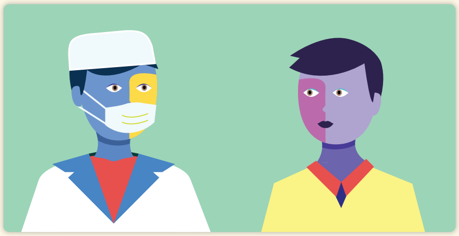
Data Path: Giving Consent



This Data Path describes a conversation between an adult male and an employee of Statistics Canada about a health survey.

Glossary

Data is information. Health data is also known as Personal health information (PHI). PHI is “identifying information” about an individual’s health or health care history. This can include quite a lot of information, such as information about your health condition(s), treatment, health care number, drugs that you may be taking, and so much more.

Population health research studies the health of an entire population (rather than just one person), to try to improve the health of that whole population. When you study population health, you are also interested in learning what factors might cause poor health (or good health).

Hello Mr. Ryan. My name is Roger and I work for Statistics Canada. You have been randomly selected to participate in the Statistics Canada annual Canadian Community Health Survey. Are you interested in taking part in this survey today?

Can you tell me more about the purpose of the survey please? How does it all work? Why was I selected?

You were selected randomly along with many other Canadians and your participation is optional. The reason Statistics Canada runs this survey every year is to gather health-related information from communities. The information, also known as **data**, we gather can help the government with **population health research** to improve the the health of all people living in Canada. The information collected will be used to monitor, plan, implement, and evaluate health and well-being related programs and services, for medical research and to raise awareness about health related prevention and care.

So what kind of information are you going to ask me for?

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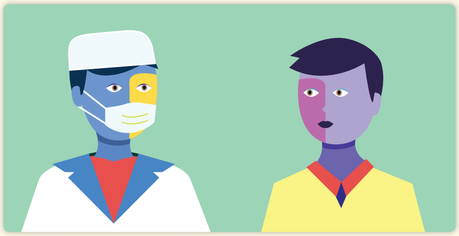

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If you decide to participate in this survey, I will ask you for some **personal health information**, such as your date of birth, address, and other information called **identifiers**. This personal health information you provide will be stored with Statistics Canada.

Statistics Canada will also be linking those pieces of data with your tax return, census data, and general data like mortality data, and hospitalization data, in order to get a more holistic understanding of many things at a population level. The reason for linking the data is to create an **integrated dataset**, which gives researchers a large **dataset** that offers more value than small ones because there is more context. Having said that, if you decide you do not want your data linked, you can simply say no (do not provide consent).

So if I say yes and I answer the questions, will Statistics Canada and all of these other groups know who I am and know all about me? What is the risk that someone will steal my identity?

There is always a level of risk when you decide to share data, but the risk level in this circumstance is low. The people who collect data are called **Data Custodians**. The Custodians are there to ensure that your data is collected in a secure way. Then there are people responsible for protecting your privacy - they are called **Data Stewards**. They would be held accountable if unapproved users accessed your data. Only approved users of data will be able to access and see your information. The people who handle personal health information must obey the laws that do not permit them to share data without your permission. If your data gets shared without your permission, the person would be held responsible.

Glossary

Personal health information (PHI) is “identifying information” about an individual’s health or health care history. This can include quite a lot of information, such as information about your health condition(s), treatment, health care number, drugs that you may be taking, and so much more. Privacy laws in Canada define and aim to protect PHI. (Ref: https://www.gov.nl.ca/hcs/files/phia-phia-faqs-feb-2011.pdf)

Identifiers are pieces of information (data) that help identify a person (for example, one’s name and birth date).

An **integrated dataset** is a set of data from different sources - it brings together different pieces of data from different people.

Datasets are sets of data.

Data Custodian: A technical entity responsible for the secure collection and/or storage of data and making initial decisions on data use, disclosure, retention, and disposal. Primarily concerned with security and privacy of information.

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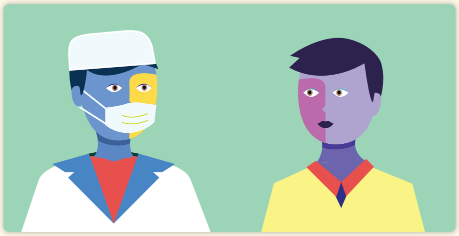

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Data Steward: An entity responsible for assuring the quality, integrity, and access arrangements of data and metadata in a manner that is consistent with applicable law, institutional policy, and individual permissions. (Source: GA4GH)

Consent: In the context of data, consent is giving someone permission to use the data they have collected from you for a specific purpose. No one can use your personal data without getting consent from you. Consent is permission.

So how do I give permission?

Permission is also called **consent**. Have you ever visited a website and been asked to give consent for your data to be shared with a third party?

Yes, I have seen those notices on websites. Sometimes there are a lot of things to read before signing. It's very confusing.

Yes, that is true. Sometimes it is very complicated. Some governments are already trying to make it easier to understand what you are saying yes to by making the rules and processes easier to understand.

So how do I know if my permission will let them see the data I want them to see?

As I mentioned earlier, if you do not want the data to be linked, then you just have to say no when they ask you that question. If you don't want any of your data to be collected, then you should say no to this survey. But if you think that your data could help build a better understanding of the health issues in your community, it is worth noting that the more data the researchers and governments have, the greater the impact will be on the people who live in our country, and in your community.

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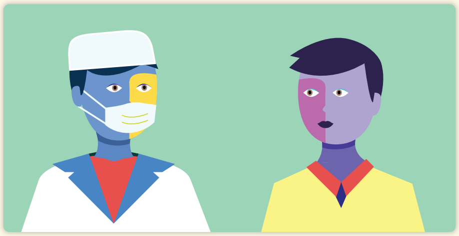

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Could you give me an example of that?

Sure. For example, if health outcomes data from this community showed that 75% of COVID-19 patients end up on ventilators, but in a big city with a similar type of population, it's only 25%, then we would know that there is an issue in our community in particular. Then our local governments could report those statistics to the provincial government and ask for more resources to tackle that specific problem.

OK. That sounds like it makes sense. I think I will do the survey because I want my government to be able to know what is going on here.

myhealthdatapath.ca

For purposes of this Data Path, Canadian terminology and definitions have been used for consistency. We acknowledge that different jurisdictions and/or data protection regulations include different terms or definitions to describe similar concepts. Please refer to the FAQs for further information.