

External Review of Pan-Canadian Health Organizations

Thank you for the opportunity to provide input for your ongoing review of the Pan-Canadian Health Organizations (PCHOs). This submission is made on behalf of Innovative Medicines Canada, which represents the research-based biopharmaceutical industry in Canada.

Our members support the federal government's efforts to assess and align the work of PCHOs. The federal government has an important role to play in helping to address pan-Canadian health system issues that transcend provincial borders. The reality of Canadian federalism and provincial jurisdiction for health care entails that pan-Canadian cooperation is often extremely complex. Given the coordination challenges, we recommend efforts be focused where federally-funded resources can have the most impact.

As such, we encourage the government to adopt a targeted approach that leverages the existing strengths of various PCHOs. While there may be several ways to enhance synergies between different PCHOs, we will like to provide our inputs on a single focused area where tangible and meaningful progress is possible. In our view, such an approach should prioritize opportunities to enhance and develop Canada's health data infrastructure and capacity.

We suggest creation of a consortium with participation from PCHOs, patients and patient organizations, public and private payers, industry, information technology experts and academia to develop a Canadian framework to improve health data infrastructure and application of health outcomes data in decision making, with the goal of improving patient care while assisting with budget sustainability.

A Focus on Health Data Infrastructure, Capacity and Application of Outcomes Data

Improving health data collection and management is a crucial step to address health system needs and improve patient health. This is within the federal government's purview, yet can have benefits across Canadian health systems, including:

- Supporting the timely adoption of health technologies that add value to patient care, appropriate prescribing of pharmaceuticals and use of medical devices;
- Aligning and improving hospital care and health system decision making; and,
- Better connecting health system resources and expenditures to the most effective and cost-effective interventions based on real-world health outcomes data in conjunction with the data reviewed by Health Canada's Health Products and Food Branch.

The data infrastructure priority touches many of the PCHOs identified in this consultation and provides an excellent opportunity to engage industry, patients, and other stakeholders on shared and tangible objectives.



Building on Current Strengths and Opportunities Related to Health Data Infrastructure

Health Canada’s discussion guide asks stakeholders to comment on the major strengths, weaknesses, and opportunities for PCHO collaboration. The table below provides a summary for those agencies most critical to the priority of improving health data infrastructure.

	Strengths	Weaknesses / Opportunities
Canadian Institute for Health Information (CIHI)	<ul style="list-style-type: none"> • Experience in health care data collection • Hospital/wait-times data • Health expenditures • Claims-based pharmaceutical data and analysis – Collaboration with Patented Medicine Prices Review Board (PMPRB) via National Prescription Drug Utilization Information System (NPDUIS) 	<ul style="list-style-type: none"> • Extent of integration into provincial decision making unclear – opportunity to enhance use of data collected by Canadian Institute of Health Information (CIHI) in decision making • Better leverage existing provincial data sources and disease registries e.g. Institute for Clinical Evaluative Sciences (ICES) • Limited linkage with health outcomes based data or patient registries
Canada Health Infoway	<ul style="list-style-type: none"> • Measuring the benefits and value of digital health • Promotion and advancement of digital health • E-prescribing service development 	<ul style="list-style-type: none"> • Key role to play in improving access to personal health information (e-health records etc.) • Adoption of e-prescribing services remains an area for future development and expansion • Opportunities to leverage digital health tools in gathering patient-reported outcomes • Interconnectivity of information technology (IT) platforms – gaps at both intra-provincial and inter-provincial levels



<p>Canadian Agency for Drugs and Technologies in Health (CADTH)</p>	<ul style="list-style-type: none"> • Strong connection to federal, provincial and territorial decision making regarding pharmaceuticals and medical devices • Increasingly active on medical devices and knowledge translation • Standards and methodology expertise in HTA 	<ul style="list-style-type: none"> • Opportunity to enhance clarity of patient role in various review processes • Limited experience and access to real-world data resources • Opportunity to play a role in lifecycle management which is a data-driven task • Opportunity to play a role in developing methodologies and standards for data collection and analysis • Opportunity to incorporate context for real-world data collection in CDR and pCODR recommendation framework for products where data development may be needed • Collaboration with Health Canada through Regulatory Review of Drugs and Devices (R2D2) initiative with the goal to create efficiencies and attain earlier access to innovative therapies
<p>Canadian Partnership Against Cancer (CPAC)</p>	<ul style="list-style-type: none"> • Patient connectivity • Partnership model CADTH-CPAC relationship • Focus on prevention, population-based screening and related data-tools • Carcinogen exposure surveillance information 	<ul style="list-style-type: none"> • Unknown level of integration in provincial cancer decision making processes e.g. with the Canadian Association of Provincial Cancer Agencies (CAPCA) • CAPCA is apparently driving the real-world data discussion in cancer space for drug funding related issues but the linkage with CPAC, CADTH and other partners is unclear

Given existing competencies and strengths, CIHI and Canada Health Infoway should continue to lead on data collection and integration of digital health and information technology platforms. This can be optimized through ongoing cooperation with provincial information providers, and agencies such as CADTH that have existing expertise in data analysis and making recommendations to policy makers.

