

Personal Health Data & Information: Patient aspirations, expectations, and concerns

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Agenda



1. What are patient aspirations for data collection, use, and sharing?
2. What are patient concerns?
3. Solutions and what could be next

Informed by:

- Survey of > 20 people with lived/living experience
- Co-facilitating focus groups for Canadian Institute of Health Information around data stewardship

We're talking about data in many forums...



Canadian Institute
for Health Information

The Government of Canada introduces the *Connected Care for
Canadians Act*

From: [Health Canada](#)

Health data stewardship principles

**DECLARATION OF PERSONAL
HEALTH DATA RIGHTS IN CANADA**

Brain-Heart Interconnectome

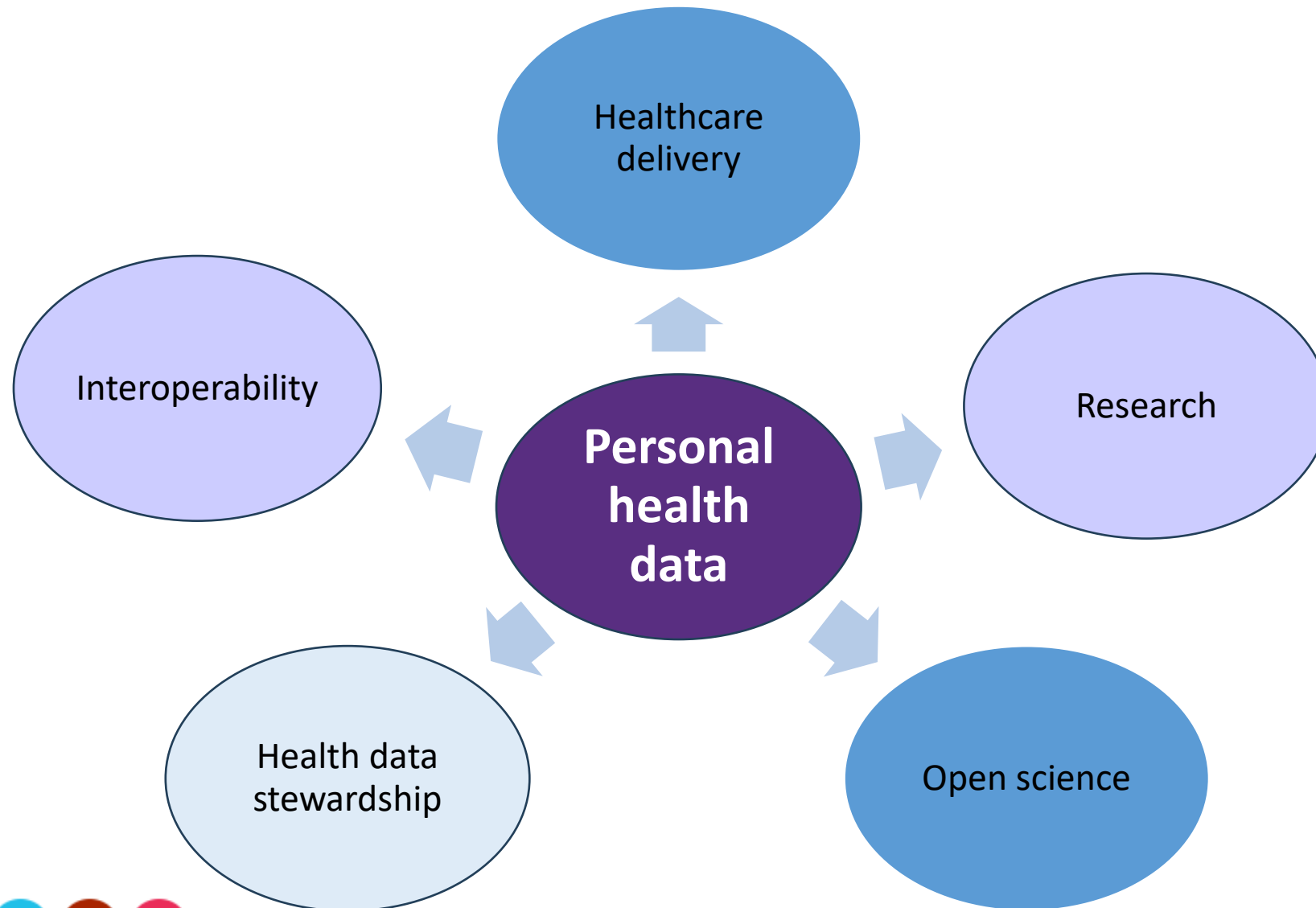


Canada Health Infoway

 ARCHIMEDES

Advanced Research Collaboration for Health
Integration, Medical Exploration,
and Data Synthesis

