

INFORMATION AND PRIVACY COMMISSIONER OF ALBERTA

**Investigation Report Concerning the Disclosure of
Health Information Using Alberta Netcare**

May 15, 2008

Alberta Health and Wellness,

David Thompson Health Region

&

Mr. Joe Gustafson, Pharmacist

Investigation Report H2008-IR-001

(Investigations H1730, H1750 and H1751)

Introduction

[1] On August 15, 2007, the Information and Privacy Commissioner (the Commissioner) received a complaint related to mandatory participation in the provincial electronic health record (Alberta Netcare). The Complainant wrote to the Commissioner on receipt of a letter from her pharmacist, Mr. Joe Gustafson (the Pharmacist), advising that he was no longer able to withhold her health information from Alberta Netcare. The Complainant stated that she was “having trouble to comprehend that [her] personal information is being forced into a ‘public database’ without [her] consent, let alone [her] informed consent.”

[2] The Complainant stated that her concerns were not limited to the disclosure of pharmacy information through Alberta Netcare and verbally clarified that she wished for this investigation to consider the disclosure of all her health information through Alberta Netcare. I contacted Alberta Health and Wellness (AHW or “the Department”) and requested that they identify all custodians who had contributed to and/or accessed the Complainant’s Netcare record¹. In response to my request, AHW produced a copy of the Complainant’s Netcare record which allowed me to determine that the Complainant’s Netcare record contained pharmaceutical information disclosed by the Pharmacist to AHW, laboratory information disclosed by the David Thompson Health Region (DTRH) to Capital Health and that no Netcare user² had accessed the Complainant’s Netcare record outside of this investigation.

[3] The Commissioner authorized me to conduct an investigation under section 85(e) of the *Health Information Act*. Section 85(e) allows the Commissioner to investigate whether health information has been collected, used, disclosed or created by a custodian in contravention of the HIA. This

¹ For the purposes of this investigation, “Netcare record” refers to the patient-centric health record that is available through the Alberta Netcare Portal. The Netcare Portal is described in detail in the Background section of this report.

² A Netcare user is a custodian or affiliate of a custodian as defined in the HIA who has been granted access to Alberta Netcare.

report lays out the findings and recommendations resulting from my investigation.

Background

[4] The Complainant and the Pharmacist both state that they have had a number of conversations over the past several years related to patient confidentiality in Alberta Netcare. On the basis of these conversations, the Pharmacist decided that he would not disclose the Complainant's health information to Alberta Health and Wellness. The Pharmacist believed that the pharmaceutical component of Alberta Netcare would "reject" any records which did not contain the individual's personal health number (PHN). In an effort to comply with the Complainant's expressed wishes and not disclose health information, the Pharmacist removed the PHN from the Complainant's health records before providing them to AHW.

[5] On April 9, 2007, the Pharmacist wrote to the Complainant and advised that he was no longer able to avoid disclosing her health information to AHW. The Pharmacist based this decision on a letter from the Minister of Alberta Health and Wellness (the "Minister") dated March 26, 2007, in which the Minister advised all pharmacists of an amendment to the *Health Information Regulation* (the Regulation) which required them to provide information about dispensed drugs³ to the Department. The Minister's letter states:

"As of September 1, 2007, all pharmacists working in Alberta's community based pharmacies are required to submit drug dispensing information... to Alberta Health and Wellness. The information will be entered into the Pharmaceutical Information Network (PIN) application which is a key component to the Alberta Netcare Electronic Health Record. The intent is to make accurate and comprehensive drug prescription and dispensing information available provincially to health practitioners providing care to patients..."

[6] On receipt of the letter from the Pharmacist, the Complainant wrote to the Commissioner and requested that he investigate the disclosure of her health information through Alberta Netcare. The Complainant also addressed her letter detailing her concerns to the Minister.

Alberta Netcare

[7] Alberta Netcare is Alberta's provincial electronic health record (EHR)⁴, and is an initiative of and primarily funded by AHW. It is made up of a number of

³ The terms "dispensed" and "drugs" are defined in the *Pharmacy and Drug Act*. I have adopted these definitions for this report.

⁴ An electronic health record is an integrated clinical health information system intended to provide a shared view of a patient's health record in a secure environment and to be a clinical decision support tool used in the provision of health services.

health information technology projects⁵. AHW states that Alberta Netcare will allow for “a single, integrated, private and secure, province-wide electronic health record solution, linking community health care providers, hospitals, pharmacies and other points of care to patient information.”⁶

[8] This investigation report specifically addresses the data flows required to operate the Alberta Netcare Portal (Netcare Portal). The Netcare Portal is a web-based application that allows information from specified registries and clinical domain repositories to be accessed by authorized users. A registry within an EHR manages identification information⁷. Clinical information is contained in clinical domain repositories. Alberta Netcare uses health information in registries to identify individuals and locations within the EHR and clinical domain repositories to manage the clinical information related to individuals. In June 2007, Alberta Netcare allowed authorized users to access health information in provincial pharmacy, laboratory and diagnostic imaging clinical repositories. Some regional health authorities have allowed additional health information from their regional clinical data repositories to be made available for access through Alberta Netcare. A complete listing of the data sources available through Alberta Netcare as of July 2007 is included as Appendix B to this report.

[9] Decisions related to the management and operation of Alberta Netcare are made by the EHR Governance Committee⁸. The mandate of this group is to provide leadership, set priorities and approve initiatives which define the scope, budget and timelines related to implementation of Alberta Netcare. The EHR Data Stewardship Committee (EHR DSC)⁹ reports to the Minister of Alberta Health and Wellness and has been given the specific mandate to oversee the management of health information in Alberta Netcare. The EHR DSC establishes the rules as to how health information in Alberta Netcare can be used and disclosed and must be managed. They also play a leadership role in developing some of the key administrative privacy documents that underpin the operation of Alberta Netcare including the Alberta Netcare Information Exchange Protocol (IEP) and Alberta Netcare Information Management Agreement (IMA).

Application of the HIA

[10] The *Health Information Act* (HIA) applies to “health information” in the custody or under the control of a “custodian”.

⁵ Other Alberta Netcare projects include the Physician Office System Program, Pharmaceutical Information Network, various provincial level clinical domain repositories, registries and the Provincial Health Information Exchange.

⁶ Alberta Netcare Electronic Health Record Portal 2006 Privacy Impact Assessment, submitted to the OIPC in January 2006

⁷ The Alberta Netcare architecture recognizes three provincial registries - a patient registry (Provincial Client Registry), a registry of health services providers (Provincial Provider Directory) and a registry that contains information on health care facilities (Delivery Site Registry).

⁸ This committee is comprised of the Deputy Minister of Health, the CEOs of Capital Health, the Calgary Health Region and the Regional Shared Health Information Program (RSHIP) along with the Executive Director of the Alberta Medical Association.

⁹ The EHR DSC membership is comprised of representatives from Capital Health, the Calgary Health Region, the RSHIP, the Alberta Cancer Board, the College of Physicians and Surgeons of Alberta, the Alberta Medical Association, the Alberta College of Pharmacists, the Pharmacists Association of Alberta, AHW and the public.

[11] “Health information” is defined in section 1(1)(k) of the HIA to include “diagnostic treatment and care information”, “health services provider information” and “registration information”.

[12] My review of the Complainant’s Netcare record found it contains demographic information, pharmacy information and laboratory information¹⁰. The demographic information is registration information as defined in the HIA and the *Health Information Regulation*. The pharmacy information and lab information is a mixture of diagnostic treatment and care information, registration information and health services provider information under the HIA. I have reviewed the data elements in question and find that this information is health information as defined by section 1(1)(k) of the HIA.

[13] The term “custodian” is defined in section 1(1)(f) of the HIA, and includes:

(iv) a regional health authority established under the Regional Health Authorities Act...

(xi) a pharmacist as defined in the Pharmaceutical Professions Act...

(xii) the Department...

(xiii) the Minister¹¹...

[14] The David Thompson Health Region is a regional health authority established under the *Regional Health Authorities Act*. Mr. Gustafson is a pharmacist as defined in the *Pharmaceutical Professions Act*. AHW is the Department administered by the Minister of Health and Wellness and the Minister of Health and Wellness is the Minister responsible for the *Health Information Act* under the *Government Organization Act*. As such, the DTHR, the Pharmacist, the Department and the Minister are all custodians under the HIA.

