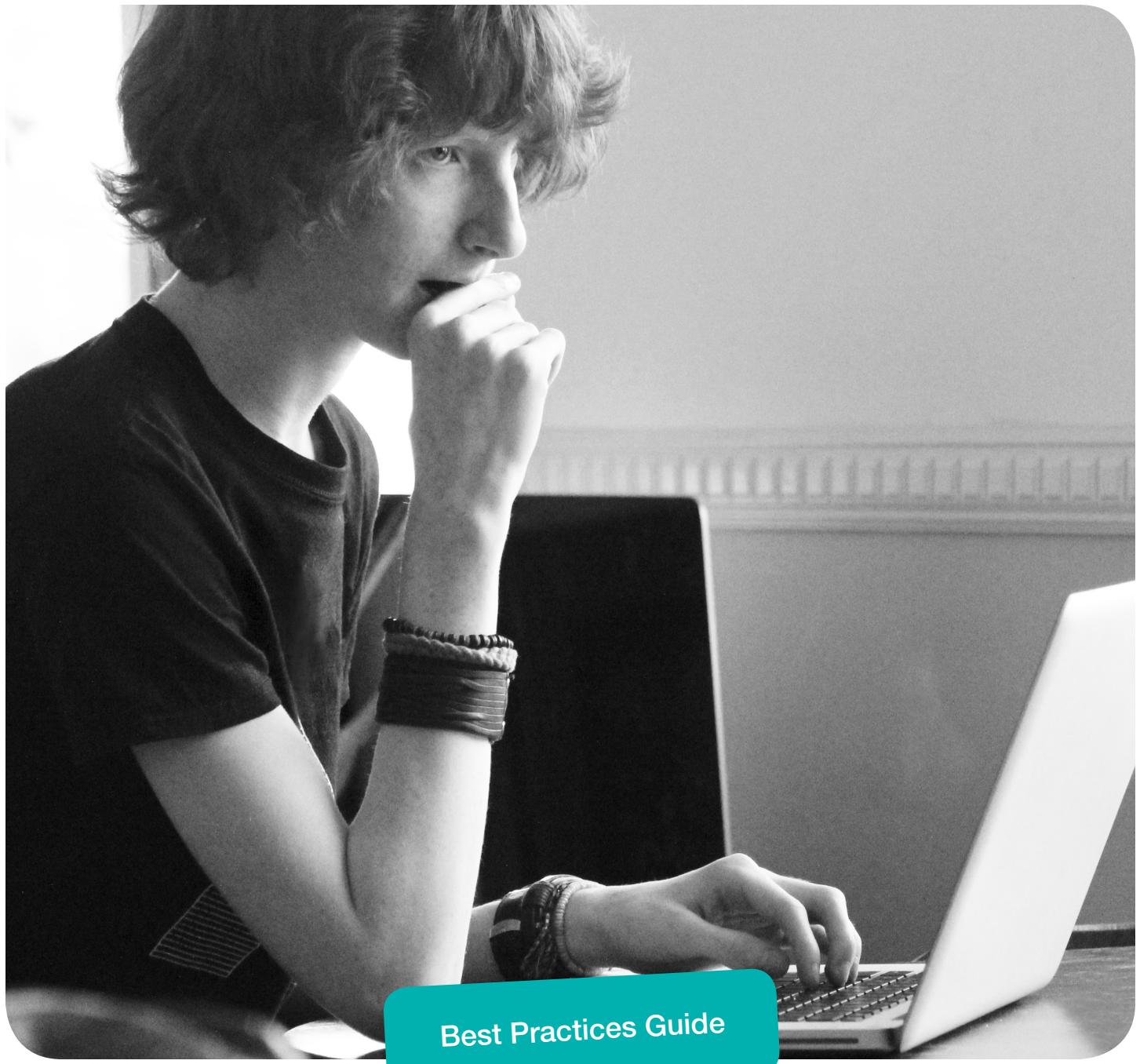


Information Sharing in the Context of Child and Youth Mental Health and Substance Use in BC



Canadian Mental
Health Association
British Columbia
Mental health for all



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- Patrick Egan, Senior Investigator, Office of the Information and Privacy Commissioner
- Monica Muller, Legal Counsel, Information Access, Vancouver Coastal Health

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Note

Readers of this report will notice the emphasis upon the child and youth mental health and substance use (CYMHSU) system. Our rationale for producing a standalone child and youth mental health and substance use issues report and best practices guide is linked to the reality that the child/youth and adult mental health and substance use systems are so contrasting that they merit distinct consideration. Further, while there are elements within existing legislative frameworks that apply to children, youth, and adults, there are particular pieces of legislation (e.g. *Child, Family, and Community Service Act*) that have particular relevance for people under the age of 19. Once government feedback has been provided on this report, the structure and content will be adapted to account for the people and their family members interfacing with the adult mental health and substance use system.

Introduction

Context

An estimated 12.6% of youth in BC (aged 4–17 years) currently experience clinically-significant mental health problems—a total of about 84,000 youth.ⁱ The majority of mental health problems originate in childhood—a critical time for intervention and prevention to mitigate the risk of future illness.ⁱⁱ Youth with mental health and/or substance use challenges are often involved with multiple health care providers and in multiple healthcare systems.

Personal information about a person experiencing mental health and/or substance use problems is often needed by service providers to provide effective care and services. Care coordination can involve sharing personal information about individuals across organizations, ministries or providers. Increasingly, care providers are working in interdisciplinary teams across sectors and geographic areas. These factors make sharing information an important facet of effective health care provision and support.

Balancing service providers' needs for information with individuals' rights to privacy and confidentiality can involve making decisions that do not have clear-cut solutions. Most information-sharing situations require service providers to use their judgment and assess the context while interpreting the legislation or guidance documents. Often judgment occurs under time constraints. There is a clear need to improve information sharing strategies across organizations and agencies while remaining respectful of privacy and confidentiality.

In particular, children and youth have complex information sharing needs. Often family members or other caregivers need to share information with health care providers. Issues of consent can further complicate information-sharing scenarios. Clinicians, physicians, school counsellors and others who work in mental health and substance use (MHSU) services in BC are seeking a better understanding of what information can be shared under which circumstances.

This guide intends to function as a reference tool that service providers can use not only to comply with relevant legislation and policies, but also to feel empowered to share information appropriately in a timely way—across sectors and with family and families. Explicit guidance in this area, however, is difficult to provide. Information sharing in the area of MHSU is complex; service providers are governed by overarching privacy legislation, as well as policies and guidance documents at the regulatory college, organization and agency level. Information sharing decisions are rarely black and white, but require sound judgment, knowledge and understanding of the particular situation, context and individual.

Key Concepts

Privacy and Confidentiality

Privacy and confidentiality, although they are often used interchangeably, have different meanings.

Privacy relates to an individual.

For example, people may not want to be seen entering a place that might stigmatize them, such as a mental health centre that is clearly identified as such by signs on the front of the building. Privacy concerns people.

Examples of privacy-related situations include the following: the curtains are closed during physical examinations; health history or exam results are discussed in a private area, which may include asking an accompanying family member to leave the room temporarily.ⁱⁱⁱ

Confidentiality relates to information or data about an individual.

For example, a counsellor's agreement with clients about how information shared during sessions will be handled, managed and shared.

Information sharing relates to sharing personal health information about an individual.

For example, information may be shared between service providers, individuals and families for the purpose of providing health care. Sometimes information sharing is called disclosure. Disclosure is showing, sending, sharing or giving personal information to another organization, agency or person.

Personal Information

Personal information is defined by the legislation as any identifiable information about an individual. This report defines personal information in the same way as legislation.

Personal information may include

- Name
- Age
- Marital status
- Employment history
- National/ethnic origin
- Political or religious beliefs
- Sex
- Contact information
- Address
- Personal opinions*
- Fingerprints
- Blood type
- Health insurance
- DNA information
- Biometrics
- An individual's health care providers
- Educational, financial and criminal history
- Health numbers (such as care card number)
- Information related to health care

*unless they are about someone else

Personal information does not include

- Business contact information, for example, an individual's title, business telephone number, business address, business email or facsimile number
- De-identified information
- Aggregate information, for example, general statistics, de-identified data used for program evaluation or quality improvement purposes or service-use data

Collecting, Using and Disclosing Personal Information

There are three main questions to consider when discussing information privacy:

1. How is personal information **collected?**
2. How is personal information **used?**
3. How is personal information **disclosed (shared)?**

How information can be collected, used and disclosed in BC is outlined in the legislation:

Legislation	Freedom of Information and Protection of Privacy Act (<i>FIPPA</i>)	Personal Information Protection Act (<i>PIPA</i>)
Who does it apply to?	Public bodies and their employees <ul style="list-style-type: none">• School boards• Health authorities• Municipal police boards• Provincial government	Private sector <ul style="list-style-type: none">• Businesses• Private organizations• Not-for-profit organizations• (Includes physicians in private practice)

Though *FIPPA* and *PIPA* are the primary Acts that address information sharing, other Acts, such as the *Child, Family and Community Service Act*, also include information about the collection, use and disclosure of personal information. Sections of several Acts are discussed in more fulsome detail in the Legislation section of the report and in the Appendices.

