

Data Path: Remote Monitoring



This Data Path describes a conversation between a female hospital administrator and a male patient trying to use a healthcare app.

My health has been getting worse lately and it's hard for me to travel into the city to see my doctors. I have a new app on my phone that has been helpful. My doctors can monitor my health through the app and we can even touch base more easily when my condition changes or I have a flare up. It has been such a relief that I don't have to wait to give my doctor an update. But there are a few things about this app that really bug me and I wish they'd make it better for patients to use. I think the app was developed by this hospital because the doctor here recommended it to me.



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.

Secondary Use of Data: When data is collected, it is collected for a specific purpose. If the person, group, or organization who collected the data takes the data (in this case, personal health information) it has collected for one reason, and uses it for a different reason, that is called secondary use.

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

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)

Thank you for sharing your concerns with me. It's important for me to understand when things aren't working for our patients. You're right that this app was developed here at our hospital. We have a technical team here who work on making these tools better for patients, and I know they would really value your feedback on the app. Would you be willing to share your feedback by sharing data with them through the app?



Can't they already see this information? I thought I already did that. I am confused.



Right now, your care team can see this information about you. What I am talking about now is a little different. This **consent** would be for app developers to see your data to help them make the tool better for you and other patients. It might mean that they see things about your health and treatment in order to make these improvements.



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Why is this so confusing? I thought when I started using the app I gave consent and that was it.



You may have only given permission for us to monitor your health and provide you with care, which means that we can only use your data for that purpose. Privacy laws require us to do this so that you are in the driver's seat and grant consent when you feel comfortable sharing your information with others, especially if sharing the information is for what we call "secondary purposes." The **secondary use** of the data, in this case to improve the way the app functions, requires additional consent from you.



Glossary

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 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.

A **shortcut** in the context of an app, is a faster way to get to a section within an app.

Oh ok. I think I actually remember seeing two options and I only checked the first box. I didn't really understand the second box but I remember seeing the words "secondary use". I didn't know what that meant.



That is also excellent feedback for us. That means we didn't do a good job of explaining the two options. I can share that with the team as well.



So is it too late for me to give that permission? I would like my data to help make the app better for me and other patients who use it.



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It is never too late to change your consent. In fact, if you give consent now and then change your mind later, you can change it back. Let me take a look at your app permission settings - I think I can show you where you go to make that change.

I have another question though. I am a little nervous about just anyone seeing stuff about my health. Will they know who I am? What if they share my information with my work or someone I know?



When app developers use data to make the app better, they don't usually need to know who you are. Your data will be **anonymized** for this secondary use, because we don't need to know your name or your identity. We only need certain pieces of information to help us make the app better.



How do you make data anonymous?



Anyone who uses your data at this hospital is called either a **Data Steward** or **Data Custodian**. As stewards and custodians of your **personal health information**, we have the responsibility to protect your privacy. When we make data anonymous, we remove information that could personally identify you. Our number one goal is to learn from the data in the app, while also protecting your privacy.



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So what will be removed?



Our tech team knows more about this than me, but my sense is that they don't need to know who you are - they just need you to allow them to use your data to improve the app. They only need to know what you click on in the app and how often. So let's say the app learns that every morning when you wake up you open the app to log how you are feeling, and it takes 5 clicks to get there. That data will help show the developers that a **shortcut** would be useful for a user like you so that you could get to where you want to go without having to make 5 clicks. And if they saw that all the other users did the same thing every morning they would know that a shortcut would be even more valuable. So your data (and the data from other users) will help the app learn and get smarter.



OK. That makes sense. Can you show me where I can make that change in the app now?



Sure. Let's look at your phone...



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Thanks again for explaining all of this to me. If you could give feedback to the app people, can you tell them that the app can be better and patients would like to help?



I will definitely deliver that message to the team, and thank you for talking to me about this today. It was really helpful to hear your thoughts and suggestions. We won't know how to make things better for users of technology unless we speak directly to those users.



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.