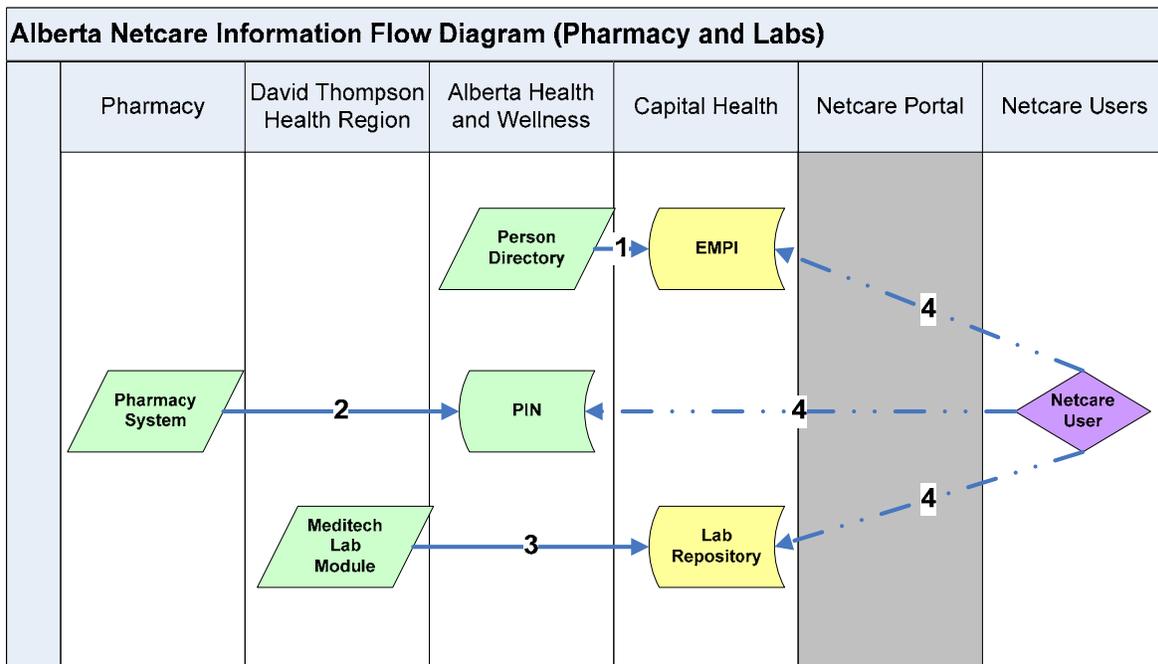
[15] As the information at issue in this investigation is health information, and the Department, the Minister, the DTHR and Mr. Gustafson are custodians, I find that the HIA applies to the information contained in the Complainant’s Netcare record in its entirety.

Data Flows

[16] The Complainant’s Netcare record contains pharmacy and laboratory information, along with the demographic information required to uniquely identify her within the EHR. The following diagram illustrates the simplified data flows required to make the Complainant’s pharmacy and lab information available through Alberta Netcare.

¹⁰ In this report, pharmacy or prescription information refers to information related to dispensed drugs as disclosed by the Complainant’s pharmacist. Laboratory or lab information refers to information related to lab tests disclosed by the regional health authority in which the Complainant lives. A comprehensive description of the types of health information contained in the Complainant’s Netcare record is provided in Appendix A.

¹¹ The Department and the Minister are further defined in sections 1(1)(h) and 1(1)(q) of the HIA and refer to the Minister responsible for the Act as determined in the *Government Organization Act* and the Department administered by the Minister.



[17] The vertical bands to the left of the Netcare Portal band in this diagram reflect the custodians and information managers involved in the transmission of demographic, pharmacy and lab information from a community pharmacy and non-metropolitan regional health authority through the Netcare Portal. Confirmed data flows are reflected with solid lines and potential data flows are reflected in broken lines.

[18] **Data Flow 1** is AHW’s disclosure of registration information from the Provincial Client Registry to Capital Health, who act as the Department’s information manager¹². The Provincial Client Registry is a registry maintained by AHW that contains the name and demographic information of Albertans who are eligible for health care services under the Alberta Health Care Insurance Plan. AHW discloses this information to Capital Health which then integrates the demographic information into an Enterprise Master Patient Index (EMPI) system on behalf of AHW. An EMPI amalgamates all of the “identifiers” assigned to a patient across the health system and creates a unique electronic identity for each patient. The use of an EMPI ensures that health information in Alberta Netcare is attributed to the correct individual.

[19] **Data Flow 2** is the disclosure of information on dispensed drugs from a community based pharmacy to the provincial pharmacy clinical domain repository, the Pharmaceutical Information Network (PIN), which is operated by AHW. The majority of all pharmacies in Alberta submit “batch uploads” to PIN. This means that the pharmacy system periodically harvests information on all new dispensed drugs and sends that information to AHW in an electronic format.

¹² The role of “information manager” is discussed at length later in this report. By way of introduction, an information manager is an entity that performs information management/information technology services for a custodian

[20] **Data Flow 3** is the disclosure of lab information from the David Thompson Health Region to Capital Health. Capital Health is an information manager for all of the non-metropolitan health regions and operates a laboratory clinical domain repository that is a connected to Alberta Netcare.

[21] **Data Flow 4** reflects the potential disclosure of health information in the EMPI, PIN and lab repository to an authorized Netcare Portal user.

Issues

[22] The issues to be considered in this investigation are:

1. Does the Pharmacist have authority to disclose the Complainant's health information to AHW without the Complainant's consent?
2. Does AHW have authority to collect the Complainant's health information from the Pharmacist without the Complainant's consent?
3. Does DTHR have authority to disclose the Complainant's health information to Capital Health?
4. Did AHW and the DTHR disclose the Complainant's health information through Alberta Netcare without the Complainant's consent?
5. Did the Pharmacist comply with the duty to consider the expressed wish of an individual?
6. Did AHW comply with the duty to consider an expressed wish of an individual?

Analysis

Issue 1 - Does the Pharmacist have authority to disclose the Complainant's health information to AHW without the Complainant's consent?

[23] The Complainant's Netcare record contains health information related to four prescriptions that were dispensed to her by Mr. Gustafson.

[24] The data flows laid out above have established the following facts:

- In order for prescription information to be available through Alberta Netcare, it is disclosed by a pharmacist to AHW, who put the prescription information into the Pharmaceutical Information Network (PIN).
- PIN is the pharmacy clinical data repository for the province of Alberta, and is the repository from which pharmacy information is made available to authorized users through the Netcare Portal.

[25] These facts are not disputed by the parties to this investigation.

[26] On April 9, 2007, the Pharmacist wrote to the Complainant and advised that he was no longer able to refuse to disclose her health information to AHW so that AHW could make it available through Alberta Netcare. The Pharmacist based this decision on a letter from the Minister dated March 26, 2007 in which the Minister advised all pharmacists of an amendment to the *Health Information Regulation* (the Regulation) which required them to provide information about dispensed drugs to the Department.

[27] The Pharmacist believes he took steps to ensure the Complainant's health information was not included PIN and, therefore, would not made available through Alberta Netcare. The Pharmacist believes that he achieved this by not including the Complainant's personal health number (PHN) in his pharmacy system. The Pharmacist understood, based on information he states he received from AHW, that PIN would "reject" records that did not contain the PHN and that the information would not available through Alberta Netcare. The Pharmacist did not state that he did not disclose the Complainant's prescription information; rather he stated that he disclosed the prescription information to AHW without the PHN and, as such, believed that he disclosed the information in such a way as to be unusable by AHW.

[28] As part of this investigation, I requested that AHW identify the sources of all health information in the Complainant's Netcare record. The evidence before me indicates that the Pharmacist disclosed the Complainant's prescription information to AHW on four occasions. While the Pharmacist may not have disclosed the PHN, he did disclose the name, address, gender, date of birth and prescription information of the Complainant. As such, I find that the Pharmacist disclosed health information related to four prescriptions to AHW, regardless of whether or not the PHN was attached to the record.

[29] I asked both the Pharmacist and AHW to tell me the legislative authority for the disclosure of information related to drugs dispensed by a community pharmacy to AHW. The Pharmacist contends that authority for the disclosure can be found in section 35(1)(a) of the HIA, which states:

35(1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual who is the subject of the information
(a) to another custodian for any or all of the purposes listed in section 27(1) or (2), as the case may be,

[30] The Department contends that legislative authority for this disclosure is found in section 46 of the HIA. Section 46 establishes a mandatory requirement to disclose health information to the Minister or the Department for specified purposes if certain criteria are met. The relevant portions of section 46 state:

46(1) The Minister or the Department may request another custodian to disclose individually identifying health information for any of the purposes listed in section 27(2)

...

