

Prepared for the Primary and Integrated Health Care Innovations Network Submitted 6/30/2021

Prepared By: Jamie Park, Yasmin Garad, Arushan Arulnamby, Dr. Christine Fahim, Dr. Sharon Straus

Knowledge Translation Program, Li Ka Shing Knowledge Institute,

St. Michael's Hospital, Unity Health Toronto

Land acknowledgement

We acknowledge the land on which we live and work is the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples and is now home to many diverse First Nations, Inuit and Metis. We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit. We remember and honour the legacy of the peoples who have been here before us and all who work to make the promise and the challenge of Truth and Reconciliation real. We are grateful to have the opportunity to live and work on this land.

Contributors

Members of the following Community Based Primary Health Care (CBPHC) Innovation Teams:

- Innovative Models Promoting Access-to-Care Transformation (IMPACT)
- Aging, Community and Health Research Unit (ACHRU)
- Patient Centred Innovations for Persons with Multimorbidity (PACE in MM)
- Implementing Integrated Care for Older Adults with Complex Health needs (iCOACH)
- Transforming CBPHC Delivery Through Comprehensive Performance
- Measurement and Reporting (TRANS-FORMATION)
- Atlantic Canada Children's Effective Service & Strategies in Mental Health (ACCESS-MH)
- Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)
- Canadian Chronic Disease Awareness and Management Program (C-ChAMP)

- Living with HIV (LHIV) Innovation Team
- TransFORmation of IndiGEnous PrimAry HEAlthcare Delivery (FORGE AHEAD)
- Innovation Supporting Transformation in Community-Based Primary
- Healthcare Research Project (iPHIT)
- Circumpolar Health Systems Innovation Team (CircHSIT)

Acknowledgements

We would like to thank each of the interview participants and the CBPHC teams for sharing their project documents and critical insights with us. We would also like to acknowledge the assistance provided by the Network Coordinating Office at the Primary and Integrated Health Care Innovations Network (PIHCIN) who supported recruitment efforts and guided the team in achieving our goal.

Funding

This Project was supported with funding from the Canadian Institutes of Health Research (CIHR) under the Strategy for Patient Oriented-Research (SPOR) initiative through the SPOR Evidence Alliance.

For questions about this report, please contact:

Jamie Park, Research Coordinator, Knowledge Translation Program, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, Canada

Email: Jamie.Park@unityhealth.to Phone: 416-864-6060 ext. 76219

Abbreviations

Access-MH	Atlantic Canada Children's Effective Service Strategies Mental Health
ACHRU	Aging, Community and Health Research Unit
CanIMPACT	Canadian Team to Improve Community-Based Cancer Care Along the Continuum
CAHS	Canadian Academy of Health Sciences Framework
СВРНС	Community Based Primary Health Care
C-ChAMP	Canadian Chronic Disease Awareness and Management Program
CIHR	Canadian Institutes of Health Research
CircHSIT	Circumpolar Health Systems Innovation Team
FORGE AHEAD	Transformation of Indigenous Primary Healthcare Delivery
iCOACH	Implementing Models of Primary Health Care for Older Adults with Complex Needs
iKT	Integrated Knowledge Translation
IMPACT	Innovative Models Promoting Access-to-Care Transformation
iPHIT	Innovation Supporting Transformation in Community-based Primary Healthcare Research Project
KT	Knowledge Translation
KTA	Knowledge to Action Framework
LHIV	Living with HIV Innovation Team
PACE MM	Patient-Centred Innovations for Persons with Multimorbidity
PCP	Primary Care Provider
РНС	Primary Health Care
PIHCIN	Primary and Integrated Health Care Innovations Network
TRANSFORMATION	Transforming CBPHC Delivery Through Comprehensive Performance Measurement and Reporting

Key definitions

Community Based Primary Health Care: covers the broad range of primary prevention (including public health) and primary care services within the community, including health promotion and disease prevention; the diagnosis, treatment, and management of chronic and episodic illness; rehabilitation support; and end of life care.

Health impacts: changes in patient-level health outcomes due to a CBPHC team's interventions. These can include improved quality of life, mental health indicators, and physical health indicators.

Integrated Knowledge Translation: model of research co-production, whereby researchers partner with knowledge users, the intended recipients of research evidence, throughout the research process.

CBPHC Intervention/Innovation: a program, service, or strategy that changes CBPHC healthcare practice or delivery at the individual, community, organizational, or health systems level.

Knowledge product: includes CBPHC team's published articles, books, book chapters, reports, presentations, conferences, workshops, media articles/interviews, and other knowledge tools (e.g., toolkits, genome maps).

Knowledge Translation: a process 'that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve... health...provide more effective health services and products and strengthen the health care system' (Canadian Institutes of Health Research, 2020.

Network-level impact: results that are achieved or influenced by the 'Network of 12 CBPHC teams' based on the 'Network' objectives and activities.

Partners: for this report, this includes any indi-

vidual, organization, community or group that collaborated, partnered, or were actively involved in planning or conducting research with a CB-PHC team (see below definition of 'Partnerships'). Also known as end-users, knowledge users, policy makers, community-partners, patient partners, caregiver partners, organizational-partners, academic-partners, governmental-partners.

Partnerships: the engagement by CBPHC teams with other groups or individuals in order to work collaboratively toward project goals. Includes any international partnerships (individual researchers or teams outside of Canada), patient partners, policy maker partners, partnerships with other researchers, advisory boards, community partners, and organizational partners.

Policy change: include health care system reorganization (healthcare restructuring), mandated healthcare practices, or direct involvement of policy makers in changing policies related to healthcare.

Project-level impact: results that are achieved or influenced by the individual project based on the project objectives and activities.

Trainees: includes undergraduate students, masters students, PhD students, postdoctoral fellows and research assistant/coordinators/other partners from communities.

Scaling-up interventions: expanding an intervention to reach more regions/individuals and broaden its effectiveness as a result.

Sustainability of interventions: additional funding obtained to continue or expand the intervention/innovation.

Table of Contents

Contributors	2
Acknowledgements	2
Land acknowledgement	2
Funding	2
Abbreviations	3
Key definitions	4
Executive summary	7
Introduction	9
Purpose of the CBPHC impact assessment	10
Methods	11
Data collection	11
Interviews	11
Document review	11
Data analysis	11
Interviews	11
Document review	11
Guiding frameworks	11
Results	15
1. Participants and documents	15
2. Overview of the CBPHC Innovation Teams and Network	16
2.1 Location of teams	16
2.2 Description of teams	17
2.3 Knowledge-to-Action Model categories of team activities	20
2.4 Description of Network activities	21
3. Overview of each CBPHC team	22
3.1 Innovative Models Promoting Access-to-Care Transformation (IMPACT)	23
3.2 Aging, Community and Health Research Unit (ACHRU)	24
3.3 Patient Centred Innovations for Persons with Multimorbidity (PACE in MM)	25

3.4 Implementing Integrated Care for Older Adults with Complex Health needs (iCOACH)	
3.5 Transforming CBPHC Delivery Through Comprehensive Performance Measurement and Reporting (TRANSFORMATION)	27
3.6 Atlantic Canada Children's Effective Service & Strategies in Mental Health (ACCESS-MH)	28
3.7 Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)	29
3.8 Canadian Chronic Disease Awareness and Management Program (C-ChAMP)	30
3.9 Living with HIV (LHIV) Innovation Team	31
3.10 TransFORmation of IndiGEnous PrimAry HEAlthcare Delivery (FORGE AHEAD)	32
3.11 Innovation Supporting Transformation in Community-Based Primary Health care Research Project (iPHIT)	
3.12 Circumpolar Health Systems Innovation Team (CircHSIT)	34
4. Impact of the CBPHC innovation teams	35
4.1 Knowledge	38
4.2 Capacity building	39
4.3 Informing decision making	40
4.4 Broad socio-economic and health impact	41
4.5 Partnerships	42
5. Factors that led to project and network success	44
6. Identified project and network challenges	45
7. Identified recommendations for the network	46
Summary	47
Recommendations for CBPHC network evaluations	47
Limitations	49
References	50

Executive summary

The Primary and Integrated Health Care Innovations Network (PIHCIN) commissioned the Knowledge Translation (KT) Program of St. Michael's Hospital-Unity Health Toronto to assess the individual and aggregate impact of the 12 Community Based Primary Health Care (CB-PHC) Innovation Teams.

The results of this activity are presented in this report and include:

- An overview of the CBPHC Innovation Teams' projects and CBPHC Network activities
- Summaries for each team's project including:
 - The project description;
 - Project impact organized by adapting the Canadian Academy of Health Sciences (CAHS) Framework categories of: Knowledge, Capacity-Building, Informing decision-making, Broad socioeconomic and health impacts, and Partnerships;
 - Research highlight
- An aggregate summary of CBPHC Team and Network-level impact organized by the adapted categories of the CAHS
- Participant identified factors that led to project and Network success
- Participant identified project and Network challenges
- Recommendations on how to evaluate future CBPHC research networks

From January to May 2021, we collected information regarding CBPHC team activities and impact through semi-structured interviews with members from each team and document reviews. We reviewed 278 documents and interviewed 22 participants with at least one representative from each team.

Collectively, the Innovation Teams produced 1306 knowledge products; involved 495 trainees, conducted 81 training initiatives, had an effect on 16 policies/guidelines, developed 24 innovations/interventions, spread/scaled innovations/ interventions to 518 communities/regions/sites, and developed over 184 partnerships. Overall, interview participants indicated that they were able to achieve their project objectives and that the projects had transformational effects on their individual knowledge and capacity-building as well as organizations/system-level changes in informing decision-making and broad socio-economic and health impacts. The largest perceived impact was the development of partnerships with both community based partners and other academic CBPHC researchers. Common factors for project success included the involvement of partners (patient, community, governmental), the availability of funds, and team dynamics/ leadership; factors that the led to an effective Network included the annual Network meetings, involvement of leadership, and strength of the sub-committees. Though there were a variety of challenges identified, a key challenge with the function of the CBPHC Network was perceived to be the timing to integrate the 'Common Indicator Project'.

Recommendations for future CBPHC research networks included continuing prioritization of stakeholder engagement with priority populations, focusing on the clarity and purpose of a network, grouping similar objectives together, reinvestment in CBPHC research, having realistic expectations for a Common Indicator Project, and evaluating research networks beyond classic academic metrics such as the number of publications and number of citations.

Furthermore, in evaluating future research networks, we propose:

- 1. Developing a conceptual framework of the purpose and aims of the network and the network evaluation in close consultation with both relevant stakeholders and partners
- 2. Developing a logic model (or strategy map) to inform the design of the network evaluation plan

- 3. Selecting an evaluation framework in the early stages of the evaluation plan
- 4. Early and ongoing communication and documentation of network planning and activities
- 5. Incorporating a multidimensional approach and adopt existing narratives and quantitative metrics for a comprehensive method of impact assessment



Introduction

Community-based primary health care (CBPHC) encompasses a broad range of preventative, public health, and primary care services within the community and is usually the first point of contact with the health system for most Canadians. Services can include health promotion and disease prevention; the diagnosis, treatment, and management of chronic and episodic illness; rehabilitation support; and end of life care. This complex system requires coordination and collaboration among diverse stakeholders (nurses, physicians, pharmacists, social workers, researchers, health-care professionals, policy-makers, health system managers, patients and families).

To support this care delivery model, in 2012, the Canadian Institutes of Health Research (CIHR) funded, in 2012, a five-year signature initiative in CBPHC research (CIHR, 2021b). The initiative was co-led by the CIHR Institute of Health Services and Policy Research and Institute of Population and Public Health with the support of a number of partners; Fonds de recherche du Québec - Santé, Michael Smith Foundation for Health Research, Australian Primary Health Care Research Institute, and the Health Research Council of New Zealand (CIHR, 2021b). The initiative was composed of three foundational components: Innovation Teams, a National CBPHC Network (i.e., the Primary and Integrated Health Care Innovations Network (PIHCIN)), and personnel awards in CBPHC (CIHR, 2021c).

This report focuses on the Innovation Teams; 12 of which were selected to conduct programmatic cross-jurisdictional research projects designed to improve access to CBPHC for priority populations and to improve quality of care for chronic disease prevention and management (CIHR, 2021a). The teams were composed of interdisciplinary, inter-professional and cross-jurisdictional researchers, clinicians, decision makers and patients/citizens (CIHR, 2021a). The objectives of the teams were to: 1) develop, compare and/or spread innovative models of CBPHC; 2) scale-up successful models; 3) build capacity in CBPHC; 4) evaluate common sets of outcome indicators and 5) improve competitiveness (CIHR, 2021a). Five teams focused on general primary care transformation challenges, four focused on managing specific conditions within the context of primary care and three teams focused on conducting primary care transformation within Indigenous communities. The CBPHC 'Network' (hereby referred to as 'the Network') was composed of formalizing links between the 12 teams through a series of annual Network meetings, cross-team sub-committees, and cross-team publications (CIHR, 2021a).

Since funding ended in 2018, each team has conducted internal evaluations of impact (CIHR, 2021a) however there has been no formal, aggregate evaluation of the Network, its performance and impact to date. Thus, PIHCIN commissioned the Knowledge Translation Program (KTP) at Unity Health Toronto to conduct an assessment of the impact of the Network, comprising the 12 CBPHC Innovation Teams.

Purpose of the CBPHC impact assessment

The purpose of this assessment is to document CBPHC Innovation Teams' activities, assess their individual and collective impact, and provide a set of recommendations for evaluating community based primary health care research networks.

This assessment has been divided into 6 parts:

- An overview of the CBPHC Innovation Teams' projects and CBPHC Network activities
- Participant-identified factors that led to project and Network success
- Summaries for each team's project including:
 - the project description;
 - project impact organized by adapting the Canadian Academy of Health Sciences (CAHS) Framework categories of: Knowledge, Capacity-Building, Informing decision-making, Broad socio-economic and health impacts, and Partnerships; and a research highlight

organized by the adapted categories

of the CAHS

Participant-identified project and Network challenges

Recommendations on how

to evaluate future CBPHC research networks

An aggregate summary of CBPHC
Team and Network-level impact

Methods

Data collection

Interviews

From January – May 2021, we used a purposive sampling strategy to recruit CBPHC Innovation Team members (1-3 members per team) to participate in an interview. An initial recruitment email was sent to the principal investigator(s) (PI(s)) of each team. The PI's were also asked to circulate the invitation to participate among other members (ex. co-investigators, research staff members, trainees, and patient partners). In some cases, CBPHC innovation team members who were not PI's were individually contacted.

Role	Number of Interviewees
Principal Investigators	12
Co-Investigators	4
Trainees	3
Patient Partner	1
Program Coordinator/Manager	2

A semi-structured interview guide was created by the KTP in partnership with key PIHCIN stakeholders and included questions on the specific project goals/objectives, and participants' perspectives on the benefits, factors of success/challenges, types of partnerships, and lessons learned from participating in the CBPHC Network (Appendix A). Interviews were audio-recorded and conducted by an experienced interviewer over teleconference platforms (Zoom or Cisco Webex) following participant consent.

Document review

Documents were identified by the study team using two strategies: (1) all interview participants were asked to identify any relevant documents; and (2) a rigorous search strategy of websites, online search engines and academic databases. The types of documents collected in-

cluded original grant proposals, website pages describing the team and/or approaches, publications, conference proceedings, poster presentations, and interim or final reports. Two reviewers independently searched websites using pre-specified search criteria related to the CBPHC teams and then independently screened all the collected documents for inclusion or exclusion. Documents were **included** if they pertained to any activities conducted by the CBPHC team. Articles were **excluded** for the following reasons:

- i. Published in a language other than English;
- ii. Related to funding outside of the CBPHC Innovation grant.

Data analysis

Interviews

Interviews were transcribed verbatim and analyzed using a thematic analysis approach. Two experienced researchers developed a codebook using three transcripts and double-coded 20% of the remaining transcripts with a goal of reaching >75% agreement. Any disagreements were resolved through consensus meetings. The remaining transcripts were coded by a single researcher; all coding was completed in NVivo 11. The findings of the impact/outputs were compiled to generate themes.

Document review

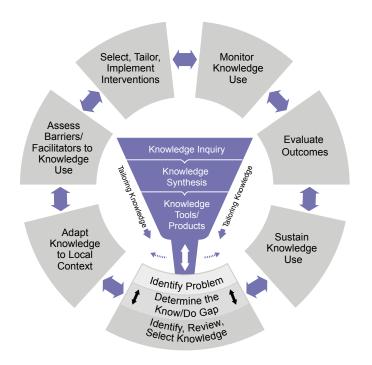
The study team employed a rigorous abstraction and analysis process. All study team members independently piloted an abstraction template (Appendix A) for a set of documents for two teams. Team members then met and reviewed coding to ensure 100% agreement, after which two reviewers independently abstracted data. Study team members met at regular intervals throughout data analysis, to discuss any indeterminate data.

A content analysis approach was used to examine and abstract content from documents based on pre-defined categories: description of the project, impact of the individual team, perception and impact of network, and suggestions for network evaluation.

Guiding frameworks

We categorized the project activities using the 'Knowledge to Action' (KTA) framework which specifies steps or phases for implementing or applying research into practice. We use the KTA as it is based on over 30 planned action theories, was developed in Canada, and is one of the most frequently cited conceptual frameworks for knowledge translation including by the CIHR (Field et al., 2014; Graham et al., 2006). The KTA includes 10 steps grouped into two distinct objectives: 1) a knowledge generation funnel, through which primary research is conducted and synthesized; and 2) an action cycle, through which the knowledge is implemented, evaluated and sustained (Figure 1).

Figure 1. Knowledge-to-Action (Graham et al. 2006)



There is little consensus on which tool or framework should be used to assess impact of research networks. Selection of a relevant framework is complex given the heterogeneity in framework objectives (e.g., accountability vs. advocacy) and conceptual and philosophical foundations (e.g., perspective vs. realist; degree of impact vs. time scale) (Banzi et al., 2011; Brownson et al., 2009).

For this assessment, we chose to organize teams' impact using a modified version of the Canadian Academy of Health Sciences (CAHS) Framework. It was selected as the guiding framework as it was designed for the Canadian health research context and reflects the four pillars of health research described by the CIHR (Graham et al., 2018). The CAHS framework includes categories of: Knowledge, Capacity-building, Decision-making, Health impacts, and Broad socioeconomic impact. For each category, a menu of metrics and measures is offered, and users are encouraged to draw on these to suit their circumstances. We combined and adapted the CAHS framework to produce a conceptual framework that would best fit our purpose and resources. For example, for the 'health impacts' and 'broad socioeconomic impacts' categories where links to research findings are much harder to identify, we merged the categories to represent changes in health, wealth, well-being, and social circumstances as 'Broad socioeconomic and health' impact. Where relevant, we identified additional measures to describe the impact of the CBPHC teams. Each impact level was linked to sub-categories or indicators to further facilitate assessment of the type of impacts that occur at each level.

Operationalized definitions of indicators

Knowledge: Defined as contributing new insights/ information to the known CBPHC literature and improving the awareness/knowledge of evidence

through knowledge translation activities. Knowledge translation is defined as the "dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (CIHR, 2020).

• The definitions of "knowledge products" included: the number of published articles, books, book chapters, reports, policy briefs, presentations, organization/hosting of conferences, workshops that were conducted, media articles/interviews, and other knowledge tools (e.g., toolkits) for each CBPHC team.

Capacity-building: Defined as supporting trainees, early career researchers, partners or stakeholders to learn and apply new skills. This outcome was captured by extracting the following data: the number of trainees involved with each team, the number of stakeholder groups trained (e.g., policy makers, healthcare providers), and the number of training courses/educational initiatives provided.

• The definition of "trainees" included undergraduate students, masters students, PhD students, postdoctoral fellows and research assistants/coordinators and community members who received ongoing training from the CBPHC Innovation Teams.

Informing decision-making: Defined as changes in clinical, organizational, or governmental practice, process, or policy. This was captured in the data by extracting information on the development/implementation of guidelines, interventions, or policies.

- "Interventions" were defined as changes in healthcare practice adopted through research/pilot studies, or organizational change
- "Practice change" was defined as involvement in an intervention as a service provider, or adoption of methodological changes

- to research practice
- "Changes at the policy level" could include health care system reorganization (healthcare restructuring), mandated healthcare practices, or direct involvement of policy makers in changing policies related to healthcare.

Broad socio-economic and health impact: Defined as the effect on socio-economic and health changes at the local level including: the scaling up of interventions (increased scale/spread), health impacts, and the sustainability of interventions.

- "Launch of interventions" was defined as the implementation of changes in healthcare practice (interventions) at the organization level, community level, and/or through research/pilot studies.
- "Scaling up of interventions" was defined as expanding an intervention to reach more regions/individuals and broaden its effectiveness as a result
- "Enhanced patient outcomes due to interventions" involved improving health outcomes at the patient level as a result of changes in healthcare (interventions) implemented at the organization level, community level, and/or through research/pilot studies. Enhanced outcomes included reports of improved quality of life, improvements in mental health (i.e., depression, hope), and improved physical health (e.g., decreased cholesterol levels, blood pressure, etc.)
- "Sustainability of interventions" was captured through additional funding obtained for continuing the intervention
- "Reduced cost due to interventions" was defined as any of the following: reports of actual cost reduction due to the implementation of an intervention (change in healthcare practice); lower cost of the in-

tervention in comparison to another similar practice; or lower expected/actual cost to the healthcare system due to potential/actual benefits of the intervention (e.g., reduced hospital admissions).

"Additional funding" was defined as funding received to continue or expand on work initiated through the CBPHC Innovation Teams (includes in-kind and financial contributions).

Partnerships: Defined as engagement by CB-PHC teams with other groups or individuals to work collaboratively toward project goals. Partnerships at the network level were defined differently, as engagement by CBPHC Innovation Network members with those outside of their

team for the purpose of building connections or collaborating on CBPHC-related work.

There were many different types of partners at the team level.

• The "types of partnerships" captured included: international partnerships (individual researchers or teams outside of Canada), partnerships with clinicians and health care practitioners, patient partners, policy maker partners, partnerships with other researchers, advisory boards, community partners, and organizational partners. We also captured whether partnerships/collaborations were sustained past the end of the 2018 funding timeline.



Results

1. Participants and documents

A total of 278 unique data sources (e.g., articles, documents, and webpages) were included in the document review. We interviewed 22 participants with each team being represented by at least one participant (Table 1).

Table 1. Total number of interview participants and documents reviewed by CBPHC Team

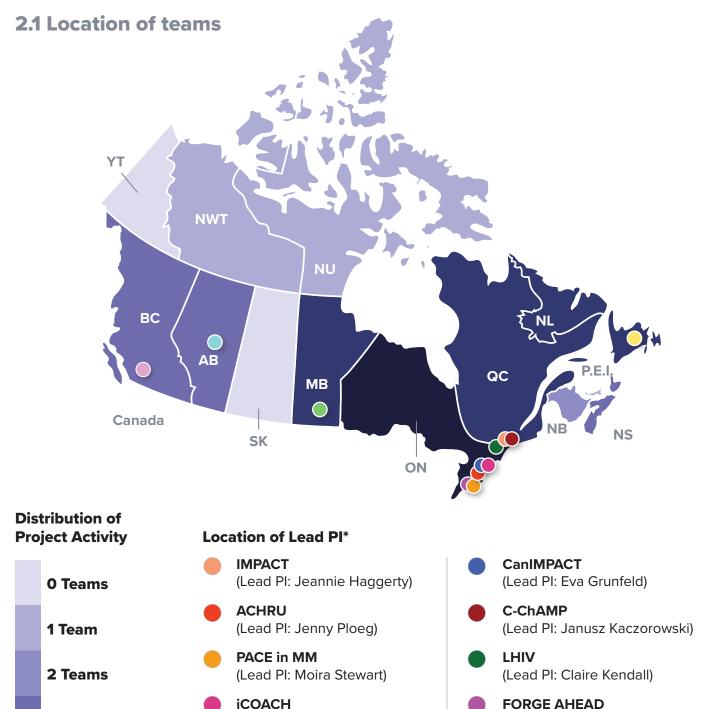
Team	Number of Interview Participants	Number of Documents Reviewed
IMPACT	2	11
ACHRU	2	16
PACE MM	2	15
iCOACH	3	43
TRANSFORMATION	2	26
Access MH	2	19
CanIMPACT	2	39
C-ChAMP	1	11
LHIV	2	45
FORGE AHEAD	2	11
iPHIT	1	8
CircHIST	2	29
General*		5
TOTAL	22***	278

^{*}General = documents not associated with a specific team (e.g., CIHR website, CBPHC meeting notes)

^{**}Please note: Team names are hyperlinked to detailed team descriptions in Appendix B.

^{***}Since one interview participant was interviewed for two teams, the total number of interviewees is 22.

2. Overview of the CBPHC Innovation Teams and Network



4 Teams

5 Teams

9 Teams

Figure 2. Distribution of the 12 CBPHC Innovation teams according to project activity and location of the Nominated Principal Investigator's academic organization

(Lead PI: Walter Wodchis)

TRANSFORMATION

ACCESS-MH

(Lead PI: Sabrina Wong)

(Lead PI: Marshall Godwin)

(Lead PI: Stewart Harris)

(Lead PI: Alan Katz)

(Lead PI: Kue Young)

iPHIT

CircHSIT

^{*}Full team names can be found on Page 2.

2.2 Description of teams

Table 2. Description of teams

CBPHC Category	Team Name	Team Description	Project Aim/ Objectives	Target Population	International	Additional Area(s) of Focus
	Innovative Models Promoting Access-to-Care Transformation (IM-PACT)	A collaboration with six sites across Canada and Australia. Each site was headed by a research lead and a local coordinator. To design, imple evaluate organizations to innovations to access to appropriate mary health car for priority populations.		Socially priority patients with compromised access to CBPHC services.	Yes	
	Aging, Community and Health Research Unit (ACHRU)	Composed of 50 interprofessional researchers from seven universities across Canada.	To improve access to health care, quality of life, and health outcomes through innovative com- munity-based interven- tions	Older adults aged 65 years and older with multiple chronic conditions and their family/friend caregivers.		Chronic diseaseOlder populationMulti-morbidityGender analysis
General CBPHC	Patient Centred Innovations for Persons with Multimorbidity (PACE in MM)	Composed of team members that represent nine disciplines including two decision-makers that are leads of their regional health authority.	To improve patient-centered care for patients with multimorbidity.	Patients with multi-morbidities (3+ chronic conditions) aged 18–80		 Chronic disease Multi-morbidity Gender analysis
	Implementing Integrated Care for Older Adults with Complex Health needs (iCOACH)	olementing Integrated e for Older Adults perts and decision makers from three jurisdictions		Older adults with co-existing, multiple chronic conditions.	Yes	• Older population
	Transforming Community-Based Primary Healthcare through Comprehensive measurement and reporting (TRANSFORMATION)	Composed of interdisci- plinary researchers, deci- sion-makers, and health professionals.	To improve the science and reporting of CBPHC performance in Canada.	Organizational leads, health care providers, and patients from family physician practices		Multi-morbidity

CBPHC Category	Team Name	Team Description	Project Aim/ Objectives	Target Population	International	Additional Area(s) of Focus
	Atlantic Canada Children's Effective Service Strategies -Mental Health (ACCESS-MH)	Composed of primary health care physicians, pol- icy makers and researchers from the four Atlantic Canada provinces.	To support improved access and experience of child/youth mental health services in Atlantic Canada.	Children/youth with mental health and oppositional be- havioural problems and their caregivers		Children/YouthMental health
ons	Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIM-PACT)	Composed of a pan-Ca- nadian group of re- searchers, primary care providers (PCPs), cancer specialists, patients and caregivers.	To identify factors associated with poor coordination of cancer care, and develop an intervention aimed at improving cancer care coordination.	Breast and colorectal cancer patients and health care providers		Chronic diseaseOlder population
Specific conditions	The Canadian Chronic Disease and Awareness Program (C-ChAMP)	A multi-disciplinary and inter-sectoral team that included experts from various fields, decision makers, and patients.	To improve community and population-based prevention and management of chronic diseases	Younger adults, immigrant communities, older adults in subsidized housing, and individuals in large urban and suburban communities		Chronic diseaseOlder population
	Living with HIV (LHIV) Innovation Team	Composed of researchers, policy makers, health professionals, and people living with HIV from each of the three provinces involved (Manitoba, Ontario, Newfoundland and Labrador).	To conduct research and interventions for HIV care to be provided in the CBPHC sector, while being integrated with specialist HIV care.	People living with HIV		• Infectious disease

CBPHC Category	Team Name	Team Description	Project Aim/ Objectives	Target Population	International	Additional Area(s) of Focus
S	TransFORmation of IndiGEnous PrimAry HEAlthcare Delivery (FORGE AHEAD)	A multi-disciplinary team that included First Nations community representatives, health- care providers, academic researchers, and policy/ decision makers.	To develop and evaluate community-driven primary healthcare models that enhance chronic disease management in First Nations communities.	First Nations communities		Multi-morbidity
Indigenous focus	Innovation Supporting Transformation in Com- munity-Based Primary Healthcare Research Project (iPHIT)	Comprised of academic primary care researchers and a dynamic team of collaborators including 8 First Nations communities.	To transform primary health care through suggestions for innovations of First Nation communities based on their health and needs.	Eight First Nation rural/remote commu- nities in Manitoba		
	Cicrumpolar Health Systems Innovation Team (CircHSIT)	Composed of researchers, clinicians and decision-makers; 2 northern-based research centres; and guidance from an elder council.	To provide research evidence to enable the transformation of PHC in remote northern commu- nities in Canada	Residents of Canada's northern regions and comparable remote settings in circumpo- lar regions	Yes	

2.3 Knowledge-to-Action Model categories of team activities

Table 3. Team activities categorized according to the KTA

KTA Cycle	Activity	IMPACT	ACHRU	PACE in MM	iCOACH	TRANSFORMATION	ACCESS-MH	CanIMPACT	C-ChAMP	LHIV	FORGE AHEAD	iPHIT	CircHSIT	Total number of teams
Knowledge	Knowledge inquiry*	•				•		•		•	•	•		12
creation	Knowledge synthesis**													10
	Knowledge tools/product***			•		•		•		•	•			11
Action cycle	Identify problem													12
	Determine the know/do gap													12
	Identify, review, select knowledge	•	•	•	•	•	•	•		•	•	•	•	11
	Adapt knowledge to local context				•					•	•	•	•	5
	Assess barriers/facilitators to knowledge use	•	•	•	•	•	•	•			•			8
	Select, tailor, implement interventions	•	•	•	•	•		•	•	•	•		•	10
	Monitor knowledge use					•				•				8
	Evaluate outcomes													8
	Sustain knowledge use													7

^{*}Knowledge inquiry = individual research studies (informs future studies and contributes to larger evidence base)

^{**}Knowledge synthesis = synthesized results from individual research studies (e.g., systematic review, scoping review, meta-analyses)

^{***}Knowledge tools/product = use of synthesized knowledge to present evidence in concise and user-friendly formats (e.g., clinical practice guidelines, decision aids/videos)

There were similarities across teams with respect to type of research activities conducted by teams. Most teams engaged in the knowledge creation process, with all 12 teams engaging in knowledge inquiry. All teams engaged in problem identification and identifying the knowldo gap. Despite the implementation of interventions by 10 teams, not all of these teams engaged in actively adapting knowledge to the local context, assessing barriers and facilitators to interventions, or monitoring knowledge use. Although the KTA cycle is an iterative process, most teams took a linear approach within the assessed funding period. The evaluation of outcomes is still in progress for some teams. Some teams may require additional funding in order to reach the stage of evaluating outcomes and sustaining knowledge use.

