







Proposal for a CIHR Institute of Integrated Primary, Home and Community Health Care

A Time for Action

The accessibility, responsiveness and quality of primary, home and community health care are key determinants of Canadians' health care experiences and outcomes. This reality is lucidly captured in a recent essay by Hugh MacLeod, former CEO of the Canadian Patient Safety Institute, in which he concludes: "Today's healthcare leaders must not only lead well but also lead *differently*. That means accepting a shift in the drivers of healthcare from care providers to individuals and communities, from hospitals to primary/home and community care, and from an emphasis on downstream/acute care to upstream/preventive and wellness factors."

High-quality research that identifies what is needed to strengthen the performance of the primary, home and community care sectors and their integration with each other and with the broader health system is needed to inform the sustainable development of health care in Canada. However, despite recent increases, investments by the Canadian Institutes of Health Research (CIHR) in primary, home and community health care research have not been commensurate with their crucial role in meeting the health needs of Canadians. To address this challenge, we propose the creation of a CIHR Institute of Integrated Primary, Home and Community Health Care.

Why an Institute of Integrated Primary, Home and Community Health Care is Needed

In 2008, Barbara Starfield, widely acknowledged internationally as the leading primary care health services researcher of the 20th century, wrote that "Canada seems to have stalled in its commitment to strengthening primary care. One reason for this lack of movement may be the poor investment in primary care research and evaluation. In this regard, Canada is probably at least 10 years behind. No governmental agency focuses on or takes responsibility for building a knowledge base for primary care practice" ⁱⁱ

Although investment in primary health careⁱⁱⁱ research and evaluation, including primary, home and community care research, has increased during the intervening decade, the situation Starfield described is fundamentally unchanged.

In her commentary, Starfield drew attention to the need for a lead agency to shepherd the continuing development of the knowledge base required to support high-performing primary care. CIHR would be the obvious agency to assume this role. However, although aspects of primary, home and community health care research are within the scope of all 13 of CIHR's institutes^{iv}, these domains have no visible presence, no coherent voice and no permanent home within the CIHR structure.

Better Health Care Experience and Outcomes for Canadians

The principles of primary health care are universally recognized as the foundation of the health care system. The Declaration of Astana, produced at the Global Conference on Primary Health Care in October 2018, marking the 40th anniversary of the Declaration of Alma-Ata, affirmed "that strengthening primary health care (PHC) is the most inclusive, effective and efficient approach to enhance people's physical and mental health, as well as social well-being, and that PHC is a cornerstone of a sustainable health system ..." Health systems with a strong primary care sector have better health outcomes, greater health equity and, often, lower health care costs. A recent Canadian study concluded that "Investment in effective primary care services may help reduce burden on the acute care sector and associated expenditures." For the vast majority of Canadians, a regular primary care provider - usually a family physician, nurse practitioner in or primary care team - is their point of entry into the health care system, provides most of their health care, maintains a continuing relationship with them, and facilitates and coordinates the health care they receive from other providers and places. Primary care is person centred rather than disease focused. The majority of all health care is delivered in the primary care setting. For example, 46 people see a primary care physician for every person admitted to hospital. in the primary care setting.

Provincial and territorial governments have identified strengthening primary, home and community care^x and their effective integration as critical priorities. In the 2017 Common Statement of Principles on Shared Health Priorities, the federal, provincial and territorial health ministers agreed to work together on "spreading and scaling evidence-based models of home and community care that are more integrated and connected with primary health care".^{xi} Strong, coordinated primary, home and community care systems are needed to support Canadians, often seniors, with complex chronic conditions to remain in their home as long as possible.

From a health system perspective, no health challenge - whether it be indigenous health, rural health, addictions, mental health, complex chronic illness, appropriate prescribing, equity, or controlling health care costs – can be successfully addressed in the absence of responsive, effective, efficient, innovative and integrated primary, home and community health care, informed by the highest quality evidence. The recently released report of the external review of federally-funded pan-Canadian health organizations (PCHOs) recommended that "Health Canada should instruct the PCHO suite to partner with the provinces and territories to accelerate the emergence of comprehensive, integrated publicly funded health systems centred in primary care." xii