Describing People with Lived Experience

• Individual, Person (or People) With Lived Experience:

Experience: This report uses the term individual to describe those who have lived experience with mental health and/or substance use problems. In this report, they are often those who are accessing mental health and/or substance use supports or who have accessed mental health and/or substance use supports in the past.

• **Family:** In this report, the term “family” encompasses the full range of relationships of importance to individuals, including significant others who provide support and/or care on a regular basis.

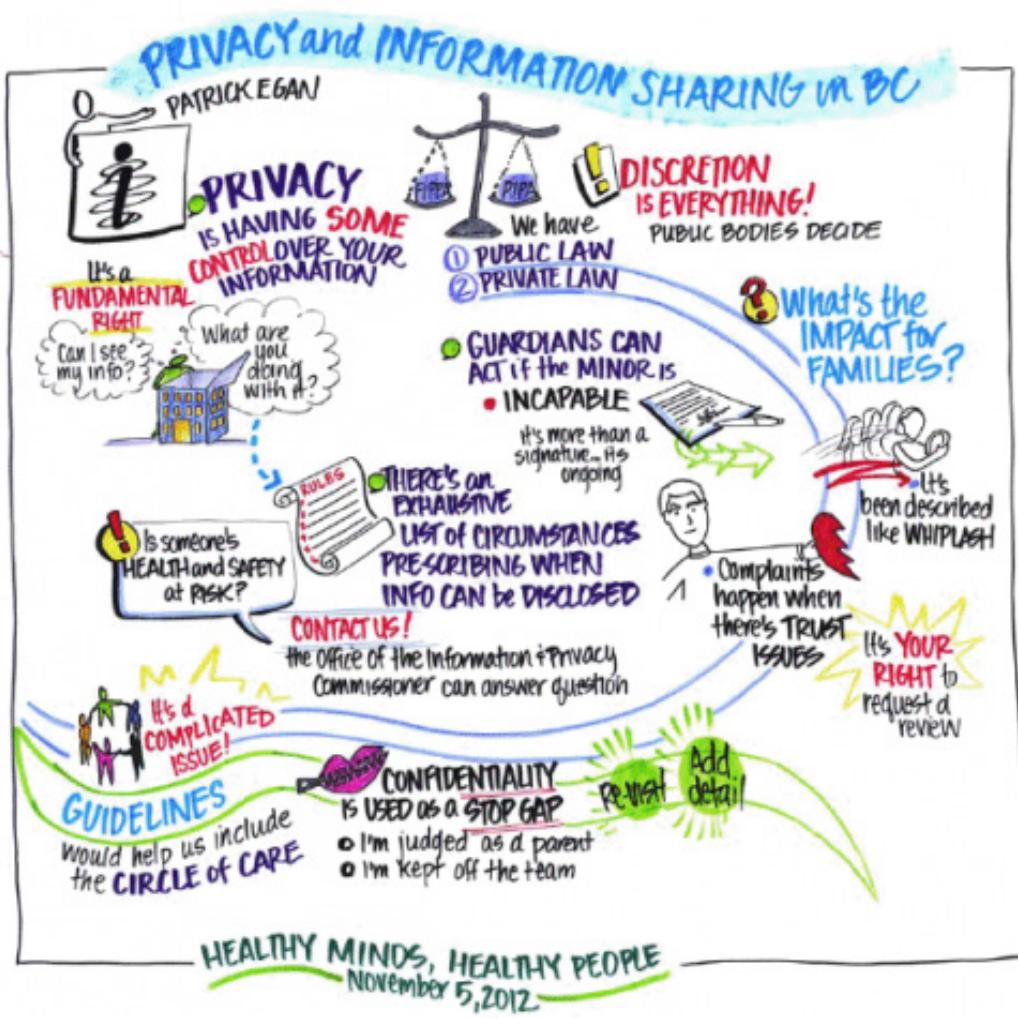
• **Service provider:** In this report, “service provider” means those who are providing mental health and/or substance use services, care, or other supports. They could be doctors, social workers, counsellors, school teachers and many others.

Background to Best Practices Guide

Families at the Centre

On November 5 and 6, 2012, a special gathering took place at the Morris J. Wosk Centre for Dialogue in Vancouver. Over 150 people—including family members, government representatives, service providers and educators—came together with a particular focus in mind: moving toward a more family-friendly mental health and substance use care system. The event convened as part of the Healthy Minds, Healthy People Knowledge Exchange Series, was designed to put the experiences of families front and centre.

During the panel discussion and audience participation, one main theme that arose from the discussion related to the experience of family members being excluded from a loved one's care^{iv}. Information sharing and the related issues of privacy and confidentiality were subsequently identified as major areas for further exploration in moving towards more family-centered mental health and substance use care. The graphic below summarizes the main discussion points of the event as it related to privacy and information sharing in BC.



Following this event, the Ministry of Health commissioned CMHA BC to complete a research project with the objective of developing a set of helpful resources for individuals, their family members and service providers. The current phase of the project is focused on the development of (a) a synthesis of current issues and the available knowledge base into a resource for service providers and (b) resources for individuals and their family members. As noted previously, the emphasis of the first set of resources is the child and youth mental health and substance use system.

CYMHSU Collaborative

In parallel to the initiation of this project, the Child and Youth Mental Health and Substance Use (CYMHSU) Collaborative in BC was established in 2013. Using the Breakthrough Series Collaborative approach to quality improvement, the Collaborative has worked to bring community partners together to strengthen the child and youth mental health and substance use system at local, regional, and provincial levels.

The purpose of the Collaborative is to engage children, youth and their families, Aboriginal peoples, physicians, clinicians, provincial ministries, health authorities, schools, and communities to:

- Increase the number of children, youth and their families receiving timely access to integrated mental health and substance use services and supports throughout the province.
- Document examples and results of the involvement of children, youth and families in decisions related to program and system design, clinical practice and policy development, which manifest the ‘family-first, people-centered’ goals of *Healthy Minds, Healthy People*.

The CYMHSU Collaborative offers assistance and provides engagement and concept/tool testing to address information sharing barriers that sectors and providers face. The CYMHSU Collaborative is funded by the Shared Care Committee with a contribution from the Specialist Services Committee.

The Collaborative is mentioned in particular because privacy, confidentiality, and information sharing have emerged as priority issues amongst Collaborative participants. The Collaborative has been very assistive to this project by providing opportunities to engage participants around this document, helped create learning opportunities to test out key ideas in this resource, and has helped create momentum for knowledge, policy, and practice shift.

Audience

There are two primary audiences for this report.

- 1. Front-line staff**—those who make decisions about disclosure and information sharing in their work to support children and youth with mental health and/or substance use issues. Front-line staff includes school counsellors and educators, clinicians and health care professionals, physicians, psychiatrists, counsellors, social workers, child protection workers, youth forensic psychiatrists and youth probation officers. Front-line staff may be primarily interested in information to help guide them in making disclosure decisions.
- 2. Decision makers**—those who work in the provincial government as well as leadership in the areas of education, healthcare, social work, child protection, youth corrections, and other areas. Decision makers may be primarily interested in principle-based best practices, which could help shape future policies or systems-level change, as well as recommendations for future research.

Appropriate and effective information sharing can improve outcomes for both children/youth and their families. Although **individuals and families** are critical stakeholders, they are not a primary audience for this report. Instead, clear and concise information sheets are being developed to support those with lived experience and families in knowing their rights to information; understanding requests for information, disclosure of personal health information and consent; and finding other resources and information they may need. The youth and children and family information sheets are currently being developed and expected public release is early 2015.

Scope

The scope of this report is information sharing restricted to the context of child and youth mental health and substance use services in BC.

Specifically, this report will describe:

1. An overview of issues in information sharing
2. A discussion of information sharing in BC
3. The Traffic Light Tool: A guide for disclosure
4. Recommendations for information sharing

The report does not address the following related topics: freedom of information requests, technical and physical barriers to information sharing (e.g., electronic health records, firewalls), secondary use of data (e.g., research and quality improvement initiatives) and sharing information which is not defined as “personal information” (as in *FIPPA*, schedule 1 and *PIPPA*, s. 1).

Research Questions

This report aimed to answer the following research questions:

1. What are the **main issues** in information sharing, specifically in the area of mental health and substance use?
2. What are the **best practices** identified in the literature and other jurisdictions?
3. What are the **information needs** of individuals, families and services providers?
4. What **guidance** can be provided to help improve information sharing in BC?
5. How can legislation, policies and best practices **be interpreted** in a BC context?
6. What are some **recommendations** for future work in his area?

