NWT's Health Specific Privacy Legislation

First Policy Discussion Paper

Issues: What is 'Health Information' and *Who* Collects, Uses, and Discloses it?

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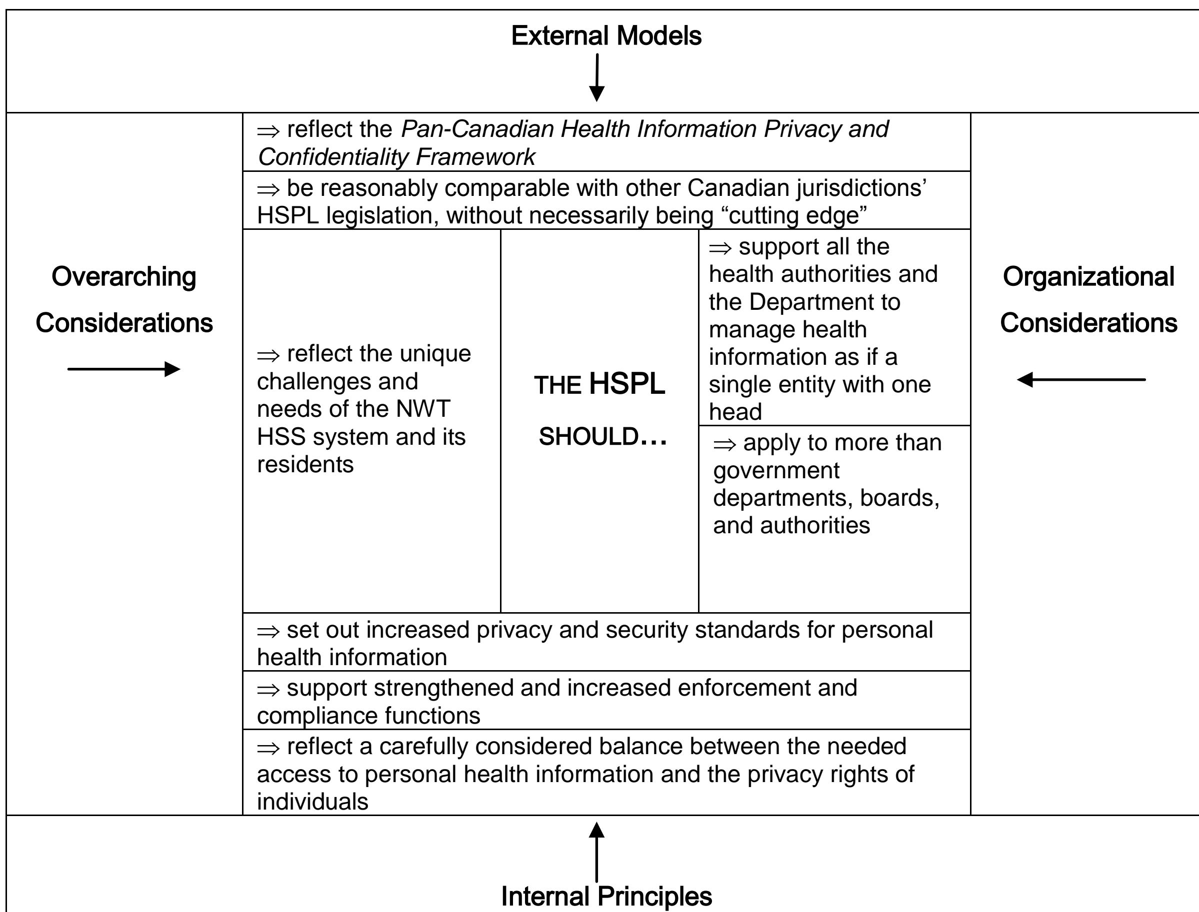
I. INTRODUCTION

As the Department of the Health and Social Services (the "Department") of Government of Northwest Territories ("GNWT") moves forward with its health specific privacy legislation ("HSPL") project, several discussion topics have been identified. This first paper sets out information to help guide discussion around the following key topics:

- WHAT IS 'HEALTH INFORMATION'?
- *WHO* COLLECTS, USES, AND DISCLOSES HEALTH INFORMATION?

It is important to discuss these two topics early because they will play important roles for the structure and basic operation of the HSPL. Since these topics will serve as the building blocks of the HSPL, it is also important to consider them in the context of the Department's general objectives for the HSPL.

The following diagram summarizes these objectives and organizes them by category:



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The objectives, and their respective categories, will be referred to in this paper to help keep the focus on the greater context and end goals.

Before continuing, note that the *Pan-Canadian Health Information Privacy and Confidentiality Framework*[1] (the "Framework") is the product of extensive work recently performed on a national level and published by Health Canada. It aims to set standards for the harmonization of HSPL across Canada. As the Framework sets out in its introductory remarks: "Consistent, or at least more consistent, privacy regimes among jurisdictions would facilitate health care renewal, including the development of electronic health record systems and primary health care reform."

II. FIRST POLICY DISCUSSION TOPIC - WHAT IS 'HEALTH INFORMATION'?

The first policy topic to discuss is what is, and what will be meant by, the term 'health information' in the NWT's HSPL. Privacy legislation is unique because it centers on the management of information, usually personal information. Before policy decisions are made about where information should be allowed flow - and to and by whom - the notion of 'information' must defined.

The term 'health information' commonly brings about the meaning of information created, collected, and used in the course of accessing the health care system. While the task of defining health information may at first seem straight forward, on closer look there are several challenges with this task. By way of example, an individual's name alone would not likely be viewed as health information but a name on a patient's hospital chart is what creates an expectation of privacy. That is, being able to identify an individual through information is the crux of privacy expectations.

Therefore, the idea of information being individually identifiable (such that an individual's identity can be readily or reasonably ascertained) serves as a good starting point in defining what information will be governed by the NWT's HSPL. As will be set out below, the concept

[1] Health and the Information Highway Division, Health Canada (January 27, 2005), online <http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index_e.html>

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of information being individually identifiable is common to all HSPL enacted in Canadian jurisdictions.

Currently four Canadian jurisdictions have their own HSPL: Alberta, Saskatchewan, Manitoba, and Ontario. These four provinces will be collectively referred to in this paper as the "HSPL Provinces". Newfoundland is working towards a draft bill for its own HSPL as is New Brunswick. As draft bills are not routinely made public and often undergo several changes before being proclaimed and brought into force, this paper will focus mainly on the HSPL Provinces.

II-1. How do Other Provinces with HSPL Define Health Information?