- (b) if the information requested relates to a health service provided by the other custodian and*
- (i) the health service is fully or partially paid for by the Department or is provided using financial, physical or human resources provided, administered or paid for by the Department, or*
 - (ii) the information is prescribed in the regulations as information the Minister or the Department may request under this section.*

(2) If the requirements of subsection (1) are met, the custodian must disclose the information to the Minister or the Department, as the case may be.

...

(4) Individually identifying health information may be disclosed under this section without the consent of the individual who is the subject of the information.

[31] Section 46(1)(b)(ii) refers to the ability of the Minister or Department to request information prescribed in the *Health Information Regulation* (the Regulation). Section 7.1 of the Regulation allows the Minister or Department to request information related to dispensed drugs. It reads:

7.1 For the purposes of section 46(1)(b) of the Act and health system management, program planning and resource allocation, the Minister or the Department may request a health service provider that dispenses drugs to a patient to provide the following information to the Minister or the Department, as the case may be:

- (a) the name of the patient;*
- (b) the gender of the patient;*
- (c) the personal health number of the patient;*
- (d) the date of birth of the patient;*
- (e) the unique product identifier of the drug dispensed;*
- (f) the dosage details of the drug dispensed;*
- (g) the dispensing details of the drug dispensed;*
- (h) the prescription details of the drug dispensed;*
- (i) the identification number of the health services provider who prescribed the drug;*
- (j) the identification number of the health services provider who dispensed the drug.¹³*

[32] Section 46(1) of the HIA references “the purposes listed in section 27(2)”. Section 27(2) authorizes provincial health boards, regional health authorities, the Department and the Minister to use health information for planning and resource allocation, health system management, public health surveillance and health policy development if these functions fall within the mandate and under the geographic jurisdiction of the custodian.

¹³ For the purpose of this investigation report, this information will be referred to as “prescription information” or “drug information”.

[33] The ability of the Minister or Department to request health information from a pharmacist under section 46(1)(b)(ii) of the HIA rests on three criteria being met. First, the health information must be used by the Minister or Department for a purpose specified by section 27(2) of the HIA. Secondly, the information must relate to a health service provided by the pharmacist. Finally, the health information must be prescribed in the Regulations as information the Minister or the Department may request.

[34] A subsequent section of this report will establish that AHW has authority under section 27(1)(b) of the HIA to use health information for the purposes of health system management. Provincial health system management falls within both the mandate and the geographic boundaries of the Department. As such, the first criteria for disclosure pursuant to section 46(1)(b)(ii) is met.

[35] The second criteria for disclosure under this provision is that the information must relate to a health service provided by the pharmacist. The term “health service” is defined in section 1(1)(m)(ii) of the HIA as a service that is provided to an individual by a pharmacist engaging in the practice of pharmacy as defined in the *Pharmacy and Drug Act*, regardless of how the service is paid for. When a pharmacist dispenses drugs, he or she is engaging in the practice of pharmacy as defined in the *Pharmacy and Drug Act* and is providing a health service as defined in the HIA.

[36] The third criteria that must be met for section 46 to apply is that the health information being requested has been prescribed in the Regulation as information the Minister or the Department may request. The April 2007 amendment to the Regulation establishes the right of the Minister or Department to request health information about dispensed drugs from pharmacists for the purposes of health system management, program planning and resource allocation.

[37] Mr. Gustafson disclosed the Complainant’s health information to AHW subsequent to receipt of a request for that information. AHW was authorized to request this information by section 46(1) of the HIA. On receipt of a request from the Department that met the requirements of section 46(1), Mr. Gustafson was required to disclose the information to AHW by section 46(2) of the HIA and was authorized by section 46(4) to do so without the Complainant’s consent.

[38] I find that Mr. Gustafson was legally required to disclose the Complainant’s prescription information to AHW and did not require the consent of the Complainant to make this disclosure.

Issue 2 - Does AHW have authority to collect the Complainant’s health information from the Pharmacist without the Complainant’s consent?

[39] AHW fulfils two separate and distinct roles in the operation of Alberta Netcare. First, AHW is a custodian as defined in section 1(1)(f)(xiii) of the HIA. As such, AHW is bound by the *Health Information Act* and is limited to collecting, using and disclosing health information in accordance with that statute.

Secondly, AHW operates as an information manager (IM) for custodians using Alberta Netcare and is bound by the terms of the Alberta Netcare Information Management Agreement¹⁴ (IMA). Section 66 of the HIA states:

66(1) In this section, “information manager” means a person or body that
(a) processes, stores, retrieves or disposes of health information,
(b) in accordance with the regulations, strips, encodes or otherwise transforms individually identifying health information to create non-identifying health information, and
(c) provides information management or information technology services.

(2) A custodian may enter into an agreement with an information manager in accordance with the regulations for the provision of any or all of the services described in subsection (1).

(3) A custodian that has entered into an agreement with an information manager may disclose health information to the information manager without the consent of the individuals who are the subjects of the information for the purposes authorized by the agreement.

(4) An information manager to which information is disclosed pursuant to subsection (3) may use or disclose that information only for the purposes authorized by the agreement.

(5) An information manager must comply with
(a) this Act and the regulations, and
(b) the agreement entered into with a custodian
in respect of information disclosed to it pursuant to subsection (3).

(6) Despite subsection (5)(a), a custodian continues to be responsible for compliance with this Act and the regulations in respect of the information disclosed by the custodian to the information manager.

[40] AHW is a custodian when it is fulfilling its mandate to set provincial health policy and manage the health system and when operating some provincial registries and clinical data repositories. AHW is an information manager for other custodians when it provides the information management and information technology (IM/IT) services required to operate Alberta Netcare. This is an important distinction in that custodians are granted significant autonomy to collect, use and disclose health information under the HIA. Information managers do not have that same autonomy and are limited by section 66(4) of the HIA to using and disclosing health information in accordance with the terms of the agreement they enter into with custodians. It stands to reason that the use and disclosure of health information by information managers will be a subset of the permissions given to custodians and must be limited to those required to provide the services specified in the agreement. Section 66(6) of the HIA specifies that a custodian remains accountable for the actions of the

¹⁴ All custodians participating in Alberta Netcare enter into an IMA with Alberta Health and Wellness.

information manager with respect to the health information the custodian disclosed to the information manager.

[41] AHW concedes that it holds dual roles within Alberta Netcare, and that they collect, use and disclose health information as a custodian in some circumstances and as an information manager in others. In order to establish the Department's authority to collect health information, it is first necessary to establish which role the Department is exercising.

[42] It is my opinion that when AHW and the Minister use the authority to request health information under section 46 of the HIA, they collect the requested information as a custodian. Section 46 of the HIA clearly ties the Department's request for information under that provision to the authorized uses of health information listed in section 27(2) of the HIA. Section 27(2) provides specific custodians with the authority to use health information for broad secondary purposes related to management of the health system for which the custodian exercises jurisdiction and responsibility. Section 27(2) recognizes the Minister and the Department as custodians; section 27(2) does not recognize an information manager. As section 46 of the HIA is tied to authorities granted by section 27 of the HIA and section 27 views the Minister and Department as custodians, this is the role they hold when making requests for information under section 46.

[43] Having established that AHW collects the health information in question as a custodian, I must now determine if they have legislative authority to do so.

[44] Section 20 of the HIA provides custodians with the authority to collect health information and states:

20 A custodian may collect individually identifying health information
(a) if the collection of that information is expressly authorized by an
enactment of Alberta or Canada, or
(b) if that information relates directly to and is necessary to enable
the custodian to carry out a purpose that is authorized under section
27.

[45] The Department contends they have collected pharmacy information as authorized by section 20(b) of the HIA in order to allow them to effectively manage Alberta's health system, which is an authorized use of health information pursuant to section 27(2)(b) of the HIA.

[46] I asked the Department to describe how they use pharmacy information to manage the health system. The Department responded that the purpose of the section 46 initiative is to improve health system management through facilitating the operation of a more efficient and effective health system. AHW believes that ensuring that comprehensive prescription information is available at the point of care will reduce medication errors, increase patient safety, reduce the costs associated with treating medication errors borne by the health system and reduce the likelihood that a patient will suffer an adverse event related to prescription drugs.

