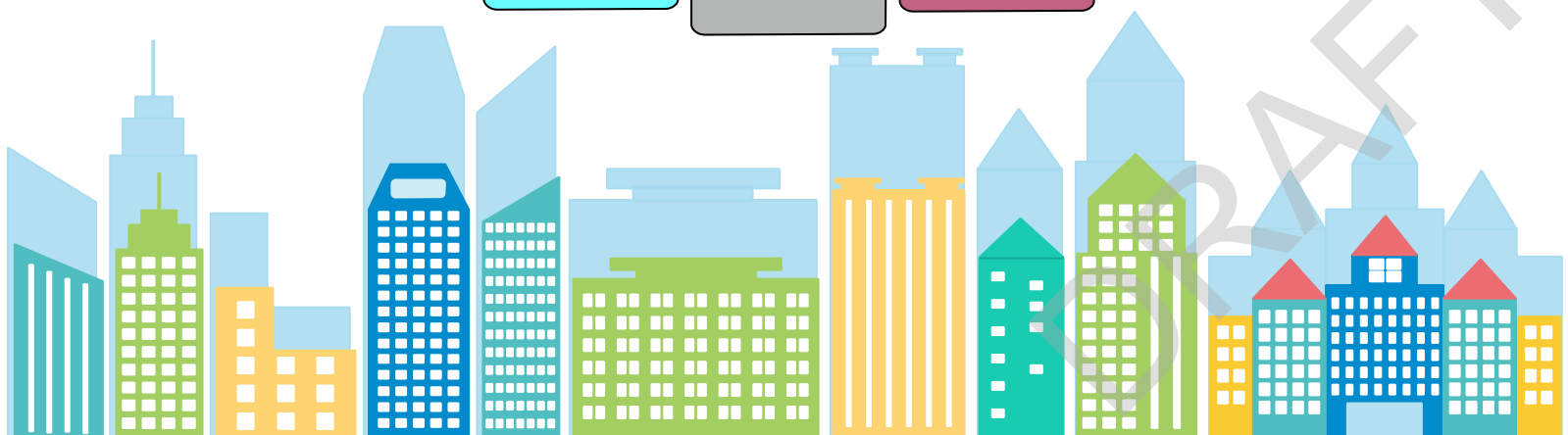
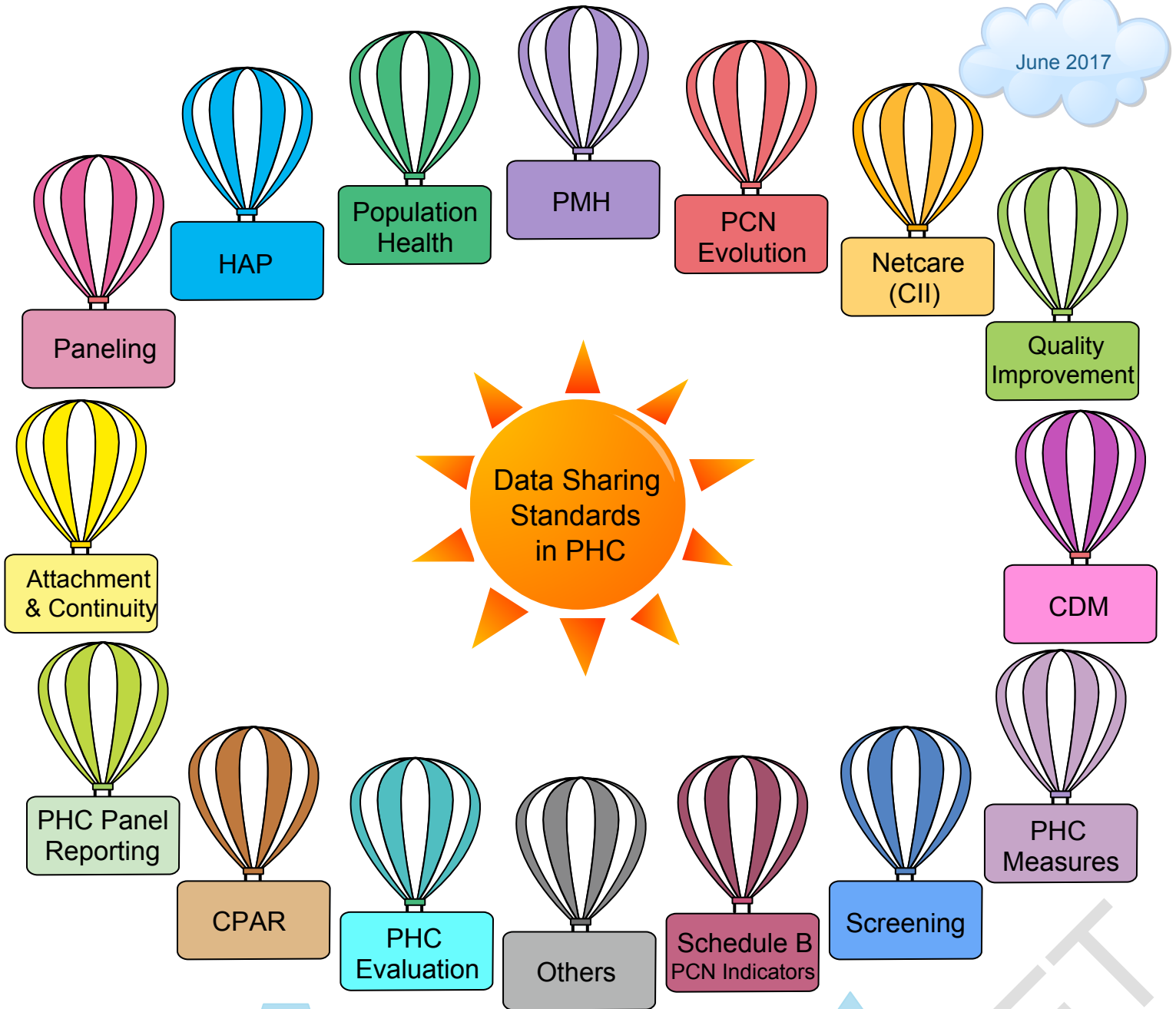