Primary Care Performance

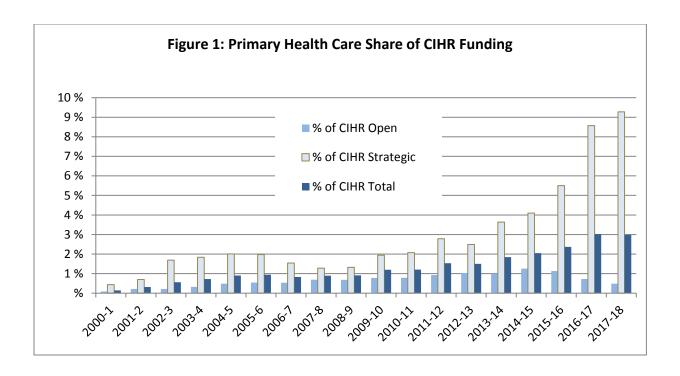
Primary care in Canada compares favorably with our peer countries in many respects. For example, in the Commonwealth Fund's 2017 International Health Policy Survey of Seniors^{xiii}, Canadians' assessment of their primary care experiences surpassed the international average. Canadian seniors were more likely to report that their primary care providers involve them in decisions about their care, spend enough time with them, encourage them to ask questions, explain things in a way that is easy to understand, talk to them about physical activity and healthy eating, and coordinate care they receive from other providers and places. Canadians' ratings of the care they receive from their "regular doctor's

practice or clinic" are considerably above the international average. However, Canada is rarely a top performer and international comparisons point to significant shortcomings, particularly in regard to timely access to care both during and outside regular office hours, access to team-based interprofessional care, frequency of home visits, primary care physicians' sense of being prepared to manage the care of patients with complex needs, use of electronic medical records, electronic communication between primary care practices and their patients and other health care providers, performance measurement, and quality improvement. Efforts to address these shortcomings need to be informed by research that assesses innovations in the organization and delivery of primary care and methods for translating research findings into practice.

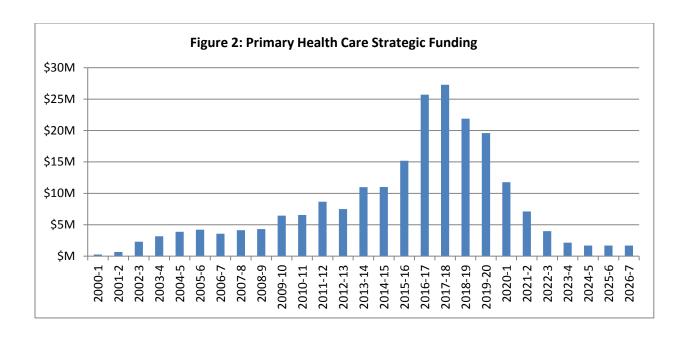
Primary, Home and Community Health Care Research in Canada

Building and maintaining high-performing health systems require the continuing generation of high-quality evidence across clinical, health services and policy domains to inform policy and practice, including the extent to which the principles of primary health care - accessibility, active public participation, health promotion and chronic disease prevention and management, the use of appropriate technology and innovation, and intersectoral cooperation and collaboration — are achieved. Currently, Canada lacks the means to produce that research evidence in a sustained fashion.

CIHR has directed time-limited strategic research funding related to primary health care through several initiatives. Beginning in 2003, CIHR provided 10 years of funding to a collaborative, pan-Canadian, interdisciplinary training program in primary health care research, Transdisciplinary Understanding and Training on Research – Primary Health Care (TUTOR-PHC) through a CIHR Strategic Training Initiative in Health Research (STIHR) grant. In 2012, the CIHR Institutes of Health Services and Policy Research and Population and Public Health launched a Signature Initiative: Community-based Primary Health Care (CBPHC). The initiative provided funding support to 12 inter-disciplinary, cross-jurisdictional (multiple provinces/territories) Innovation Teams to conduct research and provide research training and mentorship. Their focus was on access for vulnerable populations and chronic disease prevention and management. The initiative also provided salary support for 13 new investigators. In 2014, CIHR announced the Pan-Canadian SPOR Network in Primary and Integrated Health Care Innovations under its Strategy for Patient-Oriented Research and the CBPHC program. This SPOR is a network of provincial and territorial community-based primary and integrated health care networks. The Pan-Canadian Network's initial focus is on people with complex health needs. As shown in Figure 1^{xvi}, although these initiatives have resulted in an increase in CIHR funding for primary health care research over the past decade, this is principally due to the dramatic increase in time-limited strategic funding rather than funding through the open grants competitions, which peaked at 1.26% of open grants funding in 2014-15. At its highest, total primary health care research funding represented only 3% of total CIHR research funding in 2016-17 and 2017-18.

