Proposal for a Canadian Institute of Health Research (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 is 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 a new institute is needed
In 2008, Barbara Starfield, widely acknowledged as a leading primary care health services researcher, wrote “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.”

Although investment in primary health care 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. The CIHR is the obvious agency to assume this role. However, although aspects of primary, home, and community health
Better health care experiences 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 and 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 most Canadians, a regular primary care provider—usually a family physician, nurse practitioner, or primary care team—is their point of entry into the health care system and who provides most of their health care, has 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. Most health care is delivered in the primary care setting. For example, 46 people see a primary care physician for every one person admitted to a hospital.

Provincial and territorial governments have identified the critical priorities of strengthening primary, home, and community care and their effective integration. 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”. 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.”

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* The CIHR currently has 13 institutes that are virtual rather than bricks and mortar, and that link and support researchers in their area of focus and foster partnerships and collaboration among researchers, health professionals, and policy makers.
† Nurse practitioners are the primary care providers for more than three million Canadians.
Primary care performance

Primary care in Canada compares favourably with peer countries in many respects. For example, in the Commonwealth Fund’s 2017 International Health Policy Survey of Seniors, 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 regarding timely access to care both during and outside of 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 requires continually generating high-quality evidence across clinical health services and policy domains to inform policy and practice. It includes 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.

The CIHR has directed time-limited strategic research funding for primary health care through several initiatives. Beginning in 2003, the CIHR provided funding for 10 years 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 grant.

In 2012, the CIHR Institute of Health Services and Policy Research, along with the Institute of Population and Public Health, launched the Community-Based Primary Health Care (CBPHC) Signature Initiative. The initiative provided funding support to 12 interdisciplinary, multi-provincial/territorial innovation teams to conduct research and provide research training and mentorship. The teams focussed on health care access for vulnerable populations and chronic disease prevention and management. The initiative also provided salary support for 13 new investigators.

In 2014 the CIHR announced the Pan-Canadian SPOR Network in Primary and Integrated Health Care Innovations (SPOR PIHCI) under its Strategy for Patient-Oriented Research (SPOR) and the CBPHC Signature Initiative. 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.

Although these initiatives resulted in increased CIHR funding for primary health care research, it 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 per cent of open grants funding in 2014/15 (see Figure 1). At its highest, total primary health care research funding represented only three per cent of total CIHR research funding in 2016/17 and 2017/18.

Figure 1: Primary health care share of CIHR funding

The CIHR’s focused initiatives, along with others at the provincial/territorial level, have resulted in a substantial increase in primary health care research funding, capacity, and output, particularly about health care services, but less so for clinical research. They 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 SPOR PIHCI Network may be renewed but it 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 2 shows the projected steep decline in CIHR strategic funding for primary health care research over the next several years.

Figure 2: Primary health care strategic funding
In the Project Grant: Fall 2018 competition, only five of 371 funded projects (1.3 per cent) 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 projects and “social/cultural/environmental/population health” for the remaining project. Together, the five projects received one per cent 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 (see Figure 3). The 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 per cent of the CIHR total. The bulk of the 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 per cent in 2016/17. The 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.

Figure 3: Home and community health care share of CIHR funding
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 the projects were among the five funded primary care projects. A total of six successful projects (1.6 per cent) address primary and/or home and community health care, and received 1.2 per cent 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 per cent of open program funding and 3.6 per cent of total CIHR research funding. This share of research resources seems meagre given the critical contributions of primary, home, and community health care to patient experiences, health outcomes, and control of health care costs (often referred to as the “triple aim”). The basis for this low level of funding is not clear. 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 presence on the CIHR’s Governing Council, grant review panels, and Institute Advisory Boards.

The problem does not appear to lie in low quality applications. For example, in the 2017/18 open grants competition the success rate for primary and community care applications was 17 per cent compared to an overall success rate of 13 per cent. What is clear is that the current strategy of supporting primary, home, and community health care research through the existing institutes has been largely unsuccessful, particularly for 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 the CIHR. The low visibility of primary health care in the CIHR undoubtedly contributes to the longstanding perception that would-be clinician scientists were better off pursuing a clinical specialty other than family medicine, and makes

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5 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 each year, from less than one per cent to 18 per cent of total CIHR funding for primary care, but was less than 10 per cent in most years.

** For example, only six of the 13 Institute Advisory Boards have members with a primary health care background and only three have members with a background in home and community care.
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; and the development of capacity for the collection, linkage, and analysis of data about the structure, processes, and outcomes of primary, home, and community health care. An institute for 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

Practice-based research networks (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 health care practice. Many countries have invested in PBRNs, including Australia, New Zealand, the United Kingdom, and the United States. In the United States the Agency for Health Care Research and Quality provided infrastructure funding for PBRNs from 2000 to 2017. In the United Kingdom and United States, 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 use, 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 about 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. In contrast, trials based in primary care practice have greater relevance and applicability in primary care. This reality is captured in the adage “evidence-based practice requires practice-based evidence.”