FREQUENTLY ASKED QUESTIONS  
DATA SHARING STANDARDS IN PRIMARY HEALTH CARE

June 2017



## **FREQUENTLY ASKED QUESTIONS**

### **Data Sharing Standards in Primary Health Care**

#### **INTRODUCTION**

Data sharing for secondary use purposes is coming to Primary Health Care (PHC)!

[https://www.albertadoctors.org/emr\\_resources/guide-data-sharing-standards.pdf](https://www.albertadoctors.org/emr_resources/guide-data-sharing-standards.pdf)

The Data Sharing Standards will guide individually identifying health information data matching and sharing for secondary use purposes in Primary Health Care.

It will enable and align with various provincial initiatives:

- PMH – Patient's Medical Home  
[http://www.cfpc.ca/uploadedFiles/Resources/Resource\\_Items/PMH\\_A\\_Vision\\_for\\_Canada.pdf](http://www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada.pdf)  
<http://www.topalbertadoctors.org/change-concepts/introduction/patientsmedicalhomeinalberta>
- PCN Evolution – Primary Care Network Evolution  
<http://pcnevolution.ca/Pages/default.aspx>  
<http://pcnevolution.ca/SiteCollectionDocuments/PCNe%20Overview/PCN%20Evolution%20Vision%20and%20Framework.lrg.pdf>
- Netcare (CII) – Community Information Integration  
*(A link to the reference will be provided later).*
- Healthcare Quality Improvement  
<http://www.ihl.org/Pages/default.aspx>
- CDM – Chronic Disease Management initiatives  
<http://www.topalbertadoctors.org/pact/>
- PHC Measures – Development of Primary Health Care Measures  
*(A link to the reference will be provided later).*
- Screening initiatives  
<http://www.topalbertadoctors.org/asap/>
- Schedule B – PCN indicators  
*(PCNs may refer to Schedule B of their Grant Agreement for these indicators)*
- PHC Evaluation  
<http://www.health.alberta.ca/documents/PHC-Evaluation-Framework-2013.pdf>
- CPAR – Central Patient Attachment Registry  
*(A link to the reference will be provided later).*
- PHC Panel Reporting (HQCA)  
<http://hqca.ca/health-care-provider-resources/physician-panel-reports/>
- Attachment and Continuity  
<http://www.topalbertadoctors.org/tools--resources/patientsmedicalhome/#pmhevidence>
- Paneling  
<http://www.topalbertadoctors.org/file/guide-to-panel-identification.pdf>
- HAP – Health Analytics Portal  
*(A link to the reference will be provided later).*
- Population Health  
<http://www.health.alberta.ca/services/PHC-community-profiles.html>  
[http://www.ahw.gov.ab.ca/IHDA\\_Retrieval/](http://www.ahw.gov.ab.ca/IHDA_Retrieval/)
- Others