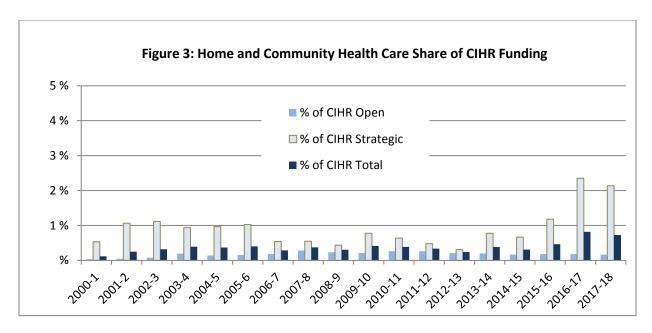


CIHR's focused initiatives together with others at the provincial/territorial level have resulted in a substantial increase in primary health care research funding, capacity and output, particularly in health services, but less so in clinical research. They vividly demonstrate the impact of funding programs that target primary health care research and career development. However, these initiatives are time-limited and do not ensure that the research capacity and production needed to support high-performing community-based primary care in Canada will be developed and sustained into the future. The CBPHC Innovation Teams and new investigator awards are ending. The Pan-Canadian SPOR Network in Primary and Integrated Health Care Innovations may be renewed but is not currently conceived as a permanent structure. Since its CIHR funding ended in 2013, TUTOR-PHC has continued to operate with significantly reduced and precarious funding, offering training to 12 Canadian applicants per year. Figure 2xvii shows the projected steep decline in CIHR strategic funding for primary health care research over the next several years.



In the Fall 2018 CIHR Project Grants competition, only five of 371 funded projects (1.3%) listed primary care, primary health care, primary healthcare, family practice, general practice or family medicine in the title, abstract or keywords. The primary theme was "Health systems/services" for four of these projects and "Social/Cultural/Environmental/Population Health" for the remaining project. Together, the five projects received 1% of the funding awarded in the competition.

The overall pattern is similar for CIHR funding of home and community health care research, but at a substantially lower level (Figure 3).xviii CIHR open grants funding for home and community health care research has been flat since the early 2000s and has remained consistently less than 0.3% of the CIHR total. The bulk of CIHR support for home and community health care research has been provided through strategic grants. Combined open and strategic CIHR funding for home and community health care research as a percentage of CIHR total grant funding reached a high of 0.8% in 2016-17. CIHR's strategic funding commitments to home and community health care research are scheduled to fall rapidly over the next several years, ending in 2022-23.



In the Fall 2018 open grants competition, three of 371 funded projects had home care, homecare, community care or community support service in the title, abstract or keywords, two of which were among the five funded primary care projects. Thus, a total of six successful projects (1.6%) address primary and/or home and community health care and received 1.2% of the funding that was awarded in the Fall 2018 competition.

In 2017-18 (which includes the Fall 2017 and Spring 2018 competitions), primary, home and community health care research received 0.6% of open program funding and 3.6% of total CIHR research funding. xix This share of research resources seems extraordinarily meagre given the critical contributions of primary, home and community health care to patient experience, health outcomes and control of health care costs, often referred to as the "triple aim".

The basis for this low level of funding is unclear. Possible reasons include an insufficient pool of well-trained primary, home and community health care researchers resulting in a low volume of applications and limited primary, home and community health care presence on CIHR's Governing Council, grant review panels and Institute Advisory Boards**. The problem does not appear to lie in low quality applications; in the 2017-18 open grants competition, for example, the success rate for primary and community care applications was 17% compared to an overall success rate of 13%. *** What is clear, however, is that the current strategy of supporting primary, home and community health care research through the existing institutes has been largely unsuccessful, particularly in regard to clinical primary, home and community health care research. This failure points to the need for a dedicated primary, home and community health care institute within CIHR. The low visibility of primary health care in CIHR undoubtedly contributes to the longstanding perception that would-be clinician scientists had best pursue a clinical specialty other than family medicine and makes research focused on primary, home and community care unappealing to research trainees in other disciplines.

Evidence-based primary, home and community health care policy and practice need to be informed by research conducted at the interface of the community and the health care system. To underpin that research, two interrelated developments are required: the expansion and support of primary care practice-based research networks (PBRNs) and the development of capacity for the collection, linkage and analysis of data on the structure, processes and outcomes of primary, home and community health care. A CIHR Institute of Integrated Primary, Home and Community Health Care could catalyze, coordinate and support the further development of PBRNs and primary health care data infrastructure.