[47] The Department did not directly respond to my question of “how” they use the information collected from pharmacists to manage the health system. That being said, the information provided in the Department’s response allows me to infer the Department’s position that facilitating the development of Alberta Netcare and ensuring that it is populated with information on all dispensed drugs will guarantee that health services providers have access to the information they need to make more informed choices about the care and treatment of patients. Increasing the cost-effectiveness and efficient operation of the health system are purposes which generally align to the Department’s mandate to ensure that the Alberta health system is managed effectively.

[48] While there is merit to AHW’s argument that authority to collect health information can be found in section 20(b) of the HIA via the Department’s authority to use health information under section 27(2)(b), I believe that the more appropriate authority to collect health information is found under section 20(a), which is the authority to collect health information where the collection of health information is expressly authorized under an enactment. I have previously established that section 7.1 of the Regulation authorizes specific health information related to dispensed drugs to be provided to AHW and that section 46(2) of the HIA requires that information to be disclosed to them. Since the definition of “collect” under the HIA is to receive or obtain health information, I conclude that the words “provided to” in section 7.1 of the Regulation authorize AHW to collect the Complainant’s health information. As such, the collection of pharmacy information stemming from a request under section 46 of the HIA and tied to section 7.1 of the Regulation constitutes a collection of health information that is expressly authorized under an enactment. Therefore, I find that AHW’s collection of health information in this case was authorized by section 20(a) of the HIA as authorized by law (namely the Minister’s directive under the Regulation) and that the consent of the Complainant was not required.

Issue 3 - Does DTHR have authority to disclose the Complainant’s health information to Capital Health?

[49] The Complainant’s Netcare record contains health information related to lab services she received from the David Thompson Health Region (DTHR). DTHR collects lab information during the course of providing health services and then provides it to Capital Health (CH), which acts as an information manager for the region. CH puts the DTHR lab information into a lab clinical domain repository then makes that information available through Alberta Netcare.

[50] It has previously been established that DTHR is a custodian and the information relating to the lab services is health information. The issue under consideration is whether DTHR had authority to disclose the Complainant’s lab information to Capital Health so it could be made available through Alberta Netcare.

[51] Capital Health is a custodian under section 1(1)(f)(iv) of the HIA and is an information manager for DTHR when providing specified IM/IT services. Capital Health did not act in the capacity of custodian when they used or disclosed lab

information when performing information management/information technology services at the request of DTHR. They performed this service on behalf of DTHR in the capacity of information manager.

[52] The DTHR has entered into an information manager agreement (IMA) with Capital Health (CH) for the provision of IM/IT services. The DTHR/CH IMA is supplemented by a series of “Participation Notices” which update the list of IM/IT services provided by CH to DTHR and specify how CH can use and disclose the health information that is disclosed to them by DTHR. A June 2006 Participation Notice states that Capital Health will make a number of information systems available to DTHR for the management and dissemination of lab information. The system which has been referred to as the “lab repository” throughout this report is one of the named systems. The Participation Notice also states that authorized users “have the ability to inquire on data on a need to know basis. This access includes the ability to view all reports through netCARE Portal 2006.”

[53] Section 66(3) of the HIA allows a custodian that has entered into an agreement with an information manager to disclose health information to the information manager without consent of the individuals for the purpose authorized by the agreement.

[54] I have reviewed the IMA and Participation Notices executed between the DTHR and CH. I find section that 66(3) of the HIA provides authority for the DTHR to disclose health information to CH to provide the information management services specified in the IMA, including facilitating access to lab information through Alberta Netcare.

Issue 4 – Did AHW and DTHR disclose the Complainant’s health information through Alberta Netcare without the Complainant’s consent?

[55] The HIA defines the terms “collect” and “use” but does not define the term “disclose”. Section 1(1)(d) states that “collect means to gather, acquire, receive or obtain information”. Section 1(1)(w) states that “use means to apply health information for a purpose and includes reproducing the information, but does not include disclosing the information”. The Alberta Netcare Information Exchange Protocol defines “disclosure” as “the provision of information from Alberta Netcare to a participating custodian, participating affiliate or the Information Manager who are accessing the information from the Alberta Netcare system”.

[56] Within an electronic health record, system users have the ability to access health information held in a variety of databases. Where a user accesses health information stored in a registry or repository which they exercise custody or control of, they have used the information. When a user accesses health information from a registry or repository which they do not exercise custody or control over, the custodian which has custody or control of the health information has disclosed the health information to the user. In the case currently under consideration, any access to the Complainant’s Netcare record using the Netcare Portal would constitute a disclosure of her health information.

[57] Section 41 of the HIA requires a custodian to maintain certain information related to the disclosure of health information. In their role as Information Manager for Alberta Netcare, AHW maintains a log of each access to an individual's Netcare Record. Review of this log allows an individual to determine if a Netcare record has been accessed by an authorized user, when the access occurred and which custodian accessed the record. Individuals can request a copy of this "disclosure log" by contacting AHW.

[58] I have reviewed the disclosure log of the Complainant's Netcare record and have determined that the only accesses to the Complainant's Netcare record relate to this investigation. These accesses were made by AHW staff in their role as Information Manager for Alberta Netcare and in response to requests I made to determine what was contained in the Complainant's Netcare record and the dates associated with data entries. No Netcare user accessed the Complainant's Netcare record through the Netcare Portal. As the audit logs demonstrate that no Netcare user accessed the Complainant's Netcare record, I find that there was no disclosure of the Complainant's health information through the Netcare Portal.

Issue 5 - Did the Pharmacist comply with the duty to consider the expressed wish of an individual?

[59] Section 58 of the HIA requires a custodian to collect, use and disclose health information in a limited manner. It states:

58(1) When collecting, using or disclosing health information, a custodian must, in addition to complying with section 57, collect, use or disclose only the amount of health information that is essential to enable the custodian or the recipient of the information, as the case may be, to carry out the intended purpose.

(2) In deciding how much health information to disclose, a custodian must consider as an important factor any expressed wishes of the individual who is the subject of the information relating to disclosure of the information, together with any other factors the custodian considers relevant.

[60] Section 58(1) requires a custodian to limit the collection, use and disclosure of health information to the amount of information that is required to carry out the intended purpose. Section 58(2) requires custodians to consider the expressed wishes of the individual when deciding how much health information to disclose. Section 58(2) does not require custodians to consider the expressed wishes of an individual related to the collection and use of health information.

[61] Sections 58(1) and (2) of the HIA must be applied together when considering the disclosure of health information. Section 58(1) presumes that a custodian will exercise their judgment prior to the disclosure of health information and will disclose the most limited amount of information necessary to allow the recipient of the information to carry out the intended purpose. Section 58(2) of the HIA then requires a custodian who has made the decision to disclose to consider the expressed wishes of the individual. The requirement to

consider the expressed wishes of the individual does not negate or otherwise impact the requirement placed on the custodian to limit the disclosure of health information to what is appropriate in the circumstances; the requirement to consider the expressed wishes of the individual is supplemental to or in addition to the duty to disclose only the most limited amount of health information that would allow the recipient of the information to carry out the intended purpose. A custodian contemplating a request for disclosure of health information must first determine the most limited amount of health information that would meet the requestor's needs then subsequently consider the expressed wishes of the individual.

[62] The health information disclosed by the Pharmacist consisted of the name, gender and date of birth of the Complainant along with information related to four prescriptions that were dispensed to her. This health information is specified as health information that the Minister or Department can request under the *Health Information Regulation*. On receipt of a request from the Minister or Department, the Pharmacist was required to make the requested disclosure. The Pharmacist limited the disclosure of health information to AHW to that which he was required to disclose by law. As such, I find that the Pharmacist met his duty under section 58(1) of the HIA to disclose the most limited amount of health information. I must now consider whether the Pharmacist discharged his duty to consider the expressed wishes of the Complainant.

[63] The Complainant and the Pharmacist discussed the Complainant's concerns about the disclosure of her health information through Alberta Netcare on several occasions. The Pharmacist interpreted these conversations to be an expressed request for non-disclosure and believed that he withheld the Complainant's health information from the provincial pharmacy clinical domain repository and, by extension, from further potential disclosure through the Netcare Portal. I have previously established that the Pharmacist, contrary to his intentions to do so, disclosed the Complainant's health information to AHW on four occasions.

[64] The HIA requires the Pharmacist to disclose information about dispensed drugs to the Minister or Department. The HIA also states that a custodian must consider the expressed wishes of an individual as an important factor when making a decision about how much health information to disclose. This creates a dilemma for the Pharmacist: one provision of the HIA, when read in conjunction with the Regulation, requires him to disclose the information; another provision (section 58(2)) requires him to consider the expressed wishes of the individual to limit the disclosure of the information.