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## SECTION A: DATA SHARING AND PANELING

### 1. What is primary and secondary use of data?

**“Primary use of health data** is the use of personal health information by the organization or entity (health facility or health provider) that produced or acquired the data in the process of providing real-time, direct care of an individual<sup>1</sup>”. In this case ‘real-time’ includes care when patient not present e.g. sharing lab results. The Health Information Act allows for the collection of health information for the purposes of assessing, diagnosing, and treating the patient or providing other health-related services, consent is not required.

**“Secondary use of health data** refers to the use of personal health information for purposes other than direct care. That includes its use for quality or safety measurement; outcome analysis; clinical and health services research or epidemiological studies; costing and funding of health services; public health surveillance; policy development; provider or institution certification and/or accreditation.”<sup>1</sup> “Secondary uses of the information are necessary to support the effectiveness, efficiency, and sustainability of the health system.”<sup>1</sup>

Please refer to section 27 of the Health Information Act to learn about specified uses of individual identifying health information (e.g., internal management purposes, planning, resource allocation, evaluation, etc.) Please note: Under the Health Information Act there is no differentiation between primary or secondary uses.

If you would like to learn more about primary and secondary use of health information, please refer to:

CPSA (2009). Data Stewardship: Secondary Use of Health Information Retrieved from [http://cpsa.ca/wp-content/uploads/2015/05/Secondary\\_Use\\_of\\_Health\\_Information\\_-\\_Final\\_December\\_2009.pdf?x91570](http://cpsa.ca/wp-content/uploads/2015/05/Secondary_Use_of_Health_Information_-_Final_December_2009.pdf?x91570)

<sup>1</sup> Abrams, K., & Gibson, C. J. (2013). Fundamentals of Health Information Management. Canadian Health Information Management Association (CHIMA). Ottawa, ON: Canadian Healthcare Association.

## 2. What is the difference between formal paneling, attachment and confirmed panel?

It is important to understand the differences between terminologies:

(a) **Panel** is the set of patients attached to a specific primary provider.

**Panel identification** is a provider-oriented process that helps identify and list the individuals who have a relationship with a provider based on information held by the provider (described in Panel Identification Guide and facilitated by TOP:

<http://www.topalbertadoctors.org/file/guide-to-panel-identification.pdf> )

(b) **Attachment** is the expression of a continuous and longitudinal relationship between individuals ("persons" or "patients") and their primary provider(s).

Primary Provider - the provider(s) mainly responsible for providing comprehensive primary health care longitudinally over time to a panel of patients.

**Attachment process** supports paneling by reaching verbal or written agreement between an individual and a primary provider to define the relationship between that individual and primary provider. There are 2 types of attachment process:

- ❖ **Formal attachment** commits a primary provider and an individual to an exclusive relationship through a signed agreement that represents their mutual expectations and obligations. This is one means by which we reinforce continuity of care.
- ❖ **Relational attachment** - is a conversation between a primary provider / interdisciplinary teams and an individual, where both agree the physician is the individual's primary provider. The relational attachment process represents an ongoing relationship and is another means by which we support continuity of care.

(c) **Confirmed Patient Panel** – is a group of individuals with whom the relationship between the physician and these individuals has been confirmed by a conversation or signed agreement between the physician or clinic staff member and the individual, where both physician and individual agree that the physician is the primary provider. The confirmed patient panel is the result of either a formal or relational attachment process.

