

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- 4) Presentations and discussions of top 10 priorities
- 5) Discuss next steps to ‘working together’

To describe the process, we will refer to these five steps.

Step 1 - On day one, the workshop started with the introductions of each participant using an ice-breaker to create a comfortable environment and encourage group cohesiveness. In addition, a set of rules on mutual respect and collaboration were presented to the group and displayed on the white board throughout the workshop. The co-facilitators (MS, SZ) provided a presentation introducing the group to POR using the CIHR framework on Patient Engagement.¹ Specifically, there was an emphasis on the four guiding principles and the importance of everyone bringing valuable expertise to the working group. Additionally, the different levels of patient engagement using a modified version of the International Association for Public Participation Spectrum framework¹⁸ were presented. For instance, patients could be ‘consulted’ when the researcher seeks their input on ad-hoc basis, or patients could ‘collaborate’ in the research project as an equal partner and be a member of the research team. After the presentation, questions addressed points on power differentials, reinforcing the notion of co-building and mutual respect.

Step 2 - Then participants were grouped in tables of five to discuss and document on flip chart papers the potential barriers and facilitators to conducting POR. This step was crucial in setting the stage for partnership building, as participants reflected on their concerns for POR, and how they could address those concerns. At each table a volunteer served as chair to monitor discussions, ensuring everyone was heard, and another individual annotated the topics discussed and presented to the entire group for final discussions. Participants discussed how POR could be operationalized. As the discussions progressed, data was collected in large flip charts stuck to the walls. Then, after all the barriers and facilitators were identified by the group, the data collected were presented & discussed together to reach the final group of barriers and facilitators. Participants were encouraged to deal with disagreement while working in groups. In case of disagreement, discussion continued until agreement was achieved. This step led to the final identification of barriers and facilitators to patient-oriented research in cardiovascular research.

Step 3 - Participants were separated for a brainstorming activity to identify what cardiovascular research priorities mattered most to them. Clinician-researchers and patients were placed in separate

groups for the initial brainstorming activity to allow participants to be comfortable in sharing their views and perspectives while identifying CV priorities. This allowed for each group to freely discuss and decide on CV priorities based on their expertise and experiences. Each table had a volunteer that chaired the discussions and another individual that presented the priorities to the larger group. Flip charts were used to collect this data, and all together the priorities were analyzed. In order to reach consensus from the 23 attendees, dotmocracy was used to narrow down to 10 priorities.¹⁹⁻²¹

Dotmocracy is a participatory large group decision-making tool.¹⁸⁻²⁰ This tool has been used in priority setting, particularly with large groups (20-30 participants) as a method to recognize points of agreement.¹⁹⁻²¹ Dotmocracy was chosen as a prioritization tool, as it has been used before with community members in other research projects of ours with success. This participatory tool engages patients in the research process, as partners in research. Dotmocracy allows participants to be fully engaged in the research process, especially if they have not participated in research before.¹⁹⁻²¹ During this process, instructions were made clear to all participants to place one sticker per research priority, and each participant had a total of ten stickers. The priorities with the least number of stickers were considered of lower priority. Then, the top ten priorities were reviewed ensuring that the group felt that what was important to them, was addressed in the top ten priorities. Before adjourning the meeting, a brief introduction to Day-2 was provided.

Step 4 - On day 2, patients and clinician-researchers worked together to co-create a short presentation focusing on the importance, relevance and feasibility of the chosen priorities. Ten teams including patient and clinician-researchers co-presented one of the top 10 priorities as a 'pitch' that follow the "Dragon's Den" format and these presentations were video recorded with their consent. This exercise enabled patients and clinician-researchers to work in partnership, co-designing and learning from one another. For example, some patients had difficulties in knowing the feasibility of conducting research for a specific priority, this provided the researcher an opportunity to help build their capacity by explaining the feasibility criteria and the steps that would need to be taken in order to conduct the research.