To begin this part of the discussion, refer to the chart attached as **Appendix A.** This chart summarizes the approach that each of the HSPL Provinces takes.

As can be seen, the ways in which health information is defined varies; however, common to each of the HSPL Provinces is the general intention to capture information generated in the course of delivering *and* administrating health care services. In doing so, the definitions of health information often in turn refer to definitions of `health' and/or `healthcare'.

Also common to each of the HSPL Provinces is the connection to the concept of information being individually identifiable. In the Ontario and Manitoba HSPL this concept is embedded in the definition of personal health information whereas the Alberta HSPL limits its application to identifiable information by qualifying key provisions that govern how health information may be managed and maintained. In further contrast, the Saskatchewan HSPL operates by setting out a general exception. That is, one of the initial provisions sets out that the Act does not apply to *de*-identified health information.

The benefits and disadvantages to these various approaches taken by the HSPL Provinces (both in terms of defining health information and how the same is connected to the concept of individually identifiable) can better understood by looking to the comments made key stakeholders interviewed in each of these jurisdictions.

II-2. What is the Advice from the People Interviewed?

Individuals from each of the HSPL Provinces as well as from Newfoundland were interviewed with a view of learning from their experience with enacting HSPL. In most cases, individuals from both the government departments responsible for the legislation as well as every day users (e.g. Privacy Officers and Chief Information Officers of health regions) were interviewed. The following summarizes the advice provided by these interviewees regarding defining health information.

Alberta:

- As the chart in **Appendix A** shows, Alberta's HSPL is unique in that its definition of health information is broken down into three parts, two of which relate to patient information and one that relates to 'health services provider information'. Not surprisingly, this unique method of defining health information was the source of much interview discussion - both from those interviewed in Alberta and those in the other jurisdictions. In general, while it was noted that including health services provider information in some cases makes for greater consistency in electronic health record environments, there was significant suggestion that if health services provider information is governed by HSPL it should be done in a way where it is not folded into the general definition of health information, which should be reserved for patient information. In doing so, it was offered that confusion about the definition health information (and the application of the HSPL generally) could be minimized.

- The definition given to `diagnostic treatment and care information' was noted to operate well. While this definitions may appear broad, it was further noted because it in turn relies on the defined term of `health service', the definition is not so broad as to be unmanageable. This is because the term 'health service' is defined to be limited to services either directly or indirectly, partially or fully, paid for out of the public purse, with the exception services provided under the operation of a pharmacy or the practice of a pharmacist. Also, Alberta's HSPL includes a general provision that causes the Act to not apply to information related to services that are not 'health services'.

- There was a general consensus that a broad definition of health information (with respect to patient information) is useful to allow for the various ways health information is used in the healthcare systems, so long as other provisions strictly controlled who and how that information can managed and maintained.
- There was also a consensus about the importance of connecting the definition of health information in some way to the concept of information being `individually identifiable'.

Saskatchewan:

- Those interviewed in Saskatchewan generally had the view that the definition of `personal health information' worked well.
- It was noted in particular that the definition's inclusion of information collected "incidentally to the provisions of health services to the individual" was important as it allowed for information collected not intentionally but later deemed useful for the delivery and administration of healthcare services.
- It was also noted that a definition of 'health service' like that of Alberta's HSPL would not likely be useful. This was based on the view that its Act's ability to control its application to sector (public v. private) was already well achieved through the definition of 'trustees' - those governed by the Act and authorized to collect, use and disclose health information.
- Saskatchewan's unique approach of exempting de-identified information (versus making reference to individually identifiable health information) was noted to be neither exceptionally useful nor particularly challenging. To that end, it was noted that the other HSPL Provinces approach of qualifying the definition of health information (or other provisions in the Acts) with the term individually identifiable may work well.

Manitoba:

- The importance of including a reference to information collected incidentally to the provision of healthcare was also noted to be of value.
- The broad definition of personal information was also noted to be useful. Of particular note was the reference to the defined term `health' that is used in the definition of personal health information. While it was acknowledged that the definition of 'health' is broad (defined as "condition of being sound in mind, body and spirit"), the same was not noted to create significant challenges to the administration or interpretation of the Manitoba's HSPL. Rather, it was noted that this definition was purposely added to capture the spiritual aspect of healthcare and allow for greater certainty that spiritual care providers were included within the 'circle of care' or 'controlled arena' of authorized users of health information.
- The importance of connecting the definition of health information to the concept of individually identifiable was stressed. As Manitoba is unique in that its Act does not define individually identifiable, some interviewees were asked whether such a definition would be useful and the responses received did not seem to indicate that such definition was necessary. It was noted that a reasonable meaning to the term had been informally adopted and practically applied. It was further noted that a definition for 'individually identifiable' could always be added by way of.

Ontario:

- Overall, those interviewed in Ontario indicated that the definition of personal health information appeared to work well. In some cases, the Act's specific reference to, and inclusion of, `mixed records' was noted to be useful while, in other cases this was noted to not be necessary.
- Varying views emerged about the Act's specific exception to a definition of health information which excludes records that relate primarily to one or more employees or other agents of the custodian, and where such records are used for a purpose other than the provision of healthcare. On one hand, it was noted that this helps clarify that the Act is not intended to apply to such records as quality assurance records while, on the other hand, others noted the definition of personal health information (as it relates to patient information) already limits its scope in this way. It was further noted

that this exception would stand in contrast to the Alberta's HSPL approach where health services provider information is included in the definition of health information.

- As with the other HSPL Provinces, the importance of connecting the concept of individually identifiable to the definition of health information was emphasized.

In summary, most interviewees noted that in all jurisdictions a continuum of health services exists whereby there is an offering of both insured and non-insured health services. While some individuals may only ever access insured services, it was noted there remain many instances where healthcare services transition to a non-insured situation. It was therefore concluded by several that connecting the definition of health information to a term such a health services, that either refers to a term defined elsewhere such as 'insured services' or refers (more broadly) to only publicly funded health services, may not be effective. Rather, many noted that the focus for the definition of health information should be to create an ordinary and understandable definition and reserve limitations on the applicability of the HSPL on sector (i.e. private v. public, or mix) to setting parameters on to whom the Act applies.

II-3. What are Some of the Unique Northern Challenges?

Before reviewing possible approaches to defining health information, it is important set to out some of the unique Northern challenges that are relevant to this policy decision. To do so, this section sets out similarities and differences that the NWT healthcare system has with other Canadian jurisdictions.