All these processes have one thing in common: an established relationship between an individual and a primary provider.

### 3. What is the difference between primary care and primary healthcare?

“**Primary care** refers to the level of the health system that provides person-focused care over time for prevention and treatment of common health problems, first contact access for new health problems, and coordination of care with other levels of service (e.g., hospital, specialty care, continuing care).[i] Traditionally primary care was organized around healthcare services provided by a primary care physician (family physician - FP), often working in collaboration with other healthcare providers to meet a broad spectrum of patient health needs. Services typically include: health and wellness promotion; disease and injury prevention; diagnosis and treatment of short-term acute health issues; referral of more complex issues; ongoing management of chronic conditions; and, coordination with other levels of care.

**Primary healthcare** encompasses a range of additional services and models of care that rely on other healthcare professionals and non-medical healthcare providers, and it places a greater emphasis on factors influencing health, such as addressing social determinants of health by connecting people with social supports that influence their health status.[ii],[iii]”

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[i] Starfield B. Deconstructing primary care. In: Showstack J, Rothman AA, Hassmiller S. The Future of Primary Care. San Francisco: CA: Jossey-Bass; 2004. p. 61-88.

[ii] Alberta Health. Primary health care [Internet]. Edmonton, Alberta, Canada: Government of Alberta; 2013 [cited 2013 Nov 26]. Available from: <http://www.health.alberta.ca/services/primary-health-care.html>

[iii] Health Council of Canada. Health Care Renewal in Canada: Accelerating Change [Internet]. Ottawa, Ontario, Canada: Health Council of Canada; 2005 Jan [cited 2014 Jan 9]. Available from: [http://healthcouncilcanada.ca/rpt\\_det.php?id=170](http://healthcouncilcanada.ca/rpt_det.php?id=170)



#### 4. What is the confirmation date & how can I report it?

The confirmation date is the most recent date on which the physician (or clinic staff member) and the individual both agreed that the physician is the individual's primary provider.

Recording the confirmation date is an extension of formal and relational attachment and is the means by which the physician / PCN evidence that the relationship has been confirmed.

Reporting the patient ID and confirmation date to the data providers (i.e., AH, AHS, the HQCA) is the means by which individually identifying data is accessed.

The Guide for Data Sharing Standards in Primary Health Care<sup>2</sup> states that individually identifying data for secondary use of health data will be shared only for individuals whose confirmation date is within three years of the date of the data request.

The Guide for Data Sharing Standards in Primary Health Care does not identify one approach to extracting the confirmation date from your EMR as this will be dependent on where you record that date. Due to different types of EMRs, there are different terminologies and extraction options for the confirmation date. We encourage you to work with TOP and your PCN to support you in developing a method that will work for you. In some cases, a manual assignment of a confirmation date may be preferable.

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<sup>2</sup> AH-AHS-HQCA-AMA/PCN PMO-PCNs. (2017, January). *The Guide for Data Sharing Standards in PHC*. Retrieved from [https://www.albertadoctors.org/emr\\_resources/guide-data-sharing-standards.pdf](https://www.albertadoctors.org/emr_resources/guide-data-sharing-standards.pdf)

#### 5. What do we do if an individual chooses to 'opt-out' of data-sharing?

All individuals have the right to an "expressed wish" that their identifiable data not be shared with other agencies. If an individual expresses their wish to any party (i.e., physician, PCN staff, AHS staff, AH staff), it is incumbent on the party who receives the request to consider the individual's expressed wish. This process should be managed by custodians in compliance with the HIA in addition to ethical considerations when sharing data between primary care providers.

**6. What is the difference between the information provided/shared by AH, AHS and HQCA?**

The Data Sharing Standards provide guidance on **HOW** individually identifying data should be shared and released to meet all privacy requirements. We still need to identify and explain **WHAT** will be shared by each agency (i.e., AH, AHS and the HQCA). This will be part of an implementation plan which is currently under development.