Step 5 - To conclude day-two of the workshop, the top ten priorities were presented back to the group for members checking. Then, the participants began to plan future steps, including the

1 establishment of the advisory council to support future POR for CV health at the Libin Cardiovascular
2 Institute of Alberta.¹⁴ The team worked also together in developing a communication strategy (e.g.,
3 how to keep in contact), and establishing the degree of patient engagement. Finally, the team worked
4 together in establishing a strategy to disseminate the findings of the study, evaluate progress and
5 assess the impact of the advisory council on POR for cardiovascular health.
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12 *Data collection*
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14 Materials for data collection included notes, flip charts, and videos. At the start of the workshop,
15 barriers and facilitators to POR were written on flip charts and agreed upon by all participants.
16 Throughout the workshop two note-takers observed and collected discussion points to support
17 discussions when needed. Then, discussions around the top ten priorities were annotated onto the
18 flip charts at each table, and later presented to the entire group. Dragon-style presentations (i.e
19 pitches on priorities) were also video-taped.
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27 *Data analysis*
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29 The notes were thematically analyzed by the research team (including patient-research partner) (SA,
30 SZ, MS) to identify the top areas of prioritization. A deductive process of identifying ideas and themes
31 was done, followed by peer debriefing by the research team. Additionally, a summarized version of
32 the top priorities was presented to the participants for member checking and further refinement. We
33 then reviewed the notes and flipcharts to ensure that no priorities were missed. Additionally, after
34 the workshop video-taped presentations and flip charts were reviewed by two members of the team
35 (SA, SZ) to confirm findings and describe the process in this paper and in other documents arising
36 from this workshop. All notes and flipcharts were stored in the Principal Investigator's office, and on
37 password protected computers.
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47 Patient and Public Involvement: This is a POR project; as such patients and a patient-research partner
48 were involved throughout different stages of the project (design conception, data collection, data
49 analysis, dissemination).
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Results

A total of 23 participants attended the workshop. 12 patients were invited, however due to time conflicts, 2 were unable to make it to the workshop. There were 10 individuals (patients) with cardiovascular conditions who participated in the workshop. They ranged in age from 35 to 70 years old, and 50% were women. Their cardiovascular conditions included coronary artery disease, arrhythmias, heart transplants and congenital heart disease. Two spouses (ages 65 to 70 years) also participated. Of the 12 patients and caregiver participants, 4 were from rural Alberta. We invited the core group of clinician-researchers of the P2 group (9 clinician researchers), however due to time conflicts, 2 were unable to join the workshop. The seven clinicians (3/7 women) were physicians and nurses with specialties in cardiovascular care, endocrinology, nephrology, and internal medicine. Four

Barriers to Patient-Oriented Research (POR)	Identified Solutions	participants were health services researchers (3/4 women). Of all the participants, there was diversity in ethnicity including participants
Lack of awareness of the existence of POR	Building networks with patient and family advisors Reaching out to communities Connecting with healthcare providers Utilizing social media (e.g. Facebook®, Twitter®)	
Lack of understanding of the role of patients – where do patients	Clear expectations and roles	

of Latino, South Asian, Filipino, Chinese, and Caucasian backgrounds.

Table 1 presents the barriers and solutions to patient-oriented research discussed by all participants.

Table 1. Barriers and their associated solutions to patient-oriented research identified by patients & clinician-researchers.

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fit into health research?	Including a protocol for conducting POR
Access/opportunities to participation in POR (distance, time)	Accommodating patient partners (i.e. using technology such as email, phone, etc. to allow for virtual meetings)
Diverse backgrounds	Working together with a collaborative mindset Ensuring there is diversity (in education, ethnicity, age, working status, sex and gender) in your team to incorporate multiple perspectives

Identifying
Research
Priorities

As depicted
in Figure 1,

participants worked independently in groups of patients and clinician-researchers to identify their top 10 priorities. Then all of these priorities were discussed and classified into three groups (displayed in Figure 2), including 5 priorities from patients, 5 common priorities to both groups (matched) and 3 priorities unique to clinician-researchers. Then out of the other 8 priorities, three were merged. Merged priorities included: patient experiences (from patients) merged with patient-reported experiences and outcomes (from clinician-researchers) and three priorities (tool to support decision-making, technology to predict and prevent cardiovascular disease, and patient and caregivers' perceptions on the role of technology in patient engagement) merged into priority 4 – e-health technology. *Matched priorities* emerged from discussions as common priorities to patients and clinician-researchers. These priorities were discussed and the top ten were selected. No disagreement was encountered throughout the workshop, as each priority was discussed among the group.