Practice-Based Research Networks (PBRNs)

PBRNs are local or, more often, regional networks of primary care practices whose aim is to stimulate the development of research that reflects the challenges and context of primary healthcare practice. Many countries have invested in PBRNs, including Australia, New Zealand, the United Kingdom and the United States. In the US, the Agency for Health Care Research and Quality provided infrastructure funding for PBRNs from 2000-2017. In the UK and US, where the development of PBRNs has been most extensive, PBRNs have engaged in a broad range of activities including the identification of patient-centred research priorities, epidemiologic, clinical and health services research, research training, quality improvement, and knowledge dissemination and exchange. PBRNs offer an interactive model of knowledge production and utilization and can serve as learning communities and drivers of quality improvement. Although PBRNs vary in size, scope of activities and emphasis, many are joining with others to establish PBRN federations or consortia, linking research and quality improvement, and forging partnerships across health sectors and with community organizations. In the process, they are transitioning from research networks to learning networks and learning health systems.

PBRNs offer an ideal setting for studies of the processes and outcomes of primary care, including pragmatic clinical trials of drugs and other health care interventions.** Typically, clinical trials have been conducted in specialized secondary and tertiary care settings. The people included in these studies usually represent a narrower spectrum than patients seen in the primary care setting. As a result, findings from such trials tend to overestimate treatment effectiveness, translate poorly to patients seen in primary care settings and may expose patients to inappropriate care that is often costly and sometimes harmful. **xvi* In contrast, trials based in primary care practice have greater relevance and applicability in the primary care context. This reality is captured in the adage: evidence-based practice requires practice-based evidence. Significantly, of the 66 projects with "Clinical" as a primary theme that were funded in the Fall 2018 CIHR Project Grants competition, only one is focused on or based in primary care.

In Canada, there are currently 15 PBRNs spread across seven provinces and one territory, encompassing 1189 family physicians and interprofessional primary care teams at 217 sites and more than 1.5 million patients. However, without exception, they lack the funding and infrastructure that would allow them to reach their potential. Their lack of resources stifles their capacity to grow and to engage their members in identifying research priorities, engaging in research that addresses both local and pan-Canadian health care challenges, and improving policy and practice at the local, regional and provincial levels. Support from federal and provincial/territorial research funders for new and expanded PBRNs and for

mechanisms to coordinate research activities across PBRNs, could generate innovative cross-jurisdictional research ranging from clinical trials to comparative studies of primary, home and community health care funding, organization and delivery, including integrated health care delivery models.

Primary, Home and Community Health Care Data Infrastructure

Data on the structure, processes and outcomes of primary, home and community health care - including patient-reported experience and outcomesxxvii – are essential to inform decision-making at the practice and system levels and to enable primary, home and community health care research. In the primary care sector, systems for the collection, sharing, linkage, analysis and dissemination of practice and system level data are woefully underdeveloped. Those systems need to incorporate clinical data from electronic medical records; patient-reported data; and provider, organizational, health care utilization, and cost data. This capacity is vital not only to underpin research but also to inform health care planning, policy making, management and quality improvement. The ultimate objective should be to collect and assemble data with appropriate privacy protections from all primary care settings, linked to health data from home, secondary and long-term care and other sources. xxviii Building this data infrastructure will allow many key research outcomes to be measured using routinely collected data rather than project-specific data collection processes, sharply reducing the costs of conducting both clinical and health services research, while "offering almost perfect generalizability".xxix McCord and Hemkens (2019) argue that "such an approach would transform the evaluation of health care interventions, allowing continuous learning from series of systematic evaluations of variations of health care procedures and policies, with aggregated and shared information continuously fed back into the original systems (the "learning health care system"), and allowing agile improvements in clinical care, service delivery and the health system."xxx

Health Services for Rural and Remote Communities

Canadians living in rural and remote communities have difficulty obtaining timely access to appropriate health services. Locally available health services are often limited; for example, rural Canadians represent 18% of the Canadian population, but are served by only 8% of Canadian physicians.**

Obtaining needed care outside the community is geographically, organizationally and socially challenging. Research is urgently needed to clarify the health care needs of rural Canadians and to develop and evaluate patient-, family- and community-centred care models that provide the right care in the right place at the right time. An Institute of Integrated Primary, Home and Community HealthCare could spearhead and coordinate the generation and application of such research. The Institute of Aboriginal Peoples' Health would be a natural partner in this work.