**7. Will the Data Sharing Standards enable physicians to access specific data to answer a specific data question, rather than an entire dataset?**

Yes. Physicians and PCNs are encouraged to engage with AH, AHS, and the HQCA to help formulate their 'questions' and get the data they require for their quality improvement initiatives.

**8. Can physicians receive individually identifying data from AH, AHS and HQCA for secondary use purposes on unattached patients (e.g. walk-ins)?**

The scope of the Data Sharing Standards is currently focused on attached patients. However, information on unattached patients can be shared depending on the purpose. For example, Physicians can receive individually identifying data for unattached patients for research purposes, but research is out of scope of the Data Sharing Standards. The privacy requirements for research are outlined in **question 17**.



## 9. What is the connection between the Data Sharing Standards and the Central Patient Attachment Registry (CPAR)?

The CPAR will be a common Provincial database where patient and primary provider attachment information will be recorded. The project is being rolled out in 3 phases:

- (a) design (Sept '17);
- (b) transition current practice to CPAR (Oct '17 - Dec '17); and
- (c) go live (Jan '18 onwards).

The registry will be a major enabler for relational continuity resulting in better health outcomes, quality of care and coordination of care, and informational continuity leading to better handoffs, better communication and less duplication of care.

Data sharing between primary providers will be governed by the appropriate privacy, access and audit control and will also enable family physicians to use data for secondary use purposes. In this sense, it will be important that the provisions for appropriate and secure data sharing for secondary use of health data for CPAR and that of the Data Sharing Standards are aligned.

## 10. What is the connection between the Data Sharing Standards and the CPCSSN portal?

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) is a national initiative that *“collects data to organize and maintain a sentinel surveillance system that contributes to the knowledge development about the health of Canadian and to conduct research that strengthens the study of Canadian primary health care”*<sup>3</sup>. All organisations with whom we share data, including CPCSSN, will need to comply with the Health Information Act and Data Sharing Standards to ensure safe, secure and appropriate data sharing between all agencies.

<sup>3</sup> CPCSSN Mission & Goals. Retrieved from <http://cpcssn.ca/about-cpcssn/mission-goals/>

## SECTION B: PRIVACY REQUIREMENTS

### 11. What is the 'Notice of Collection' and what should it contain?

The HIA requires a 'Notice of Collection' (typically a poster) to be displayed in each clinic in areas where health information is being collected (e.g., in waiting areas).

Section 22(3) of the Health Information Act states that this poster must contain the:


- 1) purpose for which the information is collected,
- 2) specific legal authority for the collection, and
- 3) title, business address and telephone number of someone (affiliate or custodian) who can answer any questions about the collection.

Please see an example of the Notice of Collection below.

[https://www.albertadoctors.org/emr\\_resources/guide-data-sharing-standards.pdf](https://www.albertadoctors.org/emr_resources/guide-data-sharing-standards.pdf)

[INSERT YOUR CLINIC NAME OR/AND LOGO]

**Your  
health  
information  
is  
collected  
and  
protected  
under  
Alberta's  
Health  
Information  
Act**



We respect your confidentiality and privacy. Your information is collected, used, disclosed and protected according to the provisions of provincial and federal legislation.

Your information is collected by your family physician and his/her team in accordance with section 20 of the *Health Information Act*. The purpose of this collection is primary for:

- Providing health services
- Determining eligibility for health services
- Processing payments for health services
- Conducting research
- Providing for health services provider education
- Internal management purposes to improve patient care

Information will be collected directly from you, except in the limited circumstance where we are authorized by the HIA to indirectly collect such information.

**Questions related to the collection and privacy of your information should be directed to:**

[INSERT YOUR PHYSICIAN LEAD NAME OR CLINIC MANAGER/PRIVACY OFFICER AND HIS/HER CONTACT INFORMATION]

## 12. What is a Privacy Impact Assessment (PIA) and when is it required?

A PIA is a legislative requirement to assess the privacy impact of collection, use and disclosure of individually identifying health information on the individuals who are subject of the information, when implementing or changing administrative practices or information systems (HIA s.64(1)). A PIA must be prepared and submitted by a custodian to the Office of the Information and Privacy Commissioner of Alberta (OIPC) for review and comment before implementing any new practices or systems, or changing any existing practices and systems relating to the collection, use and disclosure of individually identifying health information (HIA s.64(2)).