The Top Ten Cardiovascular Research Priorities

Selected top priorities are presented in order of ranking in the following paragraphs; and summarized in Appendix 1 with selected quotes from participants to further illustrate the discussions that took place during the priority setting exercise. Furthermore, after the workshop clinician-researchers met and developed some questions to conduct future research based on these priorities, including “How

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2 *can we co-design tools with patients and caregivers to predict and communicate risk factors for*
3 *cardiovascular disease?”* (see Appendix 1) These questions were presented to the patient advisory
4 council and have been used as research questions for grant proposals.
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9 ***Prevention and Prediction*** – Patients discussed that despite adhering to recommendations they had
10 to prevent recurrent events, including heart attacks, they felt being provided with information on
11 prevention was not enough. Participants identified research on prediction of future events important
12 to better inform their conversations during clinical visits.
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18 ***Access to Care-*** Accessing after regular hours care, waiting to see specialists, and access to care for
19 patients living in rural communities were identified as patient priorities. Patients emphasized the
20 importance of research focusing on providing care to underserved populations and improving
21 quality of life and efficiency by addressing travel time for care.
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27 ***Communication*** was highlighted as key to empowering patients to understand their condition,
28 promote adherence to treatment, and ultimately improve health outcomes. Participants highlighted
29 the importance of building trust through communication, not only providing information but also by
30 ensuring that the patients understand the information.
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36 ***e-Health Technology*** – the use of e-health technology was raised as a research priority by
37 researchers, especially in the facilitation of communication between patients and healthcare
38 providers.
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43 ***Patient Experience*** – the focus was on understanding what was important to patients, the
44 measurement of patient experiences and the development of strategies to address the needs of
45 patients and caregivers.
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50 ***Patient Engagement*** was identified as a pillar to support disease management and promote decision-
51 making while improving care and patient outcomes. Participants discussed empowerment strategies
52 to enhance engagement, including sharing information and opportunities to use information tools
53 available to both patients and clinicians.
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Transitions and Continuity of Care – Participants highlight the need for research on strategies to improve transitions and test interventions that will improve continuity of care.

Integrated Care – For patients, integrated care meant efficient and timely care, while for providers it implied safety and quality of care.

Patient to Patient Support – Peer support was identified as a priority and an opportunity to learn and find support from individuals that have common lived experiences.

Rare Heart Disease – Patients wanted to become their own advocates and particularly access specialists and knowledge when they had rare heart diseases.

At the end of the workshop, participants agreed on creating a patient advisory council to work together with clinician-researchers to improve cardiovascular health. The newly created group planned to meet quarterly during the year to further develop the projects based on the identified priorities and to develop a plan to ensure future sustainability of the group, with the support of the Libin Institute¹⁴ and through external funding sources (i.e., grants).

Discussion

This study described a Working Together workshop that included patients and clinician- researchers. This group co-developed cardiovascular research priorities at a Canadian academic cardiovascular health research institute. These priorities are important to inform provincial programs for cardiovascular research, funding priorities, grant proposals and research projects to ultimately improve cardiovascular health of patients and communities.

The theoretical principles guiding this workshop are of participatory health research,¹⁵⁻¹⁷ and underpinned in the four pillars of engaging patient in health research.¹ Inclusiveness was addressed by recruiting participants with diverse backgrounds, including patients with different cardiovascular conditions and clinician-researchers with different specialties. The priorities identified could be used in generic CV research projects (from hypertension, diabetes, heart failure to kidney failure and

congenital heart disease). Support was offered to patients from the beginning of the project through discussions on their expectations, establishing a safe environment and compensating them financially for their time working together. While establishing a safe environment, a set of rules were presented at the start of the workshop, emphasizing mutual respect and ensuring that patients were equal partners in the process and all partners value each other expertise. Without creating the safe and collaborative environment, partnership will be difficult. Partnership is a key aspect of working together that was developed from the beginning throughout the workshop to identify barriers and facilitators, set priorities for research and co-build knowledge translation plans.

In cardiovascular health, Vandigo et al.²² examined a hypothetical example on how patients could be engaged in cardiovascular health research. In contrast, in our study patients and clinician-researchers worked together during the two-day workshop. A patient-partner and an academic led the workshop. This leadership was strategic to ensure that patients felt represented and heard throughout the process. In addition, the leadership of a trained patient-partner reflected the high level of engagement described by the IAP2,¹⁸ leveraging patient's involvement and leadership in research activities.