Similarities

- There is a NWT Healthcare plan to enroll in, which administers billing and payment processes.
- There are significant staffing shortages of healthcare professionals, such as nurses and physicians, who choose to live in the NWT.
- Recruitment and retention of all health care professionals is a challenge.
- There is pressure to control health expenditures in the face of increasing demands, costly advances in medical technologies and an aging population.

Differences

- NWT residents do not pay healthcare premiums.
- Nurses at Health Centres provide most of patients' primary healthcare services in communities outside of the four largest NWT communities.
- Many specialized healthcare services are not provided close to the home of the patient, but are provided in another province.
- The NWT provides and administers an extensive Medical Travel system for emergencies and scheduled care in and outside of the NWT.
- Pilot projects with e-health services, such as telehealth and electronic health records have demonstrated their potential for improved services in the NWT. However, the replacement of out-dated IT infrastructure is a significant challenge facing the expansion of these e-health services such as telehealth, electronic health records.
- 20,000 aboriginal people live in the NWT and this population has its own set of challenging health issues.
- The NWT healthcare system lacks capacity in many functions, not just frontline healthcare services. This includes services such as IT, financial management, policy and health planning, privacy and quality assurance.
- Most physicians are salaried employees of the regional organizations. There are very few fee-for-service physicians.
- Increasing numbers of NWT healthcare providers are short-term locums and are mobile throughout the NWT.
- The only self-regulating healthcare profession in the NWT is Nurses. There is no professional regulatory body or structure for physicians or other healthcare professionals. The government licensing organization does not provide direction about standards or scope of practice.
- The NWT health and social services system provides many uninsured services at no or minimal cost to the client, such as, Long Term Care, Addictions Treatment, and vision care for its residents. Many of these services are provided through service agreements between the Department or regional authority and NGOs.
- Healthcare services are provided in association with social services, such as child protection, family violence and addictions services. Many of these services are provided through service agreements with NGOs.

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In light of the foregoing, the next section explores possible approaches that the Department can consider in deciding what 'health information' will be for the purposes of its HSPL.

II-4. What Are the Possible Approaches that the Department Can Consider?

There are at least three approaches to defining health information for the Department to consider. Given that the usefulness of connecting health information to the concept of 'individually identifying' is likely well accepted, this discussion will only focus on how health information can be defined and assume that in each case a connection to individually identifiable is made.

- **Approach A -** Neither linked to terms already defined in existing NWT legislation **nor** to other terms that limit sector application either by general reference to funding or specified programs/services.
- **Approach B -** Linked to terms already defined in existing NWT legislation.
- **Approach C -** Not linked to terms already defined in existing NWT legislation *but* linked to terms that limit sector application by a general reference to funding and/or a reference to specified programs/services.

The following chart sets out an explanation and the relevant considerations for each of these options.

	APPROACH A	APPROACH B	APPROACH C
EXPLANATION & EXAMPLE	- The definition of health information would refer to a set of criteria commonly associated with an individual's health status or interaction with the health system. The criteria would also reflect information routinely needed and used by health care professionals for the care of the individual. - An example would be reference to terms such as "symptoms, diagnosis, treatment, and health history." This definition could in turn refer to other definitions such as a definition of health which, for example, could includes spiritual aspects of an individual's wellbeing as well as their physical and mental states.	- The definition of health information use some form of **Approach A** but focus on reference to a term already defined in NWT legislation - An example would be reference to the term `insured service' as is set out in the *Hospital Insurance and Health and Social Service Administration Act*. By this definition `insured services' means the "in-patient and out-patient services to which insured persons are entitled under this Act and the regulations but does not include services a person is eligible for and entitled to under an Act of Canada, a Province or a Territory specified in the regulations or any other statute or law specified in the regulations."	- The definition of health information use some form of **Approach A** but focus on a link to a term *not* defined in existing NWT legislation but that limits the application by refernce to: i) a general reference to funding, ii) specified programs/services, or iii) a combination of both. - An example would include the term `health sevice' which in turn is defined as only publicly funded services. Another example, linking to a term that sets out a list of specific programs and services. A further example, a hybrid option, is would be a link to a term that limits of application by reference to funding as well as a link to a term that sets out a list of specific programs and services.

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	APPROACH A	APPROACH B	APPROACH C
COMPARABLE TO OTHER JURISDICTIONS	- Ontario - Manitoba - Saskatchewan	- None of the existing HSPL Provinces. - It remains unknown whether Newfoundland or New Brunswick are considering this approach in their current drafts for HSPL.	- Alberta. Note that Alberta’s HSPL uses a form of the hybrid approach noted above such that the definition of health information includes the defined term ‘health service’ which in turn refers only to publicly funded health services and then includes by specific provision health services connected to the operation of a pharmacy or the practice of a pharmacist irrespective of funding.

	APPROACH A	APPROACH B	APPROACH C
ADVANTAGES	- Broad and flexible definition to accommodate all forms and arenas where health information may be utilized and/or needed. - Can rely on experience of three of the HSPL Provinces. - Can still limit application of sector by setting parameters on definition of authorized users (i.e. who can collect, use, and disclose health information).	- Novel approach - Uses terminology already in use in the NWT and likely familiar to many.	- Allows for some breadth of the definition of health information while confines it to a predictable list of sources/users. -If linked term limits application by general reference to funding only, would simplify and reduce administration and cost of implementing the HSPL. That is would only apply to public sector health services. - If linked term limits application by reference to a specified list of programs and services, there may be existing familiarity with these programs and services - e.g. reference to certain terms used in NWT's *Integrated Service Delivery Model* - and other programs and services that are later developed can be edited by way of regulation. - If linked term uses hybrid approach, has benefit of applying generally to public sector health services with specific inclusion of health professionals noted to be significantly integrated in NWT's health care system (e.g. pharmacists).

	APPROACH A	APPROACH B	APPROACH C
CHALLENGES	- The limits on the application of the HSPL to sector would need to be addressed elsewhere, likely by setting parameters on definition of authorized users (i.e. who can collect, use, and disclose health information).	- No HSPL Provinces experience to draw on. - Linking to existing term may be limiting if such term does not appropriately reflect the scope of information and/or health services intended for the HSPL. - If defined term changes, or its enabling Act is amended or repealed, definition of health information is similarly affected (i.e. lack of control).	- Where linked term limits application by general reference to funding only, there may be key health care professionals not included, such as pharmacists - and other entities may be included that are not relevant to NWT's health care system, such as Women's Shelter. - Where linked term sets out list of programs or services, extensive work will be required to identify these programs and services, and either legislative amendment or provision for regulations to add other programs and services would be required to adapt to future years. - Where linked term uses hybrid approach, both challenges noted above would apply. That is, reference to public funding may be over-inclusive in some case and under-inclusive in others, and list of specific entities would require legislative amendment or regulation to adapt to future years.