[65] I think that the answer must be that the law compelling disclosure must take precedence. The Regulation is a specific law requiring the disclosure of health information. Section 58(2) is a general statement requiring consideration of someone's wishes. In legislation, specific rules prevail over general rules. Furthermore, the "expressed wishes" of an individual do not operate as a mechanism through which they have absolute veto over the disclosure of health information; expressed wishes are a just consideration, albeit an important one.

It is possible for a custodian confronted with an expressed wish from an individual to give the wishes of the individual full consideration and still determine that they cannot accede to them. This is the circumstance which faces the Pharmacist in this case.

[66] Given that the Pharmacist is required by law to provide the health information in question to the Department, he is unable to honour the expressed wishes of the Complainant related to non-disclosure of health information or otherwise limit the disclosure of health information to AHW. As such, I find that the Pharmacist discharged the duty to disclose health information in a limited manner and to consider the expressed wish of the individual, but that he was required by law to provide the health information in question to AHW and was prevented by law from limiting the disclosure.

Issue 6 - Did AHW comply with the duty to consider the expressed wish of an individual?

[67] I previously established that AHW is a custodian of health information and that it collects health information about dispensed drugs from pharmacists in this capacity. I further established that the Pharmacist met his duty to disclose the most limited amount of information to AHW and discharged his duty to consider the Complainant's expressed wishes related to the disclosure of health information. This raises the question of whether the Complainant made an expressed request to AHW and, if so, whether AHW discharged their duty to consider the expressed wish.

[68] The Complainant states that she called AHW a number of times to express concerns related to the disclosure of her health information through Alberta Netcare. She says she was verbally advised by AHW of the ability to limit disclosure of her health information through "masking"¹⁵ and was directed to make a request for masking of her health information to her pharmacist. The Complainant states that "no-one at Alberta Health... or my community pharmacy could direct me how to implement this masking". The Complainant subsequently wrote to the Department on August 15, 2007. In this letter, the Complainant specifically requested that the Minister provide her with "information to enable an individual to "block" the EHR" and "direction on how to withhold consent to participate in the EHR". This is the same letter she sent to the Information and Privacy Commissioner that gave rise to this investigation.

[69] The Minister responded to the Complainant on September 12, 2007. The Department provided the Minister's response as part of their submission in this investigation and indicated that the Minister's response is representative of how the Department responds to individuals who raise concerns about the disclosure of their health information through Alberta Netcare.

¹⁵ The Alberta Netcare Information Exchange Protocol defines "masking" as "a technical function within Alberta Netcare that obscures or restricts access to data in a patient record until an additional action by the accessor is executed or an explicit authority is granted them or recognized".

[70] I have reviewed the information provided by the Complainant that describes the response she received from AHW when she verbally expressed concerns about the disclosure of her health information along with the contents of the Minister's response. The Minister's response is consistent with the information the Complainant states she was verbally provided by the Department.

[71] In his response, the Minister advised the Complainant that custodians have an obligation to consider the expressed wishes of an individual regarding what and how much health information to disclose. The Minister also indicated that limitation of the disclosure of health information in Alberta Netcare is accomplished through masking, provided a general description of masking and encouraged the Complainant to contact her regional health authority for additional information related to the potential masking of her health information. The only variation on this response that the Complainant notes when describing how the Department responded to her verbal expression of concern is that she states she was directed to contact her pharmacist to discuss masking.

[72] In determining whether AHW discharged their duty to consider an expressed wish in this case, I must consider three questions. I must first determine if the Complainant made her wishes related to the disclosure of her health information through Alberta Netcare known to the Department. Secondly, I must consider whether the obligation to consider the expressed wishes of an individual relating to the disclosure of their information is limited to circumstances where health information has been disclosed. If I determine that the answer to either of the first two questions is "no", I must find that the Department was not obligated to consider the Complainant's expressed request. If I determine that the answer to the first two questions is "yes", I must address the third question and determine whether the Department turned their mind towards consideration of the Complainant's expressed wishes.

Issue 6A – Did the Complainant communicate an expressed wish to the Department?

[73] The Complainant says she approached AHW and made verbal requests that her health information not be disclosed through Alberta Netcare. She subsequently made a written request to this effect directly to the Minister.

[74] Section 58(2) of the HIA does not require an individual to make their wishes known in writing. An expressed wish can be made in any form; however, it is difficult to substantiate whether or not a request was made if the request was made verbally and responded to in the same fashion.

[75] The Complainant provided a reasonable level of detail when describing to me what she verbally requested of the Department and the Department's response to her. The information she said she received from AHW in response to her verbal request for exclusion of her health information from Alberta Netcare was echoed in the written response she received from the Minister approximately one month after she described the verbal request and response to me. The Department confirmed to me that the information contained in the Minister's

letter is reflective of any response that would have been given by the Department when approached by an individual raising concerns about the disclosure of health information through Alberta Netcare. They also indicated that individuals who contact the Department and request that the disclosure of their health information through Alberta Netcare be limited are routinely directed to contact a custodian with whom they have a treatment relationship.

[76] The level of detail provided by the Complainant when describing the Department's response to her verbal requests and the corroborating written response from the Minister leads me to conclude that the Complainant verbally requested that the Department exclude her health information from disclosure through Alberta Netcare. The response she received from the Department providing explicit information and direction on masking confirms that the Department understood her request to be a request for the exclusion of her health information from disclosure through Alberta Netcare. As such, I find that the Complainant conveyed her expressed wishes related to the disclosure of her health information through Alberta Netcare to AHW on at least one occasion.

Issue 6B – Is application of section 58(2) of the HIA predicated on health information having been disclosed?

[77] I previously found that AHW did not, in fact, disclose the Complainant's health information through the Netcare Portal after it came into their custody and under their control. I based this finding on my review of Netcare disclosure logs which demonstrated that no Netcare user had accessed the Complainant's health information through the Netcare Portal. That being said, the Department has integrated the Complainant's prescription information into PIN and has connected that database to Alberta Netcare. Alberta Netcare is designed to facilitate the disclosure of health information between authorized users in support of the provision of health services. As such, the Complainant's health information is available to any authorized Netcare user and could be disclosed by the Department at any time. The architecture and system design of Alberta Netcare is such that no further action is required on the part of a custodian who makes information available when information is accessed by another user. This leaves a custodian in the position of deciding to make information available through Alberta Netcare then not being aware of any subsequent access to, and disclosure of, that health information. In many cases, once a custodian makes information available through Alberta Netcare, they will not be advised of any subsequent disclosure of health information, although the HIA continues to view the custodian as accountable for that disclosure.

[78] Again, section 58(2) of the HIA reads:

58(2) In deciding how much health information to disclose, a custodian must consider as an important factor any expressed wishes of the individual who is the subject of the information relating to the disclosure of the information, together with any other factors the custodian considers relevant.

[79] Section 58(2) requires a custodian to consider the expressed wishes of an individual when deciding how much health information to disclose. The language

of section 58(2) indicates that the consideration is to take place before the disclosure of health information and after the custodian has determined the most limited amount of information that will fulfill the intended purpose, but it does not indicate a time frame within which that consideration must occur. The consideration of an expressed wish can take place any time between the collection of health information through to the discrete point in time at which the health information is disclosed. Section 58(2) of the HIA does not limit a custodian's discretion to determine the appropriate time to consider and, potentially, act upon an expressed wish.

[80] The determination of when the appropriate time to consider an expressed wish related to disclosure of health information is influenced by a number of factors including business processes, work flows, professional obligations and technological considerations. It is this last factor which bears consideration in this case. In a paper-based health records environment, a disclosing custodian receives a request for health information and is able to restrict or limit disclosure of health information based on a number of important considerations, including the purpose for which the information has been requested and the expressed wishes of the patient. In EHR systems like Alberta Netcare, the disclosing custodian is rarely, if ever, involved in the decision to permit access to specific health information after he or she has made the decision to make information available through the EHR. The disclosing custodian's primary decision in relation to the flow of health information to and through Alberta Netcare is the decision to make the health information available. The disclosing custodian is profoundly limited in his ability to consider the expressed wishes of his patient at the time that information is disclosed through the EHR as he is not directly involved in that transaction.

[81] The following scenario illustrates these differences. In a paper based environment, a specialist who needs additional information from a family physician in order to provide health services to a patient would make a request directly for supplemental information to that family physician. The family physician would consider the request, along with any expressed wishes that have been made by the patient, and determine what, if any, information should be disclosed. The family physician can then exercise their discretion and disclose only selected reports or could withhold portions of a report that they determine to be irrelevant to the specialist. In an EHR environment, a specialist who determines that they require additional clinical information in order to treat a patient could conceivably access the EHR which may contain the required information. If this happens, the family physician would not normally be aware that the specialist had accessed the information, nor would they be in a position to apply any discretion related to how much health information to disclose.