Methodology

To answer the research questions, a review of academic and grey literatures was conducted. The main focus of the literature review is on academic publications from 2000 to 2014 and grey literature, including reports and other publications, from the United States, the United Kingdom, Australia and New Zealand.

Stakeholders were directly engaged at various points throughout the research process. Stakeholders included individuals with lived experience, families, service providers, provincial government ministries and the Office of the Information Privacy Commissioner for British Columbia. These groups helped to identify current issues in information sharing in BC and, specifically, the information needs this report should address. Stakeholders also reviewed early drafts of the report and provided input on how to best create a practical and useful final product.

The next steps for this report are as follows:

- Content to be reviewed by government ministries, the Office of the Information Privacy Commissioner and/or the Officer of the Chief Information Officer, and others.
- Content to be finalized and approved for broader distribution and feedback.
- Content to be adapted to account for people and family members interfacing with the adult mental health and substance use system.
- Examination of application to diverse contexts, including Indigenous systems of care.
- Knowledge translation activities to be conducted to support services providers in implementing the principles and tools in this guide in their daily work.

Disclaimer

How to use this report

This report is for general information only. It is not intended to take the place of legal advice or legislation, policies, procedures and other formal standards. It is intended to be used as a tool for education and discussion only. The Canadian Mental Health Association, BC Division and the BC Ministry of Health accept no responsibility for the use of this material.

Limitations

This report is limited as it applies only to BC legislation, which differs from other provinces and countries. Guidance from other jurisdictions may not be of relevance in BC. Additionally, best practice in information sharing—especially in healthcare—is constantly shifting.

Given the breadth of service provider roles and areas in the scope of this guide, it is not possible to provide a comprehensive list of information sharing scenarios with specific guidance for each scenario. Disclosure decisions require professional judgment and consideration of the unique factors in each situation; therefore, absolute rules about disclosure are not provided in this report.

Best practices for a particular field or scope of practice should be documented at the local level in local or organizational practice documents and protocols.

Seeking additional guidance

Service providers are advised to contact their local privacy office, privacy officer, or other organizational advisor for further guidance on interpreting legislation and local policy or protocols. In particular, **public bodies** (such school boards, health authorities and provincial government ministries) should have an office or individual who can provide guidance on *FIPPA*'s requirements.

Businesses and **non-profit** organizations should have an appointed privacy officer who can provide guidance on *PIPA*'s requirements.

The Office of the Chief Information Officer also operates a Privacy Helpline that provides support, direction and training on *PIPA*'s requirements to the public and private sector organizations including businesses, private organizations and not-for-profits.

Phone: 250-356-1851

Email: Privacy.Helpline@gov.bc.ca

An Overview of Issues in Information Sharing

Introduction

The purpose of this overview is to provide a summary of issues in information sharing from the academic and grey literature, incorporating information gathered from consultations with identified stakeholders. This section discusses the benefits of sharing information and the known barriers to effective information sharing that are within the scope of the report. It will also explore evidence of the importance of involving families and of sharing information among service providers in order to achieve collaborative care and better outcomes for individuals.

The Benefits of Appropriate Information Sharing

Appropriate information sharing can improve outcomes for both children/youth and their families^v. Effective information sharing promotes continuity of care, safety and quality. It helps families provide more appropriate, timely care and better services. We examine some of the ways appropriate information sharing, when balanced with an individual's right to privacy, can help with the provision of integrated and coordinated care, with family member inclusion.

Better Care and Services

Appropriate information sharing is critical for enhancing continuity of care, especially in the BC child and youth mental health and substance use system. In this system, services are rarely fully integrated. Individuals access services from a variety of organizations over the course of their health care journey (e.g., Health Authorities, family physicians and the Ministry of Children and Family Development (MCFD).) Service providers can also use information sharing to promote safety on behalf of the individual and their family, themselves and other providers and, very rarely, the public.

Better Relationships with Individuals and their Families

Sharing information helps service providers provide more efficient, effective services to individuals. Without adequate information, providers may waste time duplicating efforts or risk breaking individuals' trust. Individuals may question, "Why are you asking me this again?" and have to tell their story multiple times.

Information sharing supports service providers in providing care. They can better identify appropriate services, conduct needs assessments and provide appropriate and responsive services. Additionally, it helps providers engage with families and other service providers to monitor and support treatment and more rapidly identify relapse and the need for intervention.^{vii}

Information sharing can be of benefit to families in reducing their stress and isolation and can help providers support the relationship between individuals and their families.^{viii}

Information sharing is necessary for the following:

- Providing seamless, wrap-around care and integrated services^{viii}
- Reducing duplication
- Ensuring information that is collected is complete and accurate
- Providing a complete understanding to guide other service providers and families in supporting and caring for individuals
- Avoiding adverse events^{ix}

Building Trusting Relationships

Ideally, individuals can trust that service providers will keep their information confidential, service providers can trust that their colleagues will share important information when necessary (e.g., when there are safety concerns) and families can trust that they have the information they need to support and care for their loved ones. Additionally, individuals with lived experience are less likely to share all relevant information with service providers if they lack trust in them.^x Trust is critical in the provision of quality care.

Information Sharing Among Service Providers

BC health systems, in alignment with other jurisdictions, are moving toward collaborative care models and providing service in interdisciplinary teams.^{xi} Studies show that interventions from integrated primary care and mental health and substance use teams result in better outcomes for individuals and decrease the need for emergency and hospital services^{xii}. Due to the nature of the child and youth mental health and substance use system in BC, information is shared across multiple transition points and among multiple providers. Information sharing among service providers is important within an integrated system,

but for reasons we explore later in this report, providers generally tend to err on the side of caution and under-share information with each other.

In Ontario, the policy framework for child and youth mental health describes child and youth mental health as a "shared responsibility".^{xiii} This is especially important when working with children and youth, who may have multiple people responsible for their care. Describing youth mental health as a "shared responsibility" may help foster collaboration among those who care for youth, including health care and service providers, families, communities, governments and other public sector agents.^{xiv}

It is also important to remember the schools are important settings for child and youth mental health, not only because they provide mental health promotion and prevention, but also because they provide pathways to service for children and youth. Most mental illnesses first emerge in schools, and first symptoms provide critical opportunities for early identification and intervention^{xv}.

Schools are part of a family-centered approach to care for many important reasons, including:

- Teachers, principals, and school counsellors spend significant amounts of time with students and know them well.
- Schools can connect students with resources and support them.
- School is a setting for promoting positive mental health, focusing on early identification and intervention.

Information Sharing with Families

Sharing basic information can help improve outcomes for both families and individuals and has been shown to decrease the frequency of relapse.^{xvi} Families are particularly important individuals in the care and treatment of children and youth with mental health or substance use challenges.

Some jurisdictions have taken the approach of explicitly outlining information sharing with families in legislation. As far back as the late 1990s, some states in the US had statutes in place that permitted sharing information with families without individuals' consent if it had been verified that the families were directly involved in care or monitoring treatment and the information disclosed was necessary for this purpose.^{xvii} In the UK, 'carers' have rights to information enshrined in legislation. Currently, privacy law in BC does not specifically mention families.

Families often have an in-depth knowledge of the individual receiving care, can be a source of constant

long-term support for the individual and may be able to provide support if a crisis does not occur during regular office hours.^{xxviii} Individuals can benefit from family who recognize signs of relapse, encourage them to seek help, know how to support them, can connect directly with their physician, psychiatrist or service providers.^{xxix} Families often need to know treatment goals, signs and symptoms, potential effects of medication, dose, and other information to be able to provide care for their loved ones.

Families also require information for their own mental and physical well-being.^{xx} Gathering information from families with permission from the individual is especially important when the individual is unable to provide information about their illness on their own. Symptoms of mental illness, including withdrawal, confusion and isolation, can make involving the individual's family even more crucial.^{xxi}

Recent research shows that, in general, families accept an individual's right to withhold consent, but acknowledge the impact that lacking information can have on the standard of care they provide. Families recognize how important information that is relevant to their support role is, but feel they do not need or want to know everything about the person they are supporting.^{xxii}

Despite this understanding, providers tend to under-share information with families. Questions about information sharing with families are complex. How and when should service providers share information? What information is necessary to share? What do they do if the individual does not consent to sharing information?

From our scan of policies and guidance documents, there seems to be little available in B.C. to answer these questions. We note that this may be shifting—for example, Vancouver Coastal Health (VCH) has recently taken a new approach to family involvement in mental health and addiction services^{xxiii} and implemented a new policy on this issue. They describe family involvement as a vital component in the recovery framework.^{xxiv} This document is responding to an identified gap in the resource base.

Barriers to Information Sharing

Barriers to appropriate information sharing is a cross jurisdictional issue. We have learned about barriers to information sharing from documented challenges faced in other jurisdictions and sectors. For example, challenges in sharing information between health and social services in the UK^{xxv} have been linked to professional culture, physical and systems barriers and lack of information.