2.4 Description of Network activities

Participants described the Network activities to include: 1) the annual Network meetings, 2) the cross-team sub-committees (i.e., for the 'Common Indicator Project' and capacity-building committee for trainees), and 3) identifying

cross-team publications/dissemination opportunities. Participants' engagement with the Network ranged from 'not being aware of the other 11 teams' or 'unaware of the purpose of the Network' to a high level of engagement with participants attending meetings and collaborating on Network sub-committees. The Common Indicator Project was a Network activity where teams collaborated to evaluate a set of common health system indicators to measure the impact and benefits of the CBPHC research investment on the provision of primary health care. Following a review of existing primary health care indicators (e.g. Canadian Institutes of Health Information) and the research protocols for each of 12 Teams, the working group identified, through a consensus building process, several dimensions important to primary health care including: Access, Comprehensiveness, Coordination, Effectiveness, Equity and Health Care Costs. These were defined in the early stages of the granting period and were communicated to teams post funding and project start dates.



3. Overview of each CBPHC team

In this section, we present a summary of facts and figures for each of the 12 CBPHC Innovation Teams developed from document reviews and interview analysis. Please refer to <u>Appendix B</u> for additional team details and information.



3.1 Innovative Models Promoting Access-to-Care Transformation (IMPACT)

Characteristics

Team: Dr. Jeannie Haggerty with colleagues and partners from Ontario, Alberta, Quebec, and Australia

Target population: Socially prioritized patients; broadly defined as groups whose demographic, geographic, economic and/or cultural characteristics impede or compromise their access to primary health care (PHC) services.

Objectives: To design, implement and evaluate organizational innovations to improve access to appropriate PHC for priority populations. The IMPACT program had four sub-objectives:

- Establish a network of partnerships between PHC researchers, providers and consumers
- Identify organizational interventions to improve access to appropriate care for priority populations
- Support the selection, adaptation and implementation of interventions; and
- Evaluate the effectiveness and efficiency of the interventions and the IMPACT program

Research highlight

Interventions Addressing Priority Gaps in Access to PHC for Priority Populations

The IMPACT team formed Local Innovation Partnerships (LIPs) with decision makers, researchers, clinicians and members of priority communities in six different jurisdictions to develop the following interventions:

- Telephone outreach from trained volunteer navigators to help patients attach to newly-assigned family physicians (Quebec, CA)
- Lay bilingual navigators to support individuals to reach community resources (Ontario, CA)
- Pop-up health & social service events for under-served communities (Alberta, CA)
- A web portal to improve type 2 diabetes care (New South Wales, AU)
- Support within Eldercare Residential Aged Care Facilities (South Australia, AU)
- health brokerage service to match patients to PHC providers (Victoria, AU)

The evaluation of these interventions is still in progress.

https://doi.org/10.1136/bmjopen-2018-027869

Impact



Knowledge

13 publications124 presentations2 KT tools (imple-

2 K1 tools (implementation guides)

1 Report

10 Workshops

1 article/interview in the media



Capacity-building

49 investigators 18 trainees

11 training initiatives



Partnerships

9 organizations



Informed decision-making

5 interventions



Broad socio-economic and health

Additional funding obtained



Team website:

https://www.impactresearchprogram.com/

3.2 Aging, Community and Health Research Unit (ACHRU)

Characteristics

Team: Dr. Jenny Ploeg with colleagues and partners from Ontario, Alberta, Quebec, and Prince Edward Island

Target population: Older adults aged 65 years and older with multiple chronic conditions (e.g. stroke, dementia, and type 2 diabetes mellitus) and their family/friend caregivers.

Objectives: To promote optimal aging at home for older adults with multiple chronic conditions (MCC) and to support their family caregivers through five sub-objectives:

• Co-design of interventions

Aging, Community

and Health

- Examination of the feasibility of new interventions
- Determination of the effectiveness of interventions
- Examination of intervention context and implementation barriers/facilitators
- Use of integrated knowledge translation strategies to support the use and sustainability of interventions

Research highlight

The ACHRU-Community Partnership Program (CPP)

The ACHRU team developed a client-driven intervention to promote self-management among community-living older adults with type 2 diabetes mellitus (T2DM) and MCC. In Ontario, the ACHRU-CPP improved quality of life and self-management. The program reduced depressive symptoms in older adults with T2DM and comorbidity without increasing total health care costs. This program is also being tested in Quebec and Prince Edward Island, with a focus on implementation, evaluation and scale up.

https://achru.mcmaster.ca/research-studies/client-driven-intervention-support-self-management-among-community-living-older

Impact



Knowledge

- 32 publications
- 22 reports
- 325 presentations
- 1 workshop
- 7 articles/interviews in the media
- 3 KT tools (2 mobile applications, 1 manual)



Capacity-building

- 39 investigators
- 24 trainees
- 27 undergraduate students
- 1 training initiative



Partnerships

39 organizations



Team website:

https://achru.mcmaster.ca/



Informed decision-making

- 1 policy-maker meeting
- 1 policy effects
- 3 interventions



Broad socio-economic and health

Additional funding obtained 1 scale and spread initiative

3.3 Patient Centred Innovations for Persons with Multimorbidity (PACE in MM)

Characteristics

Team: Dr. Moira Stewart with colleagues and partners from Ontario, Quebec, Manitoba, and Nova Scotia

Target population: Patients with multi-morbidities (3+ chronic conditions) aged 18–80 years

Objectives: To improve patient-centered care for patients with multi-morbidity. The sub-objectives were to:

- Identify factors responsible for the success or failure of current chronic disease prevention and management (CDPM) initiatives
- Transform consenting CDPM initiatives identified by aligning them to promising innovations on patient-centred care for multi-morbidity patients, and testing these new innovations in at least two jurisdictions to foster the scaling up of innovations

Research highlight

Connecting People with Multi-morbidity to Inter-professional Teams Using Telemedicine

A pragmatic randomized trial conducted in Ontario found that the Telemedicine Impact Plus (TIP) intervention (an innovative multi-provider case conference with a care plan) showed improvements not for all patients but only for patients who had an annual income of ≥C\$50000:

https://doi.org/10.3399/bjgp21X714293

A Quebec trial found that the intervention (an important innovation in scaled up in primary care; an interdisciplinary team providing self-management support to patients) showed a neutral effect on the primary outcomes and substantial improvement in 2 health behaviors as secondary outcomes:

https://doi.org/10.1370/afm.2650

Impact



Knowledge

17 publications

4 book chapters

2 books

40 presentations

10 workshops

9 articles/interviews in the media

1 KT tool (toolkit)



Capacity-building

23 investigators 201 trainees

57 training initiatives



Partnerships

3 organizations 4 Health Link sites



Informed decision-making

1 practice guideline

2 interventions



Broad socio-economic and health

Additional funding obtained 1 scale and spread initiative



Team website:

http://paceinmm.recherche.usherbrooke.ca/

3.4 Implementing Integrated Care for Older Adults with Complex Health needs (iCOACH)

Characteristics

Team: Dr. Walter Wodchis with colleagues and partners from Ontario, Quebec, and New Zealand

Target population: Older adults with co-existing, multiple chronic conditions, including socially and economically priority populations.

Objectives: The aim of the research program was to understand how to scale-up successful innovative models of CBPHC. More specifically, their research sought to better understand the steps to implementing innovative CBPHC models that address health and social needs and improve outcomes for older adults with complex care needs.

Research highlight

Evaluating the Spread/implementation of Innovative Cases

The iCOACH team conducted 9 case studies in Ontario, Quebec and New Zealand to understand policy context, implementation, and experiences of providers and patients with integrated care. The findings were used to create four practice guides for providers and organizations aiming to implement a connected health care system centered around patients, families and caregivers which have been foundational to the development and implementation of Ontario Health Teams. The iCOACH team also continues to work with implementation sites to adapt and spread innovative models of integrating care. iCOACH advanced our understanding of how to successfully implement integrated care and how to study integrated care in the community through it's comprehensive study of multiple cases across multiple jurisdictions

https://hspn.ca/hsprn-practice-guide-on-implementing-integrated-care/

Impact



Knowledge

2 books/book chapters

- 1 conference/ symposium hosted/ organized
- 42 publications
- 9 presentations
- 3 workshops
- 1 KT tool (toolkit)



Capacity-building

36 investigators 3 trainees

1 training initiative



Partnerships

3 organizations



Informed decision-making

1 policy meeting

4 practice guides

1 intervention



Broad socio-economic and health

Additional funding obtained 1 scale and spread initiative



Team website:

https://cihr-irsc.gc.ca/e/50370.html

3.5 Transforming CBPHC Delivery Through Comprehensive Performance Measurement and Reporting (TRANSFORMATION)

Characteristics

Team: Dr. Sabrina Wong with colleagues and partners from British Columbia, Ontario, Nova Scotia, United Kingdom and Australia

Target population: Health care decision-makers to better use evidence in managing primary care in Canada

Objectives: To improve the science and reporting of CBPHC performance in Canada. The research program's activities revolves around four major sub-objectives:

- Compare measures of CBPHC performance and healthcare equity between three regions in Canada
- Examine contextual factors that may explain variation between regions
- Develop and evaluate an approach to national reporting of CBPHC performance based on priorities and optimal reporting formats
- Identify innovations of service delivery associated with better CBPHC performance and healthcare equity

Research highlight Automated Survey For Primary Care Patients

The team developed and implemented an automated survey for primary care patients in three regions across Canada (British Columbia, Ontario, Nova Scotia). The automated survey also allowed providers to choose and share health promotion messages to specific population groups. In addition to being cost-effective, it was found that surveys sent through email was preferred by patients and had a higher response rate than those sent over phone. Five follow up research projects totaling \$1,500,000 have been funded to use this data collection infrastructure in 460 family physician practices.

https://doi.org/10.2196/21240

Impact



Knowledge

13 publications

3 reports

43 presentations

1 articles/interviews in the media

2 KT tools (suite of survey tools, performance measurement framework)



Capacity-building

22 investigators 3 trainees

1 training initiative



Partnerships

14 organizations



Informed decision-making

1 set of web tools
1 intervention



Broad socio-economic and health

Additional funding obtained



Team website:

http://transformphc.sites.olt.ubc.ca/

3.6 Atlantic Canada Children's Effective Service & Strategies in Mental Health (ACCESS-MH)

Characteristics

Team: Dr. Marshall Godwin with colleagues and partners from New Brunswick, Newfoundland and Labrador, Nova Scotia, and Prince Edward Island

Target population: Children and youth with mental health and oppositional behavioural problems and their caregivers in the four Atlantic provinces

Objectives: To support improved access and experience of, child/youth mental health services in Atlantic Canada. The project specifically focuses on the following five highly prevalent child and youth mental health conditions: autism spectrum disorder (ASD), conduct disorder, eating disorders, anxiety and depression

Research highlight

The Use of Patient Journeys for Youth

The team developed a conceptual synthesis of the literature that found youth journeys in mental health were often fractured and non-linear; barriers and facilitators existed at personal and systemic levels and often in a paradoxical fashion; and that schools were crucial locations in youth journeys.

They indicated how journey approaches to youth mental health respects the lived experiences and vast knowledge of youth with mental health challenges, and could support the implementation of Canada's mental health strategy.

https://doi.org/10.7870/cjcmh-2017-026

Impact



Knowledge

10 publications71 presentations3 workshops2 KT tools (series of tools for service providers; online

2 KT tools (series of tools for service providers; online resources for youth families, and researchers)



Capacity-building

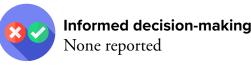
15 investigators
28 trainees

2 training initiatives



Partnerships

6 organizations





Broad socio-economic and health

None reported



Team website:

https://access-mentalhealth.ca/

3.7 Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)

Characteristics

Team: Dr. Eva Grunfeld with colleagues and partners from Ontario, Quebec, Alberta, Nova Scotia, British Columbia, United States, and Australia

Target population: Breast and colorectal cancer patients and health care providers

Objectives: To identify factors associated with poor continuity and coordination of cancer care in seven provinces, engage patients and caregivers, and develop an intervention aimed at improving care coordination for patients with cancer.

Research highlight Implementation of eOncoNote

Based on recommendations from a consultative workshop, the team identified 'Champlain BASE eConsult', a secure online communication platform, as an appropriate innovation to coordinate care between PCPs and cancer specialists. A modification of this service, 'eOncoNote', has been created to facilitate two-way communication between PCPs and cancer specialists. This intervention has been implemented since 2018 in both Ontario and Newfoundland and Labrador. Within this program of research, eConsult has been applied for genetic consultations. The evaluation of these implementation activities is still in progress.

https://canimpact.utoronto.ca/streams-and-themes/intervention-study/

Impact



Knowledge

- 31 publications
- 2 book chapters
- 3 reports
- 98 presentations
- 2 workshops
- 3 articles/interviews in the media
- 2 KT tools (toolkit, genomic medicine maps)



Capacity-building

38 investigators 13 trainees



Partnerships

2 organizations



Informed decision-making

1 practice guideline 1 intervention



Broad socio-economic and health

Additional funding obtained



http://canimpact.utoronto.ca



3.8 Canadian Chronic Disease Awareness and Management Program (C-ChAMP)

Characteristics

Team: Dr. Janusz Kaczorowski with colleagues and partners from Quebec, Alberta, and Ontario

Target population: Younger adults (Quebec and Ontario), immigrant communities (South Asians in Ontario), older adults in subsidized housing (Ontario and Quebec), and individuals in large urban and suburban communities (Alberta, Ontario and Quebec).

Objectives: To improve community and population-based prevention and management of chronic diseases (e.g., cardiovascular disease, diabetes, blood pressure, atrial fibrillation). C-ChAMP aims to continue and adapt the Cardiovascular Health Awareness Program (CHAP) program across a wider array of populations and settings.

Research highlight

The CHAP Through Emergency Medical Services (CHAP-EMS)

The team developed an innovation with paramedics on modified duty (e.g., injured), to deliver a weekly one-on-one drop-in session to older adult residents living in subsidized housing. The main elements focused on checking blood pressure, performing risk assessments, providing health education, and referrals. They found the CHAP-EMS program to reduce emergency calls (by 25%), reduce blood pressure, and lowered diabetes risk after one year of implementation.

https://doi.org/10.1186/s12873-017-0119-4

Impact



Knowledge

11 publications 1 KT tool (C-CHAMP IPhone/IPad application to manage cardiovascular diseases)



Capacity-building

27 investigators1 training initiative



Partnerships

8 organizations



Informed decision-making

2 interventions



Broad socio-economic and health

Additional funding obtained 1 scale and spread initiative

Team website:

https://cihr-irsc.gc.ca/e/47157.html

3.9 Living with HIV (LHIV) Innovation Team

Characteristics

Team: Dr. Claire Kendall with colleagues and partners from Ontario, Newfoundland and Labrador, and Manitoba

Target population: Responding to the needs of people living with human immunode-ficiency virus/ acquired immunodeficiency syndrome (HIV/AIDS).

Objectives: To conduct research and interventions surrounding the move of HIV care to the community-based primary health care (CB-PHC) sector, while being integrated with specialist HIV care. The four specific sub-objectives are to:

- Create a better understanding of the health, healthcare utilization, and quality of care of persons living with HIV;
- Implement an integrated care model for HIV care delivery;
- Examine patients' perspectives of a shift to a primary healthcare approach for HIV care; and
- Build and support with data and infrastructure, the Living with HIV (LHIV) Innovation Team

Research highlight

Expansion of the Champlain BASE eConsult Service

The partnerships developed between the LHIV Innovation Team and the Champlain BASE™ eConsult team facilitated the national spread and scale of the Champlain BASE™ eConsult service. eConsult is a secure web-based tool that allows physicians and nurse practitioners timely access to specialist advice for all patients and often eliminates the need for an in-person specialist visit. This service is now available at no cost to patients or healthcare providers in many provinces, with ongoing development work in other provinces and territories. This service and partnership has contributed to enhanced HIV primary care.

https://www.champlainbaseeconsult.com/

Impact



Knowledge

51 publications

1 book

2 reports

150 presentations

4 workshops

8 articles/interviews in the media

1 KT tool (toolkit)



Capacity-building

49 investigators 25 trainees

2 training initiatives



Partnerships

51 organizations



Informed decision-making

2 interventions



Broad socio-economic and health

Additional funding obtained 1 spread and scale initiative



Team website: https://www.lhiv.ca/

3.10 TransFORmation of IndiGEnous PrimAry HEAlthcare Delivery (FORGE AHEAD)

Characteristics

Team: Dr. Stewart Harris with colleagues and partners from Ontario, Alberta, Quebec, Newfoundland, Manitoba, and British Columbia.

Target population: Community members and clinical teams providing healthcare services to patients in First Nations (FN) communities with type 2 diabetes

Objectives: To develop and evaluate community-driven, culturally relevant, primary healthcare models that enhance chronic disease management and appropriate access to available services in First Nations communities across Canada. The five sub- objectives include to:

- Assess the current healthcare delivery, funding models, and best practices used in FN communities in Canada.
- Assess community and clinical readiness to address and adopt chronic disease care.
- Enhance patient access to available community resources for chronic disease care.
- Implement and evaluate community and clinical quality improvement initiatives
- Develop sustainment strategies and a scale-up toolkit to improve chronic disease management in FN communities.

Research highlight

Diabetes Registry and Clinical Indicators Tracking System

The FORGE AHEAD team helped develop a Diabetes Registry and Clinical Indicator Tracking System, which listed adults diagnosed with type 2 diabetes mellitus and their clinical information in each partnering community. The system also included built-in tools and clinical reminders to support improvement of diabetes care. This intervention provided communities the ability to track clinical indicators over time, understand the burden of diabetes, and improve the quality of care.

https://doi.org/10.1186/s12961-016-0127-y

Impact



Knowledge

- 2 articles/interviews in the media
- 4 publications
- 15 presentations
- 4 workshops
- 4 KT tools (online registry, readiness tools, toolkit)



Capacity-building

22 investigators125 trainees

2 training initiatives



Partnerships

3 organizations 11 FN communities



Informed decision-making

2 interventions



Broad socio-economic and health

Additional funding obtained



Team website:

https://cihr-irsc.gc.ca/e/49004.html

3.11 Innovation Supporting Transformation in Community-Based Primary Healthcare Research Project (iPHIT)

Characteristics

Team: Dr. Alan Katz with colleagues and partners from Manitoba and Saskatchewan

Target population: Eight First Nation rural/remote communities in Manitoba representing four of five local languages – Dakota, Dene, Cree and Ojibwe

Objectives: To transform primary health care through the perspectives of First Nation (FN) communities based on their health and needs. Sub-objectives included:

- Describing CBPHC service provision in FN communities.
- Exploring the understanding of FN living on reserve of primary healthcare
- Comparing the models of governance, community engagement, strengths and CBPHC service delivery across communities
- Building collaborative relationships with communities and decision-makers to support the implementation of CBPHC innovations

Research highlight

Mapping Hospitalizations for Ambulatory Care Sensitive Conditions (ACSC) in FN and Rural & Remote Communities

The iPHIT team explored and compared hospitalizations for ACSC, observing various trends using administrative data. It was found how overall rates of hospital readmissions for ACSC ending in death were slowly increasing across Manitoba, but increasing more dramatically among northern FNs, larger FNs not affiliated with Tribal Councils, and in the western region of the province. These regions have continuously been highlighted as disadvantaged in terms of access to care. The results will be used to help develop community specific plans for transformation.

https://www.fnhssm.com/copy-of-copy-page-new

Impact



Knowledge

3 articles/interviews in the media11 publications10 workshops



Capacity-building

14 investigators8 research assistants1 training initiative



Partnerships

4 organizations 8 FN communities





Broad socio-economic and health

None reported



Team website:

https://www.fnhssm.com/copy-of-copy-page-new

3.12 Circumpolar Health Systems Innovation Team (CircHSIT)

Characteristics

Team: Dr. Kue Young with colleagues and partners from Alberta, Ontario, Quebec, Manitoba, Northwest Territories, Nunavut and Labrador

Target population: Residents of Canada's northern regions (the Northwest Territories, Nunavut, and Labrador) and comparable remote settings in circumpolar regions

Objectives: To transform primary healthcare (PHC) for remote northern communities in Canada through four areas:

- Comparative health policies and health system performance
- Emergency response and search-and-rescue services;
- Delivery of primary care in the communities;
- Culturally responsive health architecture and infrastructure.

Research highlight

Policy and Practice of Pharmacy Services

The CircHSIT team examined how existing pharmaceutical administration and distribution policies and practices in Nunavut and Ottawa influenced patient care. They found deficiencies in the system with large amounts of unclaimed prescription medications and a lack of professional translation of information for Inuit patients. These findings have led to various changes including the opening of a retail pharmacy counter in a community grocery store and the Nunavut Language Commissioner making a recommendation to the Minister of Health to create a task force to improve pharmaceutical translations.

https://drive.google.com/file/d/1iCQ8yDd6_imUl1GTpnOLAdM0e5qASxva/view

Impact



Knowledge

27 publications
8 workshops/
conferences
13 articles/interviews
in the media
1 KT tool (mobile



Capacity-building

6 investigators20 trainees2 training initiatives



Partnerships

19 organizations



Informed decision-making

5 interventions

application)



Broad socio-economic and health

Additional funding obtained 1 scale and spread initiative

Team website:

http://www.ichr.ca/2014/05/cicrumpolar-health-systems-innovation-team/

4. Impact of the CBPHC Innovation Teams

Figure 3. Snapshot of Aggregate Impact Across CBPHC Innovation Teams

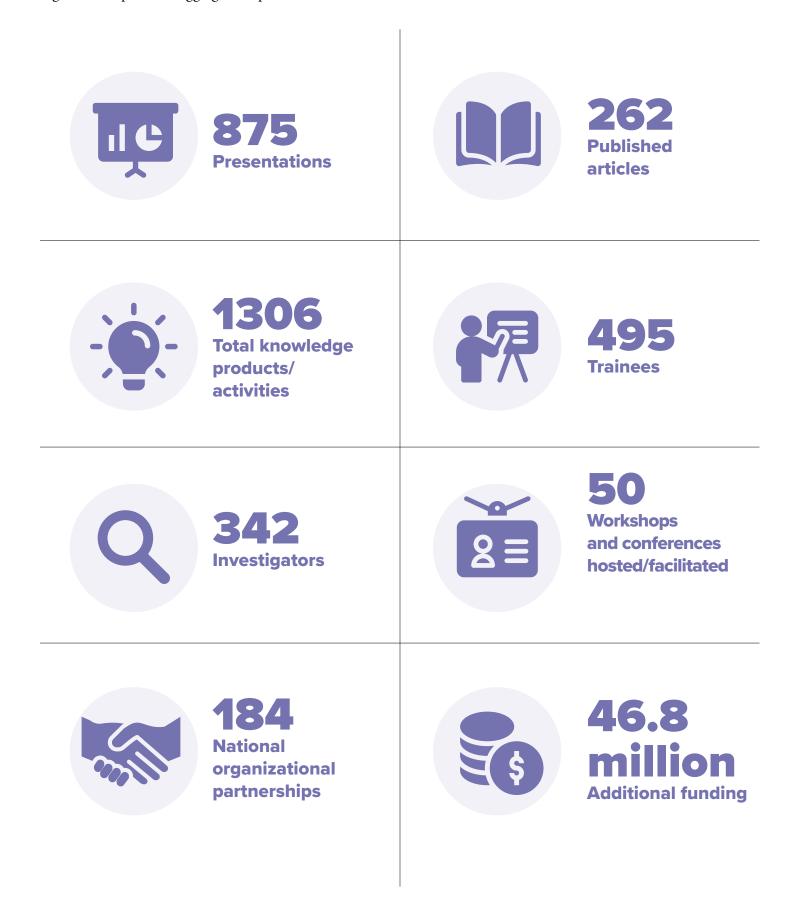


Table 4. Overview of Project- and Network-level impact

Category of Impact	Quantitative Indicators and Qualitative Themes	IMPACT	ACHRU	PACE in MM	iCOACH	TRANSFORMATION	ACCESS-MH	CanIMPACT	C-ChAMP	LHIV	FORGE AHEAD	iPHIT	CircHSIT	Total
Knowledge	# of knowledge products/ activities*	156	390	83	58	63	88	142	12	220	29	24	49	1306
	Project - level: A transformation	onal cha	nge in k	nowledg	e and ur	derstand	ding of s	takehold	ler engag	gement a	nd partr	nership r	esearch	
		"I think that as the project was going on, we realized that actually doing partnership research and doing participatory actionwe need to open up the concept as well or just create new concept for trying to capture these new types of partnerships"												
	Network-level: Growth of a stand partnership approaches	ronger (evidence	base in	primary	care rese	earch in (Canada :	and an i	ncrease i	n awarei	ness of n	nethodol	ogies
	"The CBPHC network of network as we great animated meetings as we	ell becau	se at CB	PHC, w	e would									
	trying to do this type of work	and usii	0											
Capacity-	trying to do this type of work # trainees*	18	51	201	3	3	28	13		31	125	8	20	495
Capacity- building	, , , , , ,			201 57	3	3	28 2	13	1	31 2	125 2	8	20 2	495 81
	# trainees*	18 11	51	57	1	1	2		1	2	2	1	2	81
	# trainees* # training initiatives* Project-level: Enhanced profes	18 11 ssional d	51 1 evelopm	57 ent of tr	1 rainees an	1 nd strenged traine	2 gthened	 the abili	1 ty of cor	2 nmunity	2 z-based s	1 takeholo	2 lers to ta	81 ke local
	# trainees* # training initiatives* Project-level: Enhanced profestaction "And yet now, if you look at a	18 11 ssional d ll of our s solidify	51 1 evelopm papers,	57 [commutation of the commutation of the commutat	ainees an	1 nd streng ed traine as well"	2 gthened a ge] is on	the abili	ty of cor	2 mmunity [they] le	2 z-based s	1 takeholo	2 lers to ta	81 ke local

Category of Impact	Quantitative Indicators and Qualitative Themes	IMPACT	ACHRU	PACE in MM	iCOACH	TRANSFORMATION	ACCESS-MH	CanIMPACT	C-ChAMP	LHIV	FORGE AHEAD	iPHIT	CircHSIT	Total
Informing	# policies/guidelines	N/A	1	2	4	N/A	1	1	N/A	2	N/A	3	2	16
decision-	# interventions/innovations*	5	3	2	1	1	N/A	1	2	2	2	N/A	5	24
making	Project-level: Advanced the sci	ience an	d deliver	y of con	nmunity	based p	rimary h	ealth ca	re in Cai	nada				
	"[Knowledge user] have amplified by providing additional resources to existing community based primary health care teamsin order to enable them to reach out and coordinate, integrate, provide additional services of care to patients who do not currently have access to those teams."													
	# of regions /communities/sites where interventions were spread	6	4	12	9	460	N/A	2	2	5	16	N/A	2	518
	Network-level: Increased the responsiveness of primary health services to the needs of communities and partners "We're translating some of those concepts from that theoretical work into practical design for a building we are constructing an Iqaluit. As a community health and well being center that's based on inuit care concepts and philosophy, you know, from the ground up so that's one sort of practical, pragmatic translation of the knowledge into practice"													
Partnerships	# of organizational partnerships*	9	39	7	3	14	6	2	8	51	14	12	19	184
	Project-level: Built and sustained a relationships with community stakeholders and other key stakeholders in primary health care research and delivery "I would say one of our biggest impacts was the community orientation of our work and the development of a model for community													
	member involvement in primary care research studies"													
	Network-level: Built and susta and key stakeholders	Network-level: Built and sustained a national platform and community of practice of primary health care researchers, communities, and key stakeholders											ties,	
	"The interesting thing is that with the 12 team, is that we really created a community we really belonged to a community of people having similar goals and being able to share about our experiences and learning from each other. So that was something very unique I think that that was quite a learning experience to know that, you know, this kind of community can exist."													

^{*} Refer to operationalized indicators in 'Methods' section

4.1 Knowledge



Collectively, the 12 CBPHC teams have published over 1306 knowledge products (Table 5). Some of the CBPHC Innovation projects are continuing to progress past the end date of this report. As a result, it is likely that the total number of knowledge products will continue to increase.

When asked about their project impact on knowledge, participants expressed that they personally gained knowledge in a particular approach or methodology related to community-based healthcare such as local barriers to implementation and adapting interventions, core attributes to integrated care, analyzing administrative data, and methods in health system performance. Projects also had an impact on raising awareness or the profile of the primary health care environment including re-conceptualizing where primary starts for remote populations and how complex patients could be cared for in primary care settings and not solely in hard to access specialized

settings. A number of participants expressed that there was a **transformational change in their understanding of stakeholder engagement and partnership research**; including areas of partnering with Indigenous communities, principles of co-production, integrated knowledge translation (iKT), participatory-action research and patient engagement principles

When asked about the impact on knowledge through the Network, many participants appreciated the opportunity to learn about the research being conducted by the other teams. In some cases, participants learned about methodologies that could be integrated into their current or future work. Some participants also thought the Network was helpful in identifying collaborative publication opportunities and knowledge dissemination events. Additional qualitative data on interview participants' view of 'Knowledge' can be found in Appendix C.