The Need for a CIHR Institute of Integrated Primary, Home and Community Health Care

We believe that the creation of a CIHR Institute of Integrated Primary, Home and Community Health Care would facilitate and support the ongoing generation of evidence needed to address the present and future challenges of building and maintaining strong primary, home and community health care sectors in Canada. We include home and community health care because of their critical health system

role, close links with primary care and low level of support from CIHR. Home, community and primary care are natural partners in delivering essential care and support to the large and growing number of Canadians with complex chronic illness and their family caregivers. In collaboration with provincial/territorial partners, the Integrated Primary, Home and Community Health Care Institute could be expected to maintain an overview of the state of primary, home and community health care and their integration with each other and with other sectors in order to identify and champion strategic research initiatives that will bolster health system performance and outcomes. The Institute would be well positioned to lead and facilitate the next iteration of the Pan-Canadian SPOR Network in Primary and Integrated Health Care.

Primary, home and community health care are the backbone of Canada's health care system and they are evolving at an accelerating pace in the provinces and territories. To meet the health care needs of Canadians, these sectors need to be strengthened and continuously improved based on home-grown evidence that is directly applicable to the Canadian health care environment. The establishment of a CIHR Institute of Integrated Primary, Home and Community Health Care will help to ensure the sustained production and application of the research knowledge needed to underpin high-performing primary, home and community health care in Canada. The institute's research agenda will need to address the full spectrum of clinical, health services, policy, and knowledge translation research in primary, home and community health care.

The scope of the proposed institute would clearly overlap that of other institutes, as is already the case among the existing institutes. We see this overlap as providing opportunities for fruitful partnerships with the established institutes, rather than an argument in support of the *status quo*. In recent years, the Institute of Health Services and Policy Research (IHSPR), in partnership with the Institute of Population and Public Health, has championed community-based primary health care research through the Community-based Primary Health Care Signature Initiative, a strategic funding partnership with other institutes, which is now drawing to a close. That initiative stimulated health services and policy research but, as would be expected, did not address the dearth of clinical research focused on and based in primary, home and community care. An Institute of Integrated Primary, Home and Community Health Care, in partnership with other institutes, could address that gap. Going forward, IHSPR would be a natural partner for new strategic initiatives related to health services and policy challenges in primary, home and community care.

Over the last decade, Canada has developed a strong (but still small) cohort of highly productive, internationally-acclaimed primary, home and community health care researchers who are now training and mentoring new generations of researchers. Their work is being published in high impact journals and is shaping policy and practice in Canada and internationally. Given a supportive environment, these outstanding researchers are well-positioned to lead Canadian research in primary, home and community health care to the highest international level. The presence of an Institute of Integrated, Primary, Home and Community Health Care would send a clear signal to aspiring health researchers, both clinical and non-clinical, regarding the viability of a research career centred on primary health care and/or home and community care.

Strengthening Primary, Home and Community Health Care Research

Although we believe that a new CIHR institute is required to address the needs and challenges we have identified, CIHR can take measures to strengthen the creation and application of research in primary, home and community health care that will improve the health of Canadians and the effectiveness and efficiency of our health systems, irrespective of whether a new institute is established, including:

1. New strategic funding initiatives to address priority issues in primary, home and community health care, including research focused on health care for Canadians living in rural and remote communities

In keeping with CIHR's objective of "forging an integrated health research agenda that reflects the emerging health needs of Canadians and the evolution of the health system and supports health policy decision-making" xxxiii, we recommend a process for identifying strategic research priorities that engages patients, caregivers, citizens, clinicians and health system decision-makers.

2. Development of a primary, home and community health care research training and career support strategy

This strategy could build upon the success of previous training initiatives focused on community-based primary health care, including TUTOR-PHC, which was initially funded through the CIHR Strategic Training Initiative in Health Research (STIHR) program.

- 3. Systematic tracking of primary and community health care submissions, success rates and funding in the CIHR open grants competitions
- 4. Continued funding of the Primary and Integrated Health Care Innovations SPOR Network with appropriate modifications based on the first five years' experience, including: a) formalization of a quadripartite leadership model (patients/caregivers/citizens, clinicians, policy/decision makers, and researchers); b) development of a pan-Canadian governance structure that would enable the identification and support of overarching research priorities that are shared across multiple provincial/territorial jurisdictions; c) a sharper focus on performance improvement at the practice level; and d) reconsideration of the requirement for 1:1 matching of CIHR funds with non-federal government sources, which has been a barrier to organizing projects which, with a lower matching requirement, had the potential to make important contributions to policy and practice.
- 5. Greater inclusion of primary, home and community health care perspectives on Governing Council, Institute Advisory Boards and grant review committees
- 6. Collaboration with provincial funders and other stakeholders to plan and support the development of sustainable infrastructure for: a) PBRNs and their evolution toward learning health systems; b) primary, home and community health care data collection, integration and access, including incorporation into the SPOR Canadian Data Platform and linkage to other health data; and c) a pan-Canadian survey or coordinated provincial/territorial surveys, along the lines of the UK National Health Service GP Patient Survey, that would provide patient experience data at the primary care practice, local, regional,

provincial and pan-Canadian levels to support research, practice improvement and health system planning, management and evaluation. CIHR leadership in the development of this vital infrastructure aligns with its objective of "exercising leadership within the Canadian Research Community and fostering collaboration with the provinces and with individuals and organizations in or outside Canada."xxxxiv