We can also learn about barriers to information sharing from areas outside of child and youth mental health and

substance use services. In particular, a 2012 project to develop an Information Sharing Strategy led by the Alberta Ministry of Human Services identifies several key barriers.^{xxvi} The work in Alberta was initiated to improve information sharing within government and services agencies in the areas of health, education and safety of children and families.

The following lists of barriers to information sharing are documented examples of barriers that are faced by service providers and front-line staff in their daily work. These barriers can be real or perceived. They can be legal and technical in nature. They involve professional culture, systems-level issues and general information-sharing issues.

Professional Cultural Barriers

- A lack of trust among professions^{xxvii}
- Service providers tend to be over-cautious due to concerns for patient confidentiality; this can occur on both an intra- or inter-agency level^{xxviii}
- Differences between professional cultures^{xxix}
- Cultural differences between professionals, e.g., among nurses and physicians and community-based mental health service providers
- Differences between professional ideologies, e.g., the medical model focuses on the patient and the social work model focuses on the individual and their community/networks/families^{xxx}
- A lack of role clarity
- A lack of confidence^{xxxi}
- An emphasis on the importance of privacy for individuals with lived experience
- Diversity and cultural differences between the individual and their family and service providers^{xxxi}

Information Barriers

- A lack of clarity in the information provided
- Systems Barriers
- Firewalls between ministries, health authorities, and between structures within the same jurisdiction
- Issues with integrating electronic medical records
- System complexities
- A lack of time or resources for providers to fully involve families or family^{xxxi}
- Strict and inconsistent professional codes of conduct

After recently engaging with hundreds of participants from government ministries, community service agencies, school boards, Alberta Health Services, Child and Family Services Authorities and many others, researchers found the following barriers and success factors to be of importance^{xxxiv}:

Barriers

- Multiple consent forms and different procedures and policies
- Rules not widely shared or not easy to understand
- Inconsistent application of relevant legislation
- Lack of clarity using ‘sensitive information’
- Fear of reprisal when making decisions to share information
- Lack of consistent training for all levels

The researchers also found that the barriers contributed to unintended consequences, such as less effective treatment outcomes/service delivery and duplication of efforts by each agency, resulting in higher administrative and resource costs.^{xxxv}

Success Factors

- Strong relationships—trust needs to be in place to promote the development of interpersonal and inter-organizational trust
- Clear, simple, agreed upon procedures and policies need to be developed and implemented with clear standards for consent and information sharing
- Understanding the mandates and goals of partnering organizations and having respect for differences in organizational business practices
- Support for culture change
- Individual-focused information sharing and appropriate, individual-centric risk assessment and management
- Consistent application of legislation
- Need for on-going oversight, through some form of advisory team, to ensure consistent acceptance and application of the new approach to information sharing
- Consistent training that is ongoing and mandatory for all levels
- Information sharing between government departments at all levels and with partners in a way that supports staff and individuals with lived experience

Individuals’ Information-Sharing Preferences

Recent research finds that individuals’ preferences about information sharing depend on the type of information being shared, who the information is being shared with and what role the individual receiving the information plays in the care or treatment of the individual with lived experience.^{xxxvi} Research also shows that the requirement for consent is linked to an individual’s self-esteem,

personal choice, independence, autonomy, general wellbeing and empowerment.^{xxxvii}

Though there are few studies on individuals with lived experience and their perspectives on information sharing, a recent study of individuals with lived experience in New Zealand revealed that the majority felt they had incomplete or insufficient information about how their personal health information would be shared.^{xxxviii} They were generally comfortable with information sharing among clinical staff, but less comfortable with information sharing for secondary purposes.^{xxxix}

Unlike in some areas of the United States,^x individuals in Canada generally do not have full copies of their health records. People in Canada do not have the ability to bring their information to appointments and share it as they wish. Thus, learning about and documenting information sharing preferences may be even more critical in jurisdictions like BC, where individuals do not generally have access to their full and up-to-date records without making a formal request.

Information Sharing in BC

This section will provide an overview of legislation in BC as it relates to making information sharing decisions. This section is primarily written for service providers who make disclosure decisions in their daily work.

Legislation

The first step in making a decision about disclosure is to determine which legislation applies. Any time a disclosure of personal information occurs, it must be authorized by legislation. In BC, the relevant legislation depends on the organization you work for.¹

This guide will primarily discuss the *Freedom of Information and Protection of Privacy Act (FIPPA)* and the *Personal Information Protection Act (PIPA)*. These Acts provide general legal guidance with regards to information sharing; however, the Acts are flexible frameworks, and they provide room for open information sharing. Although some direction is provided in “must/must not” terms, the majority of the relevant legislation uses the verb “may” and therefore relies on service provider judgment. Within this framework, the individual’s preferences should always be respected to the greatest extent possible.^{xli}

FIPPA applies to all records in the custody or under the control of **public bodies** (*FIPPA*, s. 3(1)) in BC. Public bodies (*FIPPA*, schedule 1) include school boards, health authorities, municipal police boards (e.g., the Vancouver

1. The federal government and its employees are governed by the federal Privacy Act, which is not discussed in this guide.

Police Department), the provincial government and its ministries, including the Ministry of Children and Family Development. *FIPPA* also applies to services providers contracted by or providing services on behalf of a public body. If an organization is not sure if they are a service provider they should ask the public body they contracted with.

PIPA applies to the **private sector**, including businesses and private or not-for-profit organizations (*PIPPA*, s. 3), including physicians in private practice and not-for-profit service providers, such as the Canadian Mental Health Association (CMHA) branches.

Other Guidance Documents

In addition to *FIPPA* and *PIPA*, you will need to be familiar with the policies and procedures of your organization, codes of ethics and college/professional association standards. These policies and standards should already be compliant with relevant legislation—including *FIPPA* or *PIPA*—and will provide guidance for interpreting and applying legislation in your role, organization or profession.

Legislation and Policies vs. Practice

During the consultation process for this guide, service providers acknowledged a discrepancy between information sharing that is authorized by legislation, organizational policies or other formal guidance documents and information sharing that occurs in

practice. Often physical or practical barriers to information sharing, such as firewalls or paper copies of records, prevent the sharing of information even when authorized by law.

This report acknowledges that in addition to legislative and formal barriers, there are practical and informal barriers to information sharing, which must be addressed. As previously discussed, local organizational culture, local knowledge and practice play a significant role in when, how and how much information is shared.

Seeking Additional Guidance

For information on seeking appropriate guidance on disclosure decisions, please see the Disclaimer: Seeking Additional Guidance.

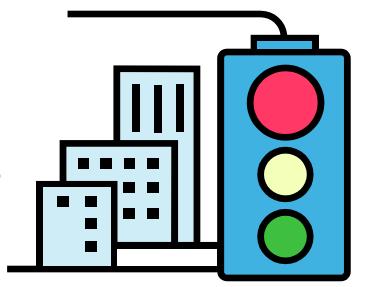
In addition, Appendix 1 provides some useful links for BC privacy legislation, tools and websites.

Requests for Information

Under both *PIPA* and *FIPPA*, individuals have a right to request information about themselves. Unless the information falls under the legislated exceptions outlined in *FIPPA* and *PIPA*, information must be disclosed within the prescribed time limits and applicants have a right to file an appeal or complaint with the Office of the Information and Privacy Commissioner of BC if they are not satisfied with the response. Further information about requests for personal information from individuals and the request and review process are not discussed in detail in this guide.

The Traffic Light Tool: A Guide for Disclosure

The traffic light tool helps summarize some of the key sections of *FIPPA* and *PIPA* that provide guidance on when information **must** be disclosed ('green light'); when it **may** be disclosed ('yellow light'); and when it generally **may not** be disclosed ('red light').



The disclaimer on the previous page applies to this whole guide, but particularly this tool. This guide is not legal advice. Always refer back to legislation and policies in your area. This guide is not a comprehensive summary of all sections of *FIPPA* and *PIPA*.

Using this Guide

To use the traffic light tool, first check if the disclosure in question meets the requirements under mandatory or required disclosures (a **must** disclose situation). If not, check if the disclosure in question meets the requirements of one of the authorized disclosures in *FIPPA* or *PIPA*, as applicable. If the disclosure is not authorized by a section of *FIPPA* or *PIPA*, then the individual's consent is required.

Relevant sections of *FIPPA*:

- **Section 32:** Use of personal information
- **Sections 33 to 36:** Disclosure of personal information
- **Sections 4 to 25:** Disclosure for Freedom of Information requests (e.g., if an individual requests their own personal information)

Relevant sections of *PIPA*:

- **Sections 17 to 22:** Disclosure of personal information
- **Section 23:** Access to information (when an individual requests their own information)

Traffic Lights

Green light

Must disclose

The tables in Appendix 2 and Appendix 3 outline some common scenarios in which information **must** be shared. They also describe which legislation mandates disclosure. Additionally, the tables include information about the agency that would require the information, their authority and the required proof of authority for disclosure.

