

Data Path: Finding a Treatment



This Data Path describes a conversation between a woman newly-diagnosed with breast cancer and her oncologist.



Hello Jane. Welcome back to our office. How are you feeling today?

Thank you. Well as you can imagine I am worried, scared, sad. Everything.



All of those emotions are normal. After we chat about next steps today, we will introduce you to someone from our Social Work team who can help you with all of those emotions. We have a strong support network for patients at our treatment centre. Speaking of treatment, the results of your **biopsy** have come back. The **data** from the biopsy confirmed that you have breast cancer, and also confirmed the type of breast cancer you have, and we can now use this information to figure out what would be the best treatment for you. Options might include surgery, radiation, and/or chemotherapy.



How did the biopsy tell you what kind of breast cancer I have? I am curious.



Biopsies can help identify **mutations**, which are changes in your **genes** that might lead to certain diseases. The good thing is that the **data** from the results will tell us which medicines have the greatest chance of giving you the longest life, and which medicine won't work at all. This means we won't delay your treatment by trying things that won't help you. The mutation that you have is HER2+, which means that you need medicines that can target that HER2+ mutation specifically.



Glossary

A **biopsy** is when some tissue is taken from the body, usually from a tumour, and then examined in a laboratory to help confirm if you have a disease, and the extent of a disease.

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.

Mutations are changes in the DNA sequence of cells. They can be helpful, harmful, or neutral (no effect).

Genes are the basic building blocks of your DNA. Genes carry information that decides what you will look like, and what colour your eyes will be, among many other things.

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Are there any risks with the biopsy results - my data - being shared with other people? Will my data be given to people I don't know?



The test results (your data) will be shared with your Care Team at this hospital, and the people you have identified as your Care Team members at home. The people at this hospital who will see your data need to know who you are so that they can ensure you get the right medicine. No one else outside of this hospital will see your data unless you want them to. For example, you gave your partner access to your Patient Portal which has your test results and other information. They could not have accessed that data without your consent.



OK, so basically you need to share that piece of data, the piece about the type, to make sure I get the right medicine? But does anyone else need that data as well? Or is that it?



Well actually, you are asking a very good question. We could also share your data with a disease registry if you decided you would like to provide consent for that.



Why would I want other people outside my Care Team to see this data? What is a registry?



Glossary

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.

A **registry** is a database that holds information about a certain disease.

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. (source: GA4GH)

Anonymized data is data that has been unlinked from identifiers (for example, data could describe details about someone with cancer without naming that person).

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A registry is a database that holds information about a certain disease. In this case, our jurisdiction has a cancer registry that includes all cancers. Most registries collect data on patients over time so that they can try to understand more about diseases. The kinds of data that are collected are any blood and tissue samples (like from your biopsy, for example), your blood counts, information on your symptoms, what kinds of medicines you might receive and how you do on those medicines, your own medical history and also the medical history of your family. Researchers use the data in the registries to learn more about the disease and understand the best ways to treat those diseases.



If I give my data to the registry, will it help me?



If you decide to give your data to this registry, you could help others with your same disease by increasing the information we have on the disease and treatments. At the same time, your Care Team will be looking at the data in the registry to see how other patients like you did during their treatment. So imagine if we see some data in the registry that says that people like you (young, female, otherwise healthy, with HER2+ breast cancer) do really well on a particular therapy, but suffer from specific side effects for a specific period of time. If you get those same side effects, we can reassure you that others like you came through those side effects on average in a certain number of days - then you would know what to expect.



Will the researchers using the registry know who I am?



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Well actually, when researchers use the data in a registry, they are really interested in large samples of data representing many people, and they would consider your identity irrelevant. It's only your care team who needs to focus on you and your care, as an individual. Furthermore, your data will be cared for by someone called a **Data Custodian**. Under the law in this jurisdiction, Data Custodians can only share your personal health information with other Data Custodians, and only if the research cannot be done without the use of personal health information.



So there is a way for them to use data that isn't my personal health information?



Yes there is. Your personal health information can be **anonymized**.



I just thought of another question - you said I was HER2+ right? I wrote that down here so I could remember. I heard that some cancers can be passed down. Do I have to tell my family members that I am HER2+ so that they can also check? Do I have to share my data with them?



Excellent question. Actually, HER2+ breast cancer is not inherited. This type of mutation actually takes place after conception, whereas inherited diseases are there at conception.



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Thank you for explaining this to me. So how will I be treated? What is the plan?



Well, we were able to conclude from your biopsy that you have Stage I breast cancer, which means we caught it very early. This is very positive news. You will not need surgery to further investigate, and we can treat your cancer with medication and radiation. You have a very positive prognosis.



That is a relief. When do we start?



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.