We found that our identified priorities had a strong emphasis on patient-centred care, as depicted in Santana et al. framework²³ including access to care, communication, improving patient experiences, patient engagement, transitions and continuity of care, and integration of care. The impact of patient-centred care in priority setting has been noted in previous studies.²⁴⁻³⁷ However, most of these studies identified priorities related to burden on symptoms and treatment, whereas in our study the priorities were related to more general challenges of healthcare. Our findings addressed healthcare system issues such as patient-provider communication, while patients in dialysis prioritized itchiness as a burdensome symptom.

In a hypertension management project, Khan et al.²⁷ found alignment with our results, as prevention and prediction was a top research priority. However, while Khan et al emphasized lifestyle interventions, our focus was on providing information to patients on how prevention strategies could predict another CV event. For instance, when patients follow all the prevention advice (lifestyle changes) that will predict the risk of preventing another heart attack. Moreover, Etchegar H et al.²⁸ in a Canadian setting conducted public consultations revealing priorities that aligned with our findings, including access to care in rural areas and prevention and health promotion.

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Recently, several approaches have emerged in an attempt to guide patient engagement. However, to date, there is no one formula on how to conduct POR.^{2-4,17,22-38} The evidence is scarce on the process, best practices and evaluation of the engagement.^{2,4,33} Recent reviews revealed that patients are not meaningfully engaged.³¹⁻³³ We framed the workshop according to the methods for engaging patients in topic generation for research, ranking priorities in a large group setting, and dotmocracy. Dotmocracy has been identified as one of the four methods for priority setting by Ontario Health.²⁰ Other research priorities approaches includes the James Lind Alliance approach,³⁷ specifically in developing research priorities for prostate cancer³⁵, hypertension management,²⁷ and gestational diabetes mellitus.³⁴ Other approaches include the Delphi³⁰ and the nominal group technique³⁶. Selection of methods depends on the purpose of the study, diversity and size of participants. A recent review by Manafo et al.³⁸ described the levels of patient engagement in priority settings as tier 1 and 2, and highlight several ways to identify priorities emphasizing that ‘one-size doesn’t fit all.’ For the purposes of our workshop, dotmocracy was the best approach in engaging clinician-researchers and patients new to patient-oriented research.

This study focused on including patients as partners in research, therefore demographics other than age, sex, and cardiovascular condition were not collected. We acknowledge this as a potential study limitation. Another study limitation in conducting POR is related to the fact that the two groups (patient and clinician-researcher) are not accustomed to working together, and therefore it is possible that they inhibited or censored themselves in contributing their ideas. However, we tried to allow for the participants to know each other, starting with an ‘ice-breaker’ exercise, emphasizing respect, partnership and providing time for patients to identify barriers and generate ideas in their own way. By working together in groups, patients and clinician-researchers were able to learn from each other, valuing their different perspectives. Participants were able to get an idea of what POR looks like, and how future partnerships can be developed. This workshop paved the way for a patient-advisory council at the Libin Institute, led by a patient who attended the workshop. Thus far, our patient partners have discussed the questions raised from the workshop and are working in research proposals to address some of these priorities. The patient advisory council is active and we have managed to secure funding from the Libin Institute to ensure sustainability for the next three years.

Conclusion

This research project is one of the first Canadian studies identifying priorities in cardiovascular health. In this study, we have explored POR needs in Alberta for cardiovascular health research by engaging patients and clinician-researchers to establish a multidisciplinary team with an array of expertise and backgrounds. We also identified barriers to conduct POR and discussed solutions. A key output of this study is the creation of the patient advisory council that will provide support and will work with clinician-researchers to improve CV health. Finally, this study can inform the design of other POR projects and enlighten high priority areas for future cardiovascular health research that is relevant to patients.

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Author Contributions

MS is the principal investigator. SZ is the patient research partner. MS and SZ conceived the idea and drafted the initial manuscript. SA, CD, MTJ, SW, HQ, NF, TA, SB provided input on various drafts of the manuscript. All authors provided important intellectual contribution and guidance throughout the development of the manuscript. All of the authors (MS, SZ, SA, CD, MTJ, SW, HQ, NF, TA, SB) contributed to critical review and revisions to the manuscript, agreeing on the final version.

