2021

PATIENT PARTNER TOOL KIT

STRATEGY FOR PATIENT ORIENTATED RESEARCH FOR INTERDISCIPLINARY CHRONIC DISEASE COLLABORATION INNOVATIVE CLINICAL TRIALS TEAM

UNIVERSITY OF CALGARY

UNIVERSITY OF ALBERTA

Alberta SPOR SUPPORT Unit

ICDC interdisciplinary chronic disease collaboration

CIHR IRSC Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

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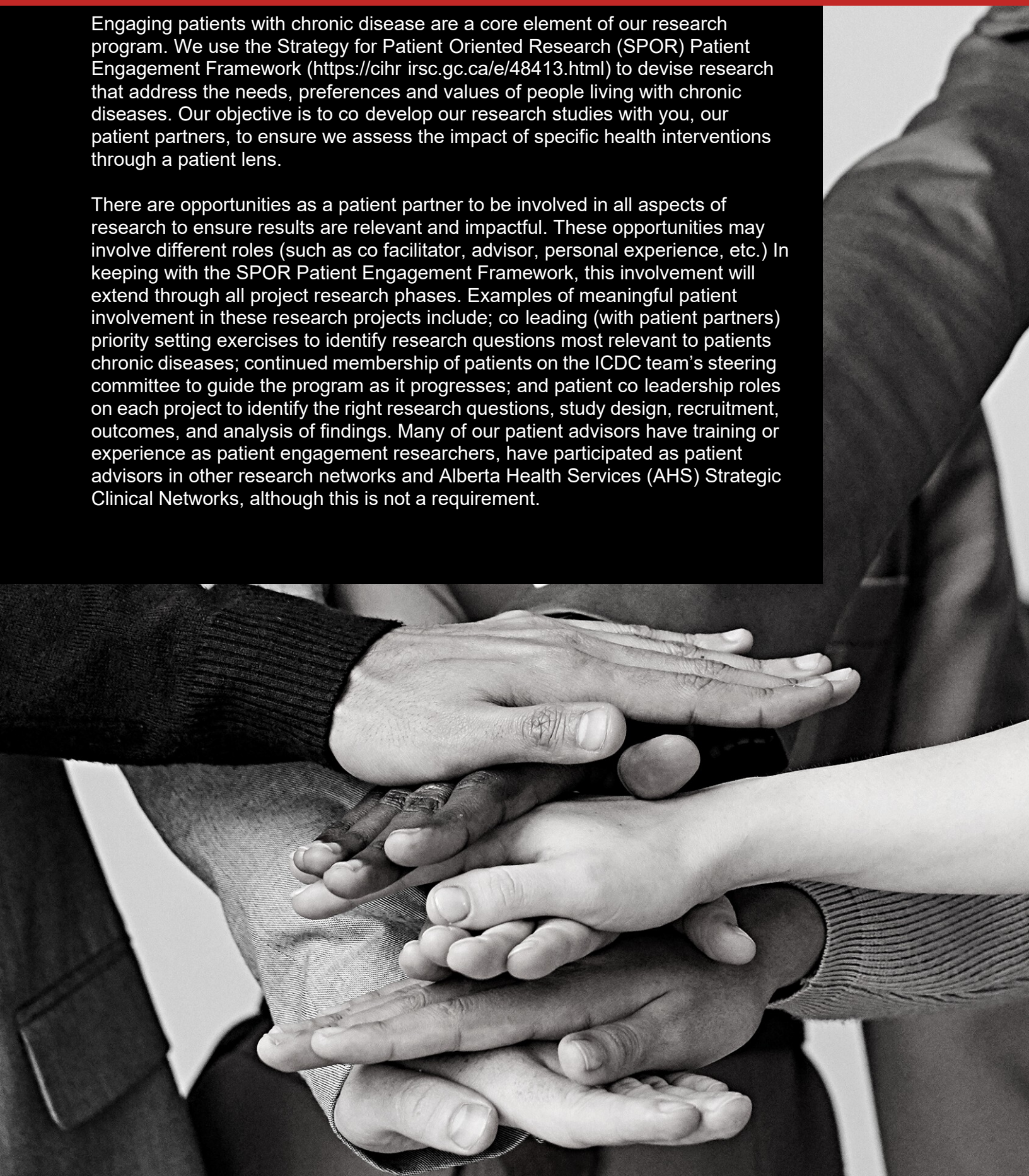
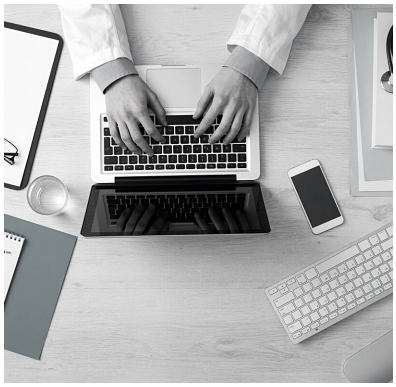
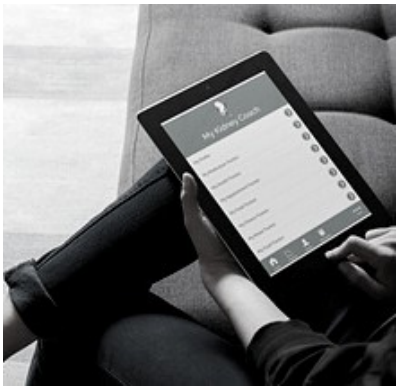
VALUE OF PATIENT ENGAGEMENT WITHIN OUR PROGRAM

