



INFORMATION SHARING FOR YOUNG PEOPLE



Canadian Mental
Health Association
British Columbia
Mental health for all

Health information—like your diagnoses and treatments—can feel very private. In some situations, though, it's helpful to share this information with other people. It's important to know who needs your information and what they can do with it. This can help you make good decisions about your private information based on your own situation.

In this factsheet, we are going to look at sharing your health information. Health information includes details like your diagnosis, past and current treatments, and personal situations that affect your health.

What is personal information?

Personal information is information about an individual person. It includes your name and address, information about your health, information about your education, your cultural background, your religious beliefs, and more. Some information isn't very sensitive, like your name or birthday. You probably wouldn't worry if other people knew your name and age. Other information is sensitive, like your mental health history and the treatments you use. You may not want everybody to have all of this information.

What does it mean to share information?

Sharing information means that one person shares some of your personal information with another person—usually so that they can provide health care to you. In many cases, others have to ask for your permission or consent before they can share your information. But there are situations when they don't have to ask first.

Before we start ...

Here are some **key terms** we use throughout this factsheet and what they mean:

By **family**, we mean the person or people who care for you. This includes your biological parents, a legal guardian, foster parents, or any other adult that helps out.

Service providers are any person, organization, or agency that you see for your health. This includes doctors, psychiatrists, psychologists, nurses, school counsellors, therapists, social workers, mental health teams, or anyone else who gives you some kind of health care or support.

Your mental health care team is the group of people who are working together to help you live well. Your team may include your doctor, a specialist like a psychiatrist, a counsellor at school, a therapist, a social worker, or anyone else who helps you. Your team also includes people who give you support, like family members or other important adults

Privacy is the right to decide who can access your personal information.

Confidentiality is the responsibility to protect someone else's personal information.

Consent means that you agree to something. In this case, consent means that you agree to let your service provider share information with family members.

Disclosure is another way of saying 'sharing.' When you disclose information, you're sharing information.

Can I give my own consent?

In BC, anyone under the age of 19 is an “infant” according to the law. This technically means that your parents or legal guardians have control of many legal issues—like consent—until you turn 19. However, there’s a big difference between a two-year-old and an 18-year-old! In most situations, people under the age of 19 can make decisions about their health care when a service provider believes that they understand what’s happening, that they can make decisions on their own, and can understand the consequences. The exact age will be different for everyone as it is based on judgement.

There are a few specific situations when you can’t give consent. For example, if you are actively experiencing certain symptoms like psychosis, you may not be able to give consent or change how you want information shared. That’s why it’s important to talk about information sharing with your service providers and family members and figure out a plan when you feel well. If you have a crisis or emergency plan with any of your service providers (a plan of what will happen in a crisis or emergency), think about including directions for how you would want your information shared.

Why does sharing information matter?

In order to work together, people on your team need information from other people on your team. Sharing information with your team can help them support you.

Sharing can improve your health care

Many people who are dealing with a health problem see more than one service provider. For example, you might see a family doctor, a psychologist, and a counsellor at school. When you make sure that one service provider is sharing information that other providers should know, everyone can give you better care. They know exactly what’s going on, what’s working for you, and what isn’t working for you. Sometimes it’s hard to keep track of your health information. Sharing information means that you don’t have to remember everything on your own.

Sharing can make it easier to see new service providers

Sharing information means that you don’t have to tell your story every time you see a new service provider, agency, or organization. Talking about difficult experiences can be really hard, especially when you’re meeting a service provider for the first time. A lot of people feel uncomfortable or embarrassed when they have to talk about problems. Sharing information means that you only have to tell your story once.

Do researchers need my information?

Some information can be shared without asking first if it doesn’t identify you. For example, researchers who are studying mental health may get information from a hospital. Some organizations or agencies might collect information for statistics, like the number of people they care for. In these cases, information can be collected without asking for your permission, but they share very specific details that doesn’t tell anyone who you are. They can’t give any information that would identify you, like your name, address, or phone number. In the very rare case that people do need information that identifies you, they must ask for your permission in writing. You have the right to say no if you don’t feel comfortable with their request.

This is how information sharing can work. One service provider can share information about your care with another service provider. For example, your doctor can share information with your school counsellor. They can only share information about your care. This is called an information-sharing agreement.

A service provider can also share information with your family. It’s often helpful if family members know about your diagnosis and treatment, but you can decide how much information a service provider shares with family member.

What does the law say? How does it work?

There are two main Acts or laws that say how your information is protected and shared. They are meant to protect your right to privacy, but they let people share specific information if you’re in trouble or need help. Here are some examples of how the laws work:

Some of your personal information must be shared when:

- Someone believes that you are in serious danger. This can happen if they’re worried about suicide (ending your life) or if someone else is harming you. They must also share information with authorities if they’re worried that you might hurt someone else. They will only share relevant information with those who need to know.

Some of your personal information may be shared when:

- You see more than one service provider, and they need to share information about your care. For example, pretend that you see a doctor and a counsellor. Your doctor may tell your counsellor about your new medication. In this case, service providers can only share information that’s necessary for your care. Even though some of this information can be shared without asking for your permission (consent), many service providers will ask you first.

- You allow (give consent to) a service provider to share information with someone else.
- Someone is concerned that you or someone else may be harmed without help.

