



Methods of consent used to share information/data/records

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Issue and Context

The increased interaction and integration between various organizations and services in the healthcare system has created a need to effectively and efficiently share information between service providers. The goal of sharing information across service providers is to prioritize the best care for every patient. Sharing of health-related information is not straightforward, and there are additional considerations concerning privacy in youth mental health. Service providers must find a balance between ensuring the confidentiality of youths' information, while also providing the most relevant and specialized care for them, which may include sharing information with multiple service providers. In order to respect the privacy and confidentiality of youth, they must be given the right to determine how their information will be used, and consent to sharing their information. However, it is not clear how to best approach this consent process in integrated youth services. The current Knowledge Exchange examines *what methods of consent (either implied or explicit) are used to share information/data/records across organizations (either within Integrated Youth Service networks or externally)?*

Uses and Limitations

This Knowledge Exchange provides a number of perspectives and resources that can be used to help inform research around information sharing in youth mental health care. This rapid response was created to help provide context to the current state of consent and information sharing in healthcare fields and is not meant to be the basis of policy or practice recommendations. Rather, we hope that this information can be used as a starting point for the continued investigation of processes around consent and information sharing in healthcare, and provide a focus for more comprehensive literature reviews.

Approach

Frayme reached out to network partners and conducted a literature search of academic journals and grey literature to address this question. Network partners were asked about the processes of consent they use in practice within their organizations around sharing patients' information with their extended networks. One network member responded with an example and explanation of their consent process and highlighted key features used to ensure the confidentiality of their patients.

Additionally, literature was collected through grey literature and academic journal searches using Google, Google Scholar, and ProQuest. The focus was placed on literature addressing processes of consent in healthcare settings, how information was shared with other healthcare service providers, and relevant laws and policies. Results from the literature review drew attention to the infancy of information sharing in healthcare, as there were very limited examples of effective systems in practice in the Canadian context. Additional resources surrounding current practices and laws may give service providers a better idea of where current systems lie in information sharing. However, examples of effective information systems using implied consent are highlighted as they may act as a framework to build new information-sharing platforms.

Network Findings

An IYS (Integrated Youth Service) hub shared the consent form that clinicians and peer navigators use with new clients, which follows an explicit initial consent process. As part of the consent form, services available to the client are clearly outlined with an explanation of how they would receive these services. The form also outlines confidentiality, stating that the IYS hub will not release any information without consent, but may acknowledge youths' involvement with other agencies. The client is then able to select their preferred consent considerations from a series of pre-made statements. Specifically, the consent options in the form include:

- Consent to services offered by the IYS hub, including requests to complete evaluations directly related to care.
- Consent for family members or caregivers to be involved with services offered by the IYS hub.
- Agreement for de-identified data to be shared with external research groups and partner agencies from (a) confidential responses to questionnaires/evaluations related to care, and/or (b) clinically relevant data from charts and databases.
- Agreement to be contacted via email only.

Finding From the Literature

Service providers work to provide the highest quality of care to their patients, which is often done with the support of other specialists operating in unique knowledge domains (Education Development, 2013). The *Personal Health Information Protection Act, 2004 (PHIPA)* was put in place to balance maximizing a patient's privacy with the benefits of collecting, using, and disclosing personal health information (Grant, 2004). To protect the privacy of the patient and conduct practice in their best interest, a list of six conditions must be met in order to assume implied consent (Information and Privacy, 2015):

1. Health information can only be shared with healthcare service providers who are entitled to rely on implied consent, including: healthcare practitioners; long-term care homes; pharmacies; ambulance services; and the Ontario Agency for Health Protection and Promotion.
2. Personal health information to be disclosed by a healthcare service provider must have been received from the patient, their substitute decision-maker, or another healthcare service provider.
3. The healthcare service provider must have received, collected, or disclosed the personal health information for the purpose of providing or assisting in the healthcare of the patient.
4. The purpose of collecting, using, or disclosing personal health information must be to provide or assist in providing healthcare to the patient.
5. Personal health information must only be disclosed to other healthcare service providers.
6. The healthcare service provider must not be aware that the patient has withheld or withdrawn their consent to the collection, use, or disclosure of personal health information.

Despite many laws in place to protect patients' privacy in cases of implied consent, the process is much more difficult in practice for Canadian healthcare service providers. Providers usually don't have access to confidential information sharing platforms to support information sharing across multiple healthcare networks, causing them to resort to linear information sharing between healthcare service providers (Burmeister, 2015). For example, many service providers still rely on fax or phone-based information sharing, as electronic health record systems differ by service and scope of practice. This lack of sharing significantly limits the potential for increased quality of healthcare for patients in Canada. Implied consent is typically preferred to explicit consent because it doesn't require ongoing consent requests, which can slow down the process of care and in turn, discourage patients from receiving treatment that they otherwise would have agreed to (Burmeister, 2015).