Taken together, these initiatives would respond to CIHR's mandate "to excel...in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened health care system" and "to build research capacity in under-developed areas", "xxxv" and its objective of "building the capacity of the Canadian health research community and the provision of sustained support for scientific careers in health research". "xxxvi

The implementation of this set of initiatives should not be seen as an alternative to an Institute of Integrated Primary, Home and Community Health Care. The added value of an institute includes:

- Signaling the value and importance of primary, home and community health care research to researchers, research trainees, research funders, health decision makers and clinicians
- Providing a structure for ongoing assessment of the state of primary, home and community health care research in Canada in relation to the health and health care needs of Canadians
- Facilitating a coordinated approach to the production and translation into policy and practice of primary, home and community health care research
- Assuring support for clinical research conducted in primary, home and community health care settings
- Assuring the continuing availability of strategic funding for targeted research, research training
 and research career support in primary, home and community health care. In the absence of an
 Institute of Integrated Primary, Home and Community Health Care, such support would be
 dependent on the unpredictable discretion of the existing institutes
- Fostering the development of a primary, home and community health care research community

Conclusion

Given the recent transitions at CIHR – the appointment of new members of the Governing Council, the appointment of a new president and a substantial increase in CIHR funding – the time is ripe for CIHR to take decisive action to strengthen primary, home and community health care research as a critical step toward better health care experience and outcomes for Canadians.

The partners in this initiative are major stakeholders in primary, home and community health care in Canada. We have come together because we see a rare window of opportunity to advance the health of Canadians through strengthened research in our sectors. We welcome the opportunity to work collaboratively to explore the application of our proposal and gain consensus on the necessary actions and timeline for implementation.

Contact Person for the Collaborating Organizations

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Barbara Starfield defined primary care as "that level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and integrates care provided elsewhere by others." (Starfield B. Primary Care: Balancing Health Needs, Services and Technology, 2nd Ed. New York and Oxford: Oxford University Press, 1998:8-9.)

^{iv} CIHR currently has 13 institutes: Aboriginal Peoples' Health; Aging; Cancer Research; Circulatory and Respiratory Health; Gender and Health; Genetics; Health Services and Policy Research; Human Development, Child and Youth Health; Infection and Immunity; Musculoskeletal Health and Arthritis; Neurosciences, Mental Health and Addiction; Nutrition, Metabolism and Diabetes; Population and Public Health. The institutes are "virtual" rather than bricks and mortar. They link and support researchers in their area of focus and foster partnerships and collaboration among researchers, health professionals and policy-makers.

^v World Health Organization and the United Nations Children's Fund (UNICEF). 2018. *Declaration of Astana*. Global Conference on Primary Health Care, Astana, Kazakhstan, October 25-26, 2018.

vi Mansfield, C.J., J.L. Wilson, E.J. Kobrinski, and J. Mitchell. 1999. Premature Mortality in the United States: The Roles of Geographic Area, Socioeconomic Status, Household Type, and Availability of Medical Care. *American Journal of Public Health* 89:893–8.

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ⁱ MacLeod, H. 2018. Seven "STOPS and STARTS" for Healthcare Transformation. Available at http://www.longwoods.com/content/25536

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Health Canada defines primary health care as "an approach to health and a spectrum of services beyond the traditional health care system. It includes all services that play a part in health, such as income, housing, education, and environment. Primary care is the element within primary health care that focuses on health care services, including health promotion, illness and injury prevention, and the diagnosis and treatment of illness and injury." Further, "Primary health care serves a dual function in the health care system: direct provision of first contact services…and a coordination function to ensure continuity and ease of movement across the health system…" (Health Canada. About Primary Health Care. Available at: http://healthycanadians.gc.ca/health-system-systeme-sante/services/primary-primaires/about-apropos-eng.php)

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vii Rahman, F., J. Guan, R. Glazier, A. Brown, A.S. Bierman, R. Croxford, and T. Stukel. 2018. Association between Quality Domains and Health Care Spending across Physician Networks. PLoS ONE 13(4):e0195222.https://doi.org/10.1371/journal.pone.0195222