Engaging patients with chronic disease are a core element of our research program. We use the Strategy for Patient Oriented Research (SPOR) Patient Engagement Framework (https://cihr irsc.gc.ca/e/48413.html) to devise research that address the needs, preferences and values of people living with chronic diseases. Our objective is to co develop our research studies with you, our patient partners, to ensure we assess the impact of specific health interventions through a patient lens.

There are opportunities as a patient partner to be involved in all aspects of research to ensure results are relevant and impactful. These opportunities may involve different roles (such as co facilitator, advisor, personal experience, etc.) In keeping with the SPOR Patient Engagement Framework, this involvement will extend through all project research phases. Examples of meaningful patient involvement in these research projects include; co leading (with patient partners) priority setting exercises to identify research questions most relevant to patients chronic diseases; continued membership of patients on the ICDC team's steering committee to guide the program as it progresses; and patient co leadership roles on each project to identify the right research questions, study design, recruitment, outcomes, and analysis of findings. Many of our patient advisors have training or experience as patient engagement researchers, have participated as patient advisors in other research networks and Alberta Health Services (AHS) Strategic Clinical Networks, although this is not a requirement.



PROGRAM OVERVIEW

Chronic diseases are associated with shorter lifespans, frequent contact with the health care system, and reduced quality of life. New ways of delivering health services are needed to promote health and ensure consistent, high quality care for Canadians living with chronic conditions. It is important, however, that new interventions and strategies are carefully studied to ensure they benefit patients and family/support and provide value. The Interdisciplinary Chronic Disease Collaboration (ICDC) is a team of health care leaders, researchers, patients, patient partners and care providers who work together to address health challenges. We research new ways of providing care for patients with chronic diseases and measure the impact of these changes on patient outcomes and experiences. We use a mix of methods, including qualitative and quantitative approaches to collect data and report our findings to the public and to health care decision makers.

Over the next four years, the team plans to test health innovations and interventions that aim to improve care, safety, and outcomes for people with three common and closely related chronic diseases: heart disease, diabetes, and kidney disease. These studies will focus on:
1. The way patients' symptoms and experiences are recorded, communicated, and acted upon during doctors' visits, and whether these changes improve patient outcomes and experiences (IMPROVE).
2. The impact of using electronic health record systems (how doctors and hospitals collect health information and use it to deliver care) on patients'' experiences and outcomes in various settings across Alberta (AIM).
3. Strategies using electronic health interventions (PAUSE) and pharmacists to improve safety of using common medications during times of illness to maximize benefits and minimize risks (RxESPOND).

These research initiatives are each designed to produce new knowledge for patients, families, healthcare providers, and policy makers. The team is skilled in research design, rigorous evaluation, knowledge translation and approaches that will allow rapid uptake of successful strategies into Alberta's health system.
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PROJECT OVERVIEW

Individualized Monitoring of Patient Reported Outcome measures for Value and Effectiveness in CardioVascular Care (IMPROVE CV Care).

The IMPROVE project is specifically exploring the way patients' symptoms and experiences are recorded, communicated, and acted upon during doctors' visits for cardiac care, and whether these changes improve patient outcomes and experiences. These measurements are collected through survey tools called Patient Reported Outcomes Measures (PROMs) and Patient Reported Experience Measures (PREMs).