II-5. What are the Implications of the Approaches?

In addition to the advantages and challenges set out in the chart above there are also other implications for these approaches that should be considered as the Department considers the various approaches. The Objectives set out in the first part of this paper are referred to here together with other factors.

With one of the Objectives being that the HSPL should reflect the Framework, a good starting point is note that the Framework defines (as a core concept) health information. This definition reads:

> … information about an identifiable individual that relates to the:
>
> - physical or mental health of the individual, or
> - provision of health services to the individual, and may include:
>
>   - information about the registration of the individual for the provision of health services,
>   - information about payments or eligibility for health care in respect to the individual,
>   - a number, symbol or particular assigned to an individual to uniquely identify the individual for health care purposes,
>   - any information about the individual that is collected in the course of the provision of health services to the individual, and
>   - information derived from the testing or examination of a body part or bodily substance.
>
> Personal health information does not include information that, either by itself or when combined with other information available to the holder, is anonymized, i.e. the identity of the individual who is the subject of the information cannot be readily ascertained from the information.

While the above definition cites the term `health services' there is not a definition for this term in the Framework's list of core provisions. Rather, and more in keeping with **Approach A,** the Framework limits application of sector by setting parameters on definition of authorized users (i.e. who can collect, use, and disclose health information). This will be reviewed in greater detail under the discussion about the second policy decision.

The Framework's approach, together with the chart's summary that indicates **Approach A** is comparable with three out of the four HSPL Provinces, suggests that **Approach A** is most likely to achieve the Objectives categorized under **External Models**.

The Objective that the HSPL should reflect the unique challenges and needs of the NWT HSS system and its residents categorized under **Overarching Considerations** can likely be best achieved under either **Approach A** or **Approach C** where there is no reliance on a term defined in existing NWT legislation, as is the case under **Approach B**. This is likely to be the case because a broader definition of health information affords greater flexibility and adaptability which may be needed to address the unique challenges and needs of the NWT healthcare system and its residents.

In respect of the Objectives categorized under **Organizational Considerations**, there are several implications to review.

- Under the specific Objective of creating an HSPL that allows the health authorities and the Department to manage health information as if a single entity, one may say that: i) **Approach B** does not have significant implications for this Objective, ii) **Approach A** could support this Objective so long as the policy decision making on who can collect, use, and disclose health information appropriately creates a 'cirle of care' or `controlled arena', and iii) **Approach C** may require something in addition to cause the health authorities and the Department to manage information as if a single entity. Overall, this specific Objective is likely better advanced under the second policy decision topic set out in this paper, namely who can collect, use and disclose health information.
- Under the specific Objective of the HSPL applying to more than government departments boards and authorities, **Approach A** and **Approach C** would likely be most successful.

In respect of the three Objectives categorized under **Internal Principles, Approach A** and **Approach C** again appear to be most likely successful. This is likely so because **Approach A** and **Approach C** provide the greatest flexibility and adaptability for the definition of health information which, in turn, would support a more far-reaching implementation of the various principles listed: increased privacy and security standards; strengthened and increased enforcement and compliance functions; and a carefully considered balance between needed access to health information and privacy rights of individuals.

In summary, it appears that **Approach B** is likely to be least effective in achieving the Objectives. On balance, **Approach A** and **Approach C** similarly meet the Objectives. The

main difference between **Approach A** and **Approach C** is that **Approach A** leaves application of the Act as to sector to be dealt with under other definitions or provisions whereas **Approach C** deals with this by reference to a linked term or terms. Accordingly, the policy decision of what is health information is very much linked to who will be governed by the HSPL; namely, how the HSPL will define *who* can collect, use and disclose health information.

III. SECOND POLICY DISCUSSION - *WHO* COLLECTS, USES AND DISCLOSES HEALTH INFORMATION?

Privacy legislation by its nature must clearly set out to whom it applies. That is, even if the definition of health information is confined or contained, the legislation must still set out who is expected to collect, use and disclose it and accordingly govern these persons.

Commonly, privacy legislation is structured such that the common users of health information (such as nurses, physicians, laboratory technicians and pharmacists) are given a similar title such as 'custodian' or 'trustee'. To allow for the use of personal health information by the Department for such matters as system planning and resource allocation, often the Government department responsible for health affairs is also given the same title. Once all the key users of health information are identified various rules can be set out for each depending on their need for information. For example, it may be that a nurse or a physician requires more specific health information than the Department does for its resource planning.

As was seen from the discussion above, limitations on a HSPL's application to a certain sector (private v. public, or mix) can be made by in the definition of health information. However, more commonly, the scope of HSPL is established in the definition of the persons to whom the HSPL applies. As was also seen above, often these two issues overlap.

As was done with the previous policy topic, the discussion will start by reviewing how the HSPL Provinces deal with this issue.

III-1. What Do The HSPL Provinces Do?

To begin this part of the discussion, refer to the chart attached as **Appendix B.** This chart summarizes the approach that each of the HSPL Provinces takes.

As can be seen, all the HSPL Provinces set out rather extensive lists of persons that are identified as either custodians, trustees or health information custodians. Unique to Alberta and Saskatchewan is the incorporation of an additional term ('affiliate' for both) that sets out additional persons that are governed by the HSPL. Alberta is unique in that it is the only jurisdiction that limits the application of its HSPL to custodians in the public sector, with the exception of pharmacies and pharmacists that are governed both in the public and private sector. This parallels the unique definition of 'health service' that is linked to the definition of health information in Alberta's HSPL, as discussed earlier. The other three HSPL Provinces refer to a list of entities that are largely public sector in nature but include regulated health professionals, which could be in both the public and private sector.

Common to all the HSPL Provinces is the inclusion of regional health authorities and their respective department responsible for health affairs. As will be discussed below, this was presumably done to allow for harmony and consistency among those responsible for the delivery of healthcare services and those responsible for administration. Also, this approach (as will be discussed in greater detail below) helps achieve many of the Objectives set out in this paper, particularly that the health authorities in the Department can act as one entity as categorized under **Organizational Considerations**.

III-2. What Is The Advice From The People Interviewed?

Alberta:

- It was noted that the following aspects about the definition of custodian and affiliate could benefit from reconsideration or amendment:
  - more clearly defined role of affiliate (particularly vis-à-vis information managers);
  - inclusion of ambulance operators and attendants as affiliates or custodians; and
  - inclusion of all health professionals regardless of sector (i.e. not only pharmacists).