The study examined quality indicators and per capita health expenditures across 77 virtual physician networks in Ontario. The networks represent groups of primary care and specialist physicians who share care for a common set of patients and admit patients to the same hospital. The researchers found that higher outpatient primary care spending was associated with lower rates of avoidable hospitalizations, higher rates of timely hospital to community transitions and lower readmission rates.

viii Nurse practitioners are the primary care providers for over three million Canadians.

ix Jaakkimainen, L., R. Upshur, J. Klein-Geltink, A. Leong, S. Maaten, S. Schultz, and L. Wang. 2006. Primary Care in the Health System. In L. Jaakkimainen et al. *Primary Care in Ontario* (Chapter 1). Toronto: Institute for Clinical Evaluative Sciences.

* Health Canada defines home and community care as "services [that] help people to receive care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community. Home and community care is delivered by regulated health care professionals (e.g., nurses), non-regulated workers, volunteers, friends and family caregivers...The goals of home and community care are to:

- Help people maintain or improve their health status and quality of life,
- Assist people in remaining as independent as possible,
- Support families in coping with a family member's need for care,
- Help people stay at or return home and receive needed treatment, rehabilitation or palliative care, and
- Provide informal/family caregivers with the support they need."

Available at https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html

Home care is an array of health and support services provided in the home, retirement communities, group homes, and other community settings to people with acute, chronic, palliative, or rehabilitative health care needs. Services offered through publicly funded home care programs include assessments, education, therapeutic interventions (nursing and rehabilitation), personal assistance with daily living activities, help with instrumental activities of daily living, and caregiver respite and support. (Canadian Home Care Association). A caregiver (also referred to as carer or family caregiver) is a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness. (Carers Canada)

xi Federal, Provincial and Territorial Ministers of Health. 2017. *A Common Statement of Principles on Shared Health Priorities*. Available at https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/principles-shared-health-priorities.html

xii Forest, P.-G., and D. Martin. 2018. Fit for Purpose: Findings and Recommendations of the External Review of the Pan-Canadian Health Organizations. Ottawa: Government of Canada. https://www.canada.ca/en/health-canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/findings-recommendations-external-review-pan-canadian-health-organization.html

The PCHOs included in the review were: Canadian Centre on Substance Abuse and Addiction, Canadian Agency for Drugs and Technologies in Health, Canadian Institute for Health Information, Canadian Foundation for Healthcare Improvement, Canada Health Infoway, Canadian Patient Safety Institute, Canadian Partnership Against Cancer and Mental Health Commission of Canada.

xiii Canadian Institute for Health Information. 2018. How Canada Compares: Results from the Commonwealth Fund's International Health Policy Survey of Seniors. Ottawa, ON: CIHI.

The survey examined the views and experiences of seniors (age 65 and older) in 11 developed countries: Australia, Canada, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, United Kingdom and United States.

xiv Canadian Institute for Health Information. 2017. How Canada Compares: Results from the Commonwealth Fund's International Health Policy Survey of Adults in 11 Countries. Ottawa, ON: CIHI.

The survey examined the views and experiences of adults (age 18 and older) in 11 developed countries: Australia, Canada, France, Germany, Netherlands, New Zealand, Norway, Sweden, Switzerland, United Kingdom and United States.

W Osborn, R., M. M. Doty, D. Moulds, D. O. Sarnak, and A. Shah. 2017. Older Americans Were Sicker and Faced More Financial Barriers to Health Care than Counterparts in Other Countries. *Health Affairs* 36:12:2123-2132. Osborn, R., D. Squires, M. M. Doty, D. O. Sarnak, and E. C. Schneider. 2016. In New Survey of Eleven Countries, US Adults Still Struggle with Access to and Affordability of Health Care. *Health Affairs* 35(12): 2317-2336. Osborn, R., D. Moulds, E. C. Schneider, M. M. Doty, D. Squires, and D. O. Sarnak. 2015. Primary Care Physicians in Ten Countries Report Challenges Caring for Patients with Complex Health Needs. *Health Affairs* 34(12):2104-2112. Osborn, R., D. Moulds, D. Squires, M. M. Doty, and Chloe Anderson. 2014. International Survey of Older Adults Finds Shortcomings in Access, Coordination, and Patient-Centered Care. *Health Affairs* 33(12):2247-2255. Schoen, C., Osborn, R., D. Squires, and M. Doty. 2013. Access, Affordability, and Insurance Complexity are Often Worse in the United States Compared to Ten Other Countries. *Health Affairs* 32(12):2205-2215. Schoen, C., Osborn, R., D. Squires, M. Doty, P. Rasmussen, R Pierson, and S. Applebaum. 2012. A Survey of Primary Care Doctors in Ten Countries Shows Progress in the Use of Health Information Technology, Less in Other Areas. *Health Affairs* 31(12):2805-2816.

