

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 |
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| 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> |

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| | | <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> |

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| | | 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? |

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| 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? |