Saskatchewan:

- In was noted that while the list of trustees is predominantly based on public sector there is merit to have had included the provisions that includes "a member of class of persons designated as health professionals in the regulations". The ability to add health professionals by way of regulation was noted as useful as not all health professionals necessarily use as much health information as others and the selection of these for the purposes defining trustees is important as times and healthcare systems evolve.
  This was noted to be of particular importance because the only other reference to a health professional in Saskatchewan's HSPL is qualified as being under the responsibility of the Minister.

- It was also noted that there were certain challenges with including as a trustee health professional bodies that regulate members of health professions as there is some sense of overlap with health professional regulatory legislation and related confusion as to which Act applies.

- Last, it was noted that it is useful to have persons who provide a health service pursuant to an agreement with another trustee included as trustees. However, it was noted that this provision could be amended to include any form of service so as to capture such individuals by contract such as information technologists or other individuals that may by necessity need to access health information. On a similar matter, it was noted that volunteers are not included in the definition of trustee and that in many cases the role of volunteers in remote areas is significant. As such, it was noted that it may be useful to include in the definition of trustee (or in a separate definition such as affiliate) any person that provides a service for a trustee whether by contract, volunteer or agency relationship.

Manitoba:

- It was noted that, being the first HSPL legislation in Canada, the definition of trustee was purposely left broad and left to refer to definitions in existing legislation. On reflection, it was noted that there could be greater flexibility and adaptability if the definition of trustee did not hinge on these established definitions in other legislation.

- It was also noted that some clarity could be afforded with respect to the role of individuals that provide services to trustees on either on a one-time or volunteer basis.

Ontario:

- Being the most recent jurisdiction to enact its HSPL, it was noted that it was still relatively early to reflect on the usefulness of the definition of health information custodian. However, it was noted that its application to both public and private sectors was well received and sapped to being implemented without significant challenge.
- As with Saskatchewan and Manitoba, it was noted that the role of service providers whether on a one-time, volunteer, or agency basis could benefit from clarification.
- Also, the specific provisions in the definition of health information custodian that exclude aboriginal healers, certain mid-wives, and spiritual providers were noted to pose some challenges with respect to implementation, particularly the delivery of healthcare services in more remote communities.
- Last, it was noted that the ability to add health information custodians by way of regulation was acknowledged as being both useful and necessary.

Overall, the general consensus from those interviewed in all the HSPL Provinces was that the definition of who the HSPL would apply to requires careful consideration as it sets the basic scope of the Act. To this end, the ability to add custodians/trustees/health information custodians as well as affiliates (or some comparable term) by way of regulation was emphasized as very important.

III-3. What Are Some Of The Northern Challenges?

The challenges set out under the first policy topic apply to policy topic as well.

From these challenges, emphasis should be placed on the manner in which healthcare services are delivered in remote areas in NWT; this may require that the HSPL be

significantly flexible to allow for situations where individuals who do not, in the ordinary course, access or transport health information but do so out of necessity.

III-4. What Seems To Be The Likely Solution?

Based on the advice of the HSPL Provinces, and the Objectives sets out in this paper, there are at least two options in determining who will be governed by the HSPL:

Option 1 - All Public Sector Entities of the Department Closely Connected to the Healthcare System (versus Social Service) and Specific Inclusion of All Pharmacists and Pharmacies: This option would include all of the NWT's health regions, the Department, health facilities and health clinics, other points of access for health care in the NWT, and specifically include pharmacies and pharmacists. This option would also allow for other entities/ persons to be added by way of regulation.

Option 2: All Public Sector Entities of the Department Closely Connected to the Healthcare System (versus Social Service) and Other Selected Healthcare Persons in Private Sector: This option would include all of the NWT's health regions, the Department, health facilities and health clinics, other points of access for health care in the NWT, as well other persons that deliver healthcare services in the private sector, including pharmacists. Under this option it may be that those private sector persons included are only those that are regulated by a health professional body, or are limited in some other manner. As is with **Option 1**, this option would also allow for other entities/ persons to be added by way of regulation.

III-5. What Are the Implications Of The Options?

In considering the implications for these options, a good starting point is the Framework. Under the Framework, the relevant core concept used is a **custodian** and its definition reads:

> … an individual or organization that collects, uses, or discloses personal health information for the purposes of care and treatment, planning and management of the health system or health research.

The related recommendation provides that in addition to the above, a jurisdiction's legislation should include coverage over the following entities:

- Health service providers - a person who is licensed or registered to provide health services or who is a member of a designated class of persons. In general terms, this includes health professionals/health service providers/health care practitioners
- The Minister and Department
- Regional Health Authorities
- Hospitals and nursing homes and other identified health care facilities
- Pharmacists and pharmacies
- Boards, agencies, committees and other organizations identified in regulations
- Affiliates/agents e.g. employees, volunteers
- Cancer Board
- Mental Health Board
- Ambulance Operators
- Persons who maintain and administer an electronic health record system

Also relevant is the Framework’s definition Agent/Affiliate which reads:

> In relation to a health information custodian, means a person/organization that, with the authorization of the custodian, acts for or on behalf of the custodian in respect of personal health information for the purposes of the custodian, and not the agent/affiliate's own purposes, whether or not the agent/affiliate is employed by the custodian and whether or not the agent/affiliate is being remunerated.

This definition appears to stress the importance of including in HSPL governance over those persons that provide services for custodians/trustees/health information custodians. Such a definition also allows for inclusion of volunteers. Accordingly, under this model, and so long as the definition of custodian/trustee/health information custodian does not specifically exclude otherwise, this definition (or a similar one) could operate to include aboriginal healers and other spiritual care providers, individuals that may be highly integrated and valued in the NWT’s healthcare system.

In light of the breath of the definitions and recommendation set out above, the Framework is likely best supported under **Option 2 -** and accordingly more likely to achieve both Objectives categorized under **External Models**. On the other hand note that with many of the NWT health services coming from Alberta health providers and institutions, **Option 1,** which is akin to Alberta’s HSPL, may be beneficial because of people’s familiarity with this legislation. This consideration should however be viewed in light of the approaches taken by the other three HSPL Provinces (that adopt model more in line with **Option 2**) and whether there is a possibility that NWT’s health services may become more integrated with these other jurisdiction in the future.

Other important implications also need to be considered.