FIPPA mandates that information must be disclosed when it pertains to a risk of significant harm to the environment or to the health or safety of a group of people or the public. When disclosure is clearly in the public interest, it must be disclosed (*FIPPA*, s. 25 (1)). This section of *FIPPA* has been interpreted with a high legal threshold: in other words, “there must be an urgent and compelling need for compulsory public disclosure.”^{xlii} If this section is used, it must also be reported to the person the information is about and the Information and Privacy Commissioner for BC (*FIPPA*, s. 25 (3) and s. 25 (4)).

Disclosure under this section does not require consent; however, this section is used very rarely due to the high threshold required.

Example must disclosures include:

- When there is a suspicion that a child is in need of protection;
- When there is a risk of harm

Anyone with reason to believe a child is being abused or neglected—or is at risk for abuse or neglect—where the parent is unwilling or unable to protect them, has a legal duty to report that concern to a child welfare worker in MCFD or to a Delegated Aboriginal Agency child welfare worker. The duty to report is defined in the *Child, Family and Community Service Act* and explained in *The BC Handbook for Action on Child Abuse and Neglect: For Service Providers* www.mcf.gov.bc.ca/child_protection/pdf/handbook_action_child_abuse.pdf

Yellow light

May disclose

Under *FIPPA* and *PIPA*, information **may** be shared with an individual's consent and for the purposes for which it was collected (i.e., to provide services or care). Both *FIPPA* and *PIPA* outline the requirements for obtaining an individual's consent. Both *FIPPA* and *PIPA* also outline situations in which information may be disclosed without an individual's consent.

If personal information was lawfully collected, **consent is not required to use or disclose it for the same purpose for which it was collected.** This applies to both *FIPPA* (see 32(a) and 33.2(a)) and *PIPA* (see 14(a) and 17(a)).

Consent

FIPPA

May disclose personal information with the consent of the individual if the information is about (s. 33.1 (1) (b))

Consent is required if disclosure is not authorized by a section of *FIPPA* (33.1 and 33.2)²

PIPA

Only allows for disclosure of personal information if the disclosure is permitted by the Act (examples are outlined below), or with consent (s. 6(1) and 6(2))

Sections 6 to 9 outline requirements for consent, including when it's required, how it's provided, types of consent, and withdrawal.

2. Legislation relating to consent is not described in full here. For individual who cannot consent (e.g., is a minor, seriously ill or mentally incapacitated) consent may be required from a legal representative (e.g., legal guardian or a person having a power of attorney).

Examples of Authorized Disclosures³

FIPPA

Under s. 33.2 (a), may disclose personal information for the purpose for which it was obtained or compiled or for a use consistent with that purpose.

This has been interpreted to mean that information for continuity of care purposes on a ‘need to know’ basis. (Disclosure must meet the necessary test under s. 33.1(1)(e) and (e.1).) Further guidance on this is not provided in the legislation, but is based on case law and best practice. Interpretation and service provider judgement is required.

In summary, a public body may only use personal information:

1. for the purpose for which it was obtained or compiled, or for a consistent purpose. A consistent purpose has a reasonable connection to the original purpose, and is necessary to perform the duties of or operating a legally authorized program, of the public body;
2. if the individual has consented to the use; or
3. for the purpose for which the personal information has been disclosed to it under *FIPPA*.

PIPA

PIPA uses a “reasonable person” test, which means disclosure of information is authorized only for purposes that a reasonable person would consider appropriate in the circumstances, and that fulfill the purposes for which information was collected (s. 17)

This is true despite consent. In other words, consent is not valid if the individual is convinced to consent to an unreasonable disclosure.

Authorized Disclosures Related to Health and Safety Concerns

FIPPA

Under s. 33.1 (1) (f), may disclose personal information to an officer or employee of a public body or to a minister, if the information is necessary for the protection of the health or safety of those individuals.

Under s. 33.1 (1) (m), the public body may disclose personal information if:

- The head of the public body determines that compelling circumstances exist that affect anyone’s health or safety, and
- Notice of disclosure is mailed to the last known address of the individual the information is about, unless the head of the public body considers that giving this notice could harm someone’s health or safety;

Two examples include:

- May disclose personal information the purpose of reducing the risk that an individual will be a victim of domestic violence, if domestic violence is reasonably likely to occur. (s. 33.1 (1) (m.1))
- May disclose personal information so that the next of kin or a friend of an injured, ill or deceased individual may be contacted (s. 33.1 (1) (n))

PIPA

Section 18 of *PIPA* outlines when organizations may disclose personal information without the consent of the individual. Some examples of situations under s. 18 (1) include:

- The disclosure is clearly in the interests of the individual and consent cannot be obtained in a timely way. (s. 18 (1) (a))
- The disclosure is necessary for the medical treatment of the individual and the individual does not have the legal capacity to give consent (s. 18 (1) (b))
- There are reasonable grounds to believe that compelling circumstances exist that affect the health or safety of any individual and if notice of disclosure is mailed to the last known address of the individual to whom the personal information relates. (s. 18 (1) (k))
- The disclosure is for the purpose of contacting next of kin or a friend of an injured, ill or deceased individual (s. 18 (1) (l))

3. *FIPPA* differentiates between authorized disclosures within Canada only, and authorized disclosures inside or outside Canada

May not disclose

While *FIPPA* and *PIPA* do not outline specific situations when you cannot share information, we can work backwards from authorized disclosures to conclude that in general, disclosure is usually not authorized if

- The disclosure is not for the purpose of continuity of care and disclosure is not mandated by law. In other words, the individual requesting the information does not have a right to it;

- You are disclosing more information than the person you're disclosing information to (such as the clinician, carer or other agency) needs to know; or
- The individual did not consent and the information is not required to provide care or services

As a general rule, it is wrong to disclose information for a purpose that is different than the purpose for which the information was collected. For example, if you have collected personal information to provide someone with health care, you cannot disclose that information to open a bank account—unless you have consent to do so.

Consent

This guide does not focus on making decisions about whether an individual is able to consent.

However, given that this report focuses on children and youth, it is important to note that in general, parents and guardians can consent on behalf of infants (please note that the legal definition of an ‘infant’ is a person under the age of 19 years). However, the Infants Act contains information regarding infants providing consent. In this legislation, infants may consent to health care without consent from the infant’s parent or guardian. Under Section 17 (3) of the *Infants Act*, this can be the case given the health care provider providing the health care intervention:

- a. has explained to the infant and has been satisfied that the infant understands the nature and consequences and the reasonably foreseeable benefits and risks of the health care, and
- b. has made reasonable efforts to determine and has concluded that the health care is in the infant’s best interests.

In addition, both *FIPPA* and *PIPA* have Regulations that state who may act on behalf of minors and others.

Best Practices for the Consent process

Consent is not required for sharing general information about mental health or substance use issues (e.g., general information about schizophrenia). General information is “information that supports families in their role, without providing new details specific to the service user”^{xliii} (p. 152). General information can be useful in addition to personal information about the individual.

A proactive approach to the consent process, on behalf of individuals and their families, helps service providers support rather than wait for individuals or families to request information.^{xliv} Further best practices on consent are listed later in the report.

For suggestions of best practices when there is no consent, see Appendix 4.

Life Trumps Privacy

When making a decision on whether or not to share information, it can be easy to focus on the consequences of potentially over-sharing information. Fear of the legal and personal ramifications of over-sharing information can cause providers to act in a more risk averse manner than necessary when considering sharing information.

The former Privacy Commissioner of BC, David Loukidelis, notes that if there are compelling circumstances affecting an individual’s health or safety, or if they are ill, the BC privacy laws allow disclosure to next of kin, school officials, health care workers and others. His comment on disclosure and BC privacy laws is as follows^{xlv}:

“Individual cases can be fuzzy. But if someone uses common sense and in good faith discloses information, my office is not going to come down on them. Privacy is important, but preserving life is more important [...] I know that frontline decisions have to be made quickly and sometimes the facts may not be as clear as you’d like. But there’s no doubt that privacy laws support disclosures to protect health and safety.” —David Loukidelis, former Privacy Commissioner of BC

Best Practices: Privacy and Information Sharing

While the legislation provides the absolute rules, best practices can be useful supplemental information in situations where judgment and interpretation is required. Best practices can also be useful to help shape procedures, guidelines, policies or standards at the organizational or professional level. In the absence of guidelines to support a deeper understanding of the legislation, service providers may default to interpret application of the legislation in its strictest form.

The following principles are derived from best practices and recommendations from a scan of relevant Canadian and international literature.

Knowledge

- Understand and comply with the law.^{xlvii}
- Know standards and ethical codes of professional bodies^{xlviii} and the information-sharing policies and procedures of your organization.
- Policies should be clear, practical and accessible^{xlviii} and be accompanied by practical guidance and education. This should fit within systems, which help ensure that rules are followed.^{xlix}
- Know whom to approach within your organization or area for guidance.
- Know your responsibilities with respect to privacy and information sharing.^l
- Differentiate between general and personal information. For example, it may be possible to still give general information without consent if diagnosis is known and information on available supports, services, or programs^{li}—this is a judgment call on a case-by-case basis.