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Competing interest statement

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There are no competing interests

Ethics approval: The study was approved by the University of Calgary Conjoint Health Research Ethics Board, REB17-0864

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement: All data relevant to the study are included in the article or uploaded as supplementary information. No additional data are available.

Patient consent for publication Not required.

Figure 1. Overview of the Study: Identifying, Refining, and Ranking the Top Ten Priorities
Figure 2. Priorities for CVD research identified by patients, caregivers and clinicians and researchers.

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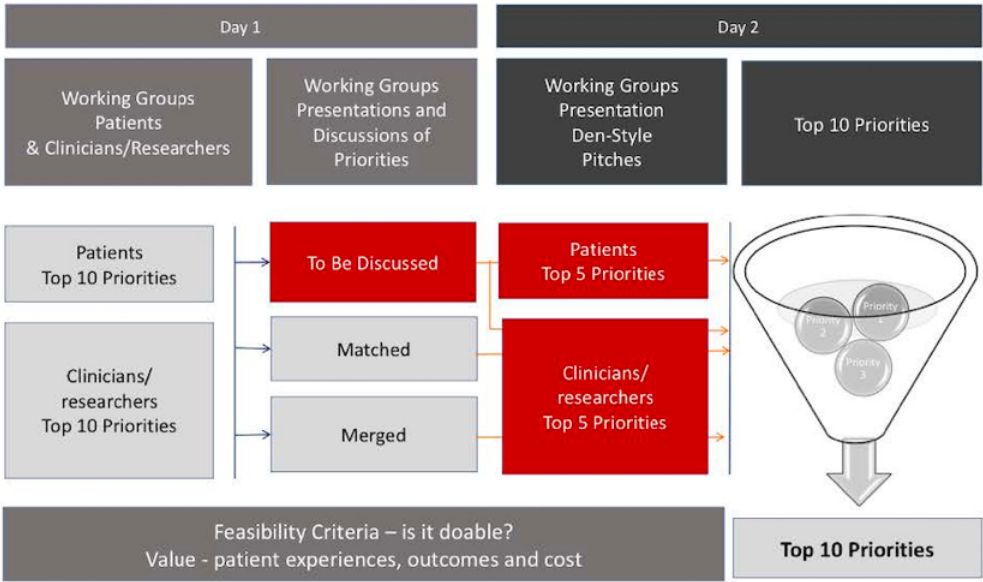


Figure 1. Overview of the Study: Identifying, Refining, and Ranking the Top Ten Priorities

Patient, Family Caregiver	Matched	Clinician-researchers
Access to Care	Continuity and Transitions of Care	Collecting and reporting of patient-reported outcome measures (PROMs) and patient reported experience measures (PREMs)
Integration of Care	Communication	Technology to predict and prevent cardiovascular disease
Experience of care	Tools to support shared decision making	Patient and caregivers' perceptions on the role of technology in patient engagement
Structure for patient-to-patient support and patient advocacy	Patient Engagement	
Rare heart disease	Prevention and Prediction	

Figure 2. Priorities for CVD research identified by patients, caregivers and clinicians and researchers.

For peer review only

Appendix 1. Top research priorities, selected quotes from participants and identified research questions

Top Priorities (ranked from most important to least)	Selected Quotes	Research Questions
Prevention & Prediction	“I have a family history of CVD, I know, and that’s why I took care of it, why didn’t work? The information I was given by the doctors was not enough, I followed it and I had another event...What else could I have done, I don’t know, ... How do we find people that are at risk of having an event?” Patient	How can we prevent and predict CVD? What tools can be used to predict CVD? How can we co-design tools with patients and caregivers to predict and communicate risk factors for CVD?
Access to Care	“There is a way to make improvements to access to care in smaller communities... technology- like the choosing wisely Canada app - which is free and can help people become more educated about what they need” – Patient	How can we improve access to care? How can we access care in small rural communities? How can we create services in these rural underserved areas? How can we improve access to specialist care for vulnerable populations?
Communication	“My background is French and when I moved to Alberta, I was talking to people here in English... One thing that shocked me... People saying “I hear you”... but do you understand what I’m trying to share with you? ...”- Patient	How can we improve communication between patients and healthcare providers across healthcare sectors? How can we develop a trusting relationship with healthcare providers?