Leads: Dr. Michelle Graham Dr. Matthew James, Dr. Tolu Sajobi. Dr. Stephen Wilton

Staggered roll out evaluation of Alberta Health Services' new electronic health record: Impact on outcome and experience Measures for patients with chronic diseases (AIM study).

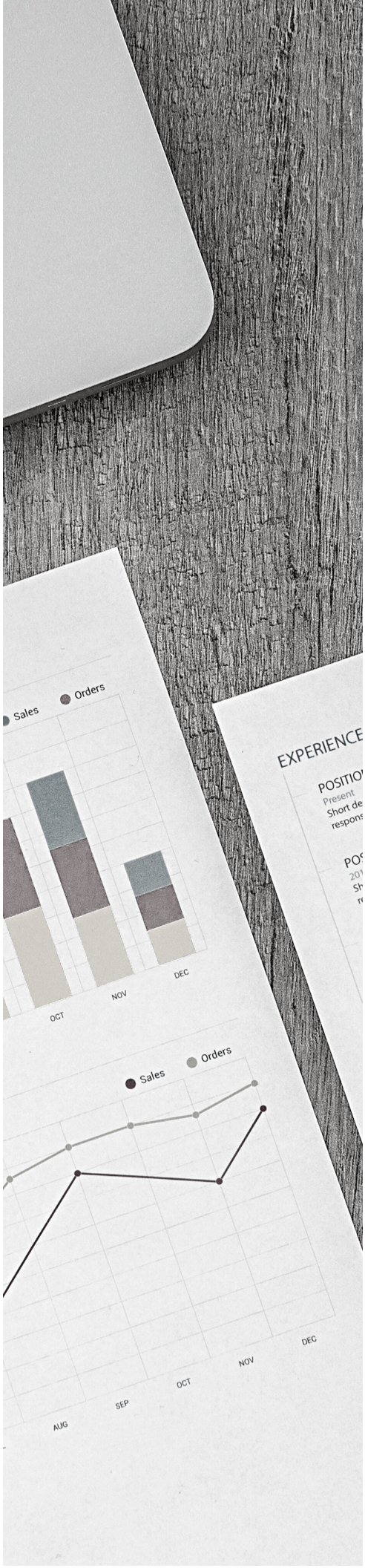
The AIM project will be evaluating the impact of implementing a new provincial electronic health record on patient care, outcomes, experiences, and costs for patients with non-communicable diseases at high cardiovascular risk across Alberta.