Responsibility

- Treat personal information confidentially and respectfully.^{lii}
- In addition to the responsibility to protect patient privacy, there is also a responsibility to share information in certain cases^{liii}. Know when information must be disclosed. Do not let privacy get in the way of health or safety.
- Keep within your scope of practice.
- Exercise sound clinical judgment and consult with colleagues or supervisors when in doubt.

Purpose

- Identify the purpose of and rationale for sharing information.^{liv} The purpose should be broad enough to capture everything you intend to do, but not so broad that it is meaningless.
- Access to personal confidential data should be on a strict need-to-know basis^{lv}, meaning that essential information is shared, but nothing more. In other words, information should be shared for the purpose of providing safe and effective care.^{lv}
- Use caution when disclosing information that is not for the purposes of providing care (the purpose for which the information was collected)—using personal information for secondary purposes requires consent.

Consent

- Seek the consent of the individual to share their information^{lvii}, and, with some exceptions, respect an individual's right to object^{lviii}.
- Use plain language to ensure the individual understands information sharing.^{lix}
- Explain the purpose and benefits of sharing information.^{lx}
- Let the individual know they can withdraw consent at any time.^{lxii}
- Document verbal consent in the individual's file, specific to named agencies rather than staff members.^{lxii}
- Seek consent early on in the care relationship (e.g., at intake) and have a conversation about how their information may be used, who should be involved in their care (e.g., family and other service providers), and document the decisions made.^{lxiii} Consent should be sought when it is easy to explain what information is being collected, why, how it will be used and to whom it may be disclosed.
- Differentiate between specific consent (sharing a particular piece of information) and general consent (may share all personal or care information with family).
- Where appropriate, review consent at key milestones (e.g., release planning) and on an ongoing basis.^{lxiv}
- For best practices on making disclosure decisions situations when there is no consent, see Appendix 4.
- For youth, seek consent of a parent or guardian, unless the youth is able to consent themselves (Infants Act, section 17).^{lxv}
- If an individual is unable to provide consent, make an attempt to seek consent when their mental state has improved.^{lxvi}

- If an individual doesn't want information shared with family, have a conversation to understand their concerns.^{lxvii} Ask: are they refusing consent because they are concerned about a particularly personal or sensitive piece of information? Without a discussion initiated by the service provider, "no consent" may be recorded and an opportunity may be missed.
- Revisit consent on an ongoing basis.
- Seeking consent for disclosure or being open about how an individuals' information may be shared, even when consent is not required, can help build trust.
- Conversations about who to share information with (e.g., seeking consent from the individual to share with family) can help encourage individuals to build their support network.^{lxviii}

Communication

- Maintain open communication between individuals, family/families, and service providers.^{lxix}
- Communicate with individuals about how their information may be collected, used and disclosed, and inform them of their right to request their own information.^{lxx}
- Encourage individuals to understand the value of collaboration and information sharing between service providers.^{lxxi}
- Be honest and up front with individuals and their families about limits to privacy and confidentiality.^{lxxii}
- Maintain open communication at key milestones for individuals, including service entry, treatment planning, team review, exit planning and relapse response.^{lxxiii}

Training and Education

These principles cannot be operationalized without clear direction and support for service providers and families. Training for service providers in the privacy legislation that applies to their practice, namely *PIPA*, *FIPPA* or other relevant legislation, will help support service providers in understanding this information and applying it to their work. Clear organizational policies, guidelines or protocols help service providers understand the requirements in the legislation in a 'real' and tangible way in order to operationalize legislation guidance.

Research shows that professionals report that when information-sharing policies are well-published in the workplace they are useful documents. In particular, when these documents provide practical guidance on how to resolve information-sharing dilemmas and outline legal and ethical boundaries of professional responsibility they are most useful.^{lxxiv}

Service providers who seek additional support or guidance for specific questions or difficult and complex situations should be offered organizational support and guidance. As decisions must often be made quickly with limited information, front line staff should have training in risk assessment.^{lxv} Organizations may also endorse an individual- and family-focused lens in all of their work. This can have positive effects at all levels: from the way information sharing and consent are framed at the initial conversation with an individual and their family, to how, when, and what information is shared, to how consent forms and other materials are designed and what language is used.

Though training and education may be easiest to organize at a local, site or organizational level, opportunities to partner with other service providers (external to the organization) for joint training in the context of local service delivery and collaboration^{lxvi} may allow for discussion and problem solving from a cross-agency perspective. To this end, information sharing questions and scenarios in privacy training would better mirror the real and complex dilemmas service providers face and the applicability of training would increase.

Training should be available to and required of all staff. In addition, if new forms, policies, guidelines or guidance documents are developed, all staff should be trained on the changes.^{lxvii}

Building Tri-Partite Relationships

Literature, evidence, and input from service providers, family, and individuals indicates that a key best practice in information sharing is building of tri-partite relationships—strong relationships between individuals, family and service providers. However, this can be a challenge. Confidentiality smokescreens are a common barrier for families and result in families feeling undervalued and treated unequally. Often this means the flow of information often moves from the family to the service provider, but less often in the other direction. Families may interpret silence, or a lack of information or information sharing, as a stigma (e.g., not talking about it because it's "shameful").^{lxviii}

Confidentiality smokescreens can make obtaining relevant information difficult for families and exclude them from decision-making, ultimately causing important information about an individual to be overlooked.^{lxix} The importance of keeping an individuals' family informed is well-known^{lxx}; however, specific guidance on how to go about sharing information with families is lacking.

The culture of information sharing is shifting toward more formal recognition of the role that family have in the care, recovery and ongoing support of individuals, largely due to initiatives across the province and in other jurisdictions. This cultural shift requires trusting and respectful partnerships, as well as a culture of inclusion, which can mean including families as partners within the circle of care. For example, the circle of care for an individual may include the family physician, care team and service providers, police acting under the *Mental Health Act* and family and families.

The cultural shift also includes a shift of moving beyond treating the individual, and instead working with the individual and identified family members. This means moving towards a Tripartite Relationship: described by a recent report as “the ideal culture of a mental health system [that] involves individuals, families and service providers working in partnership toward positive outcomes for individuals”^{lxxxii}. Tripartite relationships require trust as well as open and ongoing communication among these three groups.

The key features of effective Tri-Partite relationships echo the other findings in this report. Service providers can help by listening and receiving information from family, treating family members as part of the care team, and encouraging individuals to see the benefits of including family in treatment/care and sharing information to support the goals of recovery. These are all components of building an effective tripartite relationship.^{lxxxiii} Ideally, these conversations should occur (and be documented) at the beginning of the care or service relationship.^{lxxxiv} This means advance agreements relating to information sharing with families which are established when the individual is well and are shared with families to inform them of specifically to whom information can be shared during times of illness.^{lxxxv}

Overall, this culture shift can be supported with education and guidance documents for service providers on how to build Tripartite Relationships and how to communicate openly with families while still complying with legislation and respecting individuals’ privacy.

Recommendations

The following recommendations outline what front-line staff, government, leadership and decision makers can do to better support families and individuals and shift organizational culture toward effective information-sharing practices.

Enablers of success provide guidance for change management strategies, new initiatives or shifts in information-sharing culture. The following questions can help families to discern whether the appropriate groups have been consulted:

- Have individuals and families been appropriately consulted and involved at all stages of the initiative?
- Have front-line staff of all areas been involved and consulted appropriately to ensure that the initiative is practicable, realistic and beneficial?
- Has the Office of the Information Privacy Commissioner been consulted for expertise? (If necessary, has a Privacy Impact Assessment been completed?)

What Government, Leadership and Decision Makers Can Do

- Build trust—organizations need to clearly communicate to their staff that they will not be punished if they share information in good faith for continuity of care, health and safety purposes.
- Raise profile of local expertise, including privacy offices and OIPC hotlines.
- Align policy and procedural documents across organizations—staff of multiple agencies/organizations must collaborate on common CYMHSU goals.
- Construct a joint inter-agency consent form that is individual and family friendly.
- Develop privacy and information sharing agreements as needed between MCFD, community agencies, physicians, Health Authorities, schools and other agencies.
- The OIPC could produce or endorse a guidance document specific to this area (as has been done for interpreting PIPA for businesses and organizations).

What Front-Line Staff Can Do

- Communicate barriers to leadership and decision makers so that they can help shape the information sharing culture at a systems-level.
- Build relationships with colleagues in other agencies and organizations.
- Seek out training, education, and guidance. Consult available resources for help.