[82] Custodians that make information available through Alberta Netcare do not have the capacity to act upon the expressed wishes of the individual at the point in time at which another user determines that they need to access health information through the Netcare Portal. The reality of the chosen architecture is that the only meaningful place where the potential disclosure of health information can be limited based on an expressed wish is at some point prior to the disclosure of health information. Given that health information can be

accessed and disclosed in Alberta Netcare at any point after which the source system containing the health information has been integrated into the Netcare architecture, it stands to reason that the system must contain a mechanism for applying the expressed wish prior to any potential access and disclosure.

[83] By integrating the Complainant's health information into a database that is connected to Alberta Netcare, AHW has made the decision to make the Complainant's health information available for disclosure. As AHW has made the Complainant's health information available for disclosure through Alberta Netcare, I find that the Department has an obligation to consider the expressed wishes of the Complainant when it makes that information available for disclosure through Alberta Netcare.

Issue 6C – Did AHW consider the Complainant's expressed request?

[84] I have determined that the Complainant made an expressed request to the Department and that the obligation to consider the expressed wishes of an individual applies when a custodian decides to make health information available for disclosure through Alberta Netcare. I must now determine whether or not the Department turned their mind towards consideration of the Complainant's expressed wishes in this case.

[85] The Department and other custodians participating in the design, development and implementation of Alberta Netcare have been cognizant of the need to develop system functionality that will allow custodians to limit the disclosure of health information pursuant to an expressed request for some time. The Office of the Information and Privacy Commissioner (OIPC) was formally advised of the Department's approach towards Netcare-wide management of an expressed request in the Alberta Netcare Portal 2006 Privacy Impact Assessment (PIA), which was submitted by the Department on behalf of all participating custodians¹⁶ in January 2006. The Portal 2006 PIA described the mechanisms through which viewer access to health information contained in various clinical domain repositories and registries would be granted to authorized users via the Netcare Portal.

[86] Custodians are required by section 64 of the HIA to conduct a PIA and submit it to the Information and Privacy Commissioner for review and comment prior to the implementation of a new information system or administrative practice. A PIA assesses the potential risks to privacy introduced by administrative practices or information systems and describes how these risks will be mitigated. The Portal 2006 PIA advised the OIPC that the ability to limit disclosure of health information pursuant to an expressed wish from an individual, to that point in time, had been dictated by masking functionality developed at the clinical domain repository level and that this functionality had not been consistently developed. For example, PIN had the technical ability to mask health information at the request of the patient while the lab repositories

¹⁶ Custodians adopting Alberta Netcare leverage the master project PIA for Alberta Netcare. This PIA describes Netcare functionality, performs a system risk assessment and lays out key privacy controls. Adopting custodians then supplement this with an organizational privacy impact assessment.

did not. The Department identified that disparate masking capabilities made it difficult to consistently apply a decision related to an expressed request and introduced the corollary risk of privacy breach through clinical inference¹⁷ to the Alberta Netcare environment. That is to say that a patient may have requested that information related to a certain drug be masked, but that the lab system did not have the ability to mask lab results for that same drug and a user could infer the masked drug information through knowledge of the unmasked lab result. AHW indicated to the OIPC in the Portal 2006 PIA that this risk would be mitigated through the development and deployment of Global Person Level Masking (GPLM) and that GPLM would be the mechanism through which custodians would be able to record and act upon an expressed wish from an individual pursuant to section 58(2) of the HIA. GPLM was described to the OIPC as a function in Alberta Netcare that, once applied at the request of the individual, would restrict access to all diagnostic, treatment and care information through Alberta Netcare until an authorized Netcare user “unmasks” the information. When a Netcare record had been masked, a Netcare user who searched for the masked record would see a screen that contained the demographic information of the individual along with a message that clinical information had been masked. The Department contends that it is essential to present enough demographic information to allow a health services provider to determine with certainty that the masked record applies to the individual they are treating before they make the decision to unmask a masked record.

[87] The OIPC’s acceptance of the Portal 2006 PIA in September 2006 was predicated, in part, on our agreement that GPLM conceptually mitigates the privacy risk of clinical inference and serves as a reasonable mechanism through which an expressed wish could be managed in Alberta Netcare. I must note that GPLM is not the only way custodians could manage expressed wishes in Alberta Netcare, nor is it the only method through which they could mitigate the risk of clinical inference, but it is the method that has been chosen by AHW and accepted by our Office. I must also note that GPLM is not an absolute assurance to the individual that health information will not be disclosed through the Netcare Portal, as masked records can be unmasked. GPLM is intended to restrict disclosure of masked health information until such time as an authorized Netcare user determines that information must be unmasked to provide care. Masked information is not immediately visible to a Netcare user. A user must take the additional act of “unmasking” the masked information. Instances where health information is unmasked are logged and system administrators at AHW are advised of the unmasking event for follow-up.

[88] Subsequent to the OIPC’s acceptance of the Portal 2006 PIA, GPLM was formally endorsed by the EHR Data Stewardship Committee (EHR DSC) as the exclusive mechanism by which expressed wishes can be managed in Alberta Netcare and the Alberta Netcare Information Exchange Protocol was revised in

¹⁷ The privacy risk of clinical inference can be understood through the following example: An individual could conceivably request that health information related to a lithium prescription be masked in PIN, but the collateral ability to mask blood tests to monitor lithium levels does not exist. A user with access to lab information in Netcare would be able to infer that the patient had been prescribed Lithium through the lab results, and would be able to make a reasonable inference as to diagnosis from that.

March 2007 to include detailed direction to custodians seeking to both mask¹⁸ and unmask¹⁹ health information through the Netcare Portal. Section 5.1.2 of the IEP reflects the policy decision of the EHR DSC related to GPLM and indicates that *“Only global personal level masking may be contemplated in response to an individual’s request that any of their Alberta Netcare information be masked”*. When the revised IEP was issued to participating custodians in October 2007, GPLM became the only recognized method of masking health information in Alberta Netcare.

[89] I asked the Department to describe the masking functionality in Alberta Netcare and the timeline for deployment of that functionality as part of this investigation. The Department provided an initial written submission to me on November 21, 2007, I met with the Department to discuss this issue twice, and they provided me with a supplemental submission on May 5, 2008. In 2007, when the Complainant made her wishes related to the non-disclosure of her health information through Alberta Netcare known to the Department, technical functionality existed in Alberta Netcare that would have allowed for masking to be applied, but the Department had not yet formally decided to implemented this functionality nor had they developed the administrative controls and processes to support the effective deployment of centralized masking in Alberta Netcare. The decision to adopt a formal centralized masking process in Alberta Netcare was only reached in April 2008, although the Department indicates that it discussed the availability of centralized masking with regional health authorities in early 2007.

[90] The HIA states that health information must be protected through the adoption of physical, technical and administrative safeguards. While the technical functionality to mask health information existed in Alberta Netcare as early as 2006, the functionality cannot be considered to have been implemented or deployed until such time as participating custodians were advised of the availability of the functionality and were provided with the administrative tools to guide the use of the technology. The information provided to me by the Department indicates that the formal decision to move forward with centralized masking across Alberta Netcare was reached in April 2008, and that work on development of the required processes and administrative controls began at that time.

[91] Investigation Report H2005-IR-002 established that a custodian must be able to exercise choice based on professional judgment in order to be able to discharge its obligation to consider an expressed request pursuant to section

¹⁸ The IEP indicates that health information can be masked in Alberta Netcare if a custodian receives an explicit request from an individual that information be masked, has a current care relationship with the individual, has determined that masking would not compromise public health and safety, has determined that there is no other compelling reason to refuse to mask the information and has determined that the decision to mask information is consistent with their respective professional guidelines.

¹⁹ The IEP indicates that masked health information in Alberta Netcare can be unmasked by a participating custodian where the individual provides consent for the information to be unmasked or where the custodian has a current care relationship with the individual and they are providing a health service to the individual, access to the masked information is required for the provision of the health services and the information is related to and necessary for the current session of care.

58(2) of the HIA. The 2007 revisions to the Information Exchange Protocol clearly indicate to custodians that they have discretion related to the decision to mask health information in Alberta Netcare, indicate that individuals can make that request to a custodian or AHW and provide guidance on the decision making process a custodian should follow when confronted by an expressed wish.