Leads: Dr. David Campbell, Dr. Matthew James, Dr. Neesh Pannu, Dr. Paul Ronksley

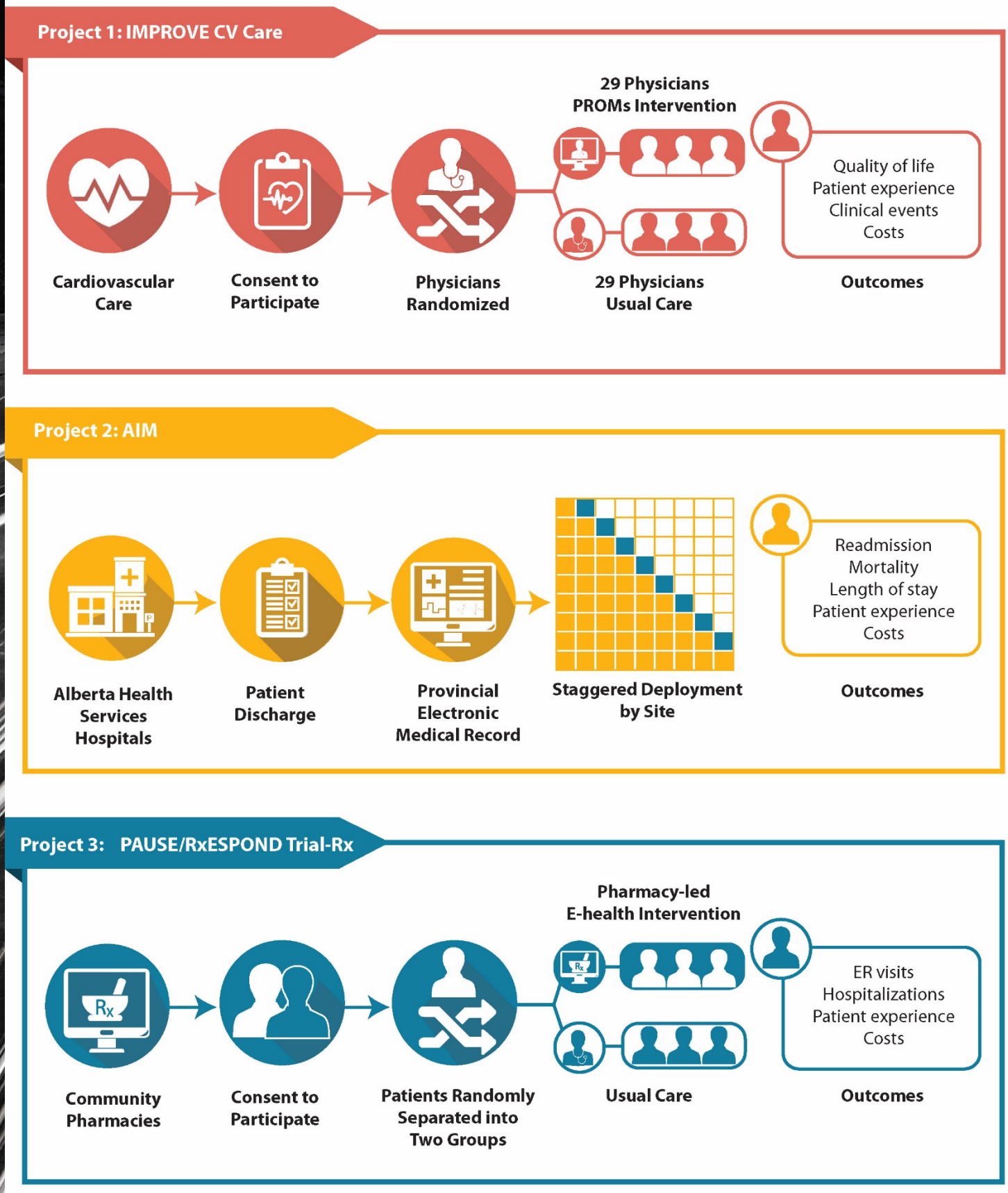
Preventing medication complications during AcUte illness through Symptom Evaluation and sick day guidance (PAUSE) - A patient-level, randomized trial of a community pharmacy intervention to Enhance the Safety of Prescriptions for Outpatients with Nephropathy and Diabetes (RxESPOND Trial)

The PAUSE project is specifically developing a health tool that will provide patients with guidance on what to do when they are sick so they can avoid severe complications. A randomized trial will test whether integrating medication sick-day guidance and support through the app into the patients' community pharmacies will help them avoid complications and improve outcomes compared to current care approaches that may be more difficult to access in a timely manner

Co-Leads: Dr. David Campbell, Dr. Matthew James, Dr. Kerry McBrien, Dr. Neesh Pannu, Dr. Ross Tsuyuki



Overview of ICDC Project Designs



SPOR ICT GRANT ORGANIZATION STRUCTURE

CONTACTS

Eleanor Benterud – Senior Project Coordinator
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Project 1 IMPROVE
Project Coordinator Pantea Amin Javaheri
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Project 2 AIM
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Project 3 PAUSE/RxESPOND
Edmonton Project Coordinator Kelsea Drall
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Calgary Project Coordinator Nicole Lamont
nclamont@ucalgary.ca

COMPENSATION AND TAXABLE INCOME INFORMATION

We appreciate your contribution to the various activities in the SPOR iCT Grant. In recognition of your dedication with your time and expertise, remuneration is being provided for selected activities. This would be discussed at the time we discuss the partnership prior to your participation on the team. There is a guideline being developed by the Canadian Institutes of Health Research (CIHR) on patient compensation and considerations for tax and disability benefits, which we are hoping to share with you as soon as it is released. In the meantime, given the timing for tax returns etc., it is important that we keep you informed and clarify some of these implications so that you may plan your finances and tax returns accordingly:

Honorarium:
The honorarium payment is considered taxable income by the Canada Revenue Agency (CRA) (for more information)

If the amount you receive exceeds $500 in a calendar year, you will receive a tax certificate (T4A Slip). This means that we will have to ask you to provide your SIN and full mailing address so that we can provide you with a tax slip.

