THE COLLEGE OF FAMILY PHYSICIANS OF CANADA

LE COLLÈGE DES MÉDECINS DE FAMILLE DU CANADA

A stronger Canada through digital infrastructures that support primary care research and practice improvement

Submitted to the New Digital Research Infrastructure Organization

by The College of Family Physicians of Canada

December 14, 2020

The vision of The College of Family Physicians of Canada is to improve lives through family medicine. This vision comes from knowing that family physicians are at the heart of Canada's health care system, acting as the first point of contact for health concerns, providing ongoing care, and supporting patients throughout all their interactions with the health care system. As primary care providers, family physicians come to know their patients as whole individuals, working with them to achieve and maintain their optimal health. Family physicians work in clinics, hospitals, patients' homes, and long-term care facilities, delivering preventive, chronic, acute, and palliative care to patients and communities throughout Canada. Canada is made stronger, in terms of both population health and our economy, through the ongoing relationships between individuals and their family physicians.

The College of Family Physicians of Canada (CFPC) is pleased to share this white paper with the New Digital Research Infrastructure Organization (NDRIO) as it develops a strategic plan that maps out "a single and unified vision of the highest DRI priorities for 2021-2024"[1]. The white paper offers a CFPC perspective on the urgent need to invest in new digital infrastructures to support family medicine and primary care research in Canada. This new digital research infrastructure (DRI) will serve as a foundational resource to guide health care and health systems improvement through evidence and knowledge. The white paper uses key passages from CFPC publications, synthesizing and honing their messages around the societal benefit of investment in new digital infrastructures to support family medicine and primary care research.

In its call for white papers the NDRIO asks,

- *What is your vision for a cohesive Canadian DRI ecosystem that would fulfill your research needs?, and*
- *What are the tools, services and/or resources NDRIO should leverage to achieve your desired future state?, and*
- *How do you see NDRIO's role in addressing current gaps in the national DRI ecosystem?*

In answer, the CFPC strongly encourages the NDRIO to advance new and enhanced digital infrastructures to support research and evidence-informed action for family medicine, the principal source of comprehensive medical care, including primary care, in Canada. This white paper cites recent federal, provincial and territorial government commitments to primary care, and the emphasis they place on sound evidence to support decision-making. We describe how practice-based research networks (PBRNs) and electronic medical records (EMRs) will be indispensable in generating the new knowledge that is needed to drive a learning healthcare system. PBRNs are led by primary care researchers and providers who are deeply committed to providing better health care and improving the lives of the people of Canada. As the NDRIO defines its role, there is a unique and powerful opportunity to advance this important work, which to-date has received inadequate support.

Investment in new digital research infrastructures must be targeted to maximize their benefit to society and the value of public spending. Given that economic growth depends on a healthy population[2] and

[1] NDRIO: Call for White Papers on Canada's Future DRI Ecosystem. The New Digital Research Infrastructure Organization, October 22, 2020. https://engagedri.ca/news/ndrio-call-for-white-papers-on-canadas-future-dri-ecosystem, accessed 7 December 2020.

[2] Working for health and growth: investing in the health workforce. Report of the High-Level Commission on

that health disparities are a persistent problem in Canada[3], significant societal benefit will accrue from digital infrastructure investment that supports family medicine and primary care research. Indeed, health challenges – be they defined by condition (e.g., opioid use, mental health, chronic illness) or populations at risk (e.g., Indigenous peoples, seniors, the homeless) – must first be addressed through highly responsive primary care.

Canada's federal, provincial and territorial (FPT) governments know that primary care is a priority, and that better evidence is needed to support decision-making. In their 2017 *Common Statement of Principles on Shared Health Priorities*, FPT 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".[4] In December 2019 the federal government expressed its commitment to "evidence-based decision-making that takes into consideration the impacts of policies on all Canadians" and mandated the health minister to "ensure that every Canadian has access to a family doctor or primary health care team"[5]. Assertions made by FPT governments signal a readiness to respond to urgent health care needs. They also underscore the need for sound data and evidence to support appropriate planning, policy development and decision-making.

In order to generate the necessary evidence and knowledge for future decision-making, Canada will first need to overcome its significant underfunding of family medicine and primary care research, including high impact research enabled by the digital infrastructures of practice based research networks. The Canadian Institutes of Health Research is the single largest funder of health research in Canada. While most health care is provided through home, community, and primary care, only 6.2% of CIHR research funding is directed toward these health care delivery sectors[6]. The under-funding of primary care research means that the communities and populations served by primary care (many of them at-risk and under-represented themselves) are also neglected.

