



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

What is Health Data?

- Information about your health, like test results, medications and visits to healthcare providers.
- Collected during healthcare visits to provide healthcare.
- Researchers and healthcare users can use the data to improve medical care.
- Kept safe by strict safeguards.

What is Social Licence for Health Data?

- Describes which uses and users of health data the public support and why.
- Using health data relies on public trust, transparency, and a commitment to community benefit.



Researchers from Nova Scotia and New Brunswick spoke with people across rural and urban Maritime communities. They talked to both men and women, aged 24–83. Most participants were white but about 1/3 were from a racial or ethnic group other than white. They held both English and French focus groups.



34
Participants



72%
Women



56%
Rural

The goal was to hear diverse views on when, how, why and with whom health data sharing is okay.

Key Findings



The public needs to be involved in conversations around health data use.



People support sharing when they trust the user, communities benefit, and data is kept safe.



The public wants health data users to have resources to do their jobs well.



Information should be easily accessible in both English and French.



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.”

Findings will inform recommendations to health data users on communicating with the public about data use.

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.