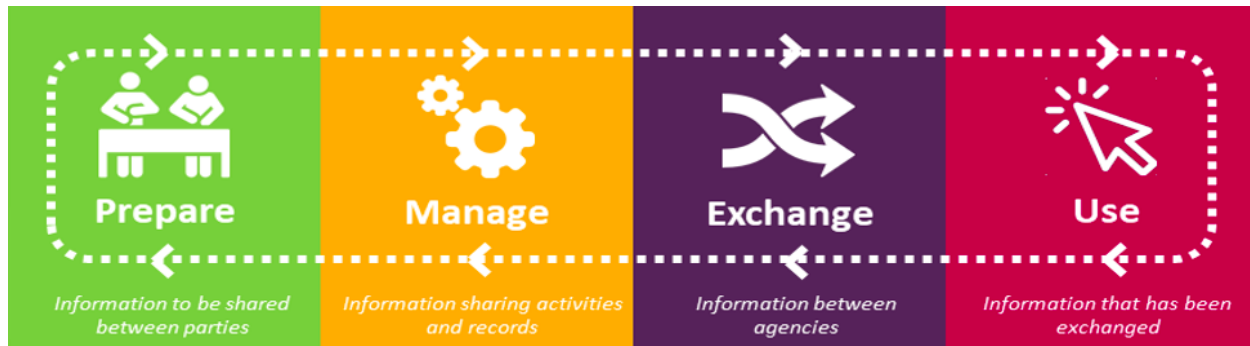
The Canadian Mental Health Association- Ontario Division (CMHA Ontario) has published a [short piece](#) on their website highlighting common legal issues in child and youth mental health. One of the most prominent legal issues surrounds consent. They argue that if a young person is capable, they should be able to give or refuse consent, but for consent to be valid, it must be:

- Related to the treatment
- Informed
- Given voluntarily
- Not obtained through misrepresentation or fraud

Importantly, the Canadian government recently [announced](#) the creation of a new privacy law called the *Canadian Consumer Privacy Protection Act (CPPA)*. This plan aims to give consumers control of their data and promote organizations to provide more transparency on the data that they use and share. When implemented, the CPPA will have significant implications for the consent process in healthcare settings. However, specific policy and practise changes resulting from CPPA have yet to be determined.

An example of implied consent in practice is the Children’s Treatment Network, an organization working with children who need long-term support with diagnoses, disabilities and developmental needs based in Ontario, Canada. During a child’s initial intake into the Network, their guardians (with the child’s consent) sign an explicit [consent form](#) that provides future implied consent for information sharing with their 40 network partners. However, parents and guardians do have the ability to exclude select organizations if they feel inclined to and record any other limitations in their consent to joining the Children’s Treatment Network.

Contrastingly, Queensland, Australia’s public health system takes a much more unified stance on incorporating information sharing and implied consent throughout all healthcare settings in the country. The *Hospital and Health Boards Act 2011 (HHB Act)* supports and requires information sharing in healthcare settings to protect the health, safety and well-being of patients, carers and the community across the state of Queensland (Queensland Health, 2016). Clinical judgment is used to determine what information is shared with whom in a patient’s network (Queensland Health, 2016). Queensland’s public health unit has created an information-sharing Open Data portal that allows all organizations to take a uniform approach (Queensland Government, 2018). Patient information goes through a cyclical process of preparation, management, exchange, and use phases in sharing information across healthcare service provider networks (Queensland Government, 2018). Implementing an open data portal has supported improvements in healthcare services overall, as clinicians are able to apply relevant information from other service providers in their own treatment of patients (Queensland Government, 2018). Below is a diagram of the phases involved in information sharing:



[A study](#) published in 2021 held by the South London and Maudsley NHS Foundation Trust (SLaM) investigated the views of individuals accessing the mental health system to explore acceptable data use and sharing systems, providing recommendations for future systems (Adanijo et al., 2021). Participants with lived experience using mental health services were asked their opinions/concerns about clinical data sharing and boundaries of consent. They were also provided summaries of current data sharing systems, such as the NHS Digital's Hospital Episode Statistics data and the Clinical Record Interactive Search (CRIS) system. Five recommendations were presented for future systems (Adanijo et al., 2021):

1. Implementing screening so that data sharing can benefit the public.
2. Informing service users on how their data is going to be shared and for what reasons it will be shared.
3. Informing service users of the safeguarding procedures to keep their data safe.
4. Incorporating service user involvement.
5. Training health care professionals to address issues of inaccurate health data.

Additional resources of interest may include:

- A summary of the *Personal Information Protection and Electronic Documents Act (PIPEDA)* is provided by the Office of the Privacy Commissioner of Canada at: https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/the-personal-information-protection-and-electronic-documents-act-pipeda/pipeda_brief/
- Clinical +Systems Transformation (CST) is creating a shared clinical information system. This system will integrate electronic patient health records with alerts and decision supports built into the system. You can find out more about this system at: <https://cstproject.ca/whats-changing/changes-clinical-work/shared-clinical-information-system>
- The Government of Alberta created a document that outlines information-sharing strategies throughout different systems in Alberta (including children's services, education, and health). The purpose of this document was to help implement the

Information Sharing Strategy in Alberta. You can access this document and additional resources at:

- <https://www.alberta.ca/information-sharing.aspx#jumplinks-2>
- <https://open.alberta.ca/dataset/af6fe72d-ac8d-4691-a141-a656d12203a7/resource/a404039c-89c5-4633-a57a-7d6c825c469a/download/information-sharing-strategy.pdf>

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