For example, physicians - custodians of the health information who are participating in the PCN data sharing initiative with AHS, AH and HQCA for secondary use purposes are required to submit a PIA prior to implementation of the data sharing initiatives.

*"PIA is a process of analysis that helps to identify and address potential privacy risks that may occur in the operation of a new or redesigned project."*

<https://www.oipc.ab.ca/action-items/privacy-impact-assessments.aspx>

Health Information Act (section 64 (1)) states that

*"Each custodian must prepare a PIA that describes how proposed administrative practices and information systems relating to the collection, use and disclosure of individually identifying health information may affect the privacy of the individual who is the subject of the information."*

Health Information Act (section 70 (2)) states that:

*"Before performing data matching under this section, the custodian or health information repository in whose custody and control the information that is created through data matching will be stored must prepare a PIA and submit the assessment to the Commissioner for review and comment".*

### 13. Do I need to create a new PIA for each data sharing activity?

No. If the practice of information sharing has already been documented in your current Privacy Impact Assessment (PIA), there is no need to create a new PIA for each new information sharing activity. The existing PIA could cover all information sharing activities at your clinic. If you are implementing changes to your data sharing practices, you must review your existing PIA to determine if amendments are required in compliance with HIA.

For example, A PIA should include information such as the type of information, information flows and legal authorities. If there are changes to what information is being shared or how the information is being used, then this will require an amendment to the PIA. Any significant change to what is described in the PIA (new vendor involvement, new security and privacy controls, etc.) should be submitted as a PIA amendment.

### 14. What is in place to protect physicians when individually identifying data is shared with PCNs for secondary use purposes?

An Information Management Agreement (IMA) should be in place between physicians and their PCNs when PCNs provide information manager services.

The IMA is a legal requirement under section 66 of the HIA. It is an agreement between a custodian of health information and an information manager (i.e., AHS, PCN, EMR vendor) that governs the terms under which the information manager, among other responsibilities prescribed by the HIA, “processes, stores, retrieves or disposes of health information; strips, encodes or otherwise transforms individually identifying health information, or provides information management or information technology services.”

It is important that the IMA includes the process / mechanism / circumstances by which a PCN can exchange individually identifying data provided by physicians on their behalf with AH, AHS & HQCA. The content of the IMA should be in compliance with the Health Information Regulation (Alberta Regulation 107/2016) section 7.2. <sup>4</sup>

<sup>4</sup>Alberta Health. *Health Information Regulation*. Retrieved from [http://www.qp.alberta.ca/documents/Regs/2001\\_070.pdf](http://www.qp.alberta.ca/documents/Regs/2001_070.pdf)

## 15. What type of agreement(s) is/are required between physicians and PCNs?

There could be three scenarios:

- ❖ **Information Management Agreement (IMA).** Physicians are required to have an IMA with their PCN when information management services are being provided to the physicians-custodians.
- ❖ All circumstances when an **Information Sharing Agreement (ISA)** is recommended are outlined in the **Standards of Practice** (College of Physicians & Surgeons of Alberta). <sup>5</sup> The HIA does not identify legal requirements for having an ISA, because the HIA was enacted to enable the sharing of health information among health care practitioners for the provision of care. There are legal authorities that allow for collection, use and disclosure of health information for the provision of care.
- ❖ A custodian is **not required to enter into an agreement** with another custodian to continue provision of health services (s.27 HIA). For example, no agreement is required when a physician shares patient information with a specialist to whom an individual was referred or with a pharmacist to whom the individual's prescription was faxed.