Table 5. Total knowledge products/activities by type

	Knowledge Products/Activities							
	262 Published articles		3 Books		7 Book chapters			
<u>&</u>	32 Reports	2=	7 conferences organized/ hosted	ЙĊ	875 Presentations	1306 Total		
	50 Workshops	6 2	47 Media articles/ interviews		21 Other knowledge tools/products			

4.2 Capacity building



Capacity building was a focus for almost all of the Innovation Teams with 11 out of the 12 teams supporting a total of 495 trainees. Additionally, teams provided training to policy makers, communities, and care providers through workshops or other educational initiatives depending on their area of focus (technical skills development or health-related areas) (Figure 3).

When asked about the impact of their projects, participants discussed a significant reciprocal impact in capacity-building with 1) the professional development of trainees and 2) the purposeful transformation with community-based stakeholders to deepen their research skills and empower them to continue the innovation. When asked how the Network

impacted capacity-building, participants noted the development of a sub-committee organized by the trainees across the teams. They also highlighted the annual Network meetings and sub-committees as impactful events for trainees to learn and connect with experts in the field. These events provided trainees across teams the opportunity to collaborate and establish connections with other early career researchers across Canada. A paper was published describing the activities and outcomes of this cross-team capacity building strategy (Nicholson et al., 2020). Additional qualitative data on interview participants' perceptions of 'Capacity-building' impacts can be found in Appendix B.

Figure 4. Type of capacity building initiative by number of teams

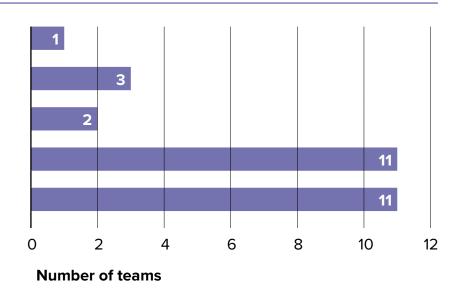
Training of policy makers

Training of communities

Training of providers

Training courses/educational initiatives

Research students/trainees



4.3 Informing decision making



The 12 teams developed 24 new types of primary health care innovations/interventions. We grouped these interventions by the outcome indicators developed through the 'Common Indicator Project' (Table 6). Many of these interventions were implemented and evaluated; many led to changes in practice for providers and some led to transformational healthcare system policies such as the use of an 'e-consult' and organization of 'Ontario Health Teams'. Providers involved in CBPHC Innovation Team programs adopted technological innovations such as apps, the use of new disease registries, and a remote presence robot. CBPHC initiatives were also launched that supported First Nations, Inuit and Metis researchers, leaders and care providers in conducting research and implementing innovations in their own communities.

Additional qualitative data on interview participants' perception of 'Informing decision-making' impacts can be found in <u>Appendix C</u>.

Table 6. CBPHC innovation/intervention categorized by the 'Common Outcome Indicators'

Common Outcome Indicator Category*	Number of Team Innovations/In- terventions
Access	13
Comprehensiveness	4
Coordination	9
Effectiveness	1
Equity	6
Healthcare costs	2

^{*} Refer to operationalized indicators in 'Methods' section



4.4 Broad socio-economic and health impact



CBPHC Innovation interventions were implemented by 10 out of the 12 teams and evaluated by 8 teams (see Figure 4). The implementation and evaluation of these interventions led to shifts in healthcare provision and improved patient outcomes at the local level in several regions across Canada and abroad. Seven teams were also able to scale up their interventions to additional sites or regions. 11 teams obtained additional funding which facilitated their ongoing implementation beyond the duration of the CIHR innovation teams grant.

Figure 5. CBPHC innovation/intervention socio-economic and health impact by number of teams

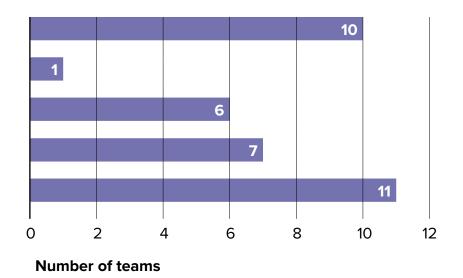
Launch of intervention(s)

Reduced cost due to intervention(s)

Enhanced patient outcomes due to...

Intervention(s) were scaled up

Additional funding



^{*} Refer to operationalized indicators in 'Methods' section

During interviews, participants expressed that their research was impactful because it scaled or spread to multiple jurisdictions and was responsive to the needs of their communities and partners. They expressed that the community orientation of the work became a model for other researchers and communities interested in becoming involved in primary health care research studies. Additional qualitative data on interview participants' view of 'Broad socio-economic impact' can be found in Appendix C.

4.5 Partnerships



Many participants expressed that they felt the largest impact of both the projects and Network was the development of partnerships and strengthening relationships between primary health care researchers and partners (communities/patients/caregivers/health authorities/ organizational leads). Additionally, they highlighted the CIHR grant was the first major investment for a team-based initiative in primary care which gave primary care a stronger voice in the research arena. The opportunity allowed individual teams to forge collaborations and partnerships with a wide range of stakeholders both nationally and internationally, these partnerships were

described as being integral to the work they produced. Project teams were multidisciplinary and ranged from 10-49 members (see Table 7) and from 2 to 39 organizations. When reviewing the type of partners across teams (Figure 5), 9 teams indicated they worked with policy makers/decision makers and 8 teams indicated they worked with other researchers. Additionally, 5 teams indicated they worked with patient partners and 2 teams worked with caregivers. Indigenous knowledge holders/community partners and practitioners/care providers were involved as partners by 4 teams.

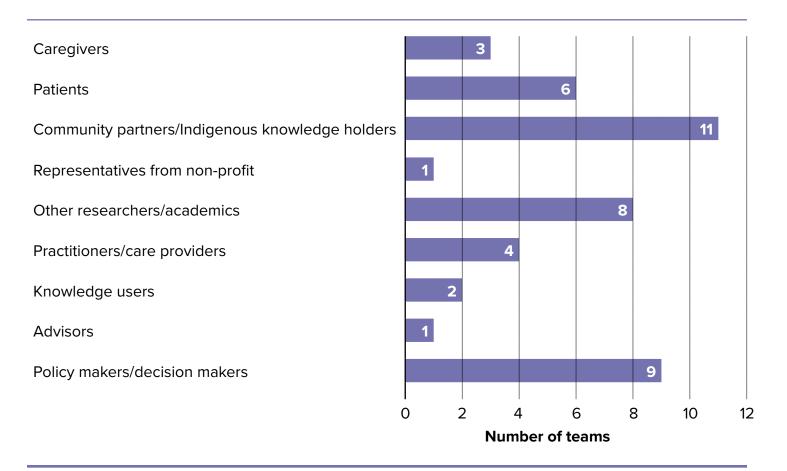
Table 7. Number of partnerships by type and team

	IMPACT	ACHRU	PACE in MM	iCOACH	TRANSFORMATION	ACCESS-MH	CanIMPACT	C-ChAMP	LHIV	FORGE AHEAD	iPHIT	CircHSIT
# of Investigators	48	35	26	36	22	15	38	27	49	22	14	10
# of partners: organization/community level	9	39	7	3	14	6	2	8	51	14	12	19
# of collaborating provinces	3	2	6	2	3	4	7	3	3	6	1	3
# of collaborating countries	1		4	1		1	3	1				

Participants indicated that the benefits of being connected as a team within their project included: 1) leveraging the voices of diverse stakeholders and 2) being able to work on additional research opportunities. When asked about the impact of Partnerships through the Network, participants reported the development and sustainment of a national platform for CBPHC research and solidifying a group of primary care researchers and stakeholders into a community of practice. This community of prac-

tice facilitated awareness and access to experts in each partnership group (patient partners, health authorities, government leads, organizational managers, community leaders), and was a stimulus for collaboration opportunities on papers, projects, and other networks. Participants reported that the network allowed them to establish new professional relationships as well as strengthen existing ones. Additional qualitative data on interview participants' view of 'Partnerships' can be found in Appendix C.

Figure 6. Partnership with different CBPHC stakeholder groups by number of teams



5. Factors that led to project and network success

Participants provided explanations of the perceived success factors of their projects or the Network (Table 8). With respect to the projects, the inclusion of partners (patient partners, community partners, and governmental partners), magnitude of funds, and team dynamics/leadership were key facilitators in their projects. The majority of participants indicated that they were satisfied (≥7 out of a score of 10) with the Network and how it functioned, while 2 participants indicated that they were less satisfied (<6 out of a score of 10) due to a lack of clarity on the Network's function and purpose. Participants noted the annual Network meetings, involvement of leadership, and strengths of the sub-committees as facilitators that enhanced the Network impact. A detailed description of each of these factors can be found in Appendix C.

Table 8. Factors of success for Projects and the Network

	Theme	Description			
Project-level success factors	Partner involvement:	Teams who had increasing partnership involvement in their research led to effective processes and outcomes			
	Magnitude of funds	 Larger investment led to greater scope of impact and flexibility to pursue novel ideas Benefit of working as a collective versus having to individually apply for grants and write papers on their own 			
	Team dynamics, leadership, and decision-making	Providing autonomy, a shared vision, respect, and communication were key features of a successful team			
Network-level success factors	Annual meetings	 Having formal opportunities to learn, gain skills, and connect with others provided focused time away from other priorities 			
	Leadership	Proactive leadership to identify cross-col- laborative opportunities for knowledge creation and sharing			
	Strength of sub-committees	• Important opportunity for trainees to learn and connect with experts in the field and in pushing the cross-project activities forward			

6. Identified project and network challenges

Participants highlighted challenges in meeting project objectives due to large team size, the diversity of jurisdictional contexts, developing and sustaining stakeholder engagement throughout the project, and underestimating of project needs for time and resources as obstacles. Additionally, when asked about challenges within the Network, teams identified competing priorities, lack of clarity on the purpose of the Network, heterogeneity of each team's objective to seamlessly collaborate, lack of funding renewal, and the 'Common Indicator Project' as difficult to implement.

The Common Indicator Project was identified as the most significant challenge, particularly because participants needed to incorporate the indicators after projects had already begun. Most participants felt that it was an important initiative and the efforts to support its development were positive; however, they felt the indicators

should have been provided during the application phase of the grant and not after the teams were awarded. Some participants expressed that they felt the idea was not fully formulated and was imposed on teams, which wasted time and money and expertise. Many participants were not sure of the outcomes of the project and if it was successful across all teams given the diversity in objectives and patient populations across all teams. Some participants were concerned that the indicators would distort project impacts and perceived the indicators to be reductionist and at times artificial in trying to measure performance of an innovation. Participants noted that although the project was visionary and they learned a lot in the process, they felt the allocated budget underestimated the magnitude and complexity of the task. Additional details on these challenges are outlined in Appendix C.



7. Identified recommendations for the network

Participants also identified a range of areas for improvement or sustainability for future CBPHC Network processes (Table 9).

Table 9. Participants' recommendations for the Network

Theme	Recommendation
Continued prioritization of stakeholder engagement with priority populations	Indigenous community based primary health care, patient partner voices and stakeholder engagement
Redefining the purpose of the Network	Providing a clear purpose, objective, and direct support to teams
Grouping project team objectives	Creating spaces for similar teams to work together
Reinvestment to promote sustainability of the CBPHC Network impact	 Continuing towards large-scale investments for primary care research for new projects, and those initiated through the CIRH Innovation Teams grant initiated through the CIHR Innovation Teams grant Continued coordination and sustainability of the Network as a community of practice (leadership, capacity-building committees) Adding more meetings or other activities to connect with other teams
Setting clear and manageable expectations for Common Indicator Projects	 Clear messaging and expectations with collecting common indicators and choosing a smaller number of indicators Understanding that primary care is broad and encompasses all diseases and social determinants of health and therefore requires different tools compared to a disease based network
Evaluating CBPHC Network beyond academic metrics	 Redefining impact beyond number of publications and having a synthesis of all the results of the projects; focusing on addi- tional knowledge exchange, mobilization, and dissemination

Information on each of the recommendations and expansion of the Network evaluation category can be found in <u>Appendix C</u>.

Summary

Overall, participants felt they achieved the goals of their studies and that their projects had impacts in each of the categories of knowledge, capacity-building, informing-decision making, and broad socio-economic and health impact. In addition to individual project-level impact, participants identified that the CBPHC Network also had a collective impact on knowledge and capacity-building for those conducting CBPHC research. However, the biggest impact participants identified from both individual and aggregate Network was the facilitation of 'partnerships'. Via these projects and the Network, participants were provided with an opportunity to develop collaborations with a wide range of stakeholders both nationally and internationally. Participants emphasized the foundational work, strong evidence base, and expansion of new CB-PHC experts in the field, which were created from this initiative. Participants indicated they thought the Network enriched the teams'work and helped teams connect to share knowledge.

Recommendations for CBPHC network evaluations

We analyzed key evaluation concepts and suggestions shared by interviewees to compile recommendations that can be used to implement a network evaluation for future CBPHC teams.

- 1. Develop a conceptual framework of the purpose and aims of the network and in the network evaluation in close consultation with relevant team members and partners
 - Ensure a common understanding of the relationship between network evaluation components

- Allow local partnerships to take ownership of project design and implementation and to play an active role in evaluation components, which may increase a network's sustainability.
- Recommendation from participants:
 - Include partners and the participants in the evaluation
- 2. Develop a logic model (also known as a results map, program logics, theories of change, strategy map) to inform the design of the network evaluation plan
 - Identify how certain initiatives (activities, outputs) are perceived as contributing to bringing about desired positive change
 - Consider assessing the effectiveness of the network to determine impact. Can depict the value of operating in a network
 - Consider assessing the efficiency or quality of the network to determine what network factors lead to greater effectiveness
 - Recommendation from participants:
 - Measuring impact on multiple levels: 1)
 policy and decision making (healthcare
 systems); 2) research process and knowledge
 translation; 3) health/patient outcomes
 - Comparing or grouping projects of similar designs during analysis
- 3. Select an evaluation framework in the early stages of the evaluation plan
 - Consider the framework based on the needs of project teams needs, as there are multiple different ways and methodologies to assess research impact and network impact
 - Select from existing methodological framework components to create a tailored tool
 - Organize and link evaluation questions, highlight information gaps, outcomes

(short and long-term), indicators, data sources, and data collection methods. It is important to identify the intended target group for each of the outcome levels

- Recommendation from participants:
 - Could use evaluation frameworks based on Inuit philosophies and conceptualizations
 - Determine early on and with clear messaging on what the requirements are for a project's research design, type of impact, and target audience
 - Identifying the communication and knowledge translation strategies early on
 - Consider use of the Canadian Institute for Health Information Quality Framework
- 4. Early and ongoing communication and documentation with network planning and activities
 - Apply measurement prospectively to ensure implementation of the evaluation plan
 - Delineate the use of two evaluation streams for 1) monitoring/process evaluations (inputs, activities, outputs) and 2) outcome evaluations/interim/final for each project
 - Use project/network monitoring guides that focus on activities and outputs instead of just outcomes to systematically gather key performance data for regular analysis
 - Recommendation from participants:
 - Including the time and resources to evaluate and building these into the grant and budget

- Allow for evaluation after an appropriate time period or else impact will be missed
- 5. Incorporate a multidimensional approach and adopt existing narratives and quantitative metrics for a comprehensive method of impact assessment
- Use both measures/indicators that help quantify research impact and social return on investment (i.e., what changed) in addition to narrative case studies of how the research generated impact (i.e., how/why change occurred)
- Use indicators along the chain of inputs, activities, outputs, outcomes and impacts. These indicators may relate to the actual achievement of the result (target), to the current situation the partners are trying to change (assessing baseline to identify gaps) or to progress or process (annual targets, intermediary benchmarks).
- For narratives, consider the use of expert panels such as government health policy makers to review and assess impact assessments
 - Recommendation from participants:
 - Use of web analytics as a method for data collection
 - Adding qualitative work to describe the context in which the innovation happened

Limitations

Overall, the data collected from each team was heterogeneous as teams were at varying stages of completing their documentation (publications, final reports). Also, some projects are still underway or are being evaluated. Therefore, the findings from this report are restricted to the available data at time of analysis. The lack of consistency in the level of detail provided in the documents may have also led to an underestimation of impact for some of the teams. The data extracted from our review of CBPHC team documents was also hand counted which may have resulted in errors in accuracy.

Additionally, qualitative data are limited to the 22 participants who agreed and were available to participate in interviews, potentially introducing sampling bias. For each team, 1-3 participants were interviewed. Conclusions drawn represent a limited number of perspectives as teams ranged from 6-49 members. As a result, the perceptions reflected may not reflect those of all CBPHC team members or partners. Also, since data on participant characteristics apart from team role were not collected, potential biases influenced by these characteristics (e.g., gender, age, duration of involvement) are unknown.

Another possible limitation is the lack of consistency across the 12 CBPHC projects in their research design, objectives and observed outcomes. Findings regarding impact may have been underestimated due to these differences. For example, some teams were focused on establishing relationships or capacity building rather than implementing an intervention. Also, in many cases, projects focused on innovation of interventions but were not at the stage of evaluating the impact of those innovations. Development of an expert panel to review impact find-

ings after a selected period of time (e.g., 5 years) and how impact was categorized may be helpful in confirming our assessment. Additionally, though we used a modified CAHS framework to assess impact, there are many other frameworks that can provide alternative depictions of project and Network impacts.

Social desirability bias may have been present with participants reporting favorable outcomes and perceptions. Interview participants may also have been more motivated and committed to the CBPHC teams/Network compared to their peers as recruitment was supported by the PI-HCIN who have an existing relationship with some of the teams/team members. Additionally, there may have been recall bias as we asked participants to recall events over the past 5 years; this reliance on retrospective reporting may also have reduced the validity of the results.

We were also unable to determine if interventions were sustained without additional funding.

These limitations were offset by a number of strengths. We used multiple methods of data collection and cross-referenced these sources. We also circulated the information compiled for each CBPHC team to interviewees and other team members to ensure accuracy of the data. Additionally, we used a rigorous qualitative analysis method in order to make conclusions based on the interview data. To reduce social desirability bias, we assured participants that interview data would remain anonymous and interviews were conduct by an independent, third-party (KTP). The data obtained from the qualitative interviews provided detailed supplemental information and context to the data extracted through document reviews.

References

Banzi, R., Moja, L., Pistotti, V., Facchini, A., & Liberati, A. (2011). Conceptual frameworks and empirical approaches used to assess the impact of health research: an overview of reviews. *Health Research Policy and Systems*, 9, 26. https://doi.org/10.1186/1478-4505-9-26

Brownson, R. C., Chriqui, J. F., & Stamatakis, K. A. (2009). Understanding evidence-based public health policy. *American Journal of Public Health*, 99(9), 1576–1583. https://doi.org/10.2105/AJPH.2008.156224

Canadian Institutes of Health Research. (2020, October 28). *Knowledge translation*. https://cihrirsc.gc.ca/e/29529.html

Canadian Institutes of Health Research. (2021a, March 19). Community-Based primary health care (CBPHC) 12 innovation teams: Summary of achievements from 2013–2019. https://cihr-irsc.gc.ca/e/52315.html

Canadian Institutes of Health Research. (2021b, April 22). Community-Based primary health care: Research profiles. https://cihr-irsc.gc.ca/e/50370.html

Canadian Institutes of Health Research. (2021c, August 17). *CBPHC overview*. https://cihr-irsc.gc.ca/e/44079.html

Field, B., Booth, A., Ilott, I., & Gerrish, K. (2014). Using the Knowledge to Action Framework in practice: A citation analysis and systematic review. *Implementation Science : IS*, 9, 172. https://doi.org/10.1186/s13012-014-0172-2

Graham, K. E. R., Langlois-Klassen, D., Adam, S. A. M., Chan, L., & Chorzempa, H. L. (2018). Assessing health research and innovation impact: Evolution of a framework and tools in Alberta, Canada. *Front. Res. Metr. Anal.*, 3, 25. https://doi.org/10.3389/frma.2018.00025

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map?. *The Journal of Continuing Education in the Health Professions*, 26(1), 13–24. https://doi.org/10.1002/chp.47

Panel on Return on Investment in Health Research. (2009). Making an impact: A preferred framework and indicators to measure returns on investment in health research. Canadian Academy of Health Sciences. https://cahs-acss.ca/wp-content/uploads/2011/09/ROI FullReport.pdf

Appendix A – Data collection materials

	Data Collection Metl	Method	
Focus Area	Document Review	Interview Guide	
individual team 2. 3.	 Description of the team (the members, their roles, research/clinical specialties, institutional affiliations where research was conducted) Project aim and objectives (the intent of the Project as presented in your grant application) Project development (information on the planned activities to achieve the desired outcome/impact and how those activities were implemented. Activities can include the processes, tools, events, and actions that were used to bring about a program's/project's intended changes or results.) All planned and targeted activities of the project were achieved/to what degree and reasons for any deviations Impacts: Advancing knowledge: All publications related to your project All conferences/workshops at which project results/impacts were presented All tools/knowledge products/toolkits created during/as a result of the project (primary healthcare models/approaches, technological innovations, conceptual frameworks) The number of patents licensed Research findings/results in newspapers/media, public policy documents, or other grey literature Building capacity:	2. Can you tell me if the program/project goals and objectives achieved and sustained? a. Was any additional funding obtained? 3. From reviewing [provided document], what would you say been the biggest impact of your research (outcomes/results): a. Probe if participant indicated their research was used to inform guidelines/policies/clinical practice changes) g/as	has

(1) Impact of individual team (cont'd)

- i. Consultations with/direct dissemination of research to policy makers, advocacy groups/patient organizations, and/or lectures to public audiences
- ii. Number of guidelines or revised/new policies (if any) your research was used to inform

d. Health impacts specific to study population of interest:

- i. All project outcomes and findings (i.e., study 'results'.
 Can include measures for specific determinants, outcome measures, effect sizes, patient-reported outcomes measures, patient experience, or reduction in risk factors)
- ii. Additional research efforts (if any) this project helped to inform (describe briefly)
- iii. Results of your project findings that were implemented into practice (if any). If not applicable, please state the reason why.

e. Broad economic and social impacts

- i. Any additional funding obtained to advance the research (matched funding, infrastructure funding, funding obtained from trainees/new research)
- ii. Any improvement in health-related quality of life for participating Canadians
- iii. Any international consulting related to Canada's health care system for your project
- iv. How your innovations were scaled up (please describe). If not applicable, please state the reason why.
- v. How the team continues to conduct research or the sustainability plan.
- vi. All stakeholders/partners (please list) and how they were engaged.
- iv. How partnerships were sustained (if applicable).
- 5. Activities (network activities you were involved in)
- 6. Partnerships: teams within the network (if any) that you collaborated and partnered with, and the main benefits of partnership/the network
 - a. How patients/community members were engaged and in what capacity

Benefits/successes and challenges

- 4. What would you say was the goal of funding all twelve teams at once vs separately (the overall purpose of the CBPHC Innovation Team network)?
- 5. Do you think the network led to improved impact than if you were stand-alone teams? If yes, why? If no, why not?

(2) Perception and impact of network

(2) Perception and impact of network (cont'd)

- a. Did the network have an impact on how your team developed, spread, and/or scaled up models of CBPHC? If so, how?
- b. (If participant indicated they conducted KT activities in doc review): Did the network have an impact on how your team conducted knowledge translation activities (e.g., the creation of new tools)? If so, how?
- c. (If participant indicated they delivered education in doc review): Did participation in the network enhance the ability for your team to build capacity (e.g., meaningful involvement of trainees, development of educational materials)?
- d. Did participation in the network enhance the ability for you to build partnerships for your team? If so, how?
- 6. What outcomes or benefits, anticipated and unanticipated, resulted from the CBPHC network?
 - Examples of individual level benefits: Increased knowledge and expertise, enhanced interpersonal/working relationships, application of knowledge to practice, and improved selfconfidence/self-efficacy, promotions, new partnerships/collaborations.
 - Example of organizational/institutional level benefits: Increased individual knowledge that has been shared with others in their home organization, individual knowledge gained in the network that was applied in their home organization, organization to organization sharing, and efficiencies gained by learning from others, obtained additional funding,
 - Example of public health benefits: Changes in health outcomes and systems, infrastructure, and changes that have allowed the organization to communicate with other organizations and agencies, developed a new model of innovative care, reduce health care spending, reduced inequities in access to CBPHC, built capacity for CBPHC research
- 7. Can you describe the factors or circumstances that you think contributed to the success (or challenges) of the network and its mission?
 - Examples of challenges include scientific challenges, a lack of institutional and individual commitment; a lack of a common

- results framework (linking the vision with planned and practical steps); a lack of joint activities among members; a lack of alignment between funding and network cycles; and a lack of donor interest to fund infrastructure, excessive time investment, excessive funding pressures, unclear roles and/or functions, and poor communication between members of the partnership.
- Examples of facilitators include strong capacity, shared goals among network members; clear governance structures; strong leadership/champions; sustained resources (infrastructure, human and financial); and effective communications support (for communications within and beyond the network); trust, respect and a good relationship among partnership members.
- 8. How would you rate the overall success of the CBPHC Innovation Teams network using a scale from one to ten, where one is a complete failure and ten is a total success? Why?

Partnerships and collaboration

- 9. Can you explain how the teams in the network interacted?
 - a. How often did your team interact with other teams?
 - b. What was the structure of these interactions (formal vs informal; centralized vs decentralized)?
 - c. What were the benefits of such interactions
 - d. How are/were decisions made within the network?
- 10. What types of relationships did you see as critical to carrying out your work and developing your network?
 - a. Did the network provide you access to such stakeholders/relationships?
 - b. Who were the key stakeholders involved in the network?
- 11. How satisfied are you with how the partnership functioned and your role in the partnership?
 - a. Where there any areas where there could be better alignment and cohesion?
- 12. Have any partnerships, relationships or collaborations been maintained or sustained as a result from the CBPHC Innovation Teams network?

Focus area: Suggestions for network evaluation

13. Do you have any suggestions on how similar networks can be evaluated for impact in the future?

- (3) Suggestions for network evaluation
- 7. suggestions for network evaluation: Any other evaluation metrics, indicators, or considerations that would highlight your team's success or the network's success that were not captured in the above sections.

Appendix B – CBPHC team summaries

1. Innovative Models Promoting Access-to-Care Transformation (IMPACT)

Principal Investigators: Jeannie Haggerty, Catherine Scott, Simone Dahrouge, Mark Harris, Jean-Frédéric Levesque, Virginia Lewis, Grant Russell, Nigel Stocks

Co-Investigators: Mylaine Breton, François Chiocchio, Debbie Feldman, William Hogg, Christine Loignon, Scott Oddie, Pierre Pluye, Kevin Pottie, Shannon Spenceley, Erin Strumpf, Robert Wedel, Vivian Welch, Jenny Advocat, Colette Browning, Benjamin Crabtree, John Glover, Jane Gunn, Terry Haines, Anthony Harris, Paul Jennings, Riki Lane, Siaw-Teng Liaw, Donna Markham, Julie Mc Donald, Lisa McKenna, William Miller, Stephen Peckham, Gawaine Powell Davies, Martin Roland, Nicolas Senn, Ann Taylor, Nicholas Zwar, Denis A. Roy, Danièle Francoeur, Stephen Christley, Antoine Groulx, Lisa Halma, Jean Rodrigue, Shelly Park, Rene Pennock, Anne Peek

Team: IMPACT was an international collaboration with three sites in Canada and three sites in Australia. It built on a network of Local Innovation Partnerships (LIPs) bringing together decision makers, researchers, clinicians and members of vulnerable communities from the six regions. Each site was headed by a research lead and a local coordinator.

Locations: Quebec, Ontario, Alberta, and 3 regions in Australia (New South Wales, South Australia, and Victoria)

Project aim/objectives: IMPACT was a 5-year research programme built on community-academic partnerships. The main aim was to design, implement and evaluate organizational innovations to improve access to appropriate primary health care (PHC) for priority populations. The IMPACT program had four objectives: (1) establish a network of partnerships between PHC researchers, providers and consumers (2) identify organizational interventions to improve access to appropriate care for priority populations (3) support the selection, adaptation and implementation of interventions; and (4) evaluate the effectiveness and efficiency of the interventions and the IMPACT program.

Target Population: Groups whose demographic, geographic, economic and/or cultural characteristics impede or compromise their access to PHC services.

Project development: The research studies that were conducted by the IMPACT team included: a scoping review of organizational interventions to improve access for priority populations; systematic reviews of the components of the interventions; and several access-oriented re-analyses of data generated by the Commonwealth Fund. Additionally, through the IMPACT team, interventions were implemented at three sites in Canada (Quebec, Ontario, Alberta) and three sites in Australia (New South Wales, Victoria, South Australia). The LIPs collaborated in the design, implementation and evaluation of unique organizational interventions.

Website: https://www.impactresearchprogram.com/

Impact on Advancing Knowledge

• Publications: 13

• Reports: 1

Policy briefs: 5Presentations: 124

Workshops: 10

Media coverage (articles/interviews): 1

• KT tools: 2 [Local Innovation Partnership Implementation Guide, Intervention Implementation Guide]

"I would say I think it was with an impact to produce different types of knowledge products. We had a newsletter, we had very active twitter – super, super active – we had a lot of followers. We produced a lot of webinars."

Impact on Building Capacity

• Trainees: 18 [5 post-doctoral fellows, 13 BSc, MSc, PhD]

• Training courses/educational initiatives: 11 [8 training webinars, 1 group facilitation, 2 trainings related to the interventions]

"I think that teaching gives you more knowledge and expertise...if you're leading and animating a discussion group for example with your students... researcher meetings are usually going to be very down to business. It's not going to enable us to brainstorm together and open up our imagination to thinking differently about health issues and things like that. So, we did a lot off that."

Informed Decision-making

• **Public partners/patients:** patient partners (individuals with lived experience) were included to inform program implementation

"So, there was a lot of impact on the team members and partners in terms of understanding how meetings can be done differently, especially when you're trying to work differently and you're trying to work using a partnerships approach and people who come from different teams and expertise."

Program Findings

Area of focus: Scoping organizational interventions to improve access for vulnerable populations

Results:

• Findings from a scoping review suggested that interventions classified as 'formal integration of services' were associated with three dimensions of access (approachability, availability

"One of the first products that the research did was to do a scoping review of all the types of intervention that would improve access to primary care for different types of vulnerable population. So, they created this typology of interventional component in relation to the vulnerable population that were identified."