Patient data & information – The full spectrum



Aspirations: Supporting patients in their care

- Gives patients access to their own data – counters power imbalances in healthcare
- Accessing research more openly to stay up to date
- Questions around portability – can I take it with me?

“I care the most about my health and thus, am often the one with the interest and time to do research to figure out next steps. To make good clinical decisions for myself, I require access to great research information - not just the info from Facebook.”

“Many times, your primary healthcare provider doesn't know the ins and outs of your condition, so being able to advocate for yourself and show the recent scientific findings is super helpful. .”

Aspirations: Data accuracy and accountability

- Some patients can view their own health data though typically less so for research data
- “Knowledge is power” but what if the data is not correct?
- What if the interpretation of data doesn’t reflect the lived experiences of patients?
- Duty to engage patient communities in the research being undertaken about them

Aspirations: Timely access to research results

“It is frustrating when paywalls and subscription costs keep me from reading the medical research and checking the facts for myself. I need to know the proper scientific terms for complications and states of wellness so that when I speak with medical providers, I can understand the full import of what they tell me, and so that my records are understandable to me.”

“As a patient and an advocate in oncology, most of the journal articles that are pertinent, including ones about patient preferences, quality of life, etc. are behind paywalls. Data about Us should be accessible to Us!”

“People would be able to see possible trials and learn what new treatments may soon become available.”

“Allow us to find communities of researchers, others who are interested in very specific topics. For example, a worldwide community interested in a specific genetic mutation.”

Patient expectations about data sharing

- De-identification is a fundamental requirement when data is shared
- Context of data sharing important and need to engage patient communities and society at large
- But what is being shared? Do I want my care provider or researcher to know this information? Can it influence the care I receive?
- An audit trail of who has accessed our health data

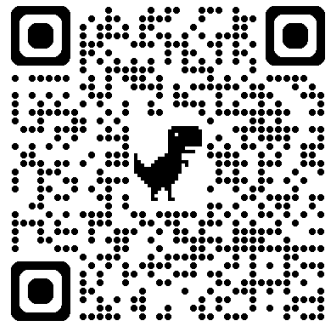
“...taking people seriously and listening to them (which is) also a sign of recognition and respect...by developing a nuanced understanding of what it is like to live with a condition.”

Patient concerns about data sharing

- Whose data is it anyways? Can patients identify how they'd like their health data/information shared and with whom?
- Different and rigorous consent processes – can we redesign data stewardship to give patients more autonomy and control?
- Security – What happens with private vendors? Are their data centres located in Canada or elsewhere?

“Depends on what the data is and how its used. Hopefully its potential use by other parties would be clearly identified during the informed consent process. For example, I would be hesitant for a 3rd party to use this data for commercial gain vs purely for research purposes.”

DECLARATION OF PERSONAL HEALTH DATA RIGHTS IN CANADA



Right to be informed

Right to de-identification

Right to consent

Right to benefit

Right to access, portability & correction

Right to object to processing

Right to restrict processing

Right to a complaint process

Right to privacy & security

Right to erasure

Right to engagement

“The invitation to participate; a user-friendly platform”

Possible solutions

- Patient engagement in designing and implementing research and healthcare projects
- Consistently sharing research results with research participants and communities at large (closing the loop)
- Patient and community-led research and quality improvement

“I would also want to have some way of being able to interpret and provided to me in simple language why, and the way the research was done and how the researchers came to the outcomes they did.”

Possible solutions: Patient & community-led research

“Being able to access research results but also patient organizations being able to use those results and apply for funding to research priorities that matter to patients.”

“I think open science would have faster Kt (knowledge translation), potentially more patient engagement and could lead to collaborations.”

“Open science needs to have patient partner council to collaborate on the activities of open science.”

“...provide a means for people with lived experience to identify gaps in research/science that are important to them and therefore make science more tailored to what people actually need.”

Questions??



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