Your personal information cannot be shared when:

- Someone asks for more information than they need to know to care for you.
- Someone who isn't providing care asks for your information.
- You don't allow one person to share your information with another person (you don't give consent)

Learn more about laws

If you want to learn more about the privacy laws in BC:

- Read the Guide to the Personal Information Protection Act at www.cio.gov.bc.ca/local/cio/priv_leg/documents/pipa/guidepipaview.pdf
- Read the Guide to the Freedom of Information and Protection of Privacy Act at www.cio.gov.bc.ca/cio_priv_leg/foippa/foippa_guide.page

What does my team need to know?

Service providers can share information on a “need to know” basis. They share information that others need to give you good health care, but they don't share information that isn't about your care. Here's an example:

A service provider may need to know ...

- Your diagnosis
- The medications you take and the treatments you receive (like therapy)
- Problems you've have with other medications or treatments, like bad side effects
- Challenges you experience at home or school because of a mental illness, plus things that help or don't help

But service providers usually don't need to share information like ...

- Your religion or beliefs
- Your thoughts and opinions
- Information that doesn't have to do with your health and your care
- Information that is very sensitive, and you want to keep it private (such as past abuse or trauma)

What about my family?

Family members can be really helpful when you're managing a mental illness.

Family members can:

- Help you watch for symptoms of your illness
- Help you find service providers and figure out where to go next
- Help you with your treatment plan and watch for problems, like side effects from medications
- Help you talk to service providers and explain the care you've already received
- Share their experiences, which gives service providers a better idea of your challenges

Do I have to share everything?

Absolutely not. You can decide what information is shared with others and what information is private. For example, you can share your diagnosis and treatment without sharing certain details of your experiences.

How do I start sharing information with my team?

Service providers want to respect your privacy and they want to build a good, trusting relationship with you. In order to make sure that you and your service providers have the same idea of what you want, it's important to talk to everyone on your team. Then you know exactly what's happening and your service providers know exactly what you want. Remember that you can have these conversations at any time. Here are three steps to working with your team.

Step One: Let everyone know who is on your team

To make sure that everyone is included in the way that you want them included, it's important to be clear about your thoughts and wishes. Your service provider should have a conversation with you when you start to work with them. Ideally, it's a good idea to have this conversation early on. If this doesn't happen, you can start the conversation yourself at any time. Let them know who is on your team: for example, it may be your family doctor, your parents, a school counsellor, and a psychiatrist.

Step Two: Ask questions

Here are some important questions to ask when you talk with your service provider:

- Do you, your organization, or your agency have any policies (rules) around sharing information? Each service provider you see might have different rules, so it's a good idea to ask each one. Their rules will tell you how they share information and what they can do.
- What do I need to do if I want to share information with my team? Some service providers need you to sign a consent form (a form that tells someone else what you want).
- What will you tell my team? Remember that you don't have to share everything with everyone. If you don't want to share certain information with your family members, make sure you tell your service provider or write it on your consent form. For example: you can let your service provider talk to your family about your diagnosis and treatment without bringing up other things that you and your service provider talk about.
- What do I do if I no longer want to share information with someone on my team? You can take back your consent at any time, but your service provider may have a process to make it official, like a form.

Step Three: Bring it up as often as you want

- Don't be afraid to ask questions if you don't understand something or don't understand what a service provider needs. It's important to understand what's happening! Also, if you don't like how someone else is using your information, you have the "right to object." It means that you can speak up if you aren't happy with the way your information is being shared.

What if I don't want to include my family?

You don't have to share information with your family. In some situations, it might not be a good option for you. Remember that you can always start sharing information later on if the situation changes.

If you're worried about sharing information with your family, try talking with your service provider about your concerns. You may be able to come to an agreement that works for everyone.

You don't have to share all information with your family. You can decide what your service providers share with your family. You can let your service provider tell your family about your diagnosis and treatment but keep other details private. This is a good way to let your family help you while still protecting your privacy.

How can I manage my medical records?

Your service provider has to give you a copy of your records if you ask for them. If you don't agree with something in your records, you can ask the service provider to fix the problem. Rarely, service providers may charge a fee to make a copy of your records. In a few situations, service providers can't give you your records. This can happen if your records include personal information about another person or if they believe that giving you your records may cause harm to you or someone else.

How can I request my records?

If you want records from a doctor or someone that you see privately, you just need to ask for your records.

If you would like records from a hospital (like during time in hospital or from a program you took at a hospital), you will likely have to fill out a form. Look up the hospital's Health Records Office or Privacy Officer for more information about the hospital's specific requirements. If you aren't sure what to do, check if the hospital has a patient advocate, patient navigator, or ombudsperson. They can help you figure out what to do next.

How can I make a complaint?

If you have a complaint against a doctor's office, you can make a complaint to the College of Physicians and Surgeons of British Columbia. You'll find their website at www.cpsbc.ca. If you have a complaint about a hospital, you can contact the Patient Care Quality Office for your health authority. You'll find a list of health authorities at www.health.gov.bc.ca/socsec.

You can also make any privacy complaint to the Office of the Information and Privacy Commissioner. You'll find their website at www.oipc.bc.ca.

Where can I go for help?

The Office of the Information and Privacy Commissioner of British Columbia makes sure that everyone follows privacy laws. The 'For the Public' section of their website has a lot of information on your rights, how to make a complaint, and where to go for more help. Visit www.oipc.bc.ca.

The People's Law School offers education and information on many different legal concerns. They can also refer you to other resources that can help. Visit www.publiclegaled.bc.ca.

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