- and affordability). They were also associated with reductions in hospitalizations, emergency department admissions, and unmet healthcare needs.
- Examples of 240 interventions innovative in helping priority populations to get access to PHC were provided through a brief online survey (respondents included 740 PHC researchers, practitioners, policy makers and stakeholders). The interventions were mainly directed at system level rather than patient level determinants of access.
- Findings from an exploratory study that was conducted in Sydney, Australia suggest that factors influencing self-management of Type 2 Diabetes Mellitus (T2DM) occur on four levels of the socio-ecological model: individual (e-health literacy, motivation, time constraints); interpersonal (family and friends, T2DM education, patient-provider relationship); organizational (affordability, multidisciplinary care); and community levels (culture, self-management resources).

Area of focus: systematic reviews of interventions to improve access for vulnerable populations

Results:

- In a review that aimed to identify whether community-based health service brokers can (a) identify individuals who may benefit from improved access to quality primary care, and (b) link these individuals with an appropriate primary care provider, six of eight studies were judged to have successfully linked their target group to primary care.
- Findings from a review that aimed to assess the benefit of using electronic, mobile and telehealth tools for priority patients with chronic disease (18 trials identified) suggest that patients were relatively passive in the interaction with these tools.

Area of focus: access-oriented reanalyzes of data generated by the Commonwealth Fund International Health Policy Survey (IHPS) Results:

- An analysis of factors associated with barriers to primary care access using the 2016 Commonwealth Fund IHPS in 11 countries (Australia, Canada, France, Germany, Norway, the Netherlands, New Zealand, Sweden, Switzerland, the United Kingdom, and United States) found that overall, one in five adults (21%) experienced multiple barriers before reaching PC practices. People with lower income, mental health problems, and those born outside the country were more likely to experience multiple barriers before reaching primary care practices.
- Most older Australian's respondents of the 2014 Commonwealth Fund IHPS were reported to have a treatment plan for their chronic condition(s). Most respondents reported that having a treatment plan was helpful in managing their health. Plans were less likely for

"They thought that they would be able to...pick one intervention that the 6 sites would do. So, at first they thought yes we're all going to choose the same intervention and we're all going to be going through the same process and adapting it, implementing it locally and have something that's much more comparable at the end of the day, but working in partnership, people were like "oh no, our access problem is XYZ and we would like to do something for this population, looking at the typology that you gave us, we are more interested in...not only using the intervention that existed, but actually kind of creating our own base from the literature. So, we did have 6 intervention. Ultimately, they all had the component of navigation embedded in it, but how we went about doing it was very, very different"

- residents of outer regional and remote areas. Indigenous respondents and respondents with providers that did not always explain things were less likely to say that a treatment plan helped.
- An assessment of barriers to accessing healthcare in Australia using the 2013
 Commonwealth Fund IHPS found that 27% of adults in Australia experienced difficulties with out-of-hours access, which was higher than 5 of 10 comparator countries.
 Additionally, 16% of Australians said they had forgone health care due to cost in the previous year

Area of focus: Interventions addressing priority gaps in access to PHC for vulnerable populations

Six interventions were implemented in different jurisdictions. Evaluation of the impact of these interventions is in progress.

Results:

- in Quebec, telephone outreach from trained volunteer navigators helped patients attach to newly-assigned family physicians
- in Ontario, lay bilingual navigators supported individuals to reach community-based PHC resources
- in Alberta, pop-up health and social service events brought services into an under-served community
- in New South Wales, a web portal provided health information and service referrals to patients with type 2 diabetes
- in South Australia, the team partnered with the Dandelion project supporting residents of Eldercare Residential Aged Care Facilities
- in Victoria, a health brokerage service matched patients from social service organizations to PHC providers

Broad Social and Economic Impacts

- Additional Funding: Amount unknown (not reported). Received a grant from the Australian Government Department of Health, under the Primary Health Care Research, Evaluation and Development Strategy.
- Scale and spread: interventions were implemented in Quebec, Ontario, Alberta, New South Wales, South Australia and Victoria.
- Number of regions/communities/sites where innovations were implemented or scaled up: 6

"We got funding for stage 2 from that project and it's a smaller group and we're still connected. We also have so much publications that need to come out. The international team is still connected"

Impact on Partnerships

- Partners (individual level): included decision makers, researchers, clinicians and, in some cases, members of priority communities in each of the six regions (Quebec, Ontario, Alberta, New South Wales, South Australia and Victoria)
- "In our project, it was an international partnership with the other countries...so, engagement of your partners was also a big, big learning and we invested a lot in this"

- Sustained partnerships: stage 2 of project is in progress
- Number of partnerships with stakeholder organizations: 9

2. Aging, Community and Health Research Unit (ACHRU)

Principal Investigators: Jenny Ploeg, Kaiyan Fu, Anne Hayes, Maureen Frances Markle-Reid

Co-Investigators: Carol Anderson, Melissa Farrell, Susan Paetkau, Noori Akhtar-Danesh, Susan Baptiste, Duane Bender, Wendy Duggleby, Anna-Marie Emili, Sid Feldman, Dorothy Forbes, Kimberly Fraser, Amiram Gafni, Rebecca Ganann, Anna Garnett, Sunita Ghosh, Margaret Gibson, Lauren Griffith, Andrea Grunier, Sandra Hirst, Sharon Kaasalainen, Janice Keefe, Nancy Matthew-Maich, Carrie McAiney, Christopher Patterson, Shelley Peacock, Carlos Rojas-Fernandez, Cheryl Sadowski, Jean Triscott, Ross Upshur, Ruta Valaitis, Allison Williams

Team description: The research unit combines the research and clinical expertise of over 50 interprofessional researchers from seven universities across Canada.

Locations: Alberta and Ontario

Project aim/objectives: The objectives of the ACHRU research program were to:

- 1) codesign integrated and person-centered interventions with older adults, family/friend caregivers, and providers;
- 2) examine the feasibility of newly designed interventions;
- 3) determine the intervention impact on Triple Aim outcomes: health, patient/caregiver experience, and cost;
- 4) examine intervention context and implementation barriers and facilitators;
- 5) use diverse integrated knowledge translation (IKT) strategies to engage knowledge users to support scalability and sustainability of effective interventions; and
- 6) build patient-oriented research capacity.

Target Population: Older adults aged 65 years and older with multiple chronic conditions and their family/friend caregivers. The main research focus is on three vascular or vascular-related diseases: stroke, dementia, and type 2 diabetes mellitus (T2DM). A unique focus of ACHRU is the inclusion of family caregivers in all six studies conducted by the team (three exploratory studies and three pragmatic randomized controlled trials).

Project development: Six individual studies were conceptualized as integrated pieces of work. The results of the three initial descriptive studies informed the subsequent three pragmatic randomized controlled trials. IKT and capacity building activities were embedded in all six studies and tailored to the unique focus of each study. One of the interventions designed and evaluated by ACHRU was a Community Partnership Program (ACHRU CPP) that involved a client-driven, customized self-management program for older adults with diabetes and multimorbidity.

Website: https://achru.mcmaster.ca/

Impact on Advancing Knowledge

Publications: 32Reports: 22

Presentations: 325Workshops: 1

Conferences hosted/organized: 0

Media coverage (articles/interviews): 7

• **KT tools: 3** [1 training manual for the Aging, Community and Health Research Unit-Community Partnership Program (a 6-month interprofessional, nurse-led program to promote self-management in older adults with T2DM and MCC and support their caregivers); 1 electronic costing manual that includes pricing for drugs, health, and social services; 1 web-based tool (My Tools for Care); a psychosocial supportive web-based transition toolkit]

"I would say yes. You know, I think we've had lots of output from conference presentations to... oh, papers written, those kinds of things... There's been some op-eds, we had some media uptake for the general community, and there's been some op ed"

"I believe we certainly increased the knowledge among decision makers about some of the self-management supports for people with diabetes."

Impact on Building Capacity

- Trainees: 51 [3 post-doctoral, 10 PhD, 11 Masters, 27 undergraduate]
- Training courses/educational initiatives: 1 [capacity building initiative led by cross-provincial trainees, and involves regular training opportunities, educational resources, bimonthly seminars, and research support and mentoring]

"We involved [the trainees] in a number of the studies and so they did various activities in the studies and then actually, many of them became co-authors on some of the papers that we wrote or co-presenters at conferences."

"...we provided fairly intensive one-to-two-day training sessions for providers... so, I believe that certainly increased their understanding of those topic areas, and the kinds of interventions we were using"

Informed Decision-making

- Public partners/patients: 200 stakeholders including researchers, policy and decision
 makers from governments, care providers, students, and patients and their family caregivers
- Guidelines/policies: 1 [1 new delivery of care model was designed and implemented for RCTs (i.e., diabetes, stroke, My Tools for Care). Some organizations have adopted some of the intervention methods into their organizations as usual practice.]

"So certainly, in the three studies where we had interventions, I would say there were changes in practice. So, we provided intensive training to them about how to do the research study. And again, some of those sites continued to use those approaches."

Program Findings

Area of focus: The Perceptions of Older Adults, Family Caregivers and Healthcare Providers in Managing Multiple Chronic Conditions (MCC) Result:

- Found that there is a large gap needs-service gap in healthcare for managing MCC in the community which is experienced as fragmented and not person centred.
- Findings suggest that there is a need for a more person/family-centered approach to care in the community which includes service navigation for needs-based services.
- Community-based healthcare providers are using many relevant and appropriate strategies
 to support older adults living with the complexity of MCC, but also identified the need for
 a more comprehensive and integrated system of care

Area of focus: The Correlates, Health Outcomes and Costs Associated with Multiple Chronic Conditions

Results:

- Found that comorbid chronic conditions are common among older adults, with half of the study sample reporting 3 or more comorbid conditions
- Service use and associated costs consistently increased as the number of comorbidities increased, suggesting that older adults with chronic conditions use expensive services (e.g., hospital emergency departments) more often.
- Overall, findings suggest the importance of focusing on prevention and health promotion
 to mitigate the risk of older adults developing multiple comorbid conditions and reduce the
 use of expensive services where possible as a result.

Area of focus: Sex- and Gender-Based Analysis of Family Caregivers of Older Adults with Multiple Chronic Conditions.

Results:

- Found four key themes were identified for the experience of family caregivers of older adults with MCC: (1) three caregiving phases (initial, middle and late phases); (2) the impact of caregiving on other areas of caregivers' lives; (3) caregiving sustainability and coping, and (4) meaning-making.
- Found masculine gender identity and confidence in the ability to deal with difficult situations were positively related to improvement in mental health for caregivers of persons with MCC.
- Results included an overview of challenges experienced by male spousal caregivers of persons with MCC, as well as coping strategies that they used.
- Findings also included strategies to overcome recruitment challenges for a sample of caregivers of older persons with MCC.

"So, the goal of our program of research was to really look at developing, implementing, and evaluating innovative approaches for older adults with multiple chronic conditions and supporting their family caregivers, And so this was really focused in the community. So overall we had six studies that were part of this program of research, the first three were a little bit more descriptive in nature, and the last three involved innovations or interventions that we tested in randomized controlled trials."

"So, we did randomized control trials for the three interventions. So based on those studies and that's in the report that I shared, there were positive outcomes in each of those studies. So for example, in diabetes study, we saw that people had improved quality of life and self-management of their diabetes and chronic conditions, and fewer depressive symptoms. So there were changes in the people who participated in the study. In the stroke study, it was a small sample, and we did not see any changes in health-related outcomes. In the transition toolkit we did see that caregivers had improved hope at the end of the study. So those were some of the outcomes."

Area of focus: Evaluation of a Transition Intervention for Family Caregivers of Persons with Alzheimer's Disease and Multiple Chronic Conditions Results:

- Found that caregivers of older adults with dementia and MCC experienced significant challenges (e.g., exhaustion, lack of personal time, impact on social life). Caregivers also reported more responsibilities as the persons in their care faced greater functional/cognitive decline with time. Caregivers coped with these significant changes by seeking support, self-caring, and adapting the caregiving approach.
- Family caregivers using the self-administered psychosocial supportive web-based transition toolkit (My Tools 4 Care or MT4C) showed greater improvement in hope. The toolkit also helped with their complex caregiving roles and responsibilities.
- Caregivers shared important recommendations for the future development of Web-based supports.

Area of focus: A Client-Driven Intervention to Support Self-Management among Community-Living Older Adults with Type 2 Diabetes Mellitus (T2DM) and Multiple Chronic Conditions: the ACHRU-Community Partnership Program (CPP) Results:

- In Ontario, found that participation in the ACHRU-CPP improved quality of life and selfmanagement and reduced depressive symptoms in older adults with T2DM and comorbidity without increasing total health care costs.
- The program is now being tested in Ontario, Quebec and Prince Edward Island, with a focus on implementation, evaluation and scale up. The findings will direct future models of care for diabetes that can be translated into clinical practice and positively impact the delivery of diabetes care across the country.
- In Alberta, results were inconclusive of the benefits of the ACHRU-CPP.

Area of focus: A Community Navigation and Rehabilitation Intervention for Stroke Survivors with Multiple Chronic Conditions
Results:

Found that a 6-month self-management intervention for older adults with multiple
diseases, was cost neutral in comparison to usual care. It was not found to improve healthrelated quality of life or secondary health outcomes. Additionally, recruitment and
retention challenges were significant obstacles.

• Results indicate that it is imperative to identify effective ways of recruiting/retaining vulnerable older adult populations and continue testing alternative ways of implementing interventions that are grounded in sound principles of managing two or more diseases

Broad Social and Economic Impacts

- Additional Funding: \$9,325,000
- Scale and spread:
 - Funding from this grant has led to a new Ontario SPOR Support Unit Research Centre in Aging, called the MIRA Collaborative for Health & Aging, bringing together world-class researchers from the McMaster Institute for Research on Aging (MIRA) and ACHRU. The Collaborative seeks to strengthen Ontario's capacity in patient-oriented research and improve health system performance and patients' experiences by advancing the science of patient engagement and patientoriented research in aging.
 - The ACHRU-CPP is being tested in Ontario, Quebec and Prince Edward Island, over four years with future adaptations for implementation across Canada.
 - Funding was received to adapt MyTools4Care, an online toolkit for caregivers, to the long-term care setting.
- Number of regions/communities/sites where innovations were implemented or scaled up: 4

Impact on Partnerships

- Partners (individual level): The research team established relationships with over 200 stakeholders, including researchers, policy and decision makers from governments, care providers, students, and patients and their family caregivers.
- Number of partnerships with stakeholder organizations: 39

"So, two of the innovations are diabetes, self-management intervention is now being tested in three provinces in six sites...and to some extent some of the sites that we had tested that with previously are continuing to use that innovation. The other innovation was an online toolkit for caregivers of older people with dementia, and that toolkit is available on the Alzheimer Society website and is currently being trialed not only in the community but also in long term care. So those two innovations, I would say have been sustained and to a degree are in the process of scale up."

"...that funding from CIHR really enabled us...there's probably over \$9 million in leveraged funding that we were able to collect because of that strong foundation...so that foundation was absolutely key and provides a great opportunity for leveraging funding over time."

"Would say effective things that came out of it would have been relationships with local providers and connection and connection with cross-Canada teams with a common interest in this work. I think we had a high level of output"

"So, it really [the CBPHC innovation network], I would say increased our network and our partnerships with people. One of the things that also happened is that we became connected with Diabetes Action Canada, a national spore network on diabetes and its related complications, and that collaboration really influenced a lot of our future work and also our funding. So those connections I think have really influenced the work that we're continuing to do."

3. Patient Centred Innovations for Persons with Multimorbidity (PACE in MM)

Principal Investigators: Moira Stewart, Martin Fortin

Co-Investigators: Martine Couture, Paul Huras, Onil Bhattacharyya, Judith Brown, Maud-Christine Chouinard, Frances Gallagher, Richard Glazier, William Hogg, Alan Katz, Christine Loignon, Jonathan Sussman, Amardeep Thind, Walter Wodchis, Sabrina Wong, Merrick Zwarenstein, Valérie Emond, Tara Sampalli, Sonja Reichert, Roxanne Borges Da Silva, Helena Piccinini-Vallis, Mathieu Belanger, Jocelyn Charles, Pauline Pariser, Thuynga Pham

Locations: Ontario, Quebec, British Columbia, Manitoba, Nova Scotia, New Brunswick, and International partners (Belgium, France, Argentina, Singapore)

Co-Investigators: Martine Couture, Paul Huras, Onil Bhattacharyya, Judith Brown, Maud-Christine Chouinard, Frances Gallagher, Richard Glazier, William Hogg, Alan Katz, Christine Loignon, Jonathan Sussman, Amardeep Thind, Walter Wodchis, Sabrina Wong, Merrick Zwarenstein, Valérie Emond, Tara Sampalli, Sonja Reichert, Roxanne Borges Da Silva, Helena Piccinini-Vallis, Mathieu Belanger, Jocelyn Charles, Pauline Pariser, Thuynga Pham.

Team: The team is predominantly a Quebec-Ontario (QC-ON) bilingual partnership with involvement of three additional provinces: British Columbia (BC), Manitoba (MB) and Nova Scotia (NS). The team members represent nine disciplines. The two named decision-makers are leads of their regional health authority and are highly respected for their innovations.

Project aim/objectives: The overall goal of PACE in MM was to improve patient-centered care for patients with multimorbidity. The objectives were to:

- 1) identify factors responsible for the success or failure of current chronic disease prevention and management (CDPM) initiatives
- 2) to transform consenting CDPM initiatives identified by aligning them to promising innovations on patient-centred care for multimorbidity patients, and testing these new innovations in at least two jurisdictions
- 3) to foster the scaling up of innovations informed by Objective 1 and tested in Objective 2.

Target Population: Patients with multi-morbidities (3+ chronic conditions) aged 18–80

Project development: The PACE in MM team identified factors responsible for the success or failure of current CDPM initiatives through analysis of electronic medical records and a literature review. The team then implemented innovations in patient-centred multimorbidity care in Quebec (DIMAC02) and Ontario (TIP/IMPACT Plus) through two parallel randomized control trials. Innovations in patient-centred multimorbidity care were scaled up to other regions in QC and ON, as well as NS.

Website: http://paceinmm.recherche.usherbrooke.ca/

Impact on Advancing Knowledge

• Publications: 17

• Books: 2

• Book Chapters: 4

• Presentations: 40

• Workshops: 10

Media coverage (articles/interviews): 9

• KT tools: 1 [PACE in MM Toolkit]

"The knowledge transfer, actually, we use an integrated knowledge transfer strategy. We had decision maker that were involved with us right at the beginning, were very helpful, particularly in the objective one, to identify all the programs in Quebec and Ontario, so were very useful."

"We've done all kinds of traditional KT, lots of papers, lots of meetings that had policymakers and practitioners attending. So, there's always this sort of, for you know, patients, practitioners, researchers and decision makers around our tables when we would have our annual meetings."

Impact on Building Capacity

• Trainees: 201 [16 trainees, 129 students and 56 postdoctoral fellows]

• Training courses/educational initiatives: 57 [57 course(s), lecture(s) or seminar(s)]

"This huge interdisciplinary, interprofessional team of multi generations of researchers was created. Our patient mm team, our patient centered innovations team had a strong capacity building."

Informed Decision-making

 Public partners/patients: 143 policy makers involved in training and capacity building activities

Guidelines/policies: 2 ["The measurement of multimorbidity" (guidelines for the choice of a measurement of multimorbidity for research studies); evidence-based framework (the PACE in MM framework) developed to support effective interventions for patient with multimorbidity.]

"We had decision makers that were involved with us right at the beginning, were very helpful, particularly in objective one, to identify all the programs in Quebec and Ontario, so were very useful."

Program Findings

Area of focus: Characteristics of consistently high primary health care (PHC) users in the Deliver Primary Healthcare Information (DELPHI) database

Involved the retrospective analysis of de-identified patient data from 23 physicians contributing to the DELPHI database of electronic medical records.

Results:

"The overall goal of our work was to reorient care from a single disease focus to a multi morbidity focus. And to center the care not only on disease, but also on the patient and the patient's expectations in context. And so this meant, this aim, this big overarching aim was to realign the healthcare system from separate silos to coordinated collaborations in care. And we did that through

- Older patients were significantly more likely to become sometimes or consistent high users of primary health care
- Multimorbidity at baseline significantly increased the odds of being a sometimes-high user of primary health care by 2.3 times and a consistent high user by 4.1 times
- Patients in rural locations were 1.8 times more likely to become consistent high users
- Significantly higher prevalence's of chronic respiratory, musculoskeletal, and psychological conditions were seen in the consistent high users.

Area of focus: A scoping review of the effective elements in patient-centered and multimorbidity care

Results:

- Common categories of interventions that had the potential to result in positive impact for patients with chronic diseases included: (1) providing patient-oriented approaches, (2) self-management support interventions and (3) developing training for healthcare providers.
- Other categories included: supporting the decision process and evidence-based practice; providing case/care management; enhancing the interdisciplinary team approach; and integrating information technology.

Area of focus: Development of measurements and a research tool to support research in multimorbidity

Results:

- A series of measurements were developed and/or validated to support research in multimorbidity
- A questionnaire to document 20 self-reported chronic conditions/categories of conditions was developed, to: (1) evaluate the self-reported burden of multimorbidity by participants and (2) encourage comparability among research studies using the same measurement.

Area of focus: Development of an Evidence-based Framework and Toolkit Results:

• An evidence-based framework (the PACE in MM framework) and a toolkit were developed to support effective interventions for patient with multimorbidity. Components of the framework included: shared philosophy (e.g., common vision), internal relations (e.g., patient in the team), external relations (e.g., collaboration), professional training (e.g., feedback), and relations with patients (e.g., individualized care plan).

several goals and objectives. The first objective was to identify the factors responsible for the success or failure of current chronic disease programs linked to primary care reform. And we did this identification of these factors through a realist synthesis of quantitative and qualitative evaluations of existing chronic disease programs in Ontario and Quebec. So that was objective number one. Objective number two was then to identify a program and transform a program identified in objective one by inviting them to align their promising intervention towards patient centered care and towards multimorbidity care. And then to test these new innovations, these new transformations, in two jurisdictions. One test in Ontario, one test in Quebec. And the third goal was to foster the scaling up of these innovations that were informed by objective one and tested in objective two, and to conduct some research on different approaches to scaling up."

"From the result of the objective one, we were able to create the innovation that was necessary for aligning the programs in objective two. So that's where the innovation fits in."

Area of focus: Social Vulnerability in Patients with Multimorbidity

Cross-sectional analysis from the baseline data of the PACE in MM Study. Participants were patients attending PHC settings in Quebec (N=301).

Results:

- There was a significant positive correlation between social vulnerability (based on a social vulnerability index) and the total number of chronic conditions
- Obesity, depression/anxiety, and cardiovascular diseases were significantly independently associated with the most socially vulnerable state in patients with multimorbidity.

Area of focus: Effect of an Intervention to Scale Up Patient-Centred Interdisciplinary Care for Multimorbidity

This Randomized Control Trial measure the effectiveness of a 4-month intervention that involved an interdisciplinary team providing self-management support to patients in Quebec. **Results:**

- A neutral effect on the primary outcomes with a significant but small effect on selfmonitoring and insight.
- Substantial improvements in 2 health behaviors as secondary outcomes (physical activity and healthy eating).

Broad Social and Economic Impacts

- Additional Funding: \$753,928
- Scale and spread:
 - O Innovations in patient-centred multimorbidity care were implemented in Quebec (DIMAC02) and Ontario (TIP/IMPACT Plus), through randomized control trials
 - O Based on the results obtained from DIMAC02 study and other previous work (PR1MaC), including the data on implantation, the Quebec Ministry of Health mandated the Research team to adapt the intervention and its evaluation framework for spreading to another region (Bas-Saint-Laurent).
 - The ON innovation has spread throughout Toronto, ON. Over 10 Toronto organizations are participating to-date along with independent family doctors.
 - Using the PACE in MM Toolkit, a similar process of scaling up is used to implement the innovation in Nova Scotia in collaboration with policy-makers. Several workshops have been conducted in NS.
 - The scaling up in Ontario (with the expansion of TIP/IMPACT PLUS across Toronto), in Quebec, to the Bas Saint-Laurent region and to Nova Scotia has been highly successful.
- Number of regions/communities/sites where innovations were implemented or scaled up: 12

"The scaling up and the integrated KT are very, very emmeshed in Quebec. So now let me turn to Ontario. So, the knowledge translation and connection in Ontario was with the local health integration networks, which was what was our governance structure way back when. And we had one of the, we had the primary care lead who was in charge of the East Ontario LHIN as our policy and decision maker connectors... they assisted us in making sure that this TIP [Telemedicine Impact Plus] program spread across Toronto."

"So, we ended up receiving a funding from the Ministry of Health, major funding, half a million from the Ministry of Health. And we were able to implement the innovation that we had evaluated here in the region, into another region of the province. And this is ongoing at the moment. So we are kind of in the third year that. It was supposed to be two years but with COVID and everything was kind of stopped at some point. But we're still pretty involved in this

other region in order to continue the implementation of this intervention."

Impact on Partnerships

- **Sustained Partnerships:** NS continues to collaborate with the PACE in MM team on a PIHCIN grant
- Number of partnerships with stakeholder organizations: 7

"So, in Nova Scotia, in particular, we have strong connections, because two folks from Nova Scotia are co-investigators on the grant... so over the period of about three years, we were there once a year at least, and talking to groups who were innovating primary care connected to chronic disease care in various regions of Nova Scotia. And then we also expanded to Newfoundland"

4. Implementing Integrated Care for Older Adults with Complex Health needs (iCOACH)

Principal Investigators: Walter Wodchis, Mylaine Breton, Toni Ashton, Timothy Kenealy

Co-Investigators/collaborators: Melissa Farrell, James Meloche, Geoffrey Anderson, Ross Baker, Janet Barnsley, Peter Carswell, Martin Connolly, Yves Couturier, Jean-Louis Denis, Janet Durbin, Dominique Gagnon, Tim Kenealy, Anna Koné Péfoyo, Kerry Kuluski, Fiona Miller, John Parsons, Nicolette Sheridan, Ross Upshur, Paul Williams, Anne Wojtak, Jay Shaw, Carolyn Steele- Gray, Frances Morton-Chang, Paul Wankah-Nji, Annette Dunham, Gaya Embuldeniya, Ann McKillop, Debra Lampshire, Tim Tenbensel, Lisa Walton, Juliet Rumball-Smith, Jodeme Goldhar

Team: The iCOACH team was comprised of over 30 members from three jurisdictions (Quebec, Ontario and New Zealand). The study team members include experts representing various disciplines (e.g., health policy, organizational behavior and change management, health economics, epidemiology), clinicians across several sectors (e.g., primary health care, mental health) and decision-makers with leadership roles in implementing changes in the health system. Additionally, the team was enhanced by engagement with patient and family carers, academic consumer advocates and indigenous advisors.

Locations: Quebec, Ontario, and New Zealand

Project aim/objectives: The aim of the research program was to understand how to scale-up successful innovative models of CBPHC. More specifically, their research sought to better understand the steps to implementing innovative CBPHC models that address health and social needs and improve outcomes for older adults with complex care needs.

Target Population: Older adults with co-existing, multiple chronic conditions, including priority populations.

Project development: The work conducted by the iCOACH team was separated into three phases of research based in Canada and New Zealand through which they aimed to discover, develop, and compare innovative delivery models of CBPHC and assess the contextual conditions associated with success or failure. The iCOACH team conducted more than 500 interviews in 9 case studies to understand the development, implementation, and essential success factors for implementing integrated care. The three phases of research that the team used to guide their work were:

- Phase I Describe models and context: seek models that have developed innovative approaches to delivering services and coordinating with other care providers to ensure continuity of comprehensive care.
- Phase II Develop conceptual framework: develop a thorough understanding of the attributes of the innovative CBPHC models and how they relate to the local context.
- Phase III Evaluate the Spread/Implementation of Innovative Cases: assess whether implementation of innovative CBPHC models will work, and what has to happen to make it work.

Website: https://cihr-irsc.gc.ca/e/50370.html

Impact on Advancing Knowledge

Publications: 42

• Books: 1

• Book Chapters: 1

• Presentations: 9

Workshops: 3

Conferences hosted/organized: 1

KT tools: 1

Conference boated/arranized 1

• Trainees: 3

• Training courses/educational initiatives: 1

"...around the kind of three-to-four-year mark, we had the teams come and we had a symposium for the day. And, and they came and gave presentations on how they were using the results of our partnership to reform their models of care...they came and told us how they were using our research."

"There are some really nice cross jurisdictional papers that kind of came out from that work to understand things like how, you know, very complex governance structures that were very top down, led to more structured rollout, but some more challenges on the ground."

Impact on Building Capacity

"And so, we had the government give the funds to sites themselves, in order to hire people to implement these programs...to enable them to actually evaluate their own work, and build that capacity within their teams, monitoring that program and also supporting them."

"i-COACH...they really embedded doctoral and postdoctoral research project in [their] research program...so for me, it was a success of the research infrastructure for the graduate student."

Informed Decision-making

Guidelines/policies: 4

"We were able to pull core findings...to inform the development of implementation guidelines and like workshops that we use to actually help people do this now."

"I would say you might trace the...a number of programs, particularly here in Ontario, that are, I would suggest, in some cases, attributable to our program of research. And in other cases, certainly, strongly supported by the research that we did... we spent

a lot of time with decision makers. And you really, after a certain period of time, can't really distinguish between what the decision makers would have done without you versus what they're doing with you."

Program Findings

Area of focus: Describe models and context (Phase I)

In phase I the iCOACH team aimed to seek models that have developed innovative approaches to delivering services and coordinating with other care providers to ensure continuity of comprehensive care.

Results:

- A literature review was conducted that yielded 32 activities of integrated CBPHC
- 32 activities of integrated CBPHC were presented to 17 participants from 3 iCOACH case study sites to determine which ones were important to models of integrated care.
 Participants identified all activities as important to models of integrated care; but reported varying needs for standardization or adaptation for specific elements.
- A systematic review and metanarrative synthesis was conducted that resulted in the synthesis of 35 reviews on implementation frameworks, theories and models. Many implementation theories and frameworks were found to neglect person-centred care.
- Findings within patient and carer data (n=28) provide evidence of all 14 components of a new taxonomy of provider self-management support. The overarching dimensions of the taxonomy helped reveal an intensity and consistency of provider behaviour that was not apparent considering the individual components.
- An analysis of sub-sectoral dynamics found that the primary care subsector was seen to bleed into several policy subfields and was perceived to variably support or challenge the efforts of both the acute and the community subsectors
- The iCOACH team compared the key institutional and policy features of Ontario, Québec and New Zealand that shape the 'space available' for models of community-based primary health care to take root and develop. The analysis suggested that two key conditions are (1) the integration of relevant health and social sector organizations, and (2) the range of policy levers that are available and used by governments.
 - O New Zealand was found to have the most favourable conditions
 - Ontario was found to have the least favourable conditions (the most significant institutional barriers to organizational integration and the fewest available policy levers)
 - All jurisdictions shared a crucial barrier: separated funding of medical and 'non-medical' primary care services.