[92] The OIPC has previously found that the duty to consider an expressed wish cannot be considered to have been discharged where a custodian is precluded from exercising a choice by administrative or technical barriers. In this case, the Department was precluded from exercising the choice to limit disclosure of health information through Alberta Netcare in response to an expressed wish by both administrative and technical barriers.

[93] The administrative barrier to consideration of an expressed request faced by the Department was its policy of referring individuals who contact the Department with an expressed request to make that same request to other custodians. Simply, the Department could not consider the wishes of the individual as they had made a policy decision that they would not consider requests of this nature. At the time the responses were provided, AHW did not believe that they were “custodians” of pharmacy information and referred the Complainant to custodians that they believed to be able to assist her in limiting the disclosure of her health information. That being said, I have determined that the Department is a custodian and is obligated to consider an expressed wish when one is presented to them. There is no evidence before me to suggest that AHW undertook any review of the Complainant’s expressed request other than to advise the Complainant to make her wishes known to her pharmacist or regional health authority.

[94] The second barrier to the Department’s consideration of an expressed wish was the Department’s failure to implement the available masking functionality and develop the administrative controls that would have allowed it to take advantage of the masking functionality that had been built in Alberta Netcare. While the technology existed in the system that would have allowed for the expressed wish to be captured and the disclosure of health information to be limited, there was no meaningful way for most Alberta Netcare users to use the functionality. Effective privacy protection is achieved only when technical safeguards, like masking, are supported by robust administrative safeguards that guide and direct staff in the appropriate use of the technology. A technological control must be clearly communicated and adequately supported by administrative controls to be effective. This is primarily where the Department failed in this case.

[95] In order to find that the Department discharged its obligation to consider the Complainant’s expressed request, I would need to establish that the Department was in a position to exercise its discretion to limit the disclosure of the Complainant’s health information; the Department needed to be in a position where it could legitimately “turn its mind” to the wishes of the individual. In this case, the Department was precluded from exercising the discretion given to it under the Act to limit the disclosure of health information in response to an expressed request from an individual in two ways. The first way in which the

consideration was limited was the Department's policy decision to refer individuals making expressed requests to other custodians. The second area of limitation was the Department's failure to adequately implement a masking solution in Alberta Netcare that would allow participating custodians to limit the disclosure of health information. While I appreciate the Department's argument that the functionality existed in 2006 and that the availability of masking was discussed with regional health authorities in 2007, it does not alter the fact that a formal decision to implement the functionality across Alberta Netcare was not reached until April 2008 and that the required administrative tools and processes are still in development.

[96] I find that AHW did not discharge their obligation to consider the expressed wishes of the Complainant and will recommend that the Department respond in writing to the Complainant's expressed request and also formalize their implementation strategy for the deployment of masking functionality in Alberta Netcare.

Summary of Findings

[97] In the course of conducting this investigation into the disclosure of health information through Alberta Netcare, I made the following findings:

- The *Health Information Act* (HIA or "the Act") applies to the Complainant's Netcare record in its entirety.
- The Pharmacist was required by the Act to disclose health information related to the Complainant's dispensed drugs to AHW and the Complainant's consent was not required for this to take place.
- AHW is authorized under the HIA to collect the Complainant's health information from the Pharmacist without the Complainant's consent.
- DTHR is authorized under the HIA to disclose the Complainant's health information to Capital Health without the Complainant's consent.
- No Netcare user accessed the Complainant's Netcare record; therefore, AHW and DTHR did not disclose the Complainant's health information through Alberta Netcare.
- The Pharmacist discharged his duty under section 58(2) of the Act to consider the expressed wishes of the Complainant related to limiting disclosure of her health information; however, he was precluded from acting on those wishes as he was required by the HIA to disclose the health information in question to AHW.
- The Complainant also conveyed her expressed wishes related to the disclosure of her health information through Alberta Netcare to AHW.
- The Department, as are all custodians participating in Alberta Netcare, is obligated to consider the expressed wishes of individuals when they make health information available for disclosure through Alberta Netcare.
- The Department did not discharge its duty under section 58(2) of the HIA to consider the Complainant's expressed request that her health information not be made available through Alberta Netcare.

Recommendations

[98] During the course of this investigation, AHW committed to fully deploy the masking functionality that exists within Alberta Netcare. Implementation of this functionality will provide some mechanism for participating custodians to advise other Netcare users of the expressed wishes of a patient related to the non-disclosure of their health information and restrict access to that information unless certain unmasking criteria are met.

[99] I acknowledge the participation of Alberta Health and Wellness, the David Thompson Health Region and Mr. Gustafson in this investigation. I also acknowledge the willingness of the Department to move towards expedited implementation of a centralized masking process, and make the following recommendations:

1. The Department respond to the Complainant's expressed request for her health information to be masked in Alberta Netcare and provide the Information and Privacy Commissioner with a copy of this response.
2. The Department, prior to May 31, 2008, provide the Commissioner with a detailed project plan for GPLM implementation and deployment for his review and comment.
3. The Department develop the administrative controls necessary to support the deployment of GPLM including policies, procedures, training materials, supporting scripts, documentation and instructional material for custodians on the use of GPLM and provide these to the Commissioner in accordance with the timelines laid out in the deployment plan described in the second recommendation.
4. The Department develop policies and procedures that detail their processes for considering an expressed request pursuant to section 58(2) of the HIA and provide those to the Commissioner for his review and comment by May 31, 2008.
5. The Department expand the scope of their current patient centered communication materials about Alberta Netcare to provide explicit information related privacy rights in Alberta Netcare, including specific information on how a patient would go about requesting that their health information be masked or unmasked in Alberta Netcare.
6. The Department update the Portal 2006 PIA to ensure that it is an accurate description of Alberta Netcare, update the associated privacy risk assessment and mitigation strategy to assess the privacy impact of a centralized approach to masking and submit the revised PIA to the Commissioner for review and comment before July 1, 2008.

[100] The Department has agreed to all of these recommendations, and has already responded to the Complainant thereby fulfilling the first recommendation.

Conclusion

[101] In order to expedite development, deployment and uptake of Alberta Netcare, Alberta Health and Wellness sought amendment of the *Health Information Regulation* in 2007 to make the disclosure of pharmacy information from community based pharmacies to the Department mandatory.

[102] The decision to invoke the unique powers given to them under section 46 of the HIA distances the Department from their role as Information Manager of Alberta Netcare and places them squarely in the role of custodian in relation to the information they compel from pharmacists. As such, the Department comes to bear all the rights, powers and obligations placed on custodians under the HIA. This includes the obligation to disclose the most limited amount of information and consider the expressed wishes of individuals related to the disclosure of health information through Alberta Netcare.

[103] The potential benefits of EHR systems like Alberta Netcare are undeniable; however, these systems must be developed with the privacy rights of Albertans and the duties laid out in the *Health Information Act* in mind. Any health information system that is designed specifically to facilitate disclosure of health information, as is Alberta Netcare, must have the capacity to limit the disclosure of health information at the request of the individual and this functionality must be communicated to those using the system and supported by robust administrative privacy controls.

[104] Failure to adequately implement masking in Alberta Netcare between system roll-out in early 2006 and the final stages of this investigation in April 2008 placed many participating custodians in the position of routinely making information available through Alberta Netcare without the ability to meet their legal requirement to limit the disclosure of health information or consider the wishes of their patients when deciding how much health information to disclose. The Department acknowledged this gap during the investigation and has taken steps to immediately implement masking functionality in Alberta Netcare, communicate the availability of the solution and develop the required administrative controls.

[105] The Department self-identified the need for GPLM in the Portal 2006 Privacy Impact Assessment, which was submitted to the OIPC in January 2006. I remain concerned over the length of time it has taken to deploy masking in Alberta Netcare. I was not comforted to learn as part of this investigation that masking functionality has been available in Alberta Netcare for almost two years but is only being meaningfully implemented now, particularly when this information is viewed in light of the exponential increase in the amount of health information available through Alberta Netcare during that same time frame and the fact that the projected number of Netcare users is expected to surpass 22 000 at some point this spring.