The data infrastructure challenge is pan-Canadian and multi-disciplinary in nature. As such, there is a strategic advisory and adoption role to be played by other PCHOs including the Canadian Patient Safety Institute, the Mental Health Commission of Canada, the Canadian Centre on Substance Use and Addiction, the Canadian Foundation for Health Improvement as well as other relevant health-related organizations including as Canadian Institutes of Health Research and its Strategy for Patient-Oriented Research and Drug Safety and Effectiveness Network.

These organizations are important partners for collaboration and can help to:



- Inform specific data collection and utilization priorities;
- Encourage and accelerate the adoption of data tools across the system;
- Encourage active involvement among their respective networks and patient communities;
- Leverage data to help inform strategies for health system and delivery improvement and,
- Study and analyze the impacts of new data-intensive methods of health delivery and make recommendations for ongoing improvement – from both a technical and policy perspective.

Current Canadian Data System Gaps Regarding Pharmaceuticals

While the data infrastructure priority impacts many elements of the health system, we would draw reviewers’ attention to some key areas of relevance to our members. There are several gaps within the current pharmaceutical decision-making system that would benefit from a more coordinated and deliberative data management approach. There is room to improve linkages between outcomes data and decision making.

Gap	Opportunity/Objective
Health outcomes data infrastructure fragmented across provinces and territories	Enhance cooperation on data-infrastructure objectives; Centralize data storage and facilitate appropriate access to data; explore government ‘open data’ initiatives
Current data infrastructure not always focused on the needs of provincial decision making	Improve data collection infrastructure to focus on the needs of decision makers
Canada lagging behind other jurisdictions regarding the generation and use of Real World Evidence (RWE)	Co-creation of a RWE framework and critical path between government and industry; Explore international models and best-practices regarding RWE
Uncertainty regarding real-world effectiveness at product launch. Protracted drug pricing negotiations and related patient access delays are sometimes due to data gaps	Outcomes-based or value-based reimbursement agreements (coverage with evidence development); CADTH expert committee recommendation framework regarding drugs with ongoing data generation requirements for conditional funding decisions
Data systems to manage appropriate prescribing	Establish data infrastructure to track and promote appropriate prescribing



Regarding oncology decision making specifically, we would note a lack of clarity on roles of various review and prioritization processes among the CAPCA-led Cancer Drug Funding Sustainability Initiative (CDFSI), CADTH's pan-Canadian Oncology Drug Review (pCODR) and its Provincial Advisory Group (PAG); and, the pan-Canadian Pharmaceutical Alliance (pCPA). There is a lack of clarity on how real-world evidence and data will be operationalized and what role it will play in decision making. Enhanced transparency, clarity and partnership is needed in this area.

Another untapped opportunity is to leverage real world data and outcomes-based reimbursement agreements to facilitate timely access to drugs for rare diseases. Data infrastructure development will be important to meet the needs of various stakeholders in this regard.

Next Steps and Recommendation

The consultation document also asks “how well do the PCHOs function as a group? Where are the synergies and the gaps? How well do they, as a group, advance key priorities for the health system?”

Our view is that collaboration could be improved through enhanced coordination of processes and connection of data to policy outputs. Equally important, is collaboration and connection with provincial decision making and health service delivery on the ground. Many of the challenges and opportunities identified above can be addressed through coordination and cooperation, and greater integration with province-level processes.

It would be helpful for the federal government to establish clear objectives for PCHOs, identify additional opportunities for stakeholders to provide input on those objectives and how to achieve them. The innovative medicines industry would welcome an opportunity to actively engage in these efforts.

Our recommended approach is to build on existing PCHO strengths to improve service delivery and integration. We do not recommend radical change to mandates within the current system or establishing new PCHO governance structures. As suggested earlier, we encourage Health Canada to seriously consider the creation of a consortium with participation of key stakeholders, including health delivery centers or networks, device manufacturers and biopharmaceutical companies, to move this initiative forward on a priority basis.

Thank you again for this opportunity to provide feedback on this important consultation.

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