"So the goals of our study, were really two, we were focused very much on the integration of different services in primary health care settings. So home and community primary care, secondary care services. And we were particularly interested in what the essential components or ingredients were to enable the sustainability of ongoing integration efforts in this... of community and health-based services, and the scale and spread of those initiatives."

"So the overarching goal of this project was to understand how community based primary health care teams are integrated with community based primary health care teams were being implemented in various jurisdictions in different kinds of organizational policy and jurisdictional contexts...and so really, we just wanted to understand how these integrated models came to be, what was working for them, and what we could learn from those experiences to help others implement their own models. And we were trying to do that from understanding everyone's perspective who was involved. So, we had...sub teams within this very large group, one team led understanding patient-caregiver experiences and these integrated models and their implementation. We have one group focusing on the provider experience, another on kind of the organizational level resources, and then a final group looking at the policy environment. And those teams had representation from all three jurisdictions participating and leading those levels of inquiry. But really, at the end of the day, we just wanted to know how these guys did it, and what we could learn to implement in other spaces."

Area of focus: Develop conceptual framework (Phase II)

Develop a thorough understanding of the attributes of the innovative CBPHC models, the specific ways that providers organize and care for older persons with complex conditions, and how these relate to the local context using comparative policy literature and patient/caregiver interviews.

Results:

- The iCOACH team drew on the comparative policy literature to develop a conceptual approach which recognizes the multidimensional nature of primary health care and PHC reform models.
- Unmet needs for older adults with complex care needs and informal carers culminated into three broad themes: Accessing Care (lack of transportation, out-of-pocket expenses, limited availability of assistive devices to support mobility, and long wait times); Quality of Care (due to a language barrier, and services that were misaligned with patient preferences); and Missing Care (respite care for carers, supports for instrumental activities of daily living, and supports to reduce social isolation)
- Many patients accessed care within CBPHC, but the model itself tended to be spread
 across multiple settings and providers. Finding ways to integrate across organizational
 boundaries may reduce areas of unmet need.
- Core attributes of care important to participants were feeling heard, appreciated, and comfortable; having someone to count on; easily accessing health and social care; knowing how to manage health and what to expect; feeling safe; and being independent.
- Relationship building was integral in supporting patients with self-management. More specifically, when providers acted upon knowledge of patient lives and priorities, these patients were often willing to try activities or medications they had resisted in the past.
- Unmet needs of caregivers of older adults with complex care needs receiving CBPHC included having an unrecognized role; lack of personal resources; and no breaks even when services are in place.

Area of focus: Evaluate the Spread/Implementation of Innovative Cases (Phase III)

9 case studies were conducted: 3 in each of Ontario, Quebec and New Zealand to understand policy context, organizational implementation, provider approach, and patient and carer experience. The iCOACH team worked with implementation sites to adapt and spread innovative model of integrating care.

Results:

• Ease of case study selection varied by policy context::

- Models of CBPHC were identified at the sub-national level: provincially in Canada, and through district health boards in New Zealand.
- Given the greater variation of CBPHC in Ontario and New Zealand, case selection was determined incrementally and adapted conventional case study selection approaches.
- O Quebec chose to vary the cases by local characteristics since it had a more uniform policy structure of local health and social networks.
- Key themes identified through the organizational case studies included: (1) The salience of organizational vision (2) The centrality of interpersonal relationships (between managers, health care providers, and patients) and (3) The mandatory inclusion of the patient perspective.
- Common challenges faced by leaders trying to integrate care across programs and organizations included: inadequate information sharing, inadequate time and human resources to launch new programs, high rates of HR turnover (in some cases), and confusion over "who owns the patient" with regard to integrated practice across multiple organizations. At the organizational level, leaders need to be able to identify and manage these tensions early to avoid inefficient and ineffective program design.
- Despite different models and contexts, all sites had Information communication technology (ICT) systems in each of the cases (most often electronic medical records) in place, and there were very similar accounts of the types of activities they supported. The barriers to more innovative use of technology were linked to three factors: (1) information access barriers, (2) limited functionality of available technology, and (3) organizational and provider inertia.
- Providers in Quebec considered that structural (government policy) and organizational (mergers) factors highly influenced the implementation of organizational and functional dimensions of integration, at the detriment of clinical integration.
- Findings from interviews regarding the implementation of a centralized-system wide integrated care model for older adults in Quebec suggest that patients and caregivers were mostly concerned by their unmet individual needs, and policymakers, managers, and providers were concerned by structural barriers to integrating care.
- A case study explored Whānau Ora and identifies the benefits of this community-based primary health care approach as perceived by the participants. Participants self-selected into a service that attempted to meet their needs and involved the integration of health and social services. This comprehensive approach met whānau / family needs, recognized poverty as a health issue, and was directly compatible with shared cultural values.
- Four primary barriers to engagement specified by patients with complex needs and their carers who were clients of selected CBPHC models (in Canada and New Zealand) were

- identified: perception of services; comfort in asking for things; beliefs about role; and access to resources.
- Patients and informal carers (from Canada and New Zealand) reported that functional limitations hindered self-management at home as well as access to CHSC. Physical barriers within the social environment included the inability to use public transportation, access community programs, and conduct daily living tasks. Consequences from not being able to access supports included greater financial strain, caregiver strain, social isolation, poor safety at home, and lack of independence.

Broad Social and Economic Impacts

- Additional Funding: Approximately 1.5 million+
- Scale and spread:
 - Work conducted by the iCOACH team has culminated in four practice guides that are relevant for any group of providers and organizations aiming to implement a connected health care system centred around patients, families and caregivers. Each of the four guides focuses on a different aspect of a more connected and better integrated approach to care and has a slightly different emphasis and target audience. The guides were prepared for Ontario Health Teams (OHTs). The guides can be read independently but achieving the overall implementation of OHTs will require attention to all dimensions presented.
 - The iCOACH team is planning an application of their knowledge in the spread of a province-wide integrated care initiative in Ontario.
 - The iCOACH team has developed a common outcome framework based on patient and carer values, goals and needs. They have uncovered a number of key mechanisms required for the successful implementation of sustained integrated care models, and are now testing these outcomes and mechanisms under three extending research programs in Ontario and New Zealand as well as an emerging program of research in Denmark.
- Number of regions/communities/sites where innovations were implemented or scaled up: 9

Impact on Partnerships

- Partners (individual level): 12 advisors (2 Patient and Family Caregivers, 2 Clinical Investigator, 2 Advisors, 2 Collaborators, 4 Knowledge Users)
- Sustained partnerships: the project has continued to a second phase, where many of the same team members from the CBPHC innovation team are involved
- Number of partnerships with stakeholder organizations: 3

"It's just a continuous stream, it's actually we've got a lot of the same team, we call it I-coach 2.0."

"We also always had spaces for patients and caregivers and community partners. Because we, you know, believe strongly and

saw the value of things like co-design and collaboration in these models of care as well, that's probably another core finding."

"It's led to, you know, collaborative book chapters, with the coauthor, with collaborators from across the three jurisdictions on this particular topic, and, you know, countless presentations internationally, and new network partnerships in the Netherlands and the United Kingdom and partnerships with the International Foundation of Integrated Care."

5. Transforming CBPHC delivery through comprehensive performance measurement and reporting (TRANSFORMATION)

Principal Investigators: Sabrina Wong, Sharon Johnston, Bill Hogg, Fred Burge

Co-Investigators: Julia Abelson, Medhi Ammi, Mary Byrnes, John Campbell, Heather Davidson, , Rick Gibson, Richard Glazier, Anna Greenberg, Jeannie Haggerty, Alan Katz, Victoria Lee, , Ruth Martin-Misener, Kim McGrail, Paul Roumeliotis, Tara Sampalli, Claudia SanMartin, Cathie Scott, Walter Wodchis

Team description: The research unit includes interdisciplinary researchers, decision-makers, and health professionals (clinicians, nurses, psychologists and other allied health professionals) from Canada, the United Kingdom (UK) and Australia.

Locations: British Columbia, Ontario, and Nova Scotia

Project aim/objectives: The objectives of the research program is to improve the science and reporting of CBPHC performance in Canada, specifically in the following regions: Fraser East, British Columbia (BC); Eastern Ontario Health Unit, Ontario (ON), and Central Zone, Nova Scotia (NS).

Target Population: The study findings will aid health care decision-makers to better use evidence in managing primary care in Canada.

Project development: The research program's activities revolves around four major studies: (1) compare measures of CBPHC performance and healthcare equity between three regions in Canada, (2) examine contextual factors that may explain variation between regions, (3) develop and evaluate an approach to national reporting of CBPHC performance based on priorities and optimal reporting formats, (4) identify innovations of service delivery associated with better CBPHC performance and healthcare equity.

Website: http://transformphc.sites.olt.ubc.ca/

Twitter: https://twitter.com/transformphc

Impact on Advancing Knowledge

• Publications: 13

• Reports: 3

Presentations: 43

Conferences hosted/organized: 1

Media coverage (articles/interviews): 1

KT tools: 2

"So, our focus was on the development and testing, translating and so on of the 3 surveys – provider, patient and office surveys and linking the results to the health admin databases...this has been a big project that's gone on for many years...but I think our best contribution from our study, was the patient survey."

"...we share health promotion messages at the beginning [of the automated survey] ... the particular message would be targeted to a segment within the practice population."

Impact on Building Capacity

• Trainees: 3

• Training courses/educational initiatives: 1

Informed Decision-making

• **Public partners/patients:** stakeholders including researchers, decision and policy makers (10), collaborators (7) students, and health professionals

"Unintended benefits was probably basically putting together multiple sources of data and which featured prominently I'd say in patients in the sense that they really helped us to deliver the dialogues to understand what were areas of importance in primary care for them to understand and how the information could be used. Although the way in which they suggested information could be used was really more aimed at decision makers."

"So, we offer a choice for that which aligns really well with Ontario health teams. So, that is probably the biggest – if it

turns out the way they are planning, that's going to be the biggest reform of health care that's ever happened in Canada short of Medicare and we will play a role in that in terms of informing the local Ontario health team leaders and more broadly, at the provincial level."

"We have the ability to aggregate the patient responses in a completely de-identified fashion across practices [through the automated survey]. When we do that, we can give feedback at a regional level. ... the Ontario government has funded us to evaluate a new health facility ... [in order to] allow the Ontario government to decide whether they should build 50 more of these kinds of facilities or not. So, we will have impact on decision makers."

Program Findings

Area of focus: Compare measures of CBPHC performance and healthcare equity between regions Result:

- Found that segmenting population data based on chronic conditions and health needs (healthy, multiple morbidities, medically complex, and frail) helped identify distinct patient groups with varying healthcare use and cost profiles
- Using the Primary Medical Home (PMH) framework to monitor primary care at the regional level, found there was variation, with the Eastern Ontario region scoring highest in seven of ten principles (patient-centered care, personal family physician, team-based care, comprehensive care, education, training and research, evaluation, and system supports)
- Through the implementation of the Patient Experiences Survey, found there was statistically significant regional variation in the following primary healthcare performance dimensions: Accessibility Orientation, Relationship-Based Care, Self-management Support, Coordination Orientation, and Contribution to a Safe Healthcare System
- Among the three regions, Ontario practices scored the highest across all seven dimensions of primary care
 - Findings from an analysis of osteoporosis screening suggest that cross-provincial comparisons of healthcare performance are possible with administrative data. Such undertakings however, require flexibility on analytic methods and constant communication.

"So, we get a 60% response rate to the questions [of the automated survey] which is phenomenal. This is probably happening because the survey questions are being sent from the patient's family physician or nurse practitioner, so people are inclined to trust in that situation and respond in high numbers."

"So, providing...sending public health messages to patients is a worthy impact. It presumably means we have a better informed public. Asking them question to help doctors and other primary care providers improve the service that they offer has impact in terms better service over time. It's a practice learning...it's creating a practice based learning network in effect. So, it is a continuous quality improvement data collection infrastructure – that's what it is."

"The biggest impact was around the ability to use multiple sources of data to look at things like performance

• Developed a core set of primary care performance indicators that was able to be implemented with comparable algorithms across provinces. The chosen 21 indicators pertained to technical care, continuity of care, and health services utilization.

Area of focus: Examine contextual factors that may explain regional variation primary health care system performance Results:

- Through the findings of a scoping review, discovered important aspects of rural primary healthcare that need to be considered during reporting: accessibility issues, increase in physician scope of practice, and low relational continuity.
- Found that all three provincial regions have been working on performance frameworks, with Ontario furthest along with regards to measurement and reporting infrastructures.
- Found that different Canadian regions were implementing the following primary care improvement strategies at varying capacities: interprofessional team-based approaches, provider skill mix expansion, physician groups and networks, information systems, remuneration and performance measurement and reporting infrastructure.

Area of focus: Develop and evaluate an approach to national reporting of CBPHC performance based on priorities and optimal reporting formats Results:

- The findings of the scoping review noted the lack of an approach that used conceptual frameworks alongside system-developed indicators
- The team developed a matrix approach for regional-level primary care measurement incorporating population segments of different care needs alongside performance domains of high-quality care.
 - Majority of stakeholders selected the following performance domains: patient centeredness, access, continuity, coordination, and comprehensiveness
- Found that patients valued the following primary care performance measures: access to primary care providers, communication with providers, information continuity, and continuing professional development
- Discovered that primary care performance reports would be used by patients for: community advocacy and participation in decision-making, selecting providers (with some barriers), and building trust on care received.

Area of focus: Identify innovations of service delivery associated with better CBPHC performance and healthcare equity Results:

measurement. So, we've had some really good ideas now about how to move forward in terms of a primary health care information system platform and what kinds of data are needed in order to look at things like performance measurement in primary care."

"It's a bit early, but the focus is...and really what's special about what we've done and no one else has yet done in Canada is the ability to aggregate the data across different participating practices. ... We have the ability to aggregate the patient responses in a completely de-identified fashion across practices. When we do that, we can give feedback at a regional level."

- Found through implementing an automated survey to recent primary-care patients that
 email was generally preferred and had a higher response rate than surveys sent over phone.
 It was also noted that response rates increased for emailed surveys as patient income
 increased.
- Found that implementing customer relationship management programs for primary care study recruitment led to challenges in obtaining enough time, support, and costs. However, researchers noted potential for use in longer-term studies.
- Through the findings of a scoping review, discovered the use of an interactive voice response telephone survey could be a feasible alternative to traditional methods due to its cost-effectiveness, decreased burden, and better patient samples. However, will need to tackle low mode effects, response rates, high set-up costs and maintenance fees.

Broad Social and Economic Impacts

- Additional Funding: \$1,500,000+ [funding for five follow up research projects; Michael Smith Foundation (grant number PT-CPH-00001-134); Institute for Health System Transformation & Sustainability (only for the July 2015 Stakeholder Workshop)]
- Scale and spread:
 - Held a workshop with stakeholders to establish the performance measurement framework for primary care specific to British Columbia (provincial level)
 - Five follow up research projects to use the TRANSFORMATION data collection infrastructure in 460 family physician practices.
- # of regions/communities/sites where innovations were implemented or scaled up: 460

Impact on Partnerships

- Partners (individual level):
 - o International Stakeholder Advisory Group (incl. experts in primary care research)
 - o Paid physician peer-to-peer recruiters in all sites
 - o Partnership with three Divisions of Family Practice in British Columbia (received recruitment and provided data back)
 - In Nova Scotia and British Columbia, Regional Stakeholder Advisory Committees were formed (incl. patients, physicians, and decision-makers)
- Sustained partnerships:
 - o In Nova Scotia, co-leading research with the provincial health authority
 - Stakeholders part of the July 2015 workshop were asked if they wanted to be part of future discussions for the project
- Number of partnerships with stakeholder organizations: 14

6. Atlantic Canada Children's Effective Service & Strategies in Mental Health (ACCESS-MH)

Principal Investigators: Marshall Godwin, Rick Audas, Jacques Richard, Scott Ronis, Kate Tilleczek, Michael Zhang

Co-Investigators: Bronwyn Davies, Colleen Simms, Roger Chafe, Olga Heath, Don McDonald, William Montelpare, Weiqui Yu, Reid Burke, Julie MacDonald

Team: ACCESS-MH is composed of primary health care physicians, policy makers and researchers from the four Atlantic Canada provinces (New Brunswick [NB], Newfoundland & Labrador [NL], Nova Scotia [NS], Prince Edward Island [PEI]).

Locations: Atlantic Canada (Prince Edward Island, New Brunswick, Nova Scotia, Newfoundland and Labrador) and an international partner (New Zealand)

Project aim/objectives: To support improved access and experience of, child/youth mental health services in Atlantic Canada. The project specifically focuses on the following five highly prevalent child and youth mental health conditions: autism spectrum disorder (ASD), conduct disorder, eating disorders, anxiety and depression.

Target Population: Responding to the needs of children and youth with mental health and oppositional behavioural problems and their caregivers in the four Atlantic provinces.

Project development: Within each of the five conditions, the team used patient journeys/process mapping, operations research and statistical analysis of large and complex databases to develop an overview of how children and youth access and experience treatment and services across various systems (ex. health, education).

Website: https://access-mentalhealth.ca/

Twitter: https://twitter.com/access_MH

Impact on Advancing Knowledge

- Publications: 10Presentations: 71
- Workshops: 3
- Conferences hosted/organized: 2 [the Atlantic Summer Institute on Healthy and Safe Communities symposium, Investing in Child and Youth Mental Health – Mobilizing Atlantic Canadians for a Positive Future (2015); the Primary Healthcare Partnership Forum (Prifor) 2018]
- **KT tools: 2** [a series of tools for service providers; website (resource for youth, families, stakeholders and researchers)]

"We compiled all of the mental health services that were available in Atlantic Canada and that's on the web, as a resource. And so, I think that we increased capacity among patients."

"...it was a mix of things [regarding resources on website], I think, like especially psychologists, publicly funded like community health centers, and publicly funded community mental health services."

Impact on Building Capacity

- **Trainees: 28** [23 graduate students, 5 postdoctoral fellows]
- Training courses/educational initiatives: 2 [student training opportunities (e.g., Qualitative Research Boot Camp at UPEI in 2014); public partners involved in research activities were given one week of training in basic research methods and interviewing skills, in addition to ongoing supervision and training]

"I think one thing I really want to emphasize is our team, because we have been working with several universities, and we focused on the training of the capacity."

"But what it did provide to me was a group of faculty and mentors who were interested in a similar area as me and that is invaluable to have as a trainee...I would say, like, the project gave back to me quite a lot in terms of mentorship and training opportunities and research opportunities."

Informed Decision-making

- Public partners/patients: advisory board (encompassed of community members, academics, representatives from non-profit organizations, and policymakers assisting in the uptake and transition of knowledge)
- Guidelines/policies: 1 [Best-practice guidelines]

"Then we get feedback, we get knowledge, information from patients, then we provide feedback from the policymakers, and the decision makers. Right? And this is very interactive...we come up with a solution together."

"So, I think we are moving in the right direction...we produce a lot of evidence to support the policy makers."

"I do think that it elevated the profile of mental health, especially in New Brunswick, and PEI and Newfoundland, where there

aren't the large research universities that have people working on this subject all the time. And so, I do think it elevated the public profile."

Program Findings

Areas of Focus: The Use of Patient Journeys for this Population Results:

- A conceptual synthesis of the literature found the following three themes, despite the lack of research on journeys in youth mental health:
 - O Youth journeys in mental health are often fractured and non-linear;
 - Barriers and facilitators exist at personal and systemic levels and often in paradoxical fashion;
 - O Schools are crucial locations in youth journeys.
- Indicated how journey approaches to youth mental health respects the lived experiences and vast knowledge of youth with mental health challenges, and could support the implementation of Canada's mental health strategy

Area of Focus: Homeless Youth Population Results:

- A self-report needs assessment found that Canadian suburban male youth who were homeless or were vulnerable to homelessness experienced a range of difficulties (ex. mental health problems, low self-esteem, substance use).
 - Around one-third of the participants reported no service use, with the most common type of service used being therapy or counseling.

Area of focus: Acute Care Utilization Results:

- A study of mental health-related hospitalizations in New Brunswick found psychiatric admissions by children and adolescents increased from 44 admissions per 100,000 in 2004 to 51 admissions per 100,000 in 2014.
 - Rates of psychiatric admissions among children, adolescents, and adults exhibited seasonality, with the highest rates of child and adolescent admissions being in February, whereas adult admissions peaked in early May.

"So, one is really to document and summarize the... how the services you know, the patient population current's accessing right. The other is the... let's really look at broadly, you know, not only in the health component, but education, social work, even some private sector providers, when really, you know, through documentation and analysis can be really better understand significant barriers and facilitators. Right, you know, from you know, for our not only our patients, their family members, you know, caregivers, also you know, from the service providers perspective, right? So, that I would say is really, I think it has been very successful. Just, you know, collecting information and documenting the information. We have done a lot."

"And there are many, many different components. Right, you know, from the data collection, you know, because we collected many different sources of data, you know from interviews, the qualitative study to the qualitative outputs, right, you know, the patient's admission, and the prevalence of a particular condition."

"But if you ask me, which one is...there's too many tools, and we have a very good understanding what tools are more effective, and with what condition."

"But at the end of the day, you know, given the timeframe, given the resources, given the efforts, we...you know, we are committed. I think we made some breakthrough, but not as significant as we anticipated, right?"

Areas of Focus: Caregivers Health and Well-Being Results:

A Canadian study found that compared to caregivers of individuals with physical or other
health problems, those who took care of persons with mental health or addiction disorders
were more likely to report that caregiving was very stressful and had a negative impact on
their emotional health.

Broad Social and Economic Impacts

 Additional Funding: Amount unknown (not reported). Received funding by Canadian Mental Health Association (CMHA-NS) and Dal and the Atlantic Summer Institute (ASI) on Healthy and Safe Communities to host a symposium in 2014. "Like New Brunswick has one mental health facility for all children and youth in the province, and they often send children and young people out of province if it's a significant mental health issue. So... you know, I don't know the extent to which there was an opportunity for like systems level change because there isn't even a system there I would argue, like there isn't even the basic elements of a system."

Impact on Partnerships

- **Partners (individual level):** Creation of an advisory board with representation from multiple sectors across the four provinces (NB, NL, NS, PEI)
- Number of partnerships with stakeholder organizations: 6

"I also, you know, over time, you know we've had, you know we had a lot of meetings with, you know, many different stakeholders, including the policymakers."

"Right now, we have [with the LHIV team], we basically, we cosupervise a master's student doing her master's thesis in healthcare services research."

"So, amongst those meetings, we, I think, I would say like 30 to 40%, really meeting with the local researchers."

7. Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT)

Principal Investigator: Eva Grunfeld, Clay Brian Holroyd

Co-Investigators: Kimberly Ann Kerns, Ulrich Mueller, Sandy Buchman, Margaret Fitch, Julie Gilbert, Jon Kerner, James Meuser, Carol Sawka, Donna Turner, Fiona Walks, Michèle Aubin, Melissa Brouwers, June Carroll, Craig Earle, Elizabeth Eisenhauer, Lise Fillion, Patti Groome, Ruth Heisey, Amna Husain, Jennifer Jones, Paul Krueger, Monika Krzyzanowska, Aisha Lofters, Donna Manca, John Maxted, Mary McBride, Baukje Miedema, Fiona Miller, Nicole Mittmann, Rahim Moineddin, Mary Ann O'Brien, Geoffrey Porter, Jeffrey Sisler, Jonathan Sussman, Fiona Webster, Marcy Winget

Location(s): British Columbia, Alberta, Manitoba, Ontario, Nova Scotia, New Brunswick, Newfoundland and Labrador, the United States, Australia, Denmark

Team: The Canadian Team to Improve Community-Based Cancer Care along the Continuum (CanIMPACT) is a pan-Canadian group of researchers, primary care providers (PCPs), cancer specialists, patients and caregivers. The team members have expertise in epidemiology, biostatistics, knowledge translation, qualitative methods, and community-based pragmatic trials.

Project aim/objectives: The goal of CanIMPACT is to identify factors associated with poor continuity and coordination of cancer care in seven provinces, engage patients and caregivers, and develop an intervention aimed at improving care coordination for patients with cancer.

Target Population: Breast and colorectal cancer patients and health care providers.

Project development: The CanIMPACT program of research is divided into two phases. In Phase 1, mixed methods research was conducted, including: 1) analysis of administrative health data; 2) qualitative interviews with patients, PCPs, and cancer specialists; 3) focus groups with primary care teams focusing on personalized medicine; and 4) an environmental scan and systematic review of initiatives designed to improve care integration. A consultative workshop to obtain recommendations from stakeholders about the intervention was then conducted for Phase 2. The stakeholders voted for eConsult as the most practical and scalable approach, with the aim of facilitating communication and coordination of care between PCPs and cancer specialists. Phase 2 involved the implementation of a cancer-specific modification of eConsult (referred to as eOncoNote): through a randomized controlled trial in the Ottawa region; through an implementation study in Newfoundland and Labrador; for personalized medicine.

Website: http://canimpact.utoronto.ca

Impact on Advancing Knowledge

Publications: 31

• Reports: 3

Book Chapters: 2Presentations: 98

Workshops: 2

Media coverage (articles/interviews): 3

• **KT tools: 3** [Personalized Cancer Genomic Medicine Resource Toolkit; Clinical Synthesis Map: Cancer Care Pathways in Canadian Health Care; Patient Synthesis Map: The Patient as Person in Relationship-Centred Care]

"There was an administrative review. I wasn't part of that subgroup, but it looked at all the administrative processes. And that was very, very successful"

"Certainly, the toolkit for genetic research, and our genetic referrals...is going to continue on."

"We were a really cohesive group of people, incredibly productive. I can't remember, how many publications we had in phase one. Like 30 or 40."

Impact on Building Capacity

Trainees: 13 [11 students, 2 postdoctoral fellows]

• Thesis supervision for 9 students

"I didn't do the presentations. I had the PhD student do all the presentations. So, I think it was valuable for her because these were the first experiences that she had in doing presentations with an audience. So, I think it was valuable at that level."

Informed Decision-making

- Public partners/patients: 11 policy makers who have participated in training and capacity building held by the team. 74 attendees from 9 provinces with representation from primary care, cancer specialists, knowledge users, researchers and patients, who contributed their ideas and expertise to provide a direction for the second phase of CanIMPACT
- Guidelines/policies: 1 [identification and management of women with a family history of breast cancer practical guide for clinicians]

"I... loved the fact that as far as I remember CIHR did specifically want patients involvement, patient or caregiver involvement. So we were, you know, I do that quite frequently, but I'm not sure if it hadn't been a requirement if I would have done it in this particular instance. So, it really set our team to thinking about what's the best way to do it, it was part of our organizational structure. So, you know, we worked on putting together the patient advisory committee, we had an organizational structure where members of the patient advisory committee were involved in each of the sub-projects that the team did. They've made a very important contribution."

"And so, you know, it was really insightful for the group... when we're having some candid conversations by saying, you know, when a patient hears that, it's not clinical for us, it's not a stat, it's like, this person is not going to survive this. So, it's a different way of looking at it, for sure."

Program Findings

Phase 1 (mixed methods research)

1) analysis of administrative health data

Area of focus: Inter-and intra-provincial variation in breast cancer diagnosis, risk factors, primary care provider utilization (British Columbia (BC), Alberta (AB), Manitoba (MB), Ontario (ON), and Nova Scotia (NS))

Results (BC, AB, MB, ON, NS):

- There was significant inter- and intra-provincial variation in the odds of screen-detected breast cancer by age
- Lower odds of screen-detection for breast cancer was associated with those in the lowest income quintile and a lack visits to primary care 30 months prior to diagnosis

Results (BC, MB, ON, NS):

- Primary care provider (PCP) use among women 18+ years of age diagnosed with stage I-III
 invasive breast cancer was greatest during treatment and decreased with each successive
 survival year in all provinces.
- Factors associated with being a high user of primary care during treatment included comorbidity and being a high user of care pre-diagnosis in all provinces. These factors were also associated with being a higher user of care during diagnosis and survival.
- Age, stage, receptor status, comorbidities, and geographic location were associated with receipt of chemotherapy in all provinces
- In all provinces, most survivors had more than the recommended number of visits to either an oncologist or primary care physician
- Underuse of surveillance breast imaging was identified in NS and BC.
- Compliance with recommended physician visits for patients with several chronic conditions was high in Ontario and NS.
- Preventive care was less than optimal in all provinces with available data.
- many breast cancer survivors (>64%) in each province received care from both primary care and oncology providers during the follow-up period

"Our study was focused on cancer, specifically breast cancer.... I remember the original call was... talked about intervention studies. So, we took that at face value in the sense that we felt it was important to include a intervention study. I think some other people interpreted intervention a little bit more loosely than we did. But we aimed to do a trial, randomized trial. But we needed to understand, we needed a lot of background work before we could do the trial. So, the goal of the study was to look at the coordination of care and continuity of care for cancer patients with their primary care physicians over the continuum of cancer care...so we didn't include prevention, and we didn't include end of life care. So, we were looking at the diagnostic period, the treatment period, and the survivorship period. S,o the goal was continuity, and assessing continuity and coordination of care over the continuum of cancer care, focusing on that with respect to primary care physicians"

"The goals were definitely achieved. We had phase one, which was the descriptive work and that involved - it was multi-methods. So, we had, I think, we had a total of seven provinces involved where we did studies using administrative health data. We had, we did a national environmental scan to look at what kind of programs had been introduced across the country to improve continuity and coordination of care. We did qualitative work with primary care physicians and patients and family caregivers. So, ... the phase one was a multi-method approach. Phase two, then we had a huge stakeholder meeting in order to present the results of phase one and have input from the stakeholders as to what they felt was the most feasible intervention to evaluate with a randomized trial. And so, we had specific criteria about what we wanted them to rate

• the mean number of breast cancer—specific visits to primary care and visits to oncology declined with each follow-up year.