the presence of any of the following terms in the title, keywords, lay abstract, CRC abstract or biocultural comment of the grant application: primary care, primary health care, primary healthcare, family practice, general practice or family medicine. Open grants funding includes Open Operating Grants and 12 smaller open grants competitions. Data on total CIHR open and strategic funding by year were retrieved from www.cihr-irsc.gc.ca/e/50218.html.

xvii Ibid

- ciller data (Richard Snell, personal communication, February 26, 2019). Community health care research was identified by the presence of any of the following terms in the title, keywords, lay abstract, CRC abstract or biocultural comment of the grant application: home care, homecare, community care or community support service. Open grants funding includes Open Operating Grants and 12 smaller open grants competitions.
- xix Some projects were identified as addressing both primary care and community health care. In this calculation, those projects were counted only once. The extent of overlap varied by year from less than 1% to 18% of total CIHR funding for primary care, but was less than 10% in most years.
- ** For example, six of the 13 Institute Advisory Boards (IABs) have no members with a background in either primary health care or home and community care. Six IABs have members with a primary health care background and three have members with a background in home and community care.
- ^{xxi} Jessica Nadigel and Rick Glazier. CIHR Institute of Health Services and Policy Research: Advancements in Primary and Community Care Research. Presentation at the North American Primary Care Research Group Annual Meeting, Chicago, November 11, 2018.
- xxii Evans, D., M. Exworthy, S. Peckham, R. Robinson, and P. Day. 1997. *Primary Care Research Networks: Report to the South and West Research and Development Directorate.* Southampton Institute for Health Policy Studies, University of Southampton.
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- ***iv For example, Réseau-1 in Quebec, a federation of four PBRNs that establishes "a common clinical infrastructure to undertake patient-oriented research...in partnership with researchers, clinicians, patients and healthcare managers" and "create(s) a culture of innovation and reflective practice in participating PBRN clinics".
- SPIDER (Structured Process Informed by Data, Evidence & Research), a randomized controlled trial funded by CIHR and 12 partner organizations which will be conducted in primary care PBRN practices that contribute EMR data to the Canadian Primary Care Sentinel Surveillance Network, is a good example of such a study. The trial will

evaluate a quality improvement intervention designed to "reduce potentially inappropriate prescriptions and improve care for elders living with polypharmacy".

- xxvi Kendrick, T., K. Hegarty, and P. Glasziou. 2008. Interpreting Research Findings to Guide Treatment in Practice. *BMJ* 337:a1499.
- xxvii Since 2007, the English National Health Service has conducted an annual GP Patient Survey that assesses patients' experience of the health care services provided by GP practices, including access to and quality of care. The survey is designed to provide reliable data at the practice, local, regional and national levels.
- xxviii The UK Department of Health's Clinical Practice Research Datalink (CPRD) incorporates many of these elements.
- wix McCord, K.A. and L.G. Hemkens. 2019. Using Electronic Health Records for Clinical Trials: Where Do We Stand and Where Can We Go? *Canadian Medical Association Journal* 191:E128-33. Doi:10.1503/cmaj.180841.
- xxx Ibid
- xxxi Canadian Institute for Health Information. 2016. *Supply, Distribution and Migration of Physicians in Canada 2015 –Data Tables.* Ottawa, ON: CIHI.
- Bosco, C. And I Oandasan. 2016. *Review of Family Medicine within Rural and Remote Canada: Education, Practice and Policy*. Missiassauga, ON: College of Family Physicians of Canada.
- xxxii Government of Canada. Canadian Institutes of Health Research Act. Accessed February 25, 2019 at https://laws.justice.gc.ca/eng/acts/C-18.1/page-1.html
- xxxiii Currently research priorities are identified separately by individual provincial/territorial Primary and Integrated Health Care Innovations networks.
- ^{xxxiv} Government of Canada. Canadian Institutes of Health Research Act. Accessed February 25, 2019 at https://laws.justice.gc.ca/eng/acts/C-18.1/page-1.html
- xxxv CIHR. 2013. Our Mandate. Accessed February 25, 2019 at http://www.cihr-irsc.gc.ca/e/7263.html
- xxxii Government of Canada. Canadian Institutes of Health Research Act. Accessed February 25, 2019 at https://laws.justice.gc.ca/eng/acts/C-18.1/page-1.html