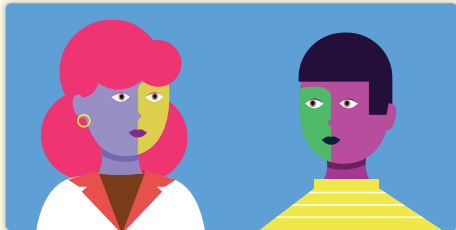


Data Path: Sharing Data with Caregivers



This Data Path describes a conversation between a caregiver and a nurse as the caregiver tries to navigate a large amount of information.

I'm always trying my best to support my mother's health care journey by better understanding what she's going through. But I have trouble keeping track of all her hospital visits, tests results, and other updates on her condition. I try to take notes and keep information where I can, but it can be hard to keep up. Are there any tools that could help me with this?



All patients in this clinic, including your mother, have an **electronic medical record**, which is often referred to as an EMR. The EMR contains updated information on their condition, visits, tests and treatment plan. By default, this information is only made available to the patient and their hospital care team. Because you are part of your mother's family care team, there is a way for you to also gain access to her records.



How can I do that? It seems like I'd be able to help her more if I had access, and even support her doctors and nurses in providing care to my mother.



In order for you to get access we'll need to have your mother provide her permission to share her health data with you. This is called **consent**. Only then, will we be able to share this data with you. In a situation where your loved one cannot provide direct consent based on their condition, we would have to discuss alternative processes.



Glossary

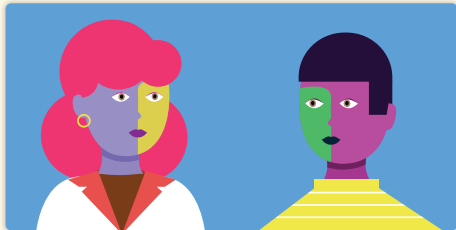
Electronic Medical Record:

An electronic record of a person's interactions with the healthcare system. EMRs are secure, and bring together all the information about a patient so that the view is comprehensive.

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.

Online patient portal: An online patient portal is a place where patients can go to see the information that has been collected about them within a healthcare institution.

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Okay, so once my mother provides consent for me to access her health data, where would I go to get the information?



For our specific clinic, we do have an **online patient portal** where you can access your mother's information. We will provide a login so that you can access the online patient portal. There you will be able to find a digital record of her hospital visits, tests results, and other updates on her condition.



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>)

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.

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)

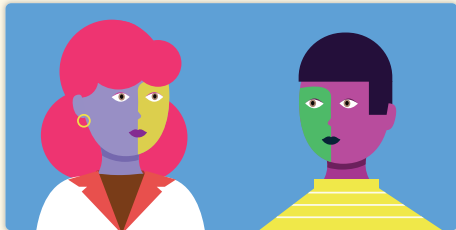
Can I share this information electronically with other people in my family who are caring for my mom? What about her support worker?



Access to your mother's EMR data would be for you only, unless your mother also grants consent to others - that is her decision. With any EMR data, institutions have privacy and security measures in place that limit access to only the people who your mother chooses to share her information with. Any other individuals wanting or needing access to her EMR data will require specific consent from your mother, similar to the process that you will go through for you to gain access her data. Having said that, there is nothing that this institution can do to prevent you from sharing information once it is in your hands. We would advise you though, to ensure your mother is OK with this because it is her **personal health information**, which is considered sensitive and private.



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Am I able to see who else currently has access to this data?



As a general rule, only your mother's health care providers can see her personal health information. Anyone else must have her consent to access their data, however there may be some exceptions such as hospital administrators who have access to the EMR system. 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 mother's data is collected in a secure way. Then there are people responsible for protecting her privacy - they are called **Data Stewards** and they are trained in this regard. They would be held accountable if unapproved users accessed her data. Only approved users of data will be able to access and see her information. The people who handle personal health information must obey the laws that do not permit them to share data without permission. If your data gets shared without permission, the person would be held responsible. Finally, if ever you discovered that your mother's data was shared inappropriately, you could pursue charges.



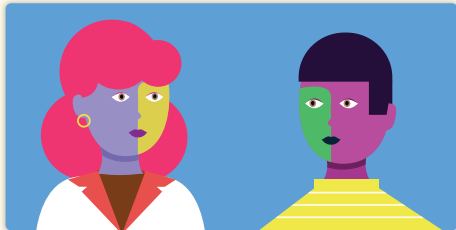
So based on the available health information, can I help make treatment decisions for my mother?



Care decisions should always be made with your mother's physician, nurses and care team. The information in the EMR could help you and your family members have more informed discussions with the care team.



Data Path: Sharing Data with Caregivers



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If I see an error in the health information, who would we contact to get this changed?



If you believe any of the information in the portal is inaccurate, out-of-date, or incomplete, your mother can request a correction. Requests for corrections should be directed to the care provider who originally collected the information (the data custodian).



If my mother changes hospitals or doctors, will this EMR be transferred to the new care team?



We try our best to ensure EMR data is accessible and available for any new member of the care team. However, the ability for her new care team to access her data is dependent on many things. We would try to facilitate access whenever possible and we would suggest that you let your mother's current and new care team know if you are planning to change hospitals, so we can be better prepared to see how we can help with access or the transfer of her data.



Great. Thank you for answering my questions. I'm glad to know there is an option to better understand my mother and any other family member's care journey. I will start by chatting with mom to see whether she is comfortable and whether she will provide me consent to access her EMR data. I think she will be relieved that we have this option and I might be able to help her more.



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.