Most notably, the NWT's Integrated Service Delivery Model ("ISDM") raises significant implications. That is, the sustained integrity and continued functioning of the ISDM is likely a high priority for the Department. Since healthcare services in the NWT are provided in association with social services (such as child protection, family violence and addictions services), work will need to be done to carve out those entities that ought not be treated as custodians/trustees/health information custodians. This work will be required under both **Option 1** and **Option 2.**

Under the ISDM, there is a focus on health prevention and health promotions, with the consequence of an expected increased of nurse practitioners, midwives, mental health workers as well as those working in Primary Community Care Teams. The possible increase in allied healthcare professionals raises the need to ensure that the HSPL can adapt to these growing groups. This is particularly the case given that the ISDM relies on various agencies including non-government organizations and private business. For this reason, **Option 2** may be more responsive. Also, as caregivers may work in several disciplines, and change roles often, **Option 2** would help to harmonize rules and make education about which privacy legislation applies easier. In connecting this to the Objectives, **Option 2** may more readily archive those Objectives categorized under **Overarching Considerations** and **Internal Principles**.

The implications associated with the HSPL governing non-government organizations and private business must also be reviewed. One implication is the possible risk of imposing standards without matching resources to educate as well as monitor and enforce compliance. If this occurs, public trust can be easily lost, as can the trust and confidence of the agencies involved. For this reason, **Option 1** may be more manageable, and be more likely to succeed. Also, other cost implication should be noted. The cost associated with proceeding under **Option 1** is likely significantly higher than **Option 2**. This is because added work will be needed to consult with and educate those health care providers that are not already under the control or direction of the Department. Also, there may be later financial implications of implementing and maintaining higher standards for hose entities governed by the HSPL. In reviewing these implications, **Option 1** can be seen as better equipped to

achieve the Objective categorized under **Organizational Considerations** of creating an HSPL that allows the health authorities and the Department to manage health information as if a single entity, but possibly not in respect of the other Objective categorized under **Organizational Considerations,** namely HSPL applying to more than government departments boards and authorities.

Another important implication, and one related to the preceding point, is that with **Option 2** implementation may be frustrated because of the relatively greater number of entities that would be included in the 'circle of care'. That is, there may less 'buy-in', from the perspective of both healthcare providers and the public. Nonetheless, it should be noted that to guard against risks of health information being mishandled by a number of authorized users perceived to be greater than the current number of authorized user, provisions would most likely be included in the HSPL so that collection, use and disclosure of health information is carried out:

- in the most limited manner (i.e. is privacy being respected as much as possible?);
- on a need-to-know basis (i.e. does the job need heath information to be accessed?); and
- with the highest degree of anonymity possible in the circumstances (i.e. are measures taken to use de-identified information when possible?)

These types of provisions are common to all of the HSPLs of the HSPL Provinces, and also cited in the Framework.

IV. CONCLUDING REMARKS

This paper was intended to stimulate discussion and present ideas for important policy decision that need to be made in the early staged of NWT's HSPL. These decisions, and those to follow, will work together to create a legislative framework that places primary emphasis on the protection of individual privacy while enabling the flow of information (where appropriate) to support effective healthcare and the management of NWT's healthcare system.

APPENDIX A

	DEFINITION OF 'HEALTH INFORMATION'	CONNECTION TO 'INDIVIDUALLY IDENTIFIABLE' CONCEPT
ALBERTA ***HEALTH INFORMATION ACT*, R.S.A. 2000, C.H-5**	- By s.1(k) **health information** means any or all of the following: (i) diagnostic, treatment and care information; (ii) health services provider information; (iii) registration information - Note, the first two sub-definitions relate to patients where as the last (as the title implies) relates to individuals providing the health services to patients. The inclusion of health services provider information in the definition of health information is unique to Alberta. - And, each of the sub-definitions are in turn defined. - By s.1(i) **diagnostic, treatment and care information** means information about any of the following: (i) the physical and mental health of an individual; (ii) a health service provided to an individual; (iii) the donation by an individual of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance; (iv) a drug as defined in the *Pharmacy and Drug Act* provided to an individual; (v) a health care aid, device, product, equipment or other item provided to an individual pursuant to a prescription or other authorization; (vi) the amount of any benefit paid or payable under the *Alberta Health Care Insurance Act* or any other amount paid or payable in respect of a health service provided to an individual, and includes any other information about an individual that is collected when a health service is provided to the individual, but does not include information that is not written, photographed, recorded or stored in some manner in a record. - By s.1(o) **health services provider information** means the following information relating to a health services provider: (i) name; (i.1) business title; (ii) business and home mailing addresses and electronic addresses; (iii) business and home telephone numbers and facsimile numbers; (iv) gender; (v) date of birth; (vi) unique identification number that (A) is assigned to the health services provider by a custodian for the purpose of the operations of the custodian, and (B) uniquely identifies the health services	- By s. 1(p) **individually identifying** is defined as when: the identity of the individual who is the subject of the information can be readily ascertained from the information. - And, the majority of the rights and obligations set out in the Act specifically include the term individually identifiable immediately before the term health information.

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	DEFINITION OF 'HEALTH INFORMATION'	CONNECTION TO 'INDIVIDUALLY IDENTIFIABLE' CONCEPT
	provider in relation to that custodian; (vii) type of health services provider and licence number, if a licence has been issued to the health services provider; (viii) date on which the health services provider became authorized to provide health services and the date, if any, on which the health services provider ceased to be authorized to provide health services; (ix) education completed, including entry level competencies attained in a basic education program and post‑ secondary educational degrees, diplomas or certificates completed; (x) continued competencies, skills and accreditations, including any specialty or advanced training acquired after completion of the education referred to in subclause (ix), and the dates they were acquired; (xi) restrictions that apply to the health services provider's right to provide health services in Alberta; (xii) decisions of a health professional body, or any other body at an appeal of a decision of a health professional body, pursuant to which the health services provider's right to provide health services in Alberta is suspended or cancelled or made subject to conditions, or a reprimand or fine is issued; (xiii) business arrangements relating to the payment of the health services provider's accounts; (xiv) profession; (xv) job classification; (xvi) employment status; (xvii) number of years the health services provider has practised the profession; (xviii) employer; (xix) municipality in which the health services provider's practice is located, (xx) provincial service provider identification number that is assigned to the health services provider by the Minister to identify the health services provider, but does not include information that is not written, photographed, recorded or stored in some manner in a record. - By s.1(u) **registration information** means information relating to an individual that falls within the following general categories and is more specifically described in the regulations: (i) demographic information, including the individual's personal health number; (ii) location information; (iii) telecommunications information; (iv) residency information; (v) health service eligibility information;	

