

What do people in the Maritimes think about health data sharing?

What is "Social Licence"?

Social licence for health data use is the publicly implied permission for organizations (like researchers, health system, government) to use their health data for public benefit, with certain safeguards in place.

Why did we do this study?

In this research study, we wanted to know which kinds of health data sharing people supported and why.

Who did we speak to?

We held English and French focus groups. We spoke to people living in rural and urban areas, both men and women, aged 24 - 83. Around 1/3 of participants identified as a racial or ethnic group other than white. We used targeted convenience sampling and shared recruitment materials with communities across Nova Scotia and New Brunswick.



34
Participants



72%
Women



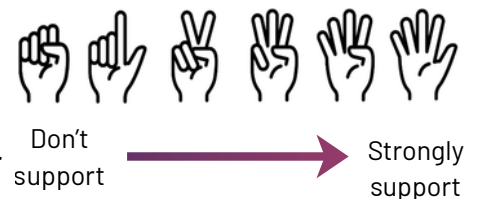
56%
Rural



Members of the public were involved as members of the research team. They supported recruitment and acted as Community Navigators, by attending and supporting focus groups and helped interpret study findings.

What did we do?

We presented real and theoretical examples of how health data is used and asked people if they supported it. People voted by holding up their hand. They voted twice, with group discussion in between.



Key Takeaways

- There is public support for health data use when there is: perceived public benefit, trust in who is accessing the data, and safeguards in place to protect privacy.
- Views evolved through dialogue, ongoing public engagement is vital to understand the conditions under which support changes and to build and maintain trust.
- **The public wants to know who is using health data and why** - health data users should make this information publicly available and easily accessible in both French and English.

Which cases had higher and lower support?

Community support was **higher** when health data was used by healthcare, government & researchers to improve patient care, health systems, and our understanding of disease and well-being.

Community support was **lower** when health data was used by private companies for commercial product development or drug trials, with benefits that may be hard for everyone to access equally.

"Absolutely, if there's one organization in which I believe, it's universities and academic research"

"If it's going to make a difference, I support it 100% ... as long as those protections are in place ... I say go for it, use that information."

"... I do have problems where it's a private company and I don't know where the data is going. Because I don't trust that."

Conditions tied to greater support



Community benefit



Creation of meaningful change



Confidence in safeguards



Trust in data users

Conditions tied to less support



Private company involvement



Financial motives



Data safety concerns



Risks for equity-denied communities

What were the health data use cases we presented?

Percentage of people who said they supported the health data use case by voting with three, four, or five fingers.

Health system decision makers use provincial and territorial data on chronic conditions to understand who is affected by Type 2 diabetes in different areas, with a goal of understanding what public resources are needed to support patients.	91.2%	↑	96.6%
A private company uses provincial and territorial data on chronic conditions to understand who is affected by Type 2 diabetes in different areas, with a goal of identifying communities and hospitals to partner with to test a new drug.	55.9%	↓	50.0%
A private company links fitness tracker data to administrative health data to understand the link between lifestyle and health outcomes, with a goal of developing new features, some of which are free and some must be purchased.	40.6%	↓	28.1%
A private company hires local analysts and uses local genetic data to understand the link between heart health and genetic disease, with a goal of developing a new treatment, but costs may be high.	75.0%	↔	75.0%
Healthcare practitioners use health data to directly improve the healthcare decisions and services provided to patients.	81.3%	↑	100%
Governments, healthcare facilities, or health system administrators use health data to understand and improve healthcare and the healthcare system.	93.8%	↑	100%
University-based researchers use health data to understand the drivers of disease and well-being.	96.9%	↑	100%

Vote 1 Vote 2
n ranged from 29-34

Contact info@mssu.ca for more information