Results (BC, MB, ON):

- In the survivorship phase, there was a decreasing trend in primary care physician (PCP) visits over time but an increase in continuity of care compared with baseline in all provinces.
- Primary care physicians were least involved during the treatment phase, but they are playing a key role with patients in all phases of cancer care

Results (BC, ON):

 In both provinces, immigrant women were significantly less likely to have a screen-detected breast cancer and had a significantly longer median diagnostic interval than long-term residents.

Area of focus: A population-based assessment of primary care visits Result:

- Patients receiving chemotherapy were found to visit a primary care physician (pcp) significantly more frequently than they had before their diagnosis and significantly more frequently than control subjects without cancer.
- More than one third of pcp visits by chemotherapy patients were related to breast cancer or chemotherapy-related side effects.
- The likelihood of experiencing an ER visit or hospitalization increased in the days immediately after a pcp visit. These results suggest an opportunity to institute measures for early detection and intervention in chemotherapy side effects.

2) Qualitative interviews with patients, PCPs, and cancer specialists

Area of focus: The role of family physicians in cancer care Results:

- Findings from interviews conducted with primary and cancer specialist health care (N=58) identified 3 key roles that family physicians (fps) currently play and should play in the future care of cancer patients across the cancer continuum. These 3 key roles were: coordinating cancer care, managing comorbidities, and providing psychosocial care to patients and their families.
- Participants discussed many challenges that prevent fps from fully performing those key roles such as communication problems (e.g., not being copied on patient reports) and a lack of patient access to fp care, leaving specialists to fill the care gaps.

potential interventions on and we had presentations about potential interventions. And the criteria were that you know, it had to be scalable, feasible, scalable, and relevant obviously, and evidence-based.

Area of focus: Coordination of cancer care between family physicians and cancer specialists Results:

- Findings from interviews with 58 health care providers (HCPs) suggest that communication challenges are the most prominent barrier to good coordination of care along the cancer care trajectory
- Five key related subthemes were identified around this core concept of communication challenges as a prominent barrier: delays in medical transcription, difficulties accessing patient information, physicians not being copied on all reports, the lack of rapport between FPs and cancer specialists, and the lack of clearly defined and broadly communicated roles.

Area of focus: Patients' experiences with continuity of cancer care in Canada Results:

- Patient perspectives shared through semi-structured interviews with 38 breast and colorectal cancer survivors 1 to 4 years after diagnosis suggest that the core components of providing good continuity and well-coordinated care include: good communication, positive relationships with HCPs, timely information sharing, and access to care.
- Patients identified good communication as a core component of feeling that they were connected to their HCPs and that their overall cancer care was well coordinated.
- 3) focus groups with primary care teams focusing on personalized medicine

Area of focus: Multigene expression profile testing in breast cancer Results:

- The family physicians (fps) and cancer specialists felt that ordering gene expression profile (gep) tests and explaining the results was the role of the oncologist
- A new fp role was identified relating to the fp—patient relationship: supporting patients in making adjuvant therapy decisions. Lack of fp knowledge and resources, and challenges in fp—oncologist communication were seen as significant barriers to that role.

Area of focus: Primary care providers (PCPs) experiences with and perceptions of, and desired role in personalized medicine, with a focus on cancer (Alberta and Ontario) Results:

Findings suggest that PCPs need better resources to support their implementation of
personalized medicine such as: increased knowledge, closer ties to genetics specialists, and
relevant, reliable personalized medicine resources accessible at the point of care.

4) an environmental scan and systematic review of initiatives designed to improve care integration.

Area of focus: Documenting coordination of cancer care (The CanIMPACT Casebook) Result:

- A pan-Canadian environmental scan of initiatives designed to improve or support coordination and continuity of cancer care between primary care providers (PCPs) and oncology specialists was used to develop the CanIMPACT Casebook
- The CanIMPACT Casebook profiled 24 initiatives aimed to improve coordination between primary care providers and oncology specialists. Initiative teams implemented the following strategies: nurse patient navigation, multidisciplinary care teams, electronic communication or information systems, PCP education, and multicomponent initiatives.

Area of focus: Family physician access to and wait times Results:

• Findings from an online survey for family physicians (N=1054) suggest that there are considerable provincial and regional differences in FP's direct access to cancer diagnostic investigations and advice from other specialists regarding investigations and referrals

Area of focus: Identification and management of women with a family history of breast cancer - practical guide for clinicians Results:

- Literature review findings on best practices suggest that taking a family history helps identify BRCA mutation carriers. Screening tools can help identify those women who should be referred for genetic counseling or enhanced screening.
- Women at substantially increased risk might have cancers detected earlier by enhanced screening with annual magnetic resonance imaging in addition to mammography
- Physical activity and moderating alcohol intake reduce breast cancer risk and should be encouraged.

Area of focus: Follow-up after treatment for breast cancer Results:

• A review of guidelines led to the development of a 4-component model for follow-up survivorship care of women treated for breast cancer that includes: (1) surveillance and screening (annual mammography); (2) assessment and management of physical and psychosocial effects (e.g., pain, fatigue, medication side effects); (3) health promotion (e.g., physical activity); and care coordination.

Area of focus: Interventions to improve care coordination

A systematic review to evaluate current or new models of care and/or interventions aimed at improving coordination between primary care and oncology care providers for patients with adult breast and/or colorectal cancer.

Results:

- The majority of the 22 studies identified through this review showed no statistically significant changes in any patient, provider or system outcomes.
- Owing to conceptual and methodological limitations in this field (imprecise results that lack generalizability), the review was unable to provide specific conclusions about the most effective or preferred model/ intervention to improve care coordination.

Phase 2 (intervention)

Area of focus: consultative workshop

CanIMPACT hosted a consultative workshop with 74 attenees that brought together our team members, various stakeholders from across Canada, and international liaisons from Australia and the United States.

Results:

- Following a deliberative process of discussion and refinement of ideas, stakeholders recommended testing a secure online asynchronous communication platform (eConsult service) for healthcare providers of cancer patients.
- The stakeholders voted for eConsult as the most practical and scalable approach, with the aim of facilitating communication and coordination of care between PCPs and cancer specialists.

Area of focus: implementation of eOncoNote (modification of eConsult) Results:

- a cancer-specific modification of eConsult (referred to as eOncoNote) was implemented in two jurisdictions in 2018 (a randomized controlled trial in the Ottawa region, and an implementation study in Newfoundland and Labrador).
- The use of eConsult is being examined for personalized medicine

Broad Social and Economic Impacts

- Additional Funding: \$10,194,871
- Scale and spread: the implementation of eOcoNote was launched in Ottawa and Newfoundland and Labrador

• Number of regions/communities/sites where innovations were implemented or scaled up: 2

Impact on Partnerships

- Sustained partnerships: project activities are still in progress
- Number of partnerships with stakeholder organizations: 2

"Well, COVID has really changed how some of the action-based research was to take place. And so it has, they're still research happening. None of it face to face. But I think the funding is, has been complete, but they held it over an extra year because it wasn't all dispersed."

"And so, and I think that there's now a long standing, you know, collegiality and cohesiveness that will, you know, lead to more projects and carry on. So, the team has been great."

8. The Canadian Chronic Disease and Awareness Program (C-ChAMP)

Principal Investigators: Janusz Kaczorowski, Tamara Daly, Lisa Dolovich, Marie-Thérèse Lussier, Simone Dahrouge

Co-Investigators: Angelique Berg, Martine Montigny, Vasanthi Srinivasan, Sheldon Tobe, Farah Ahmad, Ricardo Angeles, Maria Chiu, Alexandra Fletcher, Ron Goeree, Johanne Goudreau, Charlotte Jones, Lyne Lalonde, Beatrice Mcdonough, Véronique Grenier, Michael Paterson, Jane South, Iffath Syed, Jean-Claude Tardif, Lehana Thabane, Karen Tu, Gina Agarwal, Danielle Wolfe

Team: C-ChAMP is encompassed of a multi-disciplinary and inter-sectoral team that includes social scientists, pharmacists, family physicians, nurses, specialists, epidemiologists, biostatisticians, health economists, decision makers, and patients.

Locations: Ontario, Alberta, and Quebec and 1 international partner (Philippines)

Project aim/objectives: The program looks to improve community and population-based prevention and management of chronic diseases (ex. Cardiovascular disease, diabetes, blood pressure, atrial fibrillation). C-ChAMP aims to continue and adapt the Cardiovascular Health Awareness Program (CHAP) program across a wider array of populations and settings.

Target Population: Younger adults (Quebec and Ontario), immigrant communities (South-Asians in Ontario), older adults in subsidized housing (Ontario and Quebec), and individuals in large urban and suburban communities (Alberta, Ontario and Quebec).

Project development: C-ChAMP four expected outcomes are: social and economic benefits, improved population health, capacity development, and advancing knowledge. Sessions include: prediabetes, type 2 diabetes and mental health awareness and screenings, and detection of atrial fibrillation. The programs are offered in a variety of locations including; Family Health Teams, subsidized housing, community centres, schools, libraries and places of worship. For the various communities and populations, sessions are run by age-matched locally recruited volunteers (Quebec), university students (Markham and Ottawa, Ontario) or paramedics (Ontario).

Website: https://cihr-irsc.gc.ca/e/47157.html

Impact on Advancing Knowledge

- Publications: 11
- KT tools: 1 [C-CHAMP IPhone/IPad application to manage cardiovascular diseases]

"We've done all sorts of videos as well from different perspectives. So, we have videos that share some of our results over time and we have family physicians, pharmacists, patients participating in those, so that we can present what has happened so far, but then also get feedback on different aspects of the challenges."

Impact on Building Capacity

• Training courses/educational initiatives: 1 [Volunteers (students, paramedics, community members) received online and/or face-to-face standardized training to deliver the preventative health care program (adapted to fit each location)]

"We have formal training both video, online and depending on which initiative – in person training for volunteers, pharmacists, physician. So yeah, those are the main people involved."

"I have to admit I'm trying to think of particular evaluations on training. We have publications on the volunteer roles where they would've talked about the usefulness of the training, but we've done evaluations after our training sessions, but we haven't published that. We have sought evaluations for each experience, but not I guess once people are out in the field."

Informed Decision-making

Public partners/patients: None reported
 Guidelines/policies: None reported

"I think our approach to knowledge translation has been to meet with or bring together groups of stakeholders from across all of these arenas including the family physicians and pharmacists that have actually delivered the intervention, patients who have received it."

"So, different governments I guess in Ontario and Quebec, different knowledge users from the policy side that we've interact with on a regular basis to let them know about what was going on, talk about our plans, talk about the findings that we were generating and get input on what that meant for the health care system and other projects that were underway or other initiatives that were underway."

"I think our work has helped with or contributed to solidifying the role of pharmacy as a place where hypertension care can occur and to a lesser extent, other types of care like atrial fibrillation and diabetes."

"What else? I think our work contributed to the idea of community-based volunteers having a part in helping with chronic disease management and being a link to community. I don't know if the results did any policy changes necessarily, but it helped elevate the idea that that's a possibility that we should be exploring within the health care system."

Program Findings

Area of Focus: Capacity Development Results:

- Volunteers stated that they gained new skills and information, which they used to educate
 themselves and their family members and friends. However, also discovered there was
 tensions and sustainability challenges when relying on volunteer support for such programs
- Studies found how volunteers can provide valuable insight and important feedback on the research protocol as well as patient needs, leading to several modifications in the program

Area of focus: Greater use of new technologies Result:

- Created a C-CHAMP IPhone/IPad application to manage cardiovascular diseases using protocols defined by CHAP (ex. manage blood pressure recording, collect information about hypertension risk factors, and measure the body mass index)
- Found that a large majority of users noted the application to be helpful, easy to use, reliable, and highly functional
- Found that most of the health professionals highly rated the application in terms of diagnosis, meeting users' needs, and technological aspects
- Discovered that working group and program staff saw the application positively in terms of improvement to workflow/protocols and reduction of effort, but negatively with regards to efficiency

"I think our work — I should say, from a behaviour change point of view, we've measured a lot of process outcomes, so we've looked at our interventions and understood how many more blood pressure we've taken, community groups were sought advice for, we've got surveys of patients that look at how they've accessed and linked better with community organizations, they've self-reported their physical activity and their diets improved. So, we have that type of work and we also know from our cluster randomized trial that our intervention itself has reduced hospitalizations for heart attack, strokes and heart failure. Then, from our adaptations, we show that blood pressure is generally improved from those who are taking part. We also have looked at a large study on social housing that we're getting the results for to understand how health has been improved there."

Area of focus: Advancing knowledge Result:

- Noted how the risk factor profile (ex. Risk of diabetes, low physical activity) for older adults in subsidized housing buildings were much higher than the general older adult population
 - Found within this population, those in Quebec have a poorer risk factor profile compared Ontario.
- Found that program attendance is associated with participation of local leaders and those who did not attend looked to avoid negative interactions with other residents
- Discovered the following patients' perceptions with regards to paramedic providers within community paramedicine programs (CHAMP-EMS): had trusting and close relationships, viewed as health advocates, and valued their emergency skills set

Area of focus: Improving Population Health Result:

 The CHAP-EMS program (paramedics led) taking place in subsidized housing was associated with a reduction in emergency calls (by 25%), participant blood pressure (statistically significant), and a tendency towards lowered diabetes risk after one year of implementation

Broad Social and Economic Impacts

- Additional Funding: Amount unknown (not reported) [Funding received from Ontario Association of Paramedic Chiefs for publication costs (CHAMP-EMS, Hamilton, Ontario), the Hamilton Academic Health Sciences Organisation (HAHSO) grant (Hamilton, Ontario), Funding for EMS staffing provided in kind by all participating research sites (CHAMP-EMS) (Ex. Department of Family Medicine and Hamilton Paramedicine service)]
- Scale and spread: The program hopes to identify optimal conditions for scaling up and leveraging resources within communities to make this initiative available to all Canadians
- Number of regions/communities/sites where innovations were implemented or scaled up: 2

"I think having a strong team together at the start. Having – at least for our team and I think for many others actually, having already well-developed networks where the research had already got to a point where the work could be done the way it was done. I think working across jurisdictions was good. It forced us to expand beyond just one jurisdiction and work within different contexts which I think is important from a spread and scale perspective."

Impact on Partnerships

Sustained partnerships:

 Partnership with the Canadian Red Cross to implement intervention sites in Niagara, Ontario were sustained through a Memorandum of Understanding and regularly scheduled meetings "The goals of our research were to use multifaceted approach within the primary health care sector bringing a number of organizations together including primary care teams, pharmacy and community based organizations including volunteers — to bring them together to reconfigure how they could provide care."

- Advisory committee made up of representatives from local organizations (involved in the care of the target population) assisted with program development (Hamilton, Ontario)
- The Regional Health Authority developed the program in Laval, Quebec for patients in primary care clinics
- Number of partnerships with stakeholder organizations: 8

"We have a lot of connections to different knowledge users."

"Most [of the relationships with stakeholders] were established before CBPHC team emerged, but certainly the funding and the resources, the staff we could have to keep those relationships going was really important."

9. Living with HIV (LHIV) Innovation Team

Principal Investigators: Claire Kendall, Clare Liddy, Shabnam Asghari, Marissa Becker, Christopher P. Kaposy, Sean B. Rourke

Co-Investigators: Jill Allison, Tony Antoniou, Gordon Arbess, Jean Bacon, Ahmed Bayoumi, Christine Bibeau, Ann Burchell, Kimberley Burt, Tara Carnochan, Timothy Christie, Kayla Collins, Gerard Farrell, Richard Glazier, Dale Guenter, Jennifer Gunning, William Hogg, Laurie Ireland, Sharon Johnson, Erin Keely, Deborah Kelly, Jelani Kerr, Cynthia Kitson, Colin Kovacks, Mona Loufty, Philip Lundrigan, Douglas Manuel, Meaghan McLaren, Leonard Moore, Gerry Mugford, Elizabeth Muggah, Andrew Pinto, Kevin Pottie, Anita Rachlis, Robert Remis, Timothy Rogers, Ron Rosenes, Cheryl Schultz, Tina Sorensen, Monica Taljaard, Kednapa Thavorn, Mark Tyndall, Nancy Yu

Team: LHIV is encompassed of key researchers, policy makers, health professionals, trainees, HIV clinic managers and networks, and people living with HIV in each of the three provinces involved in the studies.

Locations: Manitoba, Ontario, Newfoundland and Labrador

Project aim/objectives: To conduct research and interventions surrounding the move of HIV care to the community-based primary health care (CBPHC) sector, while being integrated with specialist HIV care. The four specific objectives are to:

- 1) Create a better understanding of the health, healthcare utilization, and quality of care of persons living with HIV;
- 2) Implement an integrated care model for HIV care delivery;
- 3) Examine patients' perspectives of a shift to a primary healthcare approach for HIV care; and
- 4) Build and support with data and infrastructure the Living with HIV (LHIV) Innovation Team: a highly skilled, interdisciplinary HIV primary healthcare team

Target Population: Responding to the needs of people living with HIV/AIDS.

Project development: Activities took place across the following provinces: Manitoba (MB), Ontario (ON), and Newfoundland and Labrador (NL). The LHIV study used the Expanded Chronic Care Model (E-CCM) (a population-based, patient-centred, integrated team approach with decision support) to aim for improvement in the health of the target population, patient experience of care, and reduced costs. The team focused on the following initiatives:

- 1) Construct comprehensive, provincial population cohorts of people living with HIV (LHIV cohorts), to describe the care patients are receiving and improve our understanding of the gaps in care.
- 2) Develop quality indicators to evaluate the quality of care provided to people living with HIV.
- 3) Introduce an electronic-consultation system to improve primary-specialist communication and improve access to specialist care.
- 4) Create a toolkit to support providers in navigating ethical issues related to HIV care provision.
- 5) Improve self-management support strategies for people living with HIV.

Website: https://www.lhiv.ca/

Impact on Advancing Knowledge

• Publications: 51

• Reports: 3

Policy briefs: 3Presentations: 150

Workshops: 4

Media coverage (articles/interviews): 8

• KT tools: 1 [Ethics toolkit, self-management protocols]

"So, one of the key things was the McMaster policy brief that was developed and that was used in the McMaster Health Forum and that is a very structured approach to knowledge creation, dissemination. So, that's one that I would put forward as something that could be replicated and used by others."

"I think the community scholarship program we developed and we've reported on that was actually published in CMAJ. I think that was another tool that's useful for other research groups and I know we've heard from some who've used that approach to research."

Impact on Building Capacity

• Trainees: 25

• Training courses/educational initiatives: 2 [1 Course/Lecture/Seminar, specialty physicians/services and primary care providers were trained to use the e-consult service]

• Thesis supervision for 12 students

Informed Decision-making

- **Public partners/patients:** Used academic-policy-provider-community partnerships to help move knowledge and assist with knowledge translation strategy.
 - Community members and knowledge users engaged throughout the project in various committees, research activities, and in the conceptualization and grant submission process.
 - Patient partners contributed to research, also presented in meetings, co-authored papers, and were offered courses/mentoring.
- Guidelines/policies: 2 [The Community Scholars Program (CSP) guidelines framework for patient engagement, expansion of econsult]

"So, from the creation, the identification of the research questions, the designs of the study, reviews of questionnaires, analysis, writing the paper and co-presenting it, when we went to conferences and stuff, we would have community members and other stakeholders involved in co-presenting with us."

"Yeah, I mean, we certainly presented to policymakers and with our team members, including community members, and develop measures of what the impact...what high quality care would be in primary care settings that I think it did help to shift that dialogue."

"[LHIV work on eConsult] shifted policy and it shifted focus to the primary care realm in real ways and it led to a shift in policy."

Program Findings

Areas of Focus: Improve Patient Engagement – Community Scholar Program (CSP) Results:

- Along with patient partners, developed the Community Scholar Program that identified the roles and responsibilities of the patient partners and the research team leadership.
 - Provides a clear framework into patient engagement and provides support so community members can meet with academic researchers, clinicians and decisionmakers on an equal level.

Area of Focus: Developing a LHIV Performance Framework and Quality Indicators Results:

- Through a scoping review, it was found how existing performance frameworks for the care
 of people with HIV provided a comprehensive set of indicators that align well with a
 primary healthcare performance framework, with certain parts of care poorly covered by
 indicators.
- Influenced by HIV-specific indicators, data, guidelines, and stakeholder/expert input, a
 framework for assessing the quality of comprehensive community-based primary healthcare
 for people with HIV was created titled Indicator Framework for Evaluating the Quality of
 Care Delivered in the Primary Health Care System to People Living with HIV.
 - Contains 79 indicators across the following 11 domains of care: Health System
 Context; Access; Patient-Provider Relationship; Continuity; Service Integration;
 Health Promotion and Primary Prevention; Secondary Prevention; Care of
 Chronic Conditions; Satisfaction; Activation/Empowerment; Health Care
 Utilization

Area of focus: Creating Provincial LHIV Cohorts to Describe the Current State of Care Patients

The LHIV research team developed provincial clinical cohorts of people living with HIV (PLWH) and had created platforms for linking these cohorts to provincial health administrative databases.

Results:

Evaluation of Health-System Performance

"I would say one of our biggest impacts was the community orientation of our work and the development of a model for community member involvement in primary care research studies. I think another was the development of clinical cohorts that allow us to assess the care for people living with HIV and particularly the primary care in Canadian provinces. Another, I'd say, with the expansion of the e-consult program across many Canadian jurisdictions."

"[Launched in 2011, eConsult] developed in our health region and slowly accrue over time and then just as it was getting to the point in 2013 when LHIV was starting, e-consult was maturing and starting to be ready for replication. So, there's two things that happened kind of around the same timeline. So, within Ontario, the e-consult team was part of some pilot projects and eventually 20..., hope I don't get the dates wrong — 2018, it became a provincial program, but it started in 2016 as these pilot projects for other regions of Ontario. So, that was...the idea is that a family doctor or a nurse practitioner was able to reach out to...at the time when I left a year ago in the Champlain region, there were over 132 specialty services they could access."

"I think on the e-consult side — I think there's a couple of things to understand about the impact of this HIV program. It's really what gave e-consult the context and the partnerships in Manitoba, Newfoundland & Labrador to really launch this."

"I would also add – there's a couple of things I would add to that, that I think that there is a substantial number of papers that were done using health administrative data in all three provinces and I think we learned a lot about health administrative data and the

- With regards to HIV care in Ontario by physician specialty, family physicians provided the majority of out-patient visits (53.6% of all visits and 53.9% of HIV visits), internal medicine specialists provided 4.9% of all visits and 9.6% of HIV visits, and Infectious disease specialists provided 12.5% of all visits and 32.7% of HIV visits.
- From a cross-sectional survey of Canadian HIV care settings, majority were in urban settings and entirely HIV focused. Despite all settings being team based, primary care settings offered a broader range of preventative services and comprehensive access to mental health services, including addictions and peer support than specialist settings.
- Found that within Canadian primary and specialist HIV care settings basic elements of each Patient-Centered Medical Home domain has been implemented (esp. Continuous team-based healing relationships), with no significant differences between the two settings.
- Discovered how regardless of type of care setting, HIV care in Canada is well aligned with several components of the Chronic Care Model, especially linkage to community resources and collaborative and inter-professional team-based care. However, availability of electronic clinical information systems and self-management support services need improvement.

Description and Comparison of the Burden of Disease for Persons Living with HIV

- Found from 1995 to 2014 among HIV-infected people in Ontario, all-cause mortality and death from HIV/AIDS rate declined, however proportion of deaths due to various noncommunicable diseases rose.
- People living with HIV in Ontario, had significantly higher prevalence of all chronic conditions except myocardial infarction and hypertension, as well as substantially higher multimorbidity.

Typology of Care

- Developed a care typology for people living with HIV in Ontario: exclusively primary care, family physician—dominant co-management (family physician has the most visits for HIV care), specialist-dominant co-management (HIV specialist has the most visits for HIV care), exclusively HIV-specialist care, and low engagement.
- Found that among HIV-positive patients with family physicians, majority only used these professionals exclusively for their care. Among these patients, receipt of antiretroviral therapy was positively impacted by family physician's HIV experience.
- Found that HIV-patients in Ontario with an assigned family physician had higher odds of
 cancer screening than those in exclusively specialist care. However, the odds of
 hospitalization and HIV-specific hospitalization were lower among patients who saw
 exclusively family physicians, with odds of antiretroviral prescriptions being lower among
 models in which patients' HIV care was provided predominantly by family physicians.

Assessment of Health care Utilization

challenges of interprovincial use and comparison with that data. I think that was a really interesting outcome of these projects."

"Well, I'm thinking of our stakeholder dialogue with the McMaster Health Forum and the recommendations arising from that are very primary and community care oriented."

- Discovered that a large majority of Ontario patients diagnosed with HIV in hospital presented to out-patient HIV care by 90 days.
- Found HIV-positive status (among Ontario women) was associated with significantly lower odds of undergoing mammography, with influence from the type of care received (physician or specialist).
- It was found how nearly three in four HIV-positive women in Ontario were underscreened for cervical cancer.
- In Ontario, rates of emergency department use, especially for ambulatory care sensitive conditions (except hypertension), were higher among people with HIV. Also, people with HIV were also more likely to be admitted to hospital following an emergency department visit.
- With regard to end-of-life care in Ontario, it was found how HIV was associated with 4.5 more acute care days in the last 90 days of life, with mean cost of care in the last year being significantly higher among people living HIV (\$80,885.62 vs. \$53,869.77).
- Through a scoping review and framework synthesis, the most common frequently stated themes (in order) regarding healthcare access from the perspectives of people living with HIV were: Acceptability, Availability, Accessibility, Affordability, Other Barriers, Communication, Satisfaction, Accommodation, Preferences and Equity in Access. The most frequently stated concepts (in order) within these themes were: staff treatment, wait times, lack of financial resources and fear of disclosure.

Area of focus: Expansion of the Champlain BASE eConsult Service

From a proof-of-concept, the Champlain BASE[™] eConsult service became available to all PCPs in the Champlain LHIN health region.

Results:

- A total of 41,728 cases have been completed by 1,417 registered PCPs from 520 clinics in 118 towns/cities, who can access 114 specialty services.
- Improving Population Health
 - Service cuts to response times from months to two days
 - o 69% of cases did not require a face-to-face specialist visit
 - o 40% of cases avoided an originally considered referral
- Patient Experience
 - o 87% of patients considered eConsult useful
 - 97% of patients considered eConsult an acceptable alternative to traditional faceto-face referrals
- Provider Experience
 - o 92% of cases that PCPs rank eConsult as high/very high value

- Acceptance among PCPs with the quick response times, helpfulness, reassurance, and positive impact on patient care.
- o 94% of specialists report that eConsult improves communication with PCPs
 - Acceptance among specialists also with the improved access for patients, user friendliness, compensation process.
- o eConsult provides a powerful teaching tool for PCPs
- Cost Savings
 - Across specialty groups, the service costs a weighted average of \$47.35/case versus \$133.60/case for traditional referrals
 - O Costs drop dramatically after the start-up period, reaching ~\$6.45/case by year 3
- The linkages with the LHIV Innovation Team led to the introduction of eConsult in other
 parts of Ontario (Mississauga Halton Health region), ON eConsultation pilot study,
 Nunavut, Manitoba (in 2017), and Newfoundland and Labrador is on track to offer a
 provincial program with multiple specialties.

Area of focus: Health System Transformation Results:

• Created a stakeholder dialogue, consisting of 3 citizen panels in Winnipeg, Hamilton and St. John's followed by a national stakeholder dialogue (in 2019) with 23 system leaders using the validated process established by the McMaster Health Forum.

Areas of focus: Developing a toolkit for providers navigating ethical issues arising in practice

Results:

- Phase 1: Using institutional ethnography to examine complex relationships in settings where people with HIV seek medical care
 - Found that health care providers and clinic clients have developed work processes for managing various ethical issues including:
 - Conflicts between client-autonomy and public health priorities ("treatment as prevention"),
 - Difficulties associated with the criminalization of nondisclosure of HIV positive status,
 - Challenges with non-adherence to HIV treatment,
 - The protection of confidentiality,
 - Barriers to treatment access,
 - Negative social determinants of health and well-being
- Phase 2: Developing the ethics toolkit

Area of focus: Foundational work to implement self-management supports for people living with HIV

Results:

- Using the Patient Activation Measure (PAM®) survey, found that people living with HIV
 had high levels of patient activation for self-management, comparable to patients with
 diabetes mellitus.
- Established an interdisciplinary national collaborative team, Aging and Living with HIV
 (ALHIV) that met to identify the current extent of and gaps in self-management and
 rehabilitation services for people living with HIV.
- A systematic review on peer-led self-management interventions noted unclear effectiveness on improving antiretroviral therapy adherence and limited consistent findings on the various patient-reported outcomes measured (depressive symptoms, QOL, and selfefficacy).

Broad Social and Economic Impacts

- Additional Funding: \$10,603,948
- Scale and spread:
 - Generated a national network to support eConsult's expansion, seen by the CFHI's two-stage Connected Medicine eCollaborative facilitating the implementation of eConsult in seven provinces.
 - The CANImpact team chose eConsult as the innovation to help improve cancer care collaboration and a new approach to eConsult (specialist to primary care consultation for care coordination) is being evaluated.
 - The CSP Guidelines has been implemented in other projects and initiatives (ex. national expansion of the Champlain BASE™ eConsult service, Ontario Patient Engagement Resource Centre)
 - O The data from the provincial cohorts (linked to administrative data) contributed to larger pan-Canadian HIV cohort data.
- Number of regions/communities/sites where innovations were implemented or scaled up: 5

Impact on Partnerships

- Partners (individual level): Community Scholars (patient partners) were able to contribute to all stages of research and are involved in governing research, attending meetings, providing input, presenting at conferences and co-authoring papers.
- Number of partnerships with stakeholder organizations: 51

"So, early on, we adopted...we did not use the term knowledge translation, we use the term knowledge exchange and that really drove our philosophy to how we approached the whole idea of knowledge translation and dissemination of everything. So, I think

we have built relationships with community members and community partners, we partnered with some key community organizing national organizations like CATIE. So, knowledge dissemination was an integral part of everything that we did."

"The e-consult programs in [Manitoba and Newfoundland & Labrador] are now fully funded independent programs and it was led by a lot of HIV family doctors and researchers who helped implement e-consult different programs."