		<p>How we can improve information sharing across healthcare sectors?</p> <p>How can we use healthcare information solutions to aid communication in a timely manner?</p>
E-Health technology	<p>"Saving time, saving travel, can occur outside office hours-improved flexibility, and not location specific" –Patient</p>	<p>Does the use of eHealth technology improve access to care and delivery of information to patients and providers across healthcare sectors?</p> <p>Does the use of eHealth technology facilitate communication of risk reduction to patients? What software can we develop to meet individual needs?</p> <p>How can healthcare systems integrate eHealth solutions?</p>
Patient experiences	<p>How can we improve experiences with CVD care? Can we learn from other models of care? What are the gaps, what is feasible and responsive to patient's needs"- Researcher</p>	<p>What is important to patients and caregivers?</p> <p>How to improve patients' experiences</p> <p>What measures can be used to capture the patient experience?</p> <p>Strategies to report patient reported experience measures to patients, caregivers, and healthcare professionals</p>

		What strategies address the needs of the patients and families?
Patient Engagement	“My empowerment has come little by little every year from individuals who would take time to listen to me and my family”- Patient	How can we engage patients in self-management and decision making?
Transitions and continuity of care	“for us, follow up and transitions of care was not good. I tried getting in touch with a family doctor after discharge from the hospital. I could not get past the receptionist...I tried to get in touch with the cardiologist assigned to him - ‘no I’m sorry you can see him in 3 months’ -”- Family caregiver	How can we improve transitions and continuity of care? How can we involve patients and caregivers? How do we co-design transition models of care with patients and caregivers? What are the gaps in current transition models, and how can they be addressed?
Integrated Care	“Can we learn from the pediatric model and transfer it over to the adult care model?”- Researcher	How do we ensure care is coordinated and located in one setting? What can we learn from pediatric care?

Patient to Patient Support	“What we hope the pairing will do is that questions and answers can be given from one patient to the other because we know that the biggest barrier to a successful outcome is the patient’s fear” - Patient	Does the creation of a network of patient support improve health and healthcare? Does the creation of support systems and advocacy improve patients’ experiences with CVD?
Rare Heart Diseases	“It was the scariest part of my life & my family’s life to entrust the specialist and rehab facilities with my life because we didn’t know, if tomorrow I would be here. So we entrust them - their knowledge and their power, but they don’t have access to the information - why can’t we find others out there who would be willing to find out information about rare heart diseases” - Patient	How can we improve the understanding of patients’ experiences with rare heart diseases? How can we individualize care for patients with rare heart diseases? How can we improve knowledge on rare heart diseases?

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
	#1 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	1,2,5
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4
Purpose or research question	#4 Purpose of the study and specific objectives or questions	4
Qualitative approach and research paradigm	#5 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	5

recommended; rationale. 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.

Researcher characteristics and reflexivity	#6	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	5,6
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5,6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	6,17
Data collection methods	#10	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	9
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	9
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	9
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	9

1	Data analysis	#14	Process by which inferences, themes, etc. were identified and	9
2			developed, including the researchers involved in data analysis;	
3			usually references a specific paradigm or approach; rationale	
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6	Techniques to enhance	#15	Techniques to enhance trustworthiness and credibility of data	9
7	trustworthiness		analysis (e.g. member checking, audit trail, triangulation);	
8			rationale	
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11	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and themes);	9-16
12	interpretation		might include development of a theory or model, or integration	
13			with prior research or theory	
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17	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to	10-13
18			substantiate analytic findings	
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21	Intergration with prior	#18	Short summary of main findings; explanation of how findings	16
22	work, implications,		and conclusions connect to, support, elaborate on, or challenge	
23	transferability and		conclusions of earlier scholarship; discussion of scope of	
24	contribution(s) to the field		application / generalizability; identification of unique	
25			contributions(s) to scholarship in a discipline or field	
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29	Limitations	#19	Trustworthiness and limitations of findings	16
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31	Conflicts of interest	#20	Potential sources of influence of perceived influence on study	17
32			conduct and conclusions; how these were managed	
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35	Funding	#21	Sources of funding and other support; role of funders in data	17
36			collection, interpretation and reporting	
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40 Medical Colleges. This checklist can be completed online using <https://www.goodreports.org/>, a tool made by
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