For more information on tax implications, please see the following CRA guidelines:

- Receiving Gifts

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- Gifts and Income Tax

- Community Volunteer Income Tax Program

If you are receiving disability benefits, there may be some additional things to consider. For example, as per the CPP Disability Benefit guideline, you may earn up to $5,400 (before taxes) without reporting and without losing your benefits; the amount may increase in future years

For Residents of Alberta who are on Assured Income for the Severely Handicapped (AISH), please reference their guidelines

If you have any questions or concerns, please feel free to get in touch with us.

https://cihr-irsc.gc.ca/e/51466.html

GLOSSARY

AKI-Acute Kidney Injury

PROMS- Patient reported outcome Measures

PREMS- Patient Reported Experience Measures

Algorithm- a process or set of rules to be followed in calculations or other problem-solving operations

SPOR – Strategy for Patient Orientated Research

ICDC- Interdisciplinary Chronic Disease Collaboration

iCT – innovative clinical trials

e-health – electronic health is based on an electronic system versus a paper-based system

Research participants - volunteers who elect to participate in a research study as a recipient of the variable being tested. For example, in clinical trials, research participants, who may or may not be patients, receive the treatment being investigated or receive a placebo or alternate treatment. The voluntary contribution by research participants to be the 'testers' of scientific discoveries is necessary to help the researcher determine whether their treatment or intervention works in the way it is intended to.

Patient Partner - If patients are involved in a research project in any manner other than as a research participant they are considered 'patient partners.' Some examples of the patient partner role include: participation on governing boards or committees, being consulted on survey design for a study, co-developing the research methodology with a researcher, taking part in priority-setting activities to determine new areas of research, and collecting and/or analyzing data and knowledge translation.

PCN - Primary Care Network

HIA & PIPA - Health information act & Personal Information Protection Act

FOIP - Freedom of information act

PIPEDA - Personal Information protection and electronic documents act

DST - Decision Support Tool

EHR - electronic health record

CKD - Chronic kidney disease

ACP - Alberta College of Pharmacists

APA - Additional prescribing authority

HTN - Hypertension

APPENDIX 1
ACTIVITY LOG

First and Last Name	
Period of Engagement *(E.g. January 2019-April 2019)*	
Project Title	

Engagement Record:

Date *August 27, 2018*	Activity					Number of hours
	Team Meeting	Review documents	Other meetings	Other	Description (optional) *Recurring meetings to discuss business*	
August	yes	yes			reviewed toolkit	1

APPENDIX 2
PAYMENT PROCESS

Patient Partner Payment Process Information

Name of Project:

Ethics Number Associated with Project:

Patient Partner Name:

Phone Number:

Mailing Address:

Email Address:

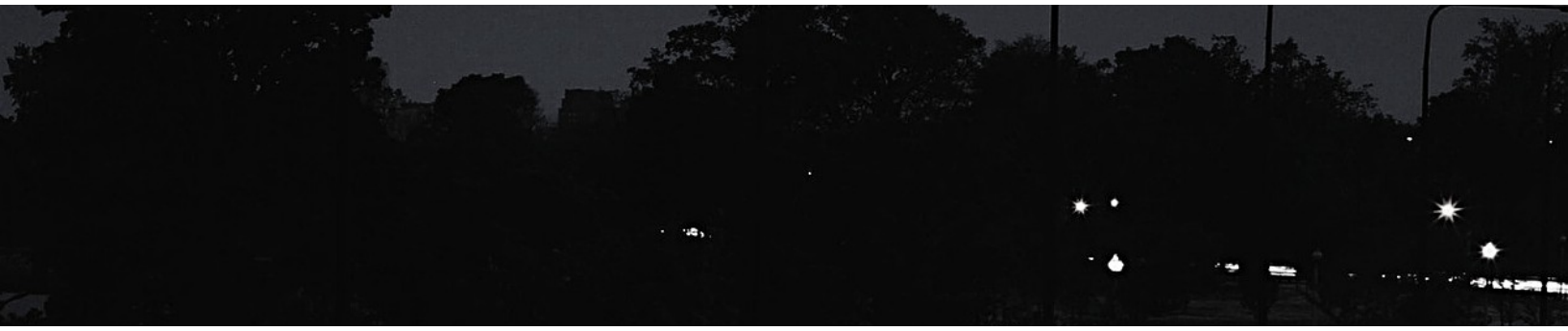
Have you ever received a payment from the University of Calgary Prior to this one?