10. TransFORmation of IndiGEnous PrimAry HEAlthcare Delivery (FORGE AHEAD)

Principal Investigator: Stewart Harris

Co-Investigators: Ed Barre, Onil Bhattacharrya, David Dannenbaum, Keith Dawson, Roland Dyck, Jo-Ann Episkenew (in memory), Michael Green, Anthony Hanley, , Ann Macaulay, Alex McComber, Monica Parry, Sonja Reichert, Jonathan Salsberg, Amardeep Thind, Sheldon Tobe, Ellen Toth, Audrey Walsh, Lloy Wylie, Merrick Zwaranstein, Heather McDonald, and Braden Te Hiwi.

Team: FORGE AHEAD involved a multi-disciplinary program team that included First Nations community representatives, Indigenous and allied healthcare providers, academic researchers, and policy/decision makers. The program involved partnership with 11 First Nations communities across six provinces (BC, AB, MB, ON, QC, NL).

Locations: British Columbia, Alberta, Manitoba, Ontario, Quebec, and Newfoundland

Project aim/objectives: FORGE AHEAD was a five-year program aimed at developing and evaluating community-driven, culturally relevant, primary healthcare models that enhance chronic disease management and appropriate access to available services in First Nations (FN) communities across Canada. The program had five main objectives:

- 1) Assess the current healthcare delivery, funding models, and best practices used in First Nations communities in Canada.
- 2) Assess community and clinical readiness to address and adopt chronic disease care.
- 3) Enhance patient access to available community resources for chronic disease care.
- 4) Implement and evaluate community and clinical quality improvement initiatives
- 5) Develop sustainment strategies and a scale-up toolkit to improve chronic disease management in FN communities.

Target population: Provider level: community members and clinical teams providing healthcare services to patients in First Nations communities with type 2 diabetes; Patient level: patients in First Nations communities with type 2 diabetes

Project development: The FORGE AHEAD team conducted a Community Profile Survey and a systematic review to identify existing healthcare delivery models and diabetes specific infrastructure/programs in Indigenous communities in Canada. The team also developed a clinical readiness tool, a community readiness tool, and an online diabetes registry and clinical indicator tracking system. Additionally, 3 workshops were conducted through the team that supported quality improvement (QI) teams to discuss their readiness reports and plan their QI initiatives. A four-month Action Period followed each QI Workshop. During this period, QI Teams were able to put their QI knowledge into practice. They tested QI innovations through PDSA cycles and integrated successful changes into their diabetes prevention and management practices.

Website: https://cihr-irsc.gc.ca/e/49004.html

Impact on Advancing Knowledge

- Journal Publications: 4
- Presentations: 15
- Workshops: 4
- Media coverage (articles/interviews): 2
- KT tools: 4 [Online diabetes registry and clinical indicator tracking system; Community Readiness Consultation Tool and Clinical Readiness Consultation Tool (the aim of these tools was to rank the level of community and clinical team readiness to develop, adopt and evaluate chronic disease care initiatives); Scale up Toolkit]

"So, the way we implemented knowledge exchange is not a one-way street. It's a two-way street, right. So, we involved our partners in the processes early on to even develop the grant for CIHR and development and testing of the tools around readiness and some of the data collection instruments. So, we had knowledge exchange in that particular setting in the preparation phase, but in terms of professional development, we integrated a lot of the clinical training, especially around diabetes and chronic disease in our training sessions and workshops."

"I think that actually really... that was part of the intervention model. But it was also part of the governance model. That the people who are engaged locally would learn from each other."

"I think there was a definitely a positive change around the awareness of the clinical stuff. Specifically, for the frontline staff and I think there was a better knowledge that developed on how to improve clinical process. Specifically, around administrative processes in the clinic and community. In terms of raising awareness, I know within the community, outside of the clinic, a lot of our partners did do quality improvement initiatives that raised awareness around nutrition, around diabetes, chronic disease."

"The scale up toolkit was successful because we actually just launched over the last few months, the version of a program that is leaner which is adaptable and flexible and we're in the process of implementing it with a number of communities across Canada."

Impact on Building Capacity

- Trainees: 125
- Training courses/educational initiatives: 2
 - The Western Research Team provided ongoing support and coaching to the Community Facilitators, Community Data Coordinators, and QI Teams as they implemented QI innovations. This included support on QI concepts, strategies to implement PDSA cycles, group facilitation skills, using the patient registry and clinical tracking system, and other topics that arose.
 - Online Training Modules to assist during role transitions

Informed Decision-making

 Public partners/patients: FORGE AHEAD partnered with 11 First Nations communities across six provinces (BC, AB, MB, ON, QC, NL) and three isolation levels (isolated, nonisolated, and remote-isolated/semi-isolated) "The professional development around the clinical stuff was fairly decent and I know that the health care staff and front line workers appreciated that."

"The capacity building in each of the communities was valuable and a positive outcome. And then we actually did manage to see some improvements in some core diabetes outcomes, which is actually very difficult to do in these sorts of health systems, you know, community level intervention type studies."

"I think there might have impacts in terms of local level policy...how communities have their own health care policies around doing things and how they change that. Part of the whole sustainment strategy, they make policy level changes to really entrench quality improvement as a methodology of how they do everything, and some communities have done that better than others"

"From my informal conversations with people who are running these initiatives on the ground, they told me outside of official data channels that these events had some impact."

Program Findings

Area of focus: Community Profile Survey (CPS)

A community-based, national-level survey designed to identify and describe existing healthcare delivery models, funding models, and diabetes specific infrastructure and programs in Indigenous communities. A total of 84 communities completed the survey (19% response rate). **Results:**

- The majority of communities had a health centre/office to provide service to their patients with diabetes, with limited on-reserve hospitals for ambulatory or case-sensitive conditions.
- Few healthcare specialists were located on-site, with patients frequently travelling off-site (> 40 km) for diabetes-related complications.
- The majority of healthcare professionals on-site were Health Directors, Community Health Nurses, and Home Care Nurses.
- Many communities had a diabetes registry, but few reported a diabetes surveillance system.

"Some of the major objectives were to test and evaluate readiness tools within indigenous contexts. We were also looking to see if we could collect national level data on community demographics and clinical conditions. The other objective was to implement and evaluate quality improvement initiatives on the study."

"We implemented readiness throughout the program and I believe we achieved that objective because almost all the communities participated in that. I think we were more successful on the clinical side compared to the community side. Like, we had the readiness on 2 different streams — we had a community based readiness and we had a clinical readiness. The clinical readiness looked at the readiness within the clinic and health care sector whereas the

• Regional variation in healthcare services, diabetes programs, and funding models were noted, with most communities engaging in some type of innovative strategy to improve care for patients with diabetes.

Area of focus: Systematic Review of Interventions/Best Practices for the Prevention and Management of Diabetes

The FORGE AHEAD team carried out a systematic review of interventions that have aimed at improving screening, treatment, prevention and management of type 2 diabetes and obesity-related chronic disease in Indigenous communities in Canada from 2008 to 2014, with the aim of identifying best practices. The knowledge gained from this review served as a guide for FORGE AHEAD program activities.

Results:

- Findings included 17 publications, comprising 13 evaluated interventions.
- Most interventions aimed at encouraging behaviour change, especially dietary change, but did little to address the underlying context of systemic marginalization and colonialism experienced in many Indigenous communities.
- Interventions that focused on improving fitness were more effective than those aimed at dietary change.
- Participatory action research methods and community ownership of the intervention were found to be essential for project success.

Area of focus: Clinical Readiness Tool Development, Validation and Consultation During the inception of the FORGE AHEAD program, there were no clinically focused readiness tools that could be used by partnering First Nations communities to assess their readiness levels. An appropriate Clinical Readiness Consultation Tool (CRCT) was developed by the FORGE AHEAD team, based on the ABCD-SAT Tool piloted in Australia.

Results:

- The 27-page Clinical Readiness Consultation Tool (CRCT) consists of five main components, 21 sub-components. Length of the tool was reported as a drawback, but respondents noted that all the items were needed to provide a comprehensive picture of the healthcare system.
- Results for internal consistency showed that all sub-components except for two were within acceptable ranges (0.77–0.93)
- Using the CRCT Tool, Clinical QI Teams were able to understand their levels of clinical readiness in five key areas: delivery system design, information systems and support, self-management support, linkages with community resources and health services, and

community based readiness really looked at prevention programs and the community at large. So, I think the clinical one was more successful and we published a paper on it as well with our findings in the process. In terms of the quality improvement initiatives, I would say definitely successful and we achieved that. We found that we had 11 partnering communities and they all implemented a variety of different things and it was definitely very good."

"The readiness tool allowed them to figure out what were some of things that were working in the community or clinic and where do they have challenges. Then, during our workshops, we supported them in figuring out how they can meet these challenges using a quality improvement method and that was throughout the program. So, when we had the workshops, we would breakout and my staff and I would work with every single partner individually and we would figure out what are some of the initiatives they could take and they would go implement it. During that particular implementation period, we would be providing support on a weekly basis."

"It was a really great project to be involved in. You know, it was a... we had a range of communities all across the country that participated, they came in in different waves. And there was a lot of excitement, it was great to see that much community engagement in each of the communities. And, you know, some of them were at different stages in their kind of preparedness to do different sorts of work. But it was great to work with all the different communities and kind of see them come along with their own ideas and on their kind of work to improve diabetes care and outcomes in their own communities."

organization in influence and integration. Using this knowledge, Clinical QI Teams engaged in consultation and were able to plan QI initiatives and prioritize their efforts.

Area of focus: Community Readiness Consultations

Assessment of a community's readiness to mobilize on an issue was an important factor as it provided a measure of available engagement and areas to build capacity. A community readiness tool piloted in the United States was modified to suit the needs of partnering First Nations communities.

Results:

- Community QI Teams used the tool to better understand the readiness levels in their community
- Community QI teams engaged in consultations to plan QI initiatives and prioritize their efforts.

Area of focus: Community-Driven and Clinical Quality Improvement Initiatives

Community-driven and Clinical QI Initiatives included a series of three Workshops (1–2 days), separated by three-month long Action Periods. During the Action Periods, support was provided by the Western Research Team (training, facilitation support, QI documentation, etc...).

Results:

- QI Workshops were the most valued component of the program
- A series of 10 inter-related and progressive program activities were designed to foster community-driven initiatives with type 2 diabetes mellitus as the action disease

Area of focus: Diabetes Registry and Clinical Indicators Tracking System

The Diabetes Registry and Clinical Indicator Tracking System focused on the development of a diabetes registry listing all adult diagnosed with T2DM in each partnering community.

Results:

 Launch and administration of the Diabetes Registry and Clinical Indicators Tracking System. The system included built-in tools and clinical reminders to support improvement of diabetes care.

Area of focus: Program Clinical Outcomes

Overall clinical outcomes for 8 communities (28,584 community members total, 2008 community members with baseline and at least 1 follow-up visit)

Results:

- Significant decreases in HbA1c, BP, LDL with individuals not meeting T2DM clinical targets at baseline
- Blood pressure, BMI, and foot exams were similar before and after the program
- Significant increases in frequency of measurement of HbA1c, BP, LDL, ACR, eGFR
- Community members were 51% more likely to have received at least 75% of guideline recommended services

Broad Social and Economic Impacts

- Additional Funding: Amount unknown (not reported). The FORGE AHEAD Program
 was funded by multiple grants from the Canadian Institutes of Health Research (CIHR). It
 was also generously supported by the Lawson Foundation and conducted with the support
 of a grant from AstraZeneca Canada Inc.
- Scale and spread:
 - Support for QI innovations were provided to 11 First Nations communities across six provinces (BC, AB, MB, ON, QC, NL). Over 100 community and regional/national reports were developed and distributed to all participating communities and key stakeholders including federal and regional government partners, and organizational partners.
 - The FORGE AHEAD program expanded to 5 additional communities after the CIHR innovation grant
- Number of regions/communities/sites where innovations were implemented or scaled up: 16

"We found that we had 11 partnering communities and they all implemented a variety of different things and it was definitely very good. In terms of sustaining it, I think some of the community sustained it, but we found that without more support post program, it was difficult for communities to keep going. Some communities did better than others — it depended on team functioning and how well organized they were. I know some communities have carried it forward and other communities have had challenges keeping up with it. In terms of cross analysis, again, that was more of an academic endeavor where we were finishing it up. We got an extension because of COVID, so we have a collaborator who is finishing up that analysis right now."

"This particular CBPHC had 11 and then, we had another CIHR grant which we worked with 4 more communities and then, we had another one with a different initiative. So, 16 communities so far. So, we would bring them on as initial founders of this network and then any community that's coming to participate in the lean scale up toolkit that we have developed from the program, they would automatically have access to the network. The idea is to bring in indigenous communities from all across Canada to partner in as they partner with us in the program. Then, eventually I don't know if it'll go further than Canada"

Impact on Partnerships

- Sustained partnerships: project is still in progress
- Number of partnerships with stakeholder organizations: 14 (including 11 FN communities)

"it was a really great project to be involved in. You know, it was a... we had a range of communities all across the country that participated, they came in in different waves. And there was a lot of

excitement, it was great to see that much community engagement in each of the communities... it was great to work with all the different communities and kind of see them come along with their own ideas and on their kind of work to improve diabetes care and outcomes in their own communities."

"There were certainly a lot of cross connections made with other groups and communities... It's been a model that's been of interest to diabetes, both Diabetes Canada, and Diabetes Action Canada and kind of their work in engagement with kind of improving First Nations diabetes care, generally. So, I think it's had, you know, significant impact outside of just the communities involved in the study."

11. Innovation Supporting Transformation in Community-Based Primary Healthcare Research Project (iPHIT)

Principal Investigators: Alan Katz, Kathi Avery Kinew, Josée Lavoie, Wanda Philips-Beck, Stephanie Sinclair, Grace Kyoon-Achan, Naser Ibrahim

Co-Investigators: Norman Bone, Valerie Gideon, Avis Gray, Marcia Anderson, Melanie MacKinnon, Stephanie Sinclair, Leona Star

Locations: 8 First Nations communities in Manitoba (Fisher River Cree Nation, Nelson House Northlands FN, Berens River, Cross Lake, Pinaymootang FN, Ebb and Flow, Birdtail Sioux).

Team description: The iPHIT team was comprised of academic primary care researchers and a dynamic team of collaborators. These include the Assembly of Manitoba Chiefs (AMC), and Nanaandewewigimig, First Nation Health and Social Secretariat of Manitoba, the MFN Centre for Aboriginal Health Research, and 8 First Nations communities in Manitoba.

Project aim/objectives: The iPHIT focused on community-based primary health care (CBPHC) within First Nations (FN) communities. The overall aim was to transform primary health care through the perspectives and suggestions for innovations of First Nation communities based on their health and needs. The goals for this project included:

- Describing CBPHC service provision in FN communities.
- Exploring the understanding of FN living on reserve of primary healthcare
- Comparing the models of governance, community engagement, strengths and CBPHC service delivery across communities
- Building collaborative relationships with communities and decision-makers to support the implementation of CBPHC innovations

Target Population: Eight First Nation rural/remote communities in Manitoba (8 of 63 FN communities in Manitoba, representing four of five local languages – Dakota, Dene, Cree and Ojibwe)

Project development: The iPHIT team conducted five independent research projects. The following methods were used:

- Qualitative community-based participatory research was used explore local perspectives of primary care.
- Retrospective longitudinal studies using administrative data were used to explore hospitalizations for ambulatory care sensitive conditions over time.
- Cross-sectional surveys were used to understand current models of CBPHC in FN communities.
- Surveys were used to further understand mental health in FN communities

Over 500 semi-structured interviews and focus groups combined were completed in Studies 1 and 5, 830 surveys were collected in Studies 3 and 5, and eight key informant interviews will be completed in Study 4. Study 2 analyzed routinely collected administrative data.

Website: https://www.fnhssm.com/copy-of-copy-page-new

Impact on Advancing Knowledge

- Journal Publications: 11 [11 published, 20 total]
- Workshops: 10 [data was shared with the 8 communities at bi-annual community
 workshops. Participants were also brought from all 8 communities to annual research
 workshops with decision and policy makers from provincial and federal departments.]
- Media coverage (articles/interviews): 3

"...It's more of a developmental research program where any information that is gathered is then fed back to those local teams and reflected upon, so that they can first get their own understanding of what research can do for them."

"There was a transformation in terms of building relationship. So now, that's given rise to a number of knowledge products."

Impact on Building Capacity

- Trainees: 8
- Training courses/educational initiatives: 1 [The research team shared expertise through the training and support of LRAs and others in the communities. On recruitment, LRAs were trained in research methods, interviewing skills, use of technology for data collection, information management, data analysis, community engagement, and strategic planning. They were also included in a national network of trainees so that they could stay connected in the research world and receive further capacity building through webinars, workshops, peer mentoring, and conferences.]

"We wanted... to have eight communities that were partnered with us as well, where we would have closer relationship and we wanted them to be involved in their own data gathering, their assessment of their community, develop their own plan and implement them. So, there were eight local research assistant that were hired one in each community, and they led the data gathering, the interviews, the analysis of their own data"

Informed Decision-making

- Public partners/patients: 5-year research collaboration between the University of Manitoba (UM), the First Nations Health and Social Secretariat of Manitoba (FNHSSM) and eight First Nations communities in Manitoba.
- Guidelines/policies: 3 [the iPHIT team has developed (1) recommendations for a national First Nations—focused holistic health strategy, (2) a blueprint for respectful CBPR, and (3) guidance on developing ethically sound and effective research practices and relationships in community—university collaborative research.]

"So, there was a new atlas of First Nation health that was produced in 2019 and was co-produced by FNHSSM and the Manitoba Center for Health Policy...that's a huge achievement, because now it's carrying us through some work that we're doing on COVID-19, where...the researchers from the Manitoba center are still quite engaged. And I think it really transformed that relationship."

Program Findings

Area of focus: Community-based Participatory Research (CBPHC Conceptualization)

"We wanted to look at, what is a First Nation model of primary health care? So, using interviews, we wanted to also look at administrative data to identify whether they were outliers that were A community-based participatory research (CBPR) approach was used for the conceptualization of the study, data collection, analysis, and knowledge translation with participating communities and Local Research Assistants (LRA's).

Results:

- Partnerships were forged with participating communities to own and sustain innovations.
- Published work that provides a blueprint for respectful CBPR that encourages a
 community-owned, widely recognized process that is sustainable while fulfilling researcher
 and funding obligations.
- Using a CBPR approach, the iPHIT team learned that successful collaborations require a) investing time and resources into developing respectful research relationships; b) strong leadership and governance; c) clearly defined roles and responsibilities; d) meaningful participation of First Nations; e) multiple opportunities for community engagement; and f) commitment to multiple, ongoing, and consistent forms of communication.
- Published work that provides guidance on developing ethically sound and effective research practices and relationships in community—university collaborative research.
- FN perspectives on primary healthcare (N=183) included that improving PHC
 performance requires delivering timely and holistic healthcare that integrates traditional
 health knowledge, comprehensive CBPHC increasing services such as healthcare and
 medical transportation, healthy food as an important preventative measure and a culturally
 informed workforce backed by local leadership and promoting cultural respect.

Area of focus: Mapping Hospitalizations for Ambulatory Care Sensitive Conditions (ACSC) in First Nation and Rural & Remote Communities

Administrative data collected by Manitoba Health was used to explore and compare hospitalizations for Ambulatory Care Sensitive Conditions (ACSC) and observe trends over time and geographically. This information was important in comparing different models of healthcare delivery and population level outcomes.

Results:

- Hospitalization rates for acute, chronic, vaccine-preventable, and mental health-related ACSCs have decreased over time in First Nation communities yet remain significantly higher in First Nations and remote non-First Nations communities as compared with other Manitobans.
- Results also show lower hospitalization rate for ACSC in the north, suggesting barriers to prevention and early diagnosis.
- Premature mortality rates (PMR) were found to be significantly higher in northern FN compared to southern FN.

more successful in terms of meeting the needs of communities for primary health care services, and these would be communities that had lower rates of avoidable hospitalizations. And we wanted to also do surveys to try to figure out what was included under that umbrella of primary health care."

- Hospitalization rates for mental health-related conditions were significantly higher in the northern First Nation communities compared to southern FN communities, and all Manitoba
- The length of stay (LOS) for all ACSC increased significantly for all Manitoba but not for FN communities. The LOS for mental health-related conditions increased only for the southern FN communities.
- Across Manitoba, overall rates of hospital readmissions for ACSC ending in death are slowly increasing, and increasing more dramatically among northern First Nations, larger First Nations not affiliated with Tribal Councils, and in the western region of the province. These regions have continuously been highlighted as disadvantaged in terms of access to care.

Area of focus: Mental Health

The iPHIT team documented patterns and trends of in-hospital mental health service use by First Nations (FN) living in rural and remote communities in the province of Manitoba.

Results:

- Rates of hospitalization for mental health are increasing for FN males and females. This is
 particularly evident for those affiliated with the Island Lake and Keewatin Tribal Councils.
- The length of stay has increased.
- Changes in rates of readmissions were not statistically significant.
- FNs are admitted for mental health conditions at a younger age when compared with other Manitobans, and trends show that the FNs' average age at admission is decreasing.

Broad Social and Economic Impacts

- Additional Funding: Amount unknown (not reported).
- Scale and spread: a better understanding of trends in health outcomes and service utilization across 8 FN communities in Manitoba, as well as capacity building related to facilitating research and knowledge translation

"So, if you ask me the biggest, from a structural level, from a policy level, that's a big piece from a community level, there was transformation of health programs that became more responsive to patients, to community members. And so that's a huge transformation from a different standpoint. I'm not sure that there was a lot... that resulted in transformation at the provincial level. But in terms of health services, the First Nation community, Manitoba is a bit different."

Impact on Partnerships

• Sustained partnerships: sustained relationship with the First Nations Health and Social Secretariat of Manitoba and Manitoba Center for Health Policy

"The biggest transformation, I think, with the Manitoba Center for Health Policy, there was a transformation in terms of building relationship."

• Number of partnerships with stakeholder organizations: 12 (including 8 FN communities)

"In terms of my relationship with FNHSS and we're now working on two other studies together. But those are long standing friendship, we've been together for 15 years....[the CBPHC innovation project] actually built on that relationship."

12. Circumpolar Health Systems Innovation Team (CircHSIT)

Principal Investigators: Kue Young, Michael Jong, James Ford, Mason White, Josée Lavoie, Arto Ohinmaa

Co-Investigators: Ewan Affleck, Adalsteinn Brown, Susan Chatwood, Gwen Healey

Team description: The CircHSIT team was composed of seasoned researchers and knowledge users with a complementary mix of broad knowledge of northern health care, front-line experience, specific content expertise, and close and long-standing past collaboration. The team was multidisciplinary and multijurisdictional. While the grant was under the oversight of the Toronto-based team leader, the research was coordinated in the North, at Yellowknife, Iqaluit and Goose Bay.

Locations: The Northwest Territories, Nunavut, Labrador

Project aim/objectives: CircHSIT focused on regions, health systems and populations, rather than specific diseases. The team was designed to provide research evidence to enable the transformation of PHC in remote northern communities in Canada. It aimed to achieve this goal through:

- Reviewing and comparing innovative PHC models
- Developing northern health system performance metrics
- Planning, implementing and evaluating PHC interventions and technology innovations
- Designing and adapting culturally and environmentally responsive health architecture and infrastructure
- Building and sustaining northern capacity in planning and evaluation
- Fostering respectful relationships and collaborations with communities and decision makers in health care
- Training the next generation of northern-based researchers and practitioners in PHC-relevant research

Target population: Residents of Canada's northern regions (the Northwest Territories, Nunavut, and Labrador) and comparable remote settings in circumpolar regions and elsewhere where there are small, scattered and isolated communities.

Project development: CircHSIT focuses on regions, populations and health systems. CircHSIT's 21 projects fall under 4 themes: (1) comparative health policies and health system performance; (2) emergency response and search-and-rescue services; (3) delivery of primary care in the communities; (4) culturally responsive health architecture and infrastructure. Multiple qualitative and quantitative methods were used. Projects were guided by Indigenous values and responsive to priorities of northerners.

Website: http://www.ichr.ca/2014/05/cicrumpolar-health-systems-innovation-team/

Impact on Advancing Knowledge

- Publications: 27 (4 commentaries)
- Workshops: 3 [workshop with 10 Indigenous and non-Indigenous scholars and practitioners; creative arts and music workshop for youth; planning workshop with partners and collaborators from Canada's northern regions, Greenland, Alaska, Iceland and northern Norway]
- Conferences hosted/organized: 3 [organized 1 international conference; team members also played a major role in organizing and presenting at two other international conferences on remote health care.]
- Media coverage (articles/interviews): 13
- KT tools: 1 [development and pilot of an app for iOS and Android devices that contained
 information that was relevant, useful, and culturally competent for new and short term
 (locum) health care providers working in Nunavut]

"As part of the grant, we hosted a rural and remote healthcare in the Arctic conference. That really had...a much further reaching audience than I could have imagined or anticipated and so I felt like that was a really important gathering"

"We were nimble enough to be able to jump on opportunities to expand knowledge in certain areas related to primary care in the Arctic...like, for example, you know, looking at medical [evacuations]...we viewed that as an extension of the primary care model and...where that wasn't a helpful exercise for different actors in the primary care systems"

"[We went about knowledge sharing] with annual meetings, reports to policymakers, like policy reports or plain language reports and then, peer review publications"

Impact on Building Capacity

- Trainees: 20 [9 graduate students and PDFs; 11 summer research students]
- Training courses/educational initiatives: 2
 - O In an effort to promote interest in research and facilitate networking among health care practitioners, government workers, and the general public, informal research rounds were held periodically at ICHR in Yellowknife, featuring student projects and a variety of discussion topics proposed by community partners.
 - O Land safety course for youth (in collaboration with the Arviat Wellness Centre)

"I was just finishing my PhD [we] were all sort of the same cohort of people finishing PhDs...like new early career investigators being mentored by the kind of well-established academics...so I think they had they leverage[d] their connections, and then we just really jumped on it."

"I think the opportunity to collaborate across the north was very important. Supporting graduate students and that next upcoming generation of researchers just because it is such a young community in the north"

Informed Decision-making

• **Public partners/patients:** The CircHSIT research partnership involved (1) policy makers, (2) practitioners, (3) researchers, and (4) Indigenous knowledge holders.

"The partners included territorial governments, indigenous governments, the health authorities...just for ability for people to

• Guidelines/policies: 2

- The use of EMR as a digital chronic disease registry established as part of routine care in one regional health authority in the NWT.
- Development and implementation of a model for a network of health facilities in Nunavut co-located with airport terminals.

connect across the territories which doesn't always happen and share information and look at common data needs. Some of the policy makers do meet in other forms, but not always governments workers. So, that was really helpful – being able to connect at those meetings and touch base on priorities and then, we were also able to touch base with international partners at times and bring them into workshops. So, where there was shared context like Alaska and Greenland."

Program Findings

I Comparative Health Policies and Health System Performance

Area of Focus: Alignment of national and Indigenous values in health systems stewardship. A workshop session that involved 10 Indigenous and non-Indigenous scholars and practitioners provided an opportunity to network and advance a shared research agenda that would inform and compliment mandates of policymakers, systems managers, Indigenous leaders, and

researchers.

Results: Built-in mechanisms for reciprocal education and capacity building were seen to be a critical component of research partnerships. The imbalance between partners' knowledge bases in different areas (e.g., research theory, northern health policy, etc...) can be bridged through reciprocal educational initiatives.

Area of Focus: Framework and indicators of health system performance.

Project activities included the adoption of the CIHI framework and selecting indicators available for North. Involved 18 northern regions in Canada.

Results:

- The worst performing health systems generally include Nunavut and the northern regions of Québec, Manitoba and Saskatchewan where indigenous people constitute the overwhelming majority of the population (70%-90%).
- The North lags behind the rest of the country in preventable mortality, hospitalization for ambulatory care sensitive conditions and other performance indicators.
- Health expenditures in Canada's northern territories are double that of Canada as a whole and are among the highest in the world.

Area of focus: Performance indicators for maternal health services

The CircHSIT team aimed to identify recommended performance/quality indicators for use in circumpolar maternity care systems.

"I think that we achieved many of the goals we set out, because it was a five-year project"

"The goals of the study were looking at, I guess, health system performance in the artic and responsiveness to indigenous communities. Also looking at mental...like working with communities to develop priorities, so we looked at mental health services... there was also some parts of the program that was also looking at search and rescue responses, delivery of primary health care in communities, and there was a piece on design and architecture...so did we meet our goals – I would say yes."

"There was... I think beginning to look at health systems performance, looking at CIHI and Stats Can and reviewing what data is currently available and what's missing... the North... CIHI reports you'll notice is not included or data is missing, so we did a scan of that and looking at also the national and regional surveys and what they're telling us... So, that was really important work because nobody's done that. So, that kind of gave a baseline"

"We had an opportunity to do quite a lot more work around search and rescue events. And, you know, sort of exploring, where primary care begins...in our very remote contexts,"

"We had eight components at one point, you know, you know, under the project like different thematic areas: health, architecture,

Results: A review of 26 documents demonstrated that, although most circumpolar health systems engage in performance reporting for maternity care, efforts to capture local priorities and values are limited in most regions.

Area of focus: Availability of health care data in national surveys – Yukon, NWT, Nunavut The CircHSIT team explored the extent to which health care issues in northern Canada can be studied through secondary analyses of existing national and regional health and social surveys, as well as identifying potential areas for research.

Results: Different surveys focus on different categories of Aboriginal people, and no single survey has covered all categories of Aboriginal people in the North consistently. To achieve adequate sample size for comparisons among Aboriginal groups within the North, several cycles of the biennial/annual Canadian Community Health Survey (CCHS) can be merged, producing a large data set with consistent coverage of topics using comparable questions.

Area of focus: System responsiveness and best practices for Indigenous communities

The CircHSIT team explored the values of circumpolar nations and indigenous people, by (1) reviewing national acts and multinational forums representative of four circumpolar nations (United States, Canada, Norway and Finland) and then (2) using a mixed methods consensus process to identify indigenous values in these nations.

Results: nine values were identified and described: humanity, cultural responsiveness, teaching, nourishment, community voice, kinship, respect, holism and empowerment. The values were left intentionally broad with the understanding that they overlap and interact with one another.

Area of focus: Mental health services responsiveness

The CircHSIT team carried out an extensive, systematic literature review to identify all promising practices about resilience promotion and suicide prevention in circumpolar regions **Results:** From the literature review, the research teams identified 10 interventions that have been formally evaluated and discussed in the literature. The teams then isolated the core ingredients of each intervention with the aim of developing an inventory of good practice models for resilience promotion and suicide prevention that could be considered in other circumpolar communities.