Shifting Culture

- Continue to build upon success of local interdisciplinary teams – build relationships, clarify roles, learn about how others operate, when they can share information and what the limits of information sharing are.
- Provide practical and applied courses and education sessions at organizations where real-life scenarios are discussed. Consider developing inter-agency training to bring diverse service providers together from different organizations.
- Recognize information sharing is not only about better guidance (i.e., legal interpretation), but also about organizational and professional culture, building trust, and building environments and systems that support information sharing. Focus on shifting culture, building trust, and fostering relationships.
- Share information with families and take a positive approach towards working with them.
- Re-frame information sharing for youth and their families in a positive, comprehensive way. Use language that empowers rather than listing what can go wrong or using complex legal jargon.

Develop a Provincial Learning Community

A community of practice (CoP) is a collaborative framework, which allows for the continual co-learning between members. A CoP is “a group of people who share a concern, a set of problems or a passion about a topic, and who deepen their knowledge and expertise by interacting on an ongoing basis.”^{lxixv}

CoPs, or similar frameworks, are used in many disciplines. They are diverse, but share three common elements^{lxxxvi}:

- 1. A community**—where members interact, discuss, collaborate and build relationships
- 2. A shared domain of interest**—in this case it would be information sharing in CYMHSU in BC
- 3. A shared practice**—tools, experiences, solutions, plans to implement knowledge that address the shared domain of interest

CoPs are active, participatory, democratic and self-organizing.^{lxxxvii} They operate on principles of transparency, community-based decision making and engagement of all members in shared practice.^{lxxxviii}

A CoP of service providers would be an effective way to organize a group of people around improving information sharing in CYMHSU in BC. Sharing knowledge, co-designing tools, sharing best practices and building relationships across professions, organizations and sectors could occur as a result of the collaboration that CoPs foster. A CoP would focus on the needs of all members as individuals while building a foundation for improved trust and collaborative relationships. This could translate into better practice and outcomes for individuals and families.

A CoP recognizes that there are individual factors and actions, as well as systems-level barriers, which must be addressed for significant and lasting change. A CoP in CYMH in BC (or several regional CoPs) may also be able to collect and analyze information to report up to decision makers and government or to monitor change after the implementation of new policies or practices.

Moving beyond a network or a local practice team, CYMHSU CoPs in BC have the potential to support shifts in both individual practice and systems-level change.

There are many available resources to support CoP development.^{lxixix xc xci xcii xciii xciv}

Develop High-Quality Education and Training

Ideally, a website with practical scenarios and guidance could be created and updated on an ongoing basis. One example is the Education Development Centre's *Information Sharing* webpage, which is part of their PromotePrevent project.^{xcvi} The Education Development Centre is a global nonprofit primarily based in the US that carries out projects in education, health and economic development.^{xcvii} Information on this initiative can be found at www.promoteprevent.org.

The website and tools they have created provide an interactive learning experience for service providers that is brief, clear, quick and engaging. They use 20 real-life case examples and walk through various options for each, answering questions such as:

- Who has the information?
- Who wants the information?
- What information does the requester want?
- What does the requester want to do with the information?

- Which laws are relevant in this situation?
- What do the laws permit and what do they prohibit?
- How can the service provider proceed?

The scenarios involve communication across multiple roles and laws. Service providers are asked to think through a scenario rather than read a list of rules. Providers practice making difficult decisions about disclosure and build capacity. Issues are identified at the beginning of each scenario so that service providers can browse the scenarios most relevant to their role or work. Learners watch illustrated dialogue, then must select which conditions of the laws are met in order to disclose/not disclose information. The training also allows the learner to select options to see how the scenario would turn out if different choices were made. There also provide seven illustrated scenario-based e-learning activities for children.

The website also describes how to use the three Bold Steps of *Partner-Plan-Act* to create an information-sharing system that works for everyone involved. More specifically, the site explains how to collaborate with others to share information; create interagency agreements support information sharing; develop uniform consent forms; train staff and use technology to share information, develop and refine policies and protocols; communicate with shareholders; and allocate time and funding for information sharing.^{xcviii}

We highlight this educational tool as an innovative approach to training that could be used as a model to develop something similar in BC.

Conclusion

Effective information sharing begins with the individual and their family. For the purposes of continuity of care, effective information sharing must be compliant with legislation and other rules. It includes up front and

ongoing communication with an individual and their family about how information will be used. Decisions regarding information sharing are documented and are a topic of ongoing discussion between individuals, families and service providers.

Effective information sharing, first and foremost, requires a cultural shift. Information sharing needs to be viewed by all as an asset, not a burden or risk. Barriers such as confidentiality smokescreens and a culture of fear surrounding privacy can prevent service providers and families from sharing information in an effective manner. We hope that by focusing on education, communication, relationship building and collaboration, families, service providers and individuals can overcome existing cultural barriers to sharing information. Following that, practical barriers to effective information sharing can be addressed.

Service providers encounter complex situations when applying relevant legislation and best practices to their daily work. Scenario-based education can provide the opportunity for providers to practice thinking through situations relevant to their practice. Education is best focused on empowering individuals by helping them understand what they can do, rather than focusing on what they cannot do. This encourages service providers to make better-informed and balanced decisions.

We hope that organizations, agencies and public bodies will focus on developing clear policies and procedures for sharing information that supports cross-system collaboration and family-centered care in a meaningful way.

Privacy should not be a barrier to health, safety or the provision of high-quality care. In fact, appropriate and effective information sharing is an important ingredient to a family-centred mental health and substance system. And above all, we all need to remember that “life trumps privacy.”^{xcix}

Appendix 1: Links to PIPPA and FIPPA Guidance

Organizations

- Office of the Information & Privacy Commissioner for British Columbia: www.oipc.bc.ca
- Office of the Chief Information Officer: <http://www.cio.gov.bc.ca>

Provincial Privacy Legislation

- BC Freedom of Information and Protection of Privacy Act (FIPPA)
- BC Personal Information Protection Act (PIPA)

Reference Guides

- A Guide to PIPA for Businesses and Organizations (April 10, 2012). Published by the Office of the Information & Privacy Commissioner for BC. Accessible on the OIPC's Guidance Documents site.
- Privacy Toolkit for Physicians (June 15, 2009). Published by the BC Medical Association, the Office of the Information & Privacy Commissioner for BC, and the College of Physicians and Surgeons

BC Privacy and Access Helpline

For public bodies and private sector organizations with inquiries specific to privacy matters can contact the BC Privacy Help Line: Phone: 250-356-1851 • Fax: 250-953-0455 • Email: Privacy.Helpline@gov.bc.ca

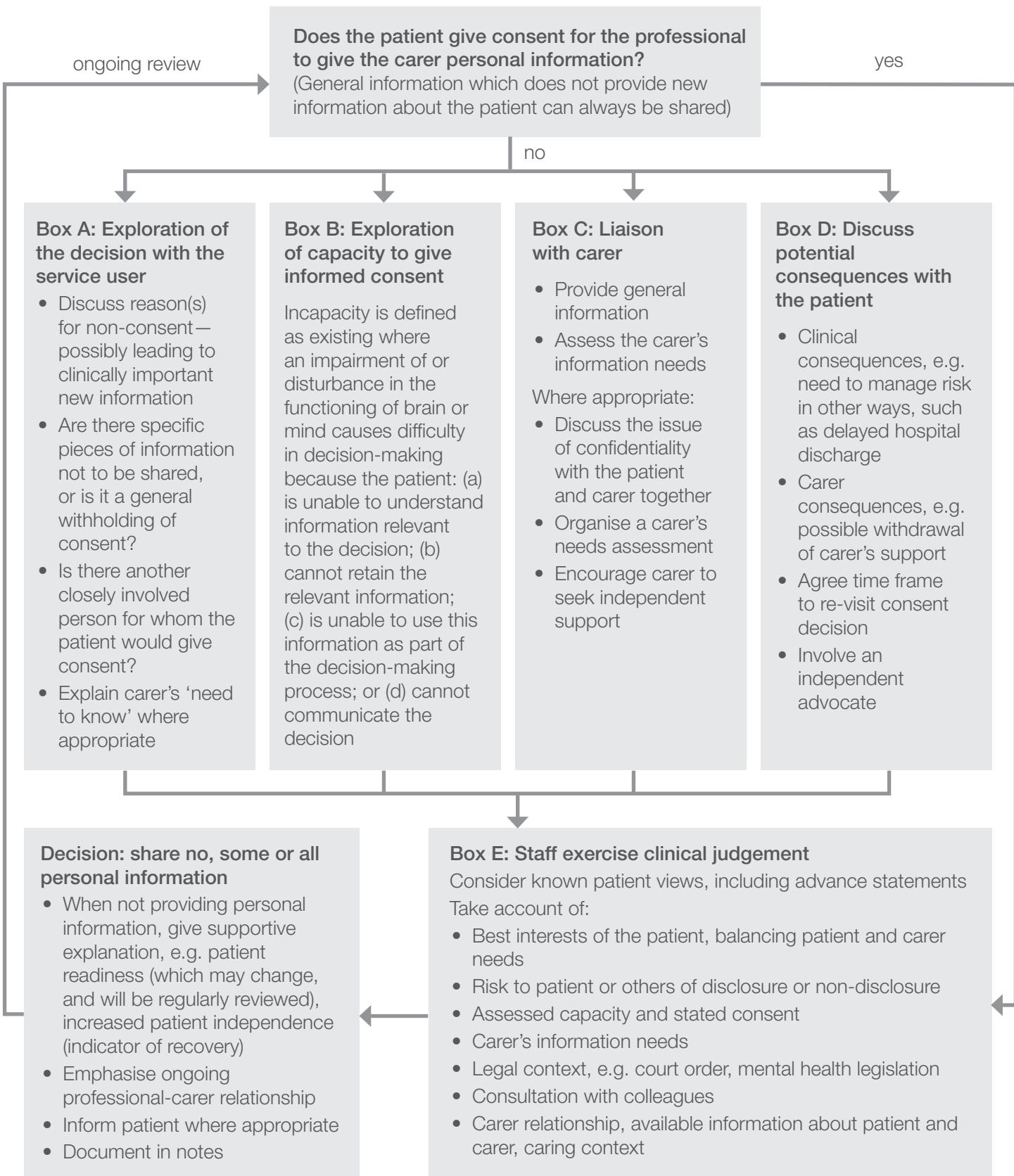
Appendix 2: Mandatory Demands for Production