<sup>5</sup> College of Physicians & Surgeons of Alberta. *Standards of Practice*. Retrieved from <http://www.cpsa.ca/wp-content/uploads/2017/05/Consolidated-Standards-of-Practice.pdf>

The following resources are available to provide the guidance in different situations of data sharing and use:

**(a) AMA Privacy Agreement Matrix:**

<https://www.albertadoctors.org/leaders-partners/emrs/privacy/what-you-need-to-know-about-privacy-agreements>

**(b) Privacy Agreements:** Companion to “A Guide for Data Sharing Standards in PHC

[https://www.albertadoctors.org/emr\\_resources/companion-data-sharing-standards.pdf](https://www.albertadoctors.org/emr_resources/companion-data-sharing-standards.pdf)

## 16. What type of agreement is required between custodians, when data matching or other data transformation is involved and /or individually identifying data is shared between organizations?

The type of agreement depends on the circumstances, for example Information Management Agreements (IMAs) are required under the circumstances specified in s. 66(1) of the HIA. A PIA is required for data matching (under HIA s.70 (2)).

## 17. In what circumstances should I have an Information Sharing Agreement (ISA) in place?

Examples:

- ❖ In case of 'shared practice', when health information for all individuals is shared between physicians within the same clinic.
- ❖ When a physician retires, leaves or moves his/her practice.

Please refer to Standards of Practice (College of Physicians & Surgeons of Alberta) to explore more examples for ISA application:

<http://cpsa.ca/wp-content/uploads/2015/07/Consolidated-Standards-of-Practice-January-1-2017.pdf?x91570>

## 18. What privacy requirements are needed for research purposes?

The use and disclosure of individually identifying health information for research purposes is governed by Alberta's Health Information Act (sections 27 (d), 49-56(1), 72) and its regulations. Research provisions require the following (**not a complete list**):

- ❖ A research proposal which has been submitted to and approved by a Research Ethics Board (REB);
- ❖ Compliance with conditions suggested by REB, including any condition regarding obtaining the consent of the subjects of the information which is to be used in the research where applicable; and
- ❖ A research agreement to be in place with any custodians who will be disclosing information to, performing data matching for, or providing other services to facilitate the research of the researcher.

## 19. Do Electronic Medical Record (EMR) vendors require PIAs?

No. Vendors do not require PIAs. Only custodians are required to submit PIAs under the Health Information Act. If vendors are interested in assisting their clients in the PIA process they MAY contact the OIPC directly for guidance on how to do this.

## 20. Do EMR vendors require IMAs?

Yes. When an EMR vendor is identified as an information manager under HIA section 66(1), a custodian (e.g., physician) is required to enter into a written agreement with the information manager (HIA s. 66(2)).

Please see an example of the Vendor IMA:

<https://www.albertadoctors.org/leaders-partners/emrs/privacy/what-you-need-to-know-about-privacy-agreements>

## 21. Is it allowed to store health information outside of Alberta?

Yes, if an appropriate agreement is in place. Under section 8(4) of the Health Information Regulation<sup>6</sup>, the “*health information that is to be stored or used by a person in a jurisdiction outside Alberta, or that is to be disclosed to a person in a jurisdiction outside Alberta, custodians must enter into a **written agreement** with the person prior to the storage, use or disclosure of the information.*”<sup>7</sup>

<sup>6</sup> [http://www.qp.alberta.ca/documents/Regs/2001\\_070.pdf](http://www.qp.alberta.ca/documents/Regs/2001_070.pdf)

<sup>7</sup> <http://www.health.alberta.ca/documents/HIA-Guidelines-Practices-Manual.pdf>



## SECTION C: DATA SHARING TERMINOLOGY

### 22. What is “data matching”?

**“Data Matching** means the creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from 2 or more electronic databases, without the consent of the individuals who are the subjects of the information” (HIA s1(1)(g)).

### 23. What is the main difference in the terminology between “data” and “report”?

- ❖ **Data** - information in raw or unorganized form. Data is a set of values of qualitative or quantitative variables.
- ❖ **Report** - a document containing information organized in a narrative, graphic, or tabular form, prepared on ad hoc, periodic, recurring, regular, or as required basis.

### 24. What is the difference between research and non-research projects?

In Alberta, to determine the appropriate health ethics review process for a project, research is differentiated from non-research (e.g., quality improvement, evaluation) by considering the project's primary purpose.

- ❖ “If the primary purpose is to provide useful information