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	DEFINITION OF 'HEALTH INFORMATION'	CONNECTION TO 'INDIVIDUALLY IDENTIFIABLE' CONCEPT
	(vi) billing information, but does not include information that is not written, photographed, recorded or stored in some manner in a record.	
SASKATCHEWAN ***HEALTH INFORMATION PROTECTION ACT*** **S.S. 1999, C.H-0.021**	- By s.2(m) **personal health information** means, with respect to an individual, whether living or deceased: (i) information with respect to the physical or mental health of the individual; (ii) information with respect to any health service provided to the individual; (iii) information with respect to the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of the individual; (iv) information that is collected: (A) in the course of providing health services to the individual; or (B) incidentally to the provision of health services to the individual; or (v) registration information; - By s.2(q) **registration information** is in turn defined as: information about an individual that is collected for the purpose of registering the individual for the provision of health services, and includes the individual's health services number and any other number assigned to the individual as part of a system of unique identifying numbers that is prescribed in the regulations.	- By s.2(d) **de-identified personal health information** means personal health information from which any information that may reasonably be expected to identify an individual has been removed; - By s.3(2)(a) the Act does not apply to: (a) statistical information or **de-identified personal health information** that cannot reasonably be expected, either by itself or when combined with other information available to the person who receives it, to enable the subject individuals to be identified

	DEFINITION OF 'HEALTH INFORMATION'	CONNECTION TO 'INDIVIDUALLY IDENTIFIABLE' CONCEPT
MANITOBA ***PERSONAL HEALTH INFORMATION ACT*, C.C.S.M. C. P33.5**	-By s.1(1) **personal health information** means recorded information about an identifiable individual that relates to: (a) the individual's health, or health care history, including genetic information about the individual, (b) the provision of health care to the individual, or (c) payment for health care provided to the individual, and includes (d) the PHIN and any other identifying number, symbol or particular assigned to an individual, and (e) any identifying information about the individual that is collected in the course of, and is incidental to, the provision of health care or payment for health care. -By s.1(1) **health** means the condition of being sound in mind, body and spirit. - By s.1(1) **health care** means any care, service or procedure: (a) provided to diagnose, treat or maintain an individual's health, (b) provided to prevent disease or injury or promote health, or (c) that affects the structure or a function of the body, and includes the sale or dispensing of a drug, device, equipment or other item pursuant to a prescription.	- The concept is embedded in the definition of **personal health information** whereby it qualifies information as being about an **identifiable individual** (see full definition in adjacent column, s.1(1)).

	DEFINITION OF 'HEALTH INFORMATION'	CONNECTION TO 'INDIVIDUALLY IDENTIFIABLE' CONCEPT
ONTARIO ***PERSONAL HEALTH INFORMATION PROTECTION* ACT, 2004, S.O. 2004, C. 3, SCH. A**	- By s.4(1) **personal health information** means identifying information about an individual in oral or recorded form, if the information: (a) relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family, (b) relates to the providing of health care to the individual, including the identification of a person as a provider of health care to the individual, (c) is a plan of service within the meaning of the *Long-Term Care Act*, 1994 for the individual, (d) relates to payments or eligibility for health care, or eligibility for coverage for health care, in respect of the individual, (e) relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance, (f) is the individual's health number, or (g) identifies an individual's substitute decision-maker. -By s.4(3) the definition of personal health information is extended to **mixed records**, such that: personal health information about an individual includes identifying information about the individual that is not personal health information described in [s.4(1)] but that is contained in a record that contains personal health information described in that subsection about the individual. -By s.4(4) the definition of personal health information is limited such that it does not include identifying information contained in a record that is in the custody or under the control of a health information custodian if: (a) the identifying information contained in the record relates primarily to one or more employees or other agents of the custodian; and (b) the record is maintained primarily for a purpose other than the provision of health care or assistance in providing health care to the employees or other agents.	- The concept is embedded in the definition of **personal health information** whereby it qualifies information as being **identifying** (see full definition in adjacent column, s.4(1)). - And, by s.4(2) **identifying information** means information that identifies an individual or for which it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify an individual.

APPENDIX B

	KEY TERMS OF *WHO* CAN COLLECT, USE, AND DISCLOSE HEALTH INFORMATION
<u>ALBERTA</u> ***HEALTH INFORMATION ACT*, R.S.A. 2000, C.H-5**	- By s.1(k) **custodian** is defined as any or all of the following: (i) the board of an approved hospital as defined in the *Hospitals A*ct other than an approved hospital that is (A) owned and operated by a regional health authority established under the *Regional Health Authorities Act*, or (B) established and operated by the Alberta Cancer Board continued under the *Cancer Programs Act*; (ii) the operator of a nursing home as defined in the *Nursing Homes Act* other than a nursing home that is owned and operated by a regional health authority established under the *Regional Health Authorities Act*; (iii) a provincial health board established pursuant to regulations made under section 17(1)(a) of the *Regional Health Authorities Act*; (iv) a regional health authority established under the *Regional Health Authorities Act*; (v) a community health council as defined in the *Regional Health Authorities Act*; (vi) a subsidiary health corporation as defined in the *Regional Health Authorities Act*; (vii) the Alberta Cancer Board continued under the *Cancer Programs Act*; (viii) a board, council, committee, commission, panel or agency that is created by a custodian referred to in subclauses (i) to (vii), if all or a majority of its members are appointed by, or on behalf of, that custodian, but does not include a committee that has as its primary purpose the carrying out of quality assurance activities within the meaning of section 9 of the *Alberta Evidence Act*; (ix) a health services provider who is paid under the Alberta Health Care Insurance Plan to provide health services; (x) a licensed pharmacy as defined in the *Pharmacy and Drug Act*; (xi) a pharmacist as defined in the *Pharmacy and Drug Act*; (xii) the Department; (xiii) the Minister; (xiv) an individual or board, council, committee, commission, panel, agency or corporation designated in the regulations as a custodian; but does not include: (xv) the Alberta Alcohol and Drug Abuse Commission continued under the *Alcohol and Drug Abuse Act*, or (xvi) a Community Board as that term is defined in the *Persons with Developmental Disabilities Community Governance Ac.,* - By s. 1(i) **affiliate** is defined as: (i) an individual employed by the custodian, (ii) a person who performs a service for the custodian as an appointee, volunteer or student or under a contract or agency relationship with the custodian, and (iii) a health services provider who has the right to admit and treat patients at a hospital as defined in the Hospitals Act, but does not include: (iv) an operator as defined in the *Ambulance Services Act*, or (v) an agent as defined in the *Health Insurance Premiums Act.*