Agency	Authority to demand	Proof of authority
Community Care Facilities Licensing Community Care and Assisted Living Act, section 9	Director of licensing or a medical health officer may require the community care facility to produce relevant records	Written request with letter of delegation or production of credentials to confirm identity.
Coroner Coroners Act, section 11	Coroner may inspect, copy and seize any records relating to the deceased person or the circumstances of the death that the coroner has reason to believe are relevant to the investigation—person receiving request must promptly comply	Written request or production of credentials to confirm identity.
ICBC Insurance (Vehicle) Act, section 28	Where a person is injured in a motor vehicle accident in BC, ICBC may require a report of injuries, diagnosis, treatment and prognosis.	Request from ICBC for completion of a CL19 Medical Report. (But refer to Health Records any other ICBC request for copies of health records).
Ministry of Children and Family Development Child, Family and Community Service Act, section 96	Director of Child Protection (or delegate) has the right to any information of a public body necessary to exercise his or her powers/duties under the Act	Written request with letter of delegation or production of credentials to confirm identity
Representative for Children and Youth Representative for Children and Youth Act, section 10	Representative has the right to any information of a public body necessary to exercise his or her powers/duties under the Act	Written request or production of credentials to confirm identity

Appendix 3: Reporting Required by Law

Law	Who must report	Report to agency	Information to be reported
Child in need of protection Child, Family and Community Service Act, section 14	Any person	Director of Child Protection, Ministry of Children and Family Development	Facts and circumstances supporting a belief that a child (a person under the age of 19) needs protection (see section 13 of the Act for examples of child in need of protection)
Death by violence, etc. Coroners Act, section 2	Any person	Coroner or Peace Officer	Facts and circumstances supporting a belief that a death has resulted from violence, negligence, suicide, during pregnancy, etc. (see section for details)
Death of patient in mental health Coroners Act, section 4	Administrator of designated mental health facility or hospital	Coroner	Facts and circumstances relating to the death of a person who dies while a patient of a designated mental health facility (see section for details)
Risk of significant harm Freedom of Information and Protection of Privacy Act, section 25	Public body	Public or an applicant who made an information request. May report to police police or other relevant agency depending on nature of information	Information necessary to avert a risk of significant harm to the environment or to the health or safety of the public or a group of people.
Gunshot or stab wound Gunshot or Stab Wound Disclosure Act	Health care facility	Police	Name and location of a person treated for a gunshot or stab wound
MSP Fraud Medicare Protection Act, s. 47.1	Practitioner or Health Authority	BC Medical Services Commission	Report a person who has fraudulently attempted to obtain benefits
Patient dangerous to drive Motor Vehicle Act, section 230	Psychologist, Optometrist, Medical Practitioner or Nurse Practitioner	Superintendent of Motor Vehicles	Name, address and medical condition of a patient who is dangerous to drive and continues to drive.
School Act s. 91(2)	School medical officer	School board (Board of Education)	The health condition and name of any student if the school medical officer believes the student's condition may endanger the health or welfare of the students of a school.
School Act s. 91(5)	Teacher, principal, vice principal or director of instruction	School medical officer, school principal and superintendent of schools for the district	A student who is suspected of suffering from a communicable disease or other physical, mental or emotional condition that would endanger the health or welfare of other students.

Appendix 4: Framework for Best Clinical Practice When Consent is Not Given⁴



4. From Slade, M.; Pinfold, V.; Rapaport, J.; Bellringer, S.; Banerjee, S.; Kuipers, E. & Huxley, P. (2007). "Best practice when service users do not consent to sharing information with carers: National multimethod study." *The British Journal of Psychiatry*, 190, 148-155.

Definitions

Access: “the process of viewing and/or obtaining data and/or personal information”.^c

Circle of Care: “a principle that recognizes and understands the practicality of the need for implied consent for relevant information to flow from one health care provider to another in order to ensure the best level of patient care, unless the health care provider who provides the information is aware that the individual has expressly withheld or withdrawn consent”.^{cii} The Circle of Care is an evolving concept that speaks to the challenges of obtaining informational consent in the health care environment.^{cii}

Collection: “the gathering, acquisition, receipt, or obtaining of personal information”.^{ciii}

Confidentiality: “the ethical principle or legal right that a physician or other health professional will hold secret all information relating to a patient, unless the patient gives consent permitting disclosure”.^{civ}

Consent: “means agreement. There are two types of consent: Express Consent and Implied or Implicit Consent. Express Consent means that you have expressed your consent either in writing or by giving verbal instructions. Implied or Implicit Consent means that it is assumed that you agree, because in the situation it is obvious why your personal health information is collected, used or disclosed”.^{cv}

Disclosure Directives: “an individual’s ability to control when and by whom his or her personal health information will be accessed”.^{cvi}

Disclosure: “making information available to another organization or third party, or to the individual the information is about”.^{cvi} Disclosure means “to give out or allow information to be seen by a person or organization”.^{cvi}

Expressed Consent or Explicit Consent: “consent signified by the willing agreement of an individual for the collection, use, and disclosure of personal information for a defined purpose (opt-in model). The consent can be given verbally or in writing—see also Implied Consent”.^{cix}

Family: Family or families may include family members, friends or other individuals who provide support or care to individuals. The term family intends to signify a broader, person-centered approach to care providers. Family members are people who have been identified by the individual, the representative or care provider who provides support to the individual on a regular basis or someone identified as being in a relationship of importance to the individual.

Freedom of Information and Protection of Privacy Act (FIPPA): “BC legislation that governs personal information collected, used, and disclosed by public bodies including Health Authorities and the Ministry of Health Services”.^{cx}

Implied Consent or Implicit Consent: “consent signified by the acceptance by a reasonable individual for the collection, use, and disclosure of information for an obvious purpose where it is understood that the individual will indicate if he or she does not accept (opt-out model). For implied consent to be meaningful, the individual has to know that he or she has the right to expressly withhold or withdraw consent at any time without fear of retribution—see also Expressed Consent”.^{cxi}

Individual: “the person/patient about whom information is collected. This includes persons who are authorized to exercise rights on behalf of an individual/patient (e.g., parents on behalf of a child; guardian or trustee; personal representative)”.^{cxii}

Need to know principle: “access to personal information based on a legitimate relationship with the patient and a need to access or use the personal information for the execution of one’s duties”.^{cxiii}

Individual with lived experience: all people receiving care or services. Sometimes individuals with lived experience are referred to as individuals, clients or patients. The term individual is used in this document.

Personal Health Information: “information about an individual that identifies the individual and the individual’s health history including physical or mental health; the provision of health services that individual; the registration of the individual for the provision of health services; payments or eligibility for health care; and any information collected in the course of the provision of health services to the individual”.^{cxiv}

Personal Information Protection Act (PIPA): “BC legislation that governs personal information collected, used and disclosed by all private sector organizations, including physicians’ private practices and other private health care facilities”.^{cxv}

Personal Information: “any information about an identifiable individual, but does not include business contact information (e.g., Individual’s title, business telephone number, business address, business email or facsimile number). Examples of personal information include: name, age, marital status, employment history, national/ethnic origin, political or religious beliefs, sex, sexual orientation, contact information, address, and health care, educational, financial, criminal, opinion (unless it is about someone else), fingerprints, blood type, DNA information, biometrics, individual’s health care providers, health numbers (such as care card number) and insurance.”^{cxvi}

Privacy: “the right to be free from intrusion and interruption. It is linked with other fundamental rights such as freedom and personal autonomy. In relation to information, privacy involves the right of individuals to determine when, how, and to what extent they share information about themselves with others”.^{cxvii}

Use: “the application of information for a specific purpose by the person or organization that collected the information”.^{cxviii}

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