



November 10, 2022

Dear Prime Minister Trudeau,

We are writing with respect to the issue of health data management across Canada. We appreciate that you are aware of the importance of the collection and sharing of relevant, interoperable data to ensure safety, make evidence-based health decisions and establish vital health policies. We know that the federal government has contributed to developing a [Pan-Canadian Health Data Strategy](#) (PCHDS). It is certainly a complex and challenging area requiring much planning and numerous experts and stakeholders. To that end, we appreciate the insights provided by the PCHDS' Expert Advisory Group in developing this Strategy.

We laud the vision of the federal government in raising this important issue at the meetings of the Ministers of Health in Vancouver on November 7-8. We also strongly support the work of the Public Health Agency of Canada in leading the PCHDS.

To ensure that these data can be implemented to maximum effect for all people in Canada for the best value for money, the synergistic impact of a pan-Canadian approach is required. We recognize that each province is at a different place in terms of how far it has gotten in developing its unique data management strategies so each will need solutions specific to its needs. Ultimately, however, the vision and foundational pillars should be the same across the country. Canadians depend on this.

We trust that the leaders at the provincial and territorial levels will be willing to work with the federal government to develop and implement a pan-Canadian Health Data Strategy that meets each of their individual needs and the collective needs of people in Canada to have a consistent, common, transparent, pan-Canadian data strategy with interoperable architecture so that accessible data follow people in Canada. It is only by doing so that we can use data to make evidence-based health decisions and develop effective policies to serve everyone in Canada.

It is essential that other relevant experts and stakeholders be integrated into these decision-making processes, including patient groups.

We would be pleased to meet with you to discuss this issue and to determine how we can support your work in this area going forward.

Sincerely,

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Christina Sit, Manager, Community Strategic Partnerships, Leukemia and Lymphoma Society of Canada
CONNECTed, a network of national patient oncology organizations
Gail Attara, President and Chief Executive Officer, Gastrointestinal Society
Jackie Herman, President, Canadian Neuroendocrine Tumour Society (CNETS)
Jackie Manthorne, President and CEO, Canadian Cancer Survivor Network
Jeffrey Beach, Executive Director, Canadian Spondylitis Association
Jim Tokos, National President, Canadian Council of the Blind
Kathleen Barnard, Founder and President, Save Your Skin Foundation
Laura Tamblyn Watts, President and CEO, CanAge
Leah Stephenson, Strategic Lead, All.Can Canada
Linda Wilhelm, President, Canadian Arthritis Patient Alliance
Dr. Martin Dawes, MB.BS, MD, DRCOG, FRCGP, Member, All.Can Canada
Michael Eygenraam, Chair, aHUS Canada
Rachel Manion, Executive Director, Canadian Skin Patient Alliance (CSPA) and Canadian Association of Psoriasis Patients (CAPP)
Sabrina Hanna, the cancer collaborative [colab]
Shem Singh, Executive Director, Lung Cancer Canada
Stephanie Michaud, President and CEO, BioCanRx