[106] In closing, I find it necessary to step back from the somewhat technical discussion of EHR architectures, masking solutions and the application of the

HIA and reflect on the experience of the Complainant in this case. In her written submissions, the Complainant clearly stated her frustration with the inconsistent and inaccurate information she received in response to her inquiries about how she could exercise her privacy rights within Alberta Netcare. She was told by her pharmacist that information could not be withheld from Alberta Netcare based on information he states he received from the Department. When she contacted the Department, she was told that information could be limited through masking but that she would have to talk to her pharmacist. Her pharmacist advised her was unable to apply masking, as the IEP he had been provided with clearly states that only GPLM is acceptable in Alberta Netcare but that he had not been told how to apply GPLM. When she wrote to the Minister to express this frustration, she was told again of the ability to mask information and was directed to make this request to her regional health authority, although this investigation has confirmed that the RHA in which the Complainant received health services, like the Pharmacist, was not aware of the ability to apply a global mask in Alberta Netcare as the Department had not yet adequately implemented and communicated the masking functionality that was available in the system.

[107] I do not believe that Albertans should be required to exert unreasonable efforts to gain knowledge about how their health information is managed in Alberta Netcare. This knowledge is essential if Albertans are to be able to meaningfully exercise the rights conveyed on them by the HIA, including the right to request access to and correction of health information in Alberta Netcare, the right to receive a disclosure log that lays out which custodians have accessed their Netcare record and the right to express wishes related to the disclosure of their health information. It is imperative that custodians communicate with Albertans on these points, and that they do so accurately and consistently.

[108] The Department has committed to move ahead with implementation of comprehensive masking in Alberta Netcare, and will be developing the required administrative controls and processes over the next several months. Our Office will work closely with the Department to ensure that it meets these commitments.

Submitted by

Leahann McElveen
Portfolio Officer, Health Information Act

Appendix A – Summary of Information in Netcare Records

Demographic Information (obtained through AHW's Person Directory and made available through Netcare through Capital Health's Enterprise Master Patient Index)

- Name
- Alberta Health Care Number
- Address
- Gender
- Date of Birth

Pharmacy Information (obtained from the Pharmacy System and made available through Netcare through Alberta Health and Wellness' Pharmaceutical Information Network)

- Name
- Gender
- Alberta Health Care Number
- Date of birth
- Product ID of dispensed drug
- Dosage details of dispensed drug
- Dispensing details of dispensed drug
- Prescription details of dispensed drug
- ID number of health service provider who prescribed the drug
- ID number of the health service provider who dispensed the drug

Laboratory Information²⁰ (obtained from the non-metro regions via RSHIP and made available through Netcare through Capital Health's Lab Repository)

- Name
- Alberta Health Care Number
- Address
- Admitting Physician Name
- Age
- Gender
- Date of birth
- Patient status (inpatient, outpatient)
- Blood type
- Ordered test
- Date of specimen collection, system enter and received
- Specimen status
- Requisitioning doctor
- Requisitioned test
- Result of requisitioned test
- Site where test performed
- Transfusion reaction

²⁰ All lab information relates to blood bank, general labs, microbiology and pathology services.

Appendix B - Alberta Netcare Data Availability (June 2007 from Alberta Health and Wellness)

Data Source	Date Available in Alberta Netcare	Results Available Back To:	Comments
Patient Demographics (see Note 1)			
Provincial Person Directory	20-Mar-06	1-Mar-93	Identifier Numbers and Demographic data for people registered through Alberta Health with a provincial Personal Health Number (PHN) and/or Unique Lifetime Identifier (ULI)
Patient Event History			
Capital Health Region	20-Mar-06	1-Jan-96	Events from all regional facilities.
Drug Data			
Prescriptions	20-Mar-06	26-Jun-05	Prescriptions entered by physicians into the PIN application for those physicians using PIN directly and those whose EMRs are messaging with PIN. Goal is 80% of Prescriptions by March 2008. Also includes "Inferred" Prescriptions generated from Group 66 and Pharmacy Batch dispenses indicated below.
Allergies and Intolerances	20-Mar-06	26-Jun-05	Allergies and intolerances entered by physicians into the PIN application
Dispensed Drugs	20-Mar-06	1-Dec-99	All dispenses for Group 66 (seniors program) patients
	20-Mar-06	1-Jul-04	Dispense records submitted from participating pharmacies through pharmacy batch. As of June 2007 there are 550 of ~1000 pharmacies participating in Pharmacy Batch with all pharmacies to be capable of submitting dispenses by September 1, 2007. Excludes hospital pharmacy on discharge.
Lab Data			
Alberta Cancer Board	10-May-06	20-Mar-06	Cross Cancer Institute lab data
	04-May-07	24-Apr-07	Tom Baker Centre lab data from CLS
Provincial Lab	20-Mar-06	1-Dec-04	Results for entire province.
Capital Health Region	20-Mar-06	1-Apr-02	Capital Health lab data (UAH labs and DKML)
	20-Mar-06	1-Oct-04	DKML Microbiology data. Tests

			performed before Oct 1/04 will only display name of test, not results.
	20-Mar-06	17-Jun-05	Tuberculin Skin Tests (TST). All records that have a PHN/ULI in the Microbiology folder.
Calgary Health Region	04-May-07	24-Apr-07	General lab, microbiology, pathology and blood bank results from Calgary Laboratory Services. Results from 8 rural Calgary sites to be added by Jan 2008
			Excludes HIV and 4 special coagulation tests where display in Portal is clinically unacceptable.
Aspen Health Region	20-Mar-06	21-Feb-06	Triple G lab results from 21-Feb-06 to 21-Jul-06
	25-May-07	16-May-07	Meditech General Lab results from regional facilities
	29-Jun-07	19-Jun-07	Meditech Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
Chinook Health Region	25-May-07	16-May-07	Meditech General Lab and Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
David Thompson Health Region	25-May-07	16-May-07	Meditech General Lab and Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
East Central Health Region	25-May-07	16-May-07	Meditech General Lab and Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
Northern Lights Health Region	20-Mar-06	1-Apr-02	All Northern Lights lab data (DKML)
Palliser Health Region	25-May-07	16-May-07	Meditech General Lab and Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
Peace Country Health Region	25-May-07	16-May-07	Meditech General Lab results from regional facilities
	29-Jun-07	19-Jun-07	Meditech Microbiology results from regional facilities
			Meditech Pathology and Blood Bank results to be added by Dec 2007
Diagnostic Imaging Data (see Note 2)			
Capital Health Facilities	20-Mar-06	1-Aug-03	DI text reports from regional facilities except as below:
	20-Mar-06	14-Oct-03	From UAH starting October 14, 2003.

	20-Mar-06	12-Mar-04	From RAH starting March 12, 2004.
Aspen Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
Chinook Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
David Thompson Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
East Central Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
Northern Lights Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
Palliser Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
Peace Country Health Region	25-May-07	16-May-07	DI text reports from regional facilities.
Alberta Cancer Board	29-Jun-07	7-Jun-07	DI text reports from the Cross Cancer Institute.
Medical Imaging Consultants (MIC)	20-Mar-06	4-Nov-04	Capital Community/Private Office DI Text Report results. After 26APR07, in .pdf format.
Insight Medical Imaging (IMI)	20-Mar-06	16-Dec-04	Capital Community/Private Office DI Text report results.
CML HealthCARE	29-Jun-07	22-Jan-07	Capital Community/Private Office DI text report results in .pdf format.
Immunizations, Emergency Department Records, ECGs			
Capital Health Region	20-Mar-06	1-Jan-95	Public Health Immunizations; all records that have a PHN/ULI.
	29-Jun-07	12-Feb-07	Scanned Emergency Department Records as of: Sturgeon - 12 February 2007, Leduc - 6 June 2007, Royal Alexandra - 21 May 2007, University - 23 May 2007, Northeast - 28 May 2007, Grey Nuns - 30 May 2007 Misericordia - 4 June 2007, Devon - 11 June 2007, Westview - 11 June 2007, Fort Saskatchewan - 13 June 2007, Redwater - 13 June 2007
	29-Jun-07	16-Feb-07	ECG results from the Sturgeon Community Hospital starting 16-February-2007. Other sites' ECGs will be available on a staggered basis beginning Summer/07.
Transcribed Reports			
Capital Health	20-Mar-06	1-Jul-03	Includes Consultations (except from UAH), Histories, Letters, Discharge Summaries, Operative Procedures from regional facilities.
	20-Mar-06	17-May-05	Community Care Client Profiles - displayed under Summary Reports

			folder.
Alberta Cancer Board	20-Oct-06	29-May-06	Physician Progress Notes, Admission Histories, Discharge Summaries, Initial Consultations
	29-Jun-07	14-Jun-07	Operative Reports from Cancer Surgery Alberta for entire province.

Note 1 - Conversion to Provincial Client Registry by summer 2008

Note 2 - PACS images to be added as per direction from Provincial PACS project