II. Emergency Response and Search-and-Rescue Services

Area of focus: Surveillance of search-and rescue (SAR) incidents. The CircHSIT team aimed to describe the extent and characteristics of travel emergencies and their health consequences in the Canadian Arctic.

monitoring and sort of things like that. So I think we had eight components at one point and so, you know, we'd meet once a year to just review those components, you know track progress, you know, sketch out like an action plan like what everybody's responsible for and that kind of thing like the pragmatic logistics of implementing a multi person team and strategy, and then, you know, just course correcting along the way"

search and rescue, medevacs, you know, robotics and health systems

Results:

- A case-series of all known incidents in Nunavut and Northwest Territories between 2004 and 2013 found that 121 incidents occurred. These incidents most commonly involved young men, and death occurred in just over 25% of cases.
- Results from a case study suggest that daily ambient temperature, ice concentration, ice thickness, and variation in types of ice to be correlated with **the** SAR rates.

Area of focus: Vulnerability to injuries from land-use activities.

The CircHSIT team examined unintentional injuries on the land (outside of hamlets) because of the importance of land-based activities to Inuit culture, health, and well-being. Data was collected using semi-structured interviews, and an analysis of SAR case data for Nunavut. The interviews were conducted in three communities that have varying rates of search and rescue (SAR).

Results: Findings suggest that risk of land-based injuries is affected by socioeconomic status, Inuit traditional knowledge, community organizations, and territorial and national policies.

Area of focus: Unmanned aerial vehicles as aids in hazard mapping and SAR.

The CircHSIT team examined search and rescue and backcountry medical response constraints in the Canadian Arctic and potential for unmanned aerial vehicles (UAV) to aid in response and preparedness. They analyzed five years of weather data to examine UAV flight suitability. **Results:** UAVs were demonstrated to have potential benefits for hazard monitoring but not for SAR or medical response due to legal restrictions, weather margins, and local capacity. There are numerous limitations to the use of consumer UAVs by Arctic communities. Prevention of backcountry medical emergencies, building resilience to disasters, and first responder training should be prioritized over introducing UAVs to the response system.

III. Delivery of Primary Care in the Communities

Area of focus: Variation in PHC accessibility.

The CircHSIT team documented and analyzed the challenges in accessing PHC services by indigenous people in remote communities in Canada's Northwest Territories (NWT) from the perspectives of users and providers of PHC services.

Results: Northern service users and service providers generally acknowledge the health consequences of living in remote communities. The provision of emergency care was found to be particularly challenging, because of the lack of qualified staff in the community and the dependence on aeromedical evacuations. However, as long as services were provided in a community, the satisfaction was high among service users.

Area of focus: clinical support and inter-professional interactions.

The CircHSIT team designed and implemented a survey to primary care providers to identify issues relating to interprofessional communication, clinical support and patient evacuation. **Results:** The majority of providers were satisfied with their ability to communicate with other providers in a timely manner, their freedom to make clinical decisions and their overall experience practicing in the NWT. However, a common theme reported by nurses was that physicians providing clinical advice, especially short-term locums, were not familiar with the local situation, while physicians remarked that the clinical information provided to them often lacked clarity.

Area of focus: Policy and practice of pharmacy services.

The CircHSIT team examined how existing pharmaceutical administration and distribution policies and practices in Nunavut and Ottawa impact patient care.

Results:

- Findings from document reviews and semi-structured interviews suggest that large quantities of unclaimed prescription medications are suggestive of significant financial losses, suboptimal patient care and low adherence rates; and that the absence of a clear policy and oversight for some controlled substances, such as narcotics, leaves communities at risk for potential illegal procurement or abuse.
- In Nunavut, many current translations of pharmaceutical language in Inuit languages were
 made by local community members without validation of the accuracy of the translations.
 Several bilingual participants shared concern regarding translations that they did not feel
 accurately reflected the transfer of instructions from one language to another (including
 medication dosage). These issues of linguistic discordance have been shown to impact
 patient care.

Area of focus: Patterns and costs of patient transportation and emergency evacuations.

The CircHSIT team conducted a study to describe the patterns, costs and providers' perspectives on patient transportation, and identify potential factors associated with utilization and performance.

Results: The proportion of the population living within 100 km of a hospital was 83% in Yukon, 63% in Northwest Territories (NWT) and 21% in Nunavut. In Nunavut and NWT, road access to a hospital was limited to residents of the cities where the hospitals were located, with the rest relying exclusively on air travel. In Yukon, all communities except one are road accessible whereas in Nunavut no communities are connected by roads. A medevac on average costs \$218 per person per year in NWT and \$700 in Nunavut. Patient transportation,

especially emergency air evacuations, is an essential but costly component of the healthcare system serving Canada's north.

Area of focus: Chronic disease registries in care improvement.

The CircHSIT team established a digital diabetes registry at the [former] Yellowknife Health and Social Services Authority and applied two decision rules for diabetes care. Patients with suboptimal care were tracked and results were fed back to care teams.

Results: There were 1187 patients identified during a 12-month period. Results showed improvement in adherence to guidelines over time. The use of EMR as a digital chronic disease registry is well established and is now part of routine care in one regional health authority in the NWT.

Area of focus: Use of remote presence technology in chronic disease management

The CircHSIT team aimed to evaluate the feasibility of remote presence for improving the health of residents in a remote northern Inuit community.

Results: A total of 252 remote presence sessions (using the RP-7 robot in Nain, Newfoundland and Labrador) occurred during the study period, with 89% of the sessions involving direct patient assessment or monitoring. Air transport was required in only 40% of the cases that would have been otherwise transported normally. Patients and their caregivers, nurses and physicians all expressed a high level of satisfaction with the remote presence technology and deemed it beneficial for improved patient care, workloads and job satisfaction. These results show the feasibility of deploying a remote presence robot in a distant northern community.

Area of focus: Orientation app for health care providers

The goal of this project was to develop and pilot an app for iOS and Android devices that contained information that was relevant, useful, and culturally competent for new and short term (locum) health care providers working in Nunavut.

Results: The app was downloaded more than 700 times between September 2017 and September 2019. Stakeholders reported that (1) the app was easy to use; (2) the content was highly relevant and would result in improved cultural competencies; and (3) they would recommend the app to colleagues and were already using it for recruitment/orientation.

IV. Culturally Responsive Health Architecture and Infrastructure Nunavut

Area of focus: Sangilirviuksaq Healing Network

The CircHSIT team aimed to engage in a theoretical study to design a health and healing facility that is based on Inuit perspectives on wellness and

is responsive to the Canadian Arctic environment.

Results: The results of the design process focused on four key factors: 1) to temporarily remove individuals from places that may contain "triggers" for traumas, abuse, or addictions; 2) to (re)connect with the land to achieve health; 3) to form new, positive relationships with others in a holistic place and 4) to learn new knowledge/revitalize land skills. The study offers a new approach to mental healthcare support, which integrates of elements of Inuit traditional and contemporary culture, best practices in health and wellness theory, and northern-specific landscapes

Area of focus: Health Hangars Concept

Health Hangars is the outcome of research for new models of Northern health care architecture and infrastructure. It involves a large regional hospital in Nunavut that is distributed amongst four communities. This project focused on (1) health infrastructures of the movement of patients, caregivers and information, and (2) the architectural scale of hospitals, clinics and boarding rooms. The project was informed by a hybrid of contemporary Inuit practices of sustainable architecture and medical practices.

Results: development of a model for a network of health facilities co-located with airport terminals. Acknowledging the necessary relationship with air travel, each hospital component is conjoined programmatically with an airport terminal. The Health Hangars network allows for easier access to care by patients, a convenient system of movement for equipment and caregivers, and a stronger integration with the medevac system.

Area of focus: Aboriginal Wellness Centre

The CircHSIT team (including a team of architecture and landscaping students from the University of Toronto) conducted a needs assessment, inspected sites in Yellowknife and consulted elders on the development of a wellness centre.

Results: development of models and plans for the centre.

Broad Social and Economic Impacts

- Additional Funding: \$1 million [The Elders Council of the Stanton Territorial Health
 Authority in the NWT leveraged funds for an Aboriginal Wellness Centre in Yellowknife.
 The process for the development of this Wellness Centre was supported through work
 conducted by the CircHSIT team. The elders were awarded a \$1 million Arctic Inspiration
 Prize to pursue the development of the Wellness Centre.]
- Scale and spread:

"With the architecture project... we're raising all the money as a grassroots non-profit community Research Center to build a building, you know, based on, Inuit care philosophy, and can't get anyone in the territorial government to help fund it for example because it's not a priority. You know, this kind of innovative carebased approach community based, you know care approach. So, it's really, it's really the bigger stuff, you know, the systemic challenges,

- O The project on pharmacy services highlighted deficiencies in the system in the provision of services in the language of the great majority of patients, an issue that has been taken up by the Nunavut Language Commissioner. The Language Commissioner made a recommendation to the Minister of Health to create a task force to improve pharmaceutical translations.
- Research conducted by the team that highlighted wastage of unclaimed medications in health centres influenced the opening of a retail pharmacy counter in the grocery store of one of the communities.
- The medical travel project team signed data agreements with the territorial health ministries of Nunavut and NWT. Special analyses on medevac data for the Qikiqtani Region and for children under five, were used to inform decision making during the 2016/17 and 2017/18 respiratory illness outbreak seasons. Also, in the NWT, a new territory-wide travel coordination system called Med-Response was implemented, and the CircHSIT provided data from the nurses and physicians survey to serve as baseline for the initiative's evaluation.
- The study team worked with the Arviat Wellness Centre in mounting a land safety course for youths. The project responded to community-voiced desires for greater access to training, reduced delays waiting for aerial support, and increasing involvement of the younger generation in SAR and more broadly in land activities.
- The use of EMR as a digital chronic disease registry is well established and is now part of routine care in one regional health authority in the NWT.
- After consultation with elders, models and plans were conducted for the development of an Aboriginal Wellness Centre in Yellowknife by the CircHSIT team. The Elders Council of the Stanton Territorial Health Authority then advocated for it's establishment and leveraged funding for it's development.
 - The project to develop an app to orient short-term and locum health care providers to Nunavut was downloaded more than 500 times and feedback was received not only from Nunavut practitioners, but also from practitioners across Canada and as far as Alaska, Greenland, and Sweden.
 - CircHSIT played a supportive role in the development of NWT's SPOR Network in Primary and Integrated Health Care Innovations, thus continuing with some of the research initiatives beyond the life of the original team grant.
- Number of regions/communities/sites where innovations were implemented or scaled up: 2

and...know the political games that are frustrating, and that's probably universal."

"[Like with our partners in] Greenland and Sweden. You know, we met through the circumpolar health systems innovation team so I for sure like that was the catalyst. And now we have multiple projects together and you know weekly meetings and lots going on and we're working on a pan Arctic COVID-19 assessment on the impact of public health restrictions on Arctic indigenous communities"

• Sustained partnerships:

- Strengthening and sustaining the Institute for Circumpolar Health Research (ICHR) and the Qaujigiartiit Health Research Centre (QHRC) is a major goal of CircHSIT.
- O ICHR has signed affiliation agreements with the schools of public health of University of Toronto and University of Alberta, formalizing research relationships and supervisory roles for students; and continues to work with the Arctic Indigenous Wellness Foundation (developed by The Elders Council of the Stanton Territorial Health Authority) in the NWT, under a memorandum of understanding to guide research relations.
- Number of partnerships with stakeholder organizations: 19

"The circumpolar innovations team project, gave us lots of great opportunities to continue working together and so we still do"

"Well, you know, the Arctic is very small. And we all continue to cross paths in one way or another but yeah, I think... I have great relationships. Like, like these ones that I've said [I've built through the CircHSIT team project] ... are going to be like lifelong career collaborations."

"We agreed to have a lot of what I think higher profile work that we're doing together now that I think it all...I absolutely attribute it to our opportunity to meet through the circumpolar health systems innovation team...it's just translated into...really good ongoing connections"

Appendix C – Qualitative Findings

1.0 IMPACT

1.1 Knowledge

Project-level impact



A transformational change in knowledge and understanding of stakeholder engagement and partnership research

- Each participant was able to identify categories of knowledge and dissemination outputs such as publications, workshop materials, conference proceedings, digital scholarships, toolkits, news articles or social media posts. Target audiences for these outputs included patients, healthcare providers, healthcare managers, communities, organizations, policy-makers, and other researchers.
- Participants also expressed that they personally gained knowledge in a specific topic
 or method and that they raised awareness of primary health care research in general.
 Specific topics included re-conceptualizing where primary starts, shifting how
 complex patients can be seen in the primary care setting, local barriers to
 implementation and adapting interventions, core attributes to integrated care,
 analyzing administrative data, and methods in health system performance.
- A number of participants expressed that there was a **transformational change in their understanding of stakeholder engagement and partnership research**; including areas of partnering with Indigenous communities, principles of coproduction, integrated knowledge translation (iKT), participatory-action research and patient engagement principles. Participants appreciated the importance of relationship-building, the benefits in making research more agile and useful for endusers, whether this was at the level of health authorities or community-based stakeholders, and how resource intensive it was to make those connections.

"We worked with the Health Directors, continuously updating them about what was going on, getting some feedback... it's more of a developmental research program where any information that is gathered is then fed back to those local teams and reflected upon, so that they can first get their own understanding of what research can do for them."

Network-level impact



Growth of a stronger evidence base in primary care research in Canada and an increase in awareness of methodologies and partnership approaches

- Generally, participants noted that the Network created a much stronger evidence base in primary health care research in Canada.
- Participants felt the target audience for Network activities were for other researchers to enhance their knowledge of the other team's research approaches and results. Key features included learning from experts in the field, the inter-disciplinary lens and seeing their research in a new light, learning how to do partnership research, hearing about common challenges and successes, and creating the foundation of a shared vision for CPBHC. Some participants indicated that they learned a lot from connecting with others in the Network while others expressed it was enjoyable to learn from others but did not feel like they took away any key learnings as the research programs were so diverse.
- Participants identified having formal opportunities, such as the in-person meetings, were enriching and productive in obtaining new knowledge and how simple conversations would open new avenues of inquiry. Some also commented on how well organized the events were, that discussions were stimulating and how they felt supported in attending these events. Another participant shared that the events were important to know what others were doing and so they were not replicating any activities.
- Participants also acknowledged the efforts and throughput in the cross-team
 publications and how they showcased the interdisciplinary work across teams.
 Generally, participants indicated that their methods were not informed by the other
 teams, however they found value in sharing instruments and questionnaires and
 tried to apply the operational definitions of the common indicators whenever
 possible.
- The common indicator project made participants think about evaluating cohesively across projects/jurisdictions and thought that this would translate into people picking the same tools and indicators after having worked together.

"The CBPHC network of network itself was super prolific and productive and just driving a lot of publications and having these really great animated meetings as well because at CBPHC, we would have this super rich exchange where people are sharing how it's going in trying to do this type of work and using this type of approach."

1.2 Capacity-building

Project-level impact



Enhanced professional development of trainees and strengthened the ability of community-based stakeholders to take local action

- Some participants identified their team developed capacity-building workshops or resources targeted to enhance end-users knowledge and skills (organizations, providers, patients) specific to their intervention or health priority.
- Participants also identified that they enhanced their own skills in building
 relationships with new stakeholders and communities (E.g., Indigenous and First
 Nations, health authorities) and applying new methodological approaches in their
 work (iKT, data analytics, community engagement). Participants explained that the
 skills were gained through experiential learning where researchers needed to interact
 with their environment in order to reflect, adapt and learn.
- Participants discussed the greatest impacts in reciprocal capacity-building was with
 1) the professional development of trainees and 2) the purposeful
 transformation with community-based stakeholders to deepen their research
 skills and empower them to continue the innovation.
 - O Participants described the directed strategy to provide trainees/early career investigators with resources, mentorship, and leadership opportunities for publications, conference presentations, and project meetings. Participants also expressed the importance of having new career investigators manage projects and expanding their reach with funders and other researchers in order to boost their professional development and become the new generation of inter-disciplinary community-based healthcare researchers in Canada.
 - With community-based stakeholders, participants identified a long-term strategic goal to enhance skills in grant writing, research methods, data collection and analytics. In this way, communities would be able to selfadvocate and sustain their own achievements.

"I think the opportunity to collaborate across the north was very important. Supporting graduate students and that next upcoming generation of researchers just because it is such a young community in the north"

Network-level impact



Enhanced the skills of the next generation of CBPHC researchers and stakeholders

- Participants conveyed that they had learned transversally from the other teams in that they looked at common themes, methodologies, and technologies among the teams to potentially change how they conducted their research.
- Participants highlighted the meetings and committees as impactful events for trainees to learn and connect with experts in the field. They identified enhancing skills and having opportunities to present and discuss findings outside of their institutions, attending webinars, and publishing. One participant noted that the discussions and interactions back and forth during the development of knowledge products (publications) would have been very significant for trainees' development.
- Participants commended the Network in recognizing the contributions of trainees and found that capacity-building led to boosting the next generation of CBPHC innovators who now had a national outlook embedded into their vision.

"The trainees could kind of get together and talk about what each other were doing and present on our portions or on the projects themselves, which helped build a training networking as well."

1.3 Informing decision-making

Project-level impact



Advanced the science and delivery of community based primary health care in Canada

- Participants indicated that they personally changed their behavior regarding applying new research methodologies relating to the increase in knowledge and skills as mentioned above (i.e., iKT, stakeholder engagement, and analytical methods).
- Participants also indicated that their own projects having an impact in the way health services were being delivered in multiple ways including examples of:
 - o Reforming models of care;
 - Improving links from primary care to specialty care
 - Improving the coordination of care for patients with complex health care needs
 - Changing clinic operations across jurisdictions
 - Embedding a culture of continuous quality improvement and data collection with local health authorities and communities;

- Provision of knowledge tools (guidelines, toolkits) to support healthcare providers or caregivers
- Supporting the development of an architecture project based on Inuit care philosophy
- Providing evidence to support policies and decision-making for scaling-up or investing in large-scale initiatives
- Creating a cross-jurisdictional infrastructure for data collection for performance management
- Development of clinical cohorts which allows for the assessments of complex patients in the primary health care setting

"[LHIV work on eConsult] shifted policy and it shifted focus to the primary care realm in real ways and it led to a shift in policy. For example, at the Royal College of Physicians and Surgeons, at the College of Family Physicians of Canada. So, you can...and in some of the national organizations that surrounded it, there were statements supporting e-consults and although it might not be HIV specific, that's really the genesis of how...not e-consult as a program, but how it spread across the country. So, really profound impact on the e-consult program, I would say that led to significant policy shifts across the country."

1.4 Broad socio-economic and health impact

Project-level impact



Increased the responsiveness of primary health services to the needs of communities and partners

- Participants expressed that the impact of their research as being more responsive to the needs of their communities and partners; specifically by focusing on integrating Indigenous care concepts and philosophies within programs and health care organizations or the development of a model for community member involvement in primary care research studies
 - One participant specified a purposeful strategy in adapting their research towards dimensions of social stratification (language, ethnicity, place of residence)
 - Two participants identified developing a cost-effective and sustainable innovation that would engage patients and enable providers to implement a data collection tool for service performance
 - Other participants spoke of improving specific health outcomes such as reduced hospitalizations for heart attack, strokes, heart failure; improved physical activity

- and diets for their community partner sites; improved quality of life and selfmanagement of diabetes and chronic conditions, fewer depressive symptoms and improved hope for caregivers.
- A few participants indicated being awarded additional funding to spread or scale-up their innovations including team based care expansions out of the primary health care branch in Ontario, expansion of an e-consult program across Canadian jurisdictions, replicating their study in other regions, provinces and countries (Australia), and partnering with national and international organizations to build additional supports.

"And you know, we continue to expand...with the primary health care branch and now with two other provinces, we are working on understanding within these types of team-based initiatives, how those teams are actually creating, you know, what I would describe as actual functional integrated teams."

1.5 Partnerships

Project-level impact



Built and sustained relationships with community stakeholders and other key stakeholders in primary health care research and delivery

- Many participants expressed the biggest impact of their project was in building partnerships, engaging communities, and building professional relationships.
- Participants expressed that the grant was a catalyst in allowing them to make connections with team colleagues from all over the world and from different disciplines. Participants were able to connect with other researchers, patient partners, stakeholders from health authorities, governments, community leads, trainees, and funders and integration their knowledge and support. This was particularly significant for early career investigators in being connected to leaders in the field and in preparing of their own research programs and for connecting community researchers with university researchers.
- Benefits in being connected as a team included:
 - Leveraging everyone's voices
 - O Being able to work on additional opportunities to collaborate and disseminate results, spread or scale the innovation, or work on other projects and grants.
 - O The 'magnitude or scale' of the project's impact when working as a collective versus having to individually apply for grants and write papers on their own
- Most participants spoke of the importance of investing time and resources towards building those connections and the importance of trust. Participants expressed that key

- activities such as face-to-face meetings and workshops were critical in creating trust and relationship-building.
- Most participants indicated that they maintained connections and pursued additional
 collaborations with other project team members; either with the original work or on
 new research agendas. Some maintained connections through becoming graduate
 supervisors and trainees, obtaining faculty positions, applying for grants, copublications, and development of new research networks.

"It's led to, you know, collaborative book chapters, with the co-author, with collaborators from across the three jurisdictions on this particular topic, and, you know, countless presentations internationally, and new network partnerships in the Netherlands and the United Kingdom and partnerships with the International Foundation of Integrated Care."

Network-level impact



Built and sustained a national platform and community of practice of primary health care researchers, communities, and key stakeholders

- Participants indicated that the major impact of the Network was developing a national platform for CBPHC research through creating connections and collaborations. Participants expressed the Network solidified a group of primary care researchers and stakeholders into a community of practice. This increased awareness and access to experts in each stakeholder groups (patient partners, health authorities, government leads, organizational managers, community leaders), and was a stimulus for collaboration opportunities on papers, projects, and other networks.
- Participants mentioned the annual meetings as being vital to create those
 connections as they provided focused time, away from other professional priorities,
 to meet the teams and learn about what they were doing. Participants suggested that
 invitations and opportunities materialized from these interactions including being
 asked to be on graduate committees or speaking at conferences to working closely
 together on grants and new projects.
- Participants indicated that they were more likely to work with other project teams that encompassed similar populations or health priorities. Others indicated that they didn't connect with the other teams due to a perceived disconnect with the type of work and population of interest.
- One factor that was associated with the success of the network was the leadership at
 the level of the funder right at the beginning. Leadership was encouraging and
 creative in bringing everyone together and in finding synergies between the teams to
 disseminate the work. The project-level leaders were also highlighted in pushing the

cross-project activities forward and advancing the field of performance measurement in primary care across the country.

"The interesting thing is that with the 12 team, is that we really created a community... we really belonged to a community of people having similar goals and being able to share about our experiences and learning from each other. So that was something very unique.... I think that that was quite a learning experience to know that, you know, this kind of community can exist."

2.0 KEY FACTORS OF SUCCESS

Project-level



End user involvement

- Participants described that teams who were deeply collaborative and worked closely with their populations seem to be doing well in terms of their research impact. Additionally, having end-user involvement specific to their population of interest in leadership roles (e.g. Investigators, steering committees, advisory boards) assured the work would be translatable into policy and practice. Many participants expressed that end-users/local engagement and co-designs were impactful in shaping the research and identifying barriers to tailor solutions. They appreciated the different perspective they brought to the team and how dialogues were shifted to within their context and allowed the team to broaden their understanding of the problem, focus efforts on the priorities identified as important to the end-user, and have innovations that could be implemented quickly and with greater reach.
- Some participants noted that end-user involvement was a relatively new concept at the
 time, in 2015, and that the idea had evolved and deepened as the project progressed. By
 the end of the project, this led to end users writing papers and grants and spreading the
 innovation throughout their communities. Additionally, some participants identified
 that they are incorporating end user partnerships into all their projects going
 forward.
- A participant also noted that when inviting patient/caregiver partners to projects there
 needs to be an effort to make sure they are welcomed, comfortable, informed, and
 supported throughout the process as they could be sharing vulnerable experiences to a
 wider group. They also noted that having funding/resources to support roles within
 communities was a critical factor in success.

"We also always had spaces for patients and caregivers and community partners. Because we, you know, believe strongly and saw the value of things like co-design and collaboration in these models of care as well, that's probably another core finding. The ones who were deeply collaborative and worked closely with their populations seem to be doing well."



Allocation of funds

Participants identified several aspects of the grant that impacted the project's success.
 One benefit was the flexibility to de-centralize it towards health authorities/community organizations so that they may hire local talent and have full autonomy to build internal

- capacity. Participant also noted that the research felt more nimble and they could modify course based on new opportunities that arose during the granting period.
- Participants expressed that the significant investment to make the funding over 5 years allowed teams to take on larger programs of research with a broader view and reach compared to a single 2-3 year grant at one site. Participants also identified that a large investment was needed to iteratively build the team and that building relationships with community sites took time in developing trust.

"Like, 5-year terms and large multi-million grants that really allowed people to get serious about taking on a program rather than just a little project...when it's program, you can take a much broader view and say we're going to improve this for everybody. So, I think the fact that it was 5-years, and it was multimillion dollars and so competitive and peer reviewed, I thought that was fabulous, just fabulous and overdue."



Team dynamics, decision making, and leadership

- Participants expressed that team dynamics, decision-making, and leadership were all
 important aspects for a successful project and allowed them to take an in-depth
 approach to understand the complex systems they were working in.
- Participants indicated that decisions made within the team by consensus and people
 were generally solution-focused and pragmatic in their approaches. Participants
 mentioned being autonomous and given the freedom to perform their work as well
 as the importance of working together towards a shared vision of the program of
 research as a whole.
- Participants highlighted important aspects of the team to include respect, trust, a supportive attitude, collaborative spirit, strong communication, and a culture of openness. Many participants expressed that they were part of a welcoming team that created an environment that promoted sharing and discussion.
- Participants noted that an important aspect of leadership was capitalizing on other
 people's strengths and identifying areas for when they needed to take a step back and
 support others led to natural productivity and drive. Other factors associated with
 strong leadership included their experience/knowledge, pragmatism, ability to delegate
 and share responsibilities, empathy, and effective communication.

"As a team we worked well together which I appreciate you know from, from my worldview as someone from Nunavut who is a researcher...relationships, and how we work with others, form the foundation for any research project...like we can't come to know something, unless we have a relationship with others, you know, from whom we learn or, with whom we discuss and deliberate and come to know and understand something. And so, from that perspective I felt the team was very strong."

3.0 KEY CHALLENGES

Project-level



Challenges

- Participants working with communities noted varying capabilities for communities to stay engaged on project activities due to external factors and that context (local to provincial) is critical to evaluate during the process.
- Participants also noted that changes to the project team with staff turnovers and
 changes in government partners or other end-users were a factor in the momentum of
 their research activities. Participants stressed the importance of having those
 relationships between providers, researchers, policy-makers, end-users at all levels were
 important and without them the work could not be accomplished.
- One common theme was that people were unable to fulfill all the work they were hoping to accomplish (e.g., project team capacity to write and publish results) and that the initial grant proposal may have been written with a wider scope than was feasible.
- Participants noted the complexity of the field and the partnerships/collaborations that were required to organize research activities. One participant noted the time needed for administrative processes (data sharing agreements, REBs) led to delays in the project.
- Some participants found an unanticipated challenge of the level of resources needed to create collaboration and partnership relationships (i.e. for meetings). This was notable important for projects working across remote communities or working with government stakeholders
- Some participants noted the challenge of losing momentum to keep publishing once funding had been completed and losing capacity to continue with the work without additional opportunities to renew. Participants highlighted the disappointment when funding was not renewed and described the lack of renewal as a 'national loss'.
- One participant noted that though the team-based aspect of the grant was positive, they cautioned for keeping the size of teams to a manageable number so that governance was simple and activities were expeditious.
- For the Common Indicator Project, participants highlighted that it was a challenge to integrate into their work after projects had already started. Though they were appreciative that funding was allocated for this activity, they also felt it was imposed and was not well thought out/planned or part of the objectives of the original grant
- Participants were concerned with the Common Indicator Project and how it tried to cohesively evaluate projects when each team's research agendas/interests were so disparate; they emphasized the nature of primary health care as encompassing all diseases and populations

"I think one of the challenges we faced, we didn't anticipate as well, is the turnover in the teams. So, our training wasn't set up to really address that... but I think ongoing training and much more of a check in around people's abilities to undertake quality improvement initiatives and really understand them well. I think some things really

took to it like honey to a bee, but other teams were struggling with it because their contexts were just much more difficult, and they were already stretched then."

4.0 Recommendations

Recommendations for the CBPHC Network

- Clear concise messages on the purpose, goals, and objective of the Network and the provisions (support units, other research networks, data analytics) it would connect teams to
- Continuing towards large-scale investments for primary care research and having each province/territory involved or renewing the grant
- Prioritizing Indigenous centric community based primary healthcare and having each team develop Indigenous specific research programs
- Prioritizing the patient voice, end-user, at the very beginning
- Additional meetings, breakout rooms, online forums, or other activities focusing on information sharing and priority setting for shared initiatives earlier on
- Redefining impact beyond number of publications and having a synthesis of all the results of the projects; focusing on additional knowledge exchange, mobilization, and dissemination
- Continued coordination and sustainment of the Network as a community of practice and its impact
- Identifying opportunities and creating spaces for similar teams to work together to reduce any feeling on isolation and create additional collaborations
- Clear messaging and expectations ahead of time with the Common Indicator Project and choosing a smaller number of indicators to focus on
- Formalized leadership committee to help with coordination and communication of activities that spanned across all teams
- Continuation of capacity-building and highlighting the role of trainees
- Recognition of the time and funding for purposeful engagement and balancing the availability of policy makers, community members, and patients
- Broadening the lens on primary care to include social determinants of health
- Coordinated approach to interact with policy makers
- Continued autonomy with research teams

"I think there could've been resources put into personnel that looked across what the teams were doing, found commonalities in methodologies or differences in methodologies and helped almost knowledge translate that across the teams at the time, helped with people working on common cause analyses, publications. I mean there have been some that emerged looking at certain data, certain definitions across the 12 teams and some data that has been come forward, but not a lot considering the breadth of the work that was undertaken through CBPHC."