

## EXECUTIVE SUMMARY:

# Declaration of Personal Health Data Rights In Canada

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People own their personal health data while stewards of that data own the records. Since people own their personal health data, they have corresponding rights over the personal health data they provide.

## Declaration of Personal Health Data Rights in Canada

1

**Right to be informed:** Individuals have the right to formal notice prior to the collection of their personal health data. Individuals have the right to be informed, using concise, accessible, plain language, about how a steward will be processing or commercializing their personal health data.

2

**Right to consent:** Individuals have the right to consent, and withdraw consent, to the processing or commercialization of their personal health data. Different intended purposes require different degrees of consent, either implied consent or express consent, including health care provision and the circle of care; research for public benefits using de-identified data; research using identifiable data; and commercial purposes.

3

**Right to access, portability & correction:** Individuals have the right to request a portable copy of the personal health data they provided to a steward and to the correction of their data where they identify inaccuracies. Individuals have the right to receive their data in a structured, commonly used, machine-readable format at no cost. For individuals without digital devices and/or internet, timely access will be provided to them in another format (e.g. hard copy) ideally at no cost.

4

**Right to de-identification:** Whenever feasible and reasonable, individuals have the right for their personal health data to be de-identified prior to its being shared with anyone other than themselves or their circle of care for purposes for which they have given informed consent.



5

**Right to benefit:** Individuals have the right to benefit from their personal health data, including from their data being processed or shared for research or any other purposes. In order to benefit, patients recognize the importance of sharing their personal health data, while recognizing stewards' duty to respect, protect, and fulfill personal health data rights.

6

**Right to object to processing:** Individuals have the right to object to the non-care related processing of their personal health data, such as processing for direct marketing.

7

**Right to restrict processing:** Individuals have the right to restrict the processing of personal health data in specific situations, such as where the individual contests the accuracy of the data, or where the individual has objected to the processing of their data and is awaiting the decision of a complaint.

8

**Right to a complaint process:** Individuals have the right to a complaint process by their data protection authority if they believe the processing or commercialization of their personal health data violates legislation.

9

**Right to privacy and security:** Individuals have a right to have their personal health data processed in a way that meets current standards and regulations of privacy and security.

10

**Right to erasure:** Individuals have the right to request that their personal health data be erased, which is sometimes called the right to be forgotten. This right only applies in certain specific circumstances, such as where the data are no longer necessary for the purpose(s) for which they were processed.

11

**Right to engagement:** Patients, and their caregivers, have the right to be part of decision-making related to personal health data to ensure their views, perspectives, and values are meaningfully incorporated into decision-making processes.

# Endorsements as of December 22, 2023

## Organizations

save your skin  
FOUNDATION



LA FONDATION  
sauve ta peau

Canadian  
Psoriasis  
Network



Réseau  
canadien  
du psoriasis



Canada

CAPA

Canadian Arthritis  
Patient Alliance

CANADIAN COUNCIL  
OF THE BLIND



LE CONSEIL CANADIEN  
DES AVEUGLES

Unmasking  
**PSORIASIS**



hpv vph  
global action  
action globale

lung  
health  
starts  
now

lung health  
foundation

ami québec

Agir contre la maladie mentale  
Action on mental illness

REXNIHL  
breast cancer

CanAge



Mood Disorders Society of Canada

La Société Pour Les Troubles de L'Humeur du Canada

MELANOMA  
CANADA

CCRAN  
Colorectal Cancer  
Resource &  
Action Network



RISCC  
Réseau d'informations  
et soutien pour le  
cancer colorectal

A PATIENT-FOCUSED ORGANIZATION



CANADIAN  
CONGENITAL  
HEART ALLIANCE

Canadian  
Spondylitis  
Association

Réseau sur les innovations  
en soins de santé de  
première ligne et intégrés



Primary and Integrated  
Health Care Innovations  
Network

CANCER  
ACTION  
NOW

MYÉLOME  
CANADA

MISSION - MAÎTRISER LE MYÉLOME



MYELOMA  
CANADA

MAKING MYELOMA MATTER

SSC  
SCHIZOPHRENIA  
SOCIETY OF CANADA

SCS  
SOCIÉTÉ CANADIENNE  
DE LA SCHIZOPHÉNIE



HeartLife  
FOUNDATION



badgut.org  
Gastrointestinal Society  
Canadian Society of Intestinal Research



GIST Sarcoma Life Raft Group Canada  
Groupe Sauvetage GIST Sarcome Canada  
Ensuring that no one has to face GIST alone

BioCanRx  
Canada's Immunotherapy Network  
Le réseau canadien d'immunothérapie



ICN  
Imagine Citizens Network

AYA  
CAN



CANADIAN  
NEUROENDOCRINE  
TUMOUR SOCIETY

PATIENTS REDEFINING  
THE FUTURE OF HEALTH CARE IN CANADA



Executive Summary



If you are an organization or individual who wants to endorse, visit:  
<https://saveyourskin.ca/declaration-of-personal-health-data-rights-in-canada-endorsements/>