☐ I have included my activity log with this form

☐ I have include any agendas or calendars as evidence

Date Range	Total number of hours	Amount based on $25.00 per hour
EXAMPLE: Focus Group 3 hours		*75.00*

Approved by: ***Date:***



APPENDIX 3
GUIDING PRINCIPLES

INCLUSIVENESS

SUPPORT

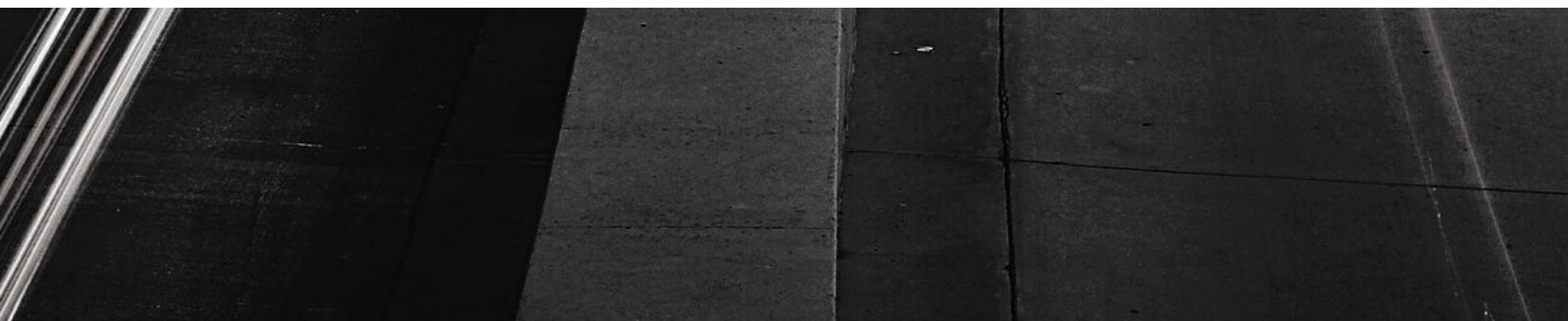
MUTUAL RESPECT

CO-BUILDING

If you feel that any one of these principles is not being adhered, please contact

Eleanor Benterud
Eleanor.benterud@ucalgary.ca
Or
Dr. Matthew James
mjames@ucalgary.ca

To view details of the principles please go to
https://cihr-irsc.gc.ca/e/48413.html



APPENDIX 4
EVALUATION QUESTIONS

This survey is 18 questions and should take less than 10 minutes. Participation is voluntary. The anonymous data will be kept within a secure, password-protected file at the University of Calgary. All data will be destroyed 7 years after the project closes. Responses will be analyzed in aggregate and at no time will individual responses be made available to anyone. The survey will go to an independent administrative assistant who will compile the information and pass it on the executive committee. Compiled results of this study may be presented in peer-reviewed publications and scientific presentations. This study has been approved by the Universities of Calgary and Alberta, Health Research Ethics Boards. If you have any concerns you can contact the ethics board at 403-220-2297.

Thank you for your time. If you have any questions or would prefer a paper copy mailed to you, please contact Eleanor Benterud

The survey is electronic and can be accessed by copying the link below and pasting it into your browser:

https://survey.ucalgary.ca/jfe/form/SV_0MWLs89FtIZToX4

or scan the QR CODE with your phone

UNIVERSITY OF CALGARY

Cumming School of Medicine, Division of Nephrology Research Group User Confidentiality Agreement

This is an agreement between you and the University of Calgary, Cumming School of Medicine, Division of Nephrology. By signing this agreement, you are accepting the terms and conditions outlined below. Please read this Agreement carefully. If you do not wish to accept the terms and conditions of this Agreement, access to confidential information will be denied.

WHEREAS:

The University of Calgary, Cumming School of Medicine, Division of Nephrology, is bound by the Health Information Act ('HIA') of Alberta and by the Freedom of Information and Protection of Privacy Act ('FOIP') of Alberta.

I AGREE THAT:

1. All health information (as defined in the HIA) and all personal information (as defined in the FOIP) that is collected, used, and disclosed in order to perform my duties and responsibilities for my role, on the behalf of the Faculty are private and confidential.
2. I agree to keep health and personal information confidential for as long as required under HIA, FOIP, and as outlined in User and University policies.
3. I will not access, collect, use, or disclose identifiable health information for non-business purposes. I will not access my own health information nor will I access the information belonging to my relatives, friends, colleagues, or acquaintances under the custody and control of the University of Calgary, Cumming School of Medicine; unless I make a formal request as per the Protection and Privacy of Health Information.
4. I agree that I will not store identifiable health information on removable media and/or mobile computing equipment unless otherwise authorized by the Access and Privacy Officer.
5. I agree to immediately notify my Investigator or a member of the team if I am aware of any breach of this agreement.

By signing below, I agree to accept the terms and conditions of this agreement and intend to be legally bound by them.

Name: Signature:
Date:

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