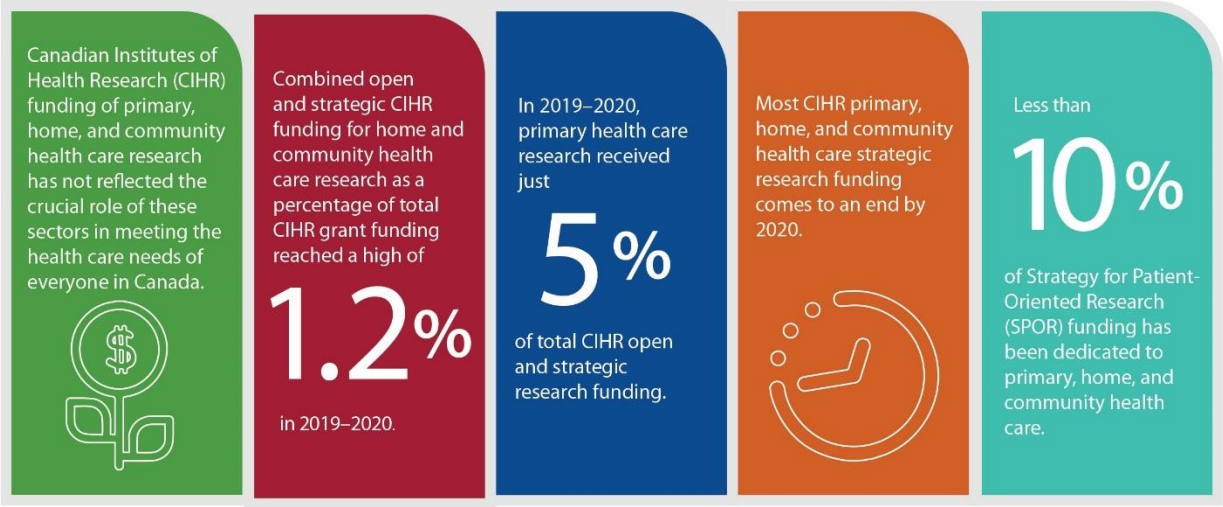
Health Employment and Economic Growth. World Health Organization 2016. https://apps.who.int/iris/bitstream/handle/10665/250047/9789241511308-eng.pdf?sequence=1, accessed 8 December 2020.

[3] Key Health Inequalities in Canada: A National Portrait. Public Health Agency of Canada, 2018. https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research/key-health-inequalities-canada-national-portrait-executive-summary/key_health_inequalities_full_report-eng.pdf, accessed 8 December 2020.

[4] Federal, Provincial and Territorial Ministers of Health. 2017. A Common Statement of Principles on Shared Health Priorities. https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/principles-shared-health-priorities.html, accessed 8 December 2020.

[5] Minister of Health Mandate Letter. Government of Canada, December 2019. https://pm.gc.ca/en/mandate-letters/2019/12/13/minister-health-mandate-letter, accessed 8 December 2020.

[6] Richard Snell, personal communication, September 11, 2020 and CIHR Grants and Awards Expenditures 2019-20. https://cihr-irsc.gc.ca/e/51250.html, accessed 12 December 2020.



Evidence-based primary care planning and decision-making needs to be informed by research conducted at the interface of the community and the health care system. To achieve this Canada needs to expand, connect, and support primary care practice-based research networks (PBRNs). This includes investments in technology as well as the development of capacity for the collection, linkage, and analysis of data on the structure, processes and outcomes of primary care.

PBRNs are networks of primary care practices whose aim is to stimulate the development of research that reflects the challenges and context of primary care practice. In the UK and US, where the development has been most extensive, PBRNs engage 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[7,8,9,10,11].

PBRNs offer an interactive model of knowledge production and utilization and can serve as learning communities and drivers of quality improvement[12,13]. 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

[7] 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.
[8] Thomas, P., F. Griffiths, J. Kai, and A. O'Dwyer. 2001. Networks for Research in Primary Health Care. British Medical Journal 322:588-590.
[9] Rait, G., S. Rogers, and P. Wallace. 2002. Primary Care Research Networks: Perspectives, Research Interests and Training Needs of Members. Primary Care Research and Development 3:4-10.
[10] Rhyne, R.L., and L.J. Fagnan. 2018. Practice-based Research Network (PBRN) Engagement: 20+ Years and Counting. Journal of the American Board of Family Medicine 31:833—9.
[11] Binienda, J., A.V. Neale, and L.S. Wallace. 2018. Future Directions for Practice-Based Research Networks (PBRNs): A CERA Survey. Journal of the American Board of Family Medicine 31:917-23.
[12] Mold, J.W., and K.A. Peterson. 2005. Primary Care Practice-based Research Networks: Working at the Interface of Research and Quality Improvement. Annals of Family Medicine 3(Suppl):S12-20.
[13] Peckham, S., and B. Hutchison. 2012. Developing Primary Care: The Contribution of Primary Care Research Networks. Healthcare Policy 8(2):56-70.

organizations. In the process, they are transitioning from research networks to learning networks and learning health systems.