†† An example is 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.”

‡‡ For example, a Structured Process Informed by Data Evidence and Research (SPIDER) randomized controlled trial funded by the CIHR and 12 partner organizations that will be conducted in primary care PBRN practices that contribute EMR data to the Canadian Primary Care Sentinel Surveillance Network. The trial will evaluate a quality improvement intervention designed to “reduce potentially inappropriate prescriptions and improve care for elders living with polypharmacy.”
Significantly, of the 66 projects with “clinical” as a primary theme that were funded in the Project Grant: Fall 2018 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 1,189 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, engage in research that addresses both local and pan-Canadian health care challenges, and improve 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 for the structure, processes, and outcomes of primary, home, and community health care—including patient-reported experiences and outcomes—are essential to inform decision making at practice and system levels, and to enable primary, home, and community health care research. In the primary care sector, systems for collecting, sharing, linking, analyzing, and disseminating 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 use, and cost data. This capacity is vital not only to underpin research but also to inform health care planning, policy making, managing, and improving quality.

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. 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.” Researchers 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.”

**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

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§§ Since 2007 the United Kingdom’s 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.

*** The United Kingdom’s Department of Health’s Clinical Practice Research Datalink (CPRD) incorporates many of these elements.
18 per cent of the Canadian population but are served by only eight per cent 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 health care could spearhead and coordinate the generation and application of such research. The Institute of Indigenous 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 new CIHR institute would facilitate and support generating the 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 roles, close links with primary care, and low level of support from the CIHR. Primary, home, and community care are natural partners for delivering essential care and support to the large and growing number of Canadians with complex chronic illnesses and their family caregivers. In collaboration with provincial/territorial partners, the institute could 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 directly applies to the Canadian health care environment. Establishing this new CIHR institute will help 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 overlap that of other institutes, as is the case among the existing institutes. We see this overlap as providing opportunities for fruitful partnerships with the established institutes, rather than an argument supporting 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 CBPHC 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 did not address the lack of clinical research focused on and based in primary, home, and community care. The proposed institute in partnership with other institutes could address that gap. Going forward, the 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 small but strong 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 around the world. 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**

We believe that a new CIHR institute is required to address the needs and challenges we have identified. However, the 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, whether or not a new institute is established, including:

- 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 the 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,” we recommend a process for identifying strategic research priorities that engages patients, caregivers, citizens, clinicians, and health system decision makers.

- Development of a primary, home, and community health care research training and career support strategy. This strategy could build on 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 program.

- Systematic tracking of primary and community health care submissions, success rates, and funding in the CIHR open grants competitions.

- Continued funding of the SPOR Network in Primary and Integrated Health Care Innovations with appropriate modifications based on the first five years’ experience. This includes: formalize a four-part leadership model (patients/caregivers/citizens, clinicians, policy/decision makers, and researchers); develop a pan-Canadian governance structure for identifying and supporting overarching research priorities that are shared across multiple provincial/territorial jurisdictions; create a sharper focus on performance improvement at the practice level; and reconsider the requirement for 1:1 matching of CIHR funds with non-federal government sources, which has been a barrier to organizing projects that, with a lower matching requirement, had the potential to make important contributions to policy and practice.

- Greater inclusion of primary, home, and community health care perspectives on the Governing Council, Institute Advisory Boards, and grant review committees.
• Collaboration with provincial funders and other stakeholders to plan and support developing 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 in the SPOR Canadian Data Platform and linkage to other health data; and c) a pan-Canadian survey or coordinated provincial/territorial surveys (similar to the United Kingdom’s National Health Service (NHS) GP Patient Survey) that would provide patient experience data from 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 developing 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....”

Taken together, these initiatives would respond to the 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 “building research capacity in under-developed areas”, 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.”.

Implementing this set of initiatives should not be seen as an alternative to creating 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 relative to the health and health care needs of Canadians
• Facilitating a coordinated approach to the production and translation into policy and practice the primary, home, and community health care research
• Assuring support for clinical research conducted in primary, home, and community health care settings
• Assuring continued availability of strategic funding for targeted research, research training, and research career support in primary, home, and community health care; without the proposed institute, such support would depend 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 the CIHR—the appointment of new members to the Governing Council, the appointment of a new president, and a substantial increase in CIHR funding—the time is ripe for the 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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Research priorities are currently identified separately by individual provincial/territorial primary and integrated health care innovations networks.


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