	KEY TERMS OF *WHO* CAN COLLECT, USE, AND DISCLOSE HEALTH INFORMATION
SASKATCHEWAN ***HEALTH INFORMATION PROTECTION ACT*** **S.S. 1999, C.H-0.021**	- By s.2(t) **trustee** is defined as any of the following that have custody or control of personal health information: (i) a government institution; (ii) a regional health authority or a health care organization; (iii) a person who operates a special-care home as defined in *The Housing and Special-care Homes Act*; (iv) a licensee as defined in *The Personal Care Homes Act*; (v) a person who operates a facility as defined in *The Mental Health Services Act*; (vi) a licensee as defined in *The Health Facilities Licensing Act*; (vii) an operator as defined in *The Ambulance Act*; (viii) a licensee as defined in *The Medical Laboratory Licensing Act*, 1994; (ix) a proprietor as defined in *The Pharmacy Act*, 1996; (x) a community clinic: (A) as defined in section 263 of *The Co-operatives Act*, 1996; (B) within the meaning of section 9 of *The Mutual Medical and Hospital Benefit Associations Act*; or (C) incorporated or continued pursuant to *The Non-profit Corporations Act, 1995*; (xi) the Saskatchewan Cancer Foundation; (xii) a person, other than an employee of a trustee, who is: (A) a health professional licensed or registered pursuant to an Act for which the minister is responsible; or (B) a member of a class of persons designated as health professionals in the regulations; (xiii) a health professional body that regulates members of a health profession pursuant to an Act; (xiv) a person, other than an employee of a trustee, who or body that provides a health service pursuant to an agreement with another trustee; (xv) any other prescribed person, body or class of persons or bodies. - By s.2(a) **affiliate** is an affiliate as defined in *The Regional Health Services Act*, which in turn is defined as: a person who is the operator of a hospital approved pursuant to The Hospital Standards Act or a not-for-profit special-care home licensed pursuant to *The Housing and Special-care Homes Act*, and includes any successor to that operator but does not include a regional health authority or a prescribed person.

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MANITOBA ***PERSONAL HEALTH INFORMATION ACT*, C.C.S.M. C. P33.5**	-By s.1(1) **trustee** is defined as a health professional, health care facility, public body, or health services agency that collects or maintains personal health information. -And in turn: **health professional** is defined as a person who is licensed or registered to provide health care under an Act of the Legislature or who is a member of a class of persons designated as health professionals in the regulations. **public body** is defined as the same is defined in *The Freedom of Information and Protection of Privacy Act*, and for the purpose of this definition, the definitions of "department", "educational body", "government agency", "health care body", "local government body" and "local public body" in that Act apply.
ONTARIO ***PERSONAL HEALTH INFORMATION PROTECTION* ACT, 2004, S.O. 2004, C. 3, SCH. A**	- By s.3(1) a **health information custodian** means a person or organization described in one of the following paragraphs who has custody or control of personal health information as a result of or in connection with performing the person's or organization's powers or duties or the work described in the paragraph, if any: 1. A health care practitioner or a person who operates a group practice of health care practitioners. 2. A service provider within the meaning of the *Long-Term Care Act*, 1994 who provides a community service to which that Act applies. 3. A community care access corporation within the meaning of the *Community Care Access Corporations Act*, 2001. 4. A person who operates one of the following facilities, programs or services: i. A hospital within the meaning of the *Public Hospitals Act*, a private hospital within the meaning of the *Private Hospitals Act*, a psychiatric facility within the meaning of the Mental Health Act, an institution within the meaning of the *Mental Hospitals Act* or an independent health facility within the meaning of the *Independent Health Facilities Act*. ii. An approved charitable home for the aged within the meaning of the *Charitable Institutions Act*, a placement co-ordinator described in subsection 9.6 (2) of that Act, a home or joint home within the meaning of the *Homes for the Aged and Rest Homes Act*, a placement co-ordinator described in subsection 18 (2) of that Act, a nursing home within the meaning of the *Nursing Homes Act*, a placement co-ordinator described in subsection 20.1 (2) of that Act or a care home within the meaning of the *Residential Tenancies Act*, 2006. ii. A long-term care home within the meaning of the *Long-Term Care Homes Act*, 2007, a placement co-ordinator described in subsection 40 (1) of that Act, or a care home within the meaning of the *Tenant Protection Act*, 1997. iii. A pharmacy within the meaning of Part VI of the *Drug and Pharmacies Regulation Act*. iv. A laboratory or a specimen collection centre as defined in section 5 of the *Laboratory and Specimen Collection Centre Licensing Act*. v. An ambulance service within the meaning of the *Ambulance Act*. vi. A home for special care within the meaning of the *Homes for Special Care Act*. vii. A centre, program or service for community health or mental health whose primary purpose is the provision of health care. 5. An evaluator within the meaning of the *Health Care Consent Act*, 1996 or an

	KEY TERMS OF *WHO* CAN COLLECT, USE, AND DISCLOSE HEALTH INFORMATION
	assessor within the meaning of the *Substitute Decisions Act*, 1992. 6. A medical officer of health of a board of health within the meaning of the *Health Protection and Promotion Act.* 7. The Minister, together with the Ministry of the Minister if the context so requires. 8. Any other person prescribed as a health information custodian if the person has custody or control of personal health information as a result of or in connection with performing prescribed powers, duties or work or any prescribed class of such persons. -By s.2 **health care practitioner** means: (a) a person who is a member within the meaning of the *Regulated Health Professions Act,* 1991 and who provides health care, (b) a person who is registered as a drugless practitioner under the *Drugless Practitioners Act* and who provides health care, (c) a person who is a member of the Ontario College of Social Workers and Social Service Workers and who provides health care, or (d) any other person whose primary function is to provide health care for payment. - And note, there are several specific exception to the definition of health information custodian, the majority of which are designed to clarify that a relative of a patient if also a health care practitioner cannot use information available to him/her for professional purposes to access information about the relative, unless duly caring for that relative. There are however some other exceptions that should be highlighted; by s.3(4)a health information custodian does not include a person described in one of the following paragraphs who has custody or control of personal health information as a result of or in connection with performing the work described in the paragraph: 1. An aboriginal healer who provides traditional healing services to aboriginal persons or members of an aboriginal community. 2. An aboriginal midwife who provides traditional midwifery services to aboriginal persons or members of an aboriginal community. 3. A person who treats another person solely by prayer or spiritual means in accordance with the tenets of the religion of the person giving the treatment.

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