In Canada, there are 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[14]. 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 advancing research that addresses both local and pan-Canadian health care challenges, while improving policy and practice at the local, regional and provincial levels.

Data on the structure, processes and outcomes of primary care – including patient-reported experience and outcomes – are essential to inform decision-making at the practice and system levels and to enable primary research. Yet, in the primary care sector, systems for the collection, sharing, linkage, analysis and dissemination of practice and system level data are woefully underdeveloped.

New and enhanced digital research infrastructures are needed to collect and integrate real world, clinical data from electronic medical records. The data must encompass patient-reported experiences as well as information about health care providers and organizations. This DRI is vital not only to underpin research but also to inform health care and workforce planning, policy making, management and quality improvement. The ultimate objective should be to collect and assemble data with appropriate privacy protections from all family medicine, primary, home, long-term and other care settings. The digital infrastructure should support linkages to authoritative health workforce databases, such as administrative systems maintained by professional associations. Building this data infrastructure will allow many key research outcomes to be measured using real world data rather than project-specific data collection processes, sharply reducing the costs of conducting both clinical and health services research.

The NDRIO is asking important questions about where Canada should develop its DRI. Flowing from the preceding information, the CFPC strongly encourages the NDRIO to advance digital infrastructures that will support research and knowledge creation leading to broad societal impact. Family physicians foster healthy populations through the comprehensive care they provide in a broad variety of health care delivery environments. The evidence of family medicine's impact, coupled with its chronic research underfunding, suggests an urgent need to develop new and enhanced digital infrastructures to support evidence-informed decision making.

The CFPC learned about the NDRIOs call for white papers from members of the *Health Data Research Network Canada* (HDRNC) and the *Canadian Primary Care Sentinel Surveillance Network* (CPCSSN). HDRNC and CPCSSN bring together networks of organizations that work together to facilitate and accelerate multi-jurisdiction research in Canada. They support the efforts of many practices and providers who are ready to lead research that will improve health care and the health of Canadians.

[14] Proposal for a CIHR Institute of Integrated Primary, Home and Community Health Care. College of Family Physicians of Canada, Canadian Nurses Association, Society of Rural Physicians of Canada, Canadian Homecare Association. https://portal.cfpc.ca/ResourcesDocs/uploadedFiles/Research/CIHR-Backgrounder-Integrated-Primary-Home-and-Community-Health-Care-Research-Institute-May14-2019-ENG.pdf, accesses 8 December 2020.

In response to the enormous threats posed by the COVID-19 pandemic, HDRNC and CPCSSN call for digital research infrastructure investment that would "stabilize funding for collection, data transformation, maintenance, access, and analytic support of expanded EMR data platforms approaching population wide coverage". The proposed DRI would support primary care research and practice improvement as described throughout this white paper. More importantly, it would support future infectious disease tracking and clinical trials for virtually the entire population of Canada. As Canada recovers from the devastating effects of the COVID-19 pandemic, the CFPC strongly encourages the NDRIO to advance the DRI proposed by the HDRNC and CPCSSN partners.

In a similar vein, the CFPC supports the research and quality improvement efforts of the Canadian Primary Care Information Network (CPIN). CPIN is a data collection infrastructure that integrates with electronic medical record systems used in primary care. It provides primary care practices with the ability to efficiently communicate with their patient populations and to collect patient experience information that can support research and guide practice improvement. CPIN has responded to the NDRIO call for white papers and, as with the HDRNC and CPCSSN vision, the CFPC strongly encourages NDRIO to heed the DRI recommendations offered by CPIN.

In closing, the CFPC would like to wish the NDRIO success in defining and achieving its important mandate. It is refreshing to see NDRIO seek broad input as it develops its strategic plan . We hope that our advice, and that of others, will help to identify DRI priorities and guide investment that will serve the people of Canada. We look forward to engaging with the NDRIO in the future and invite you to reach out to the CFPC if you require further assistance on your road ahead.

For further information, please contact:

Francine Lemire, MD CM, CCFP, FCFP, CAE, ICD. D
Executive Director & Chief Executive Officer
The College of Family Physicians of Canada
fl@cfpc.ca

Steve Slade, Director of Research
The College of Family Physicians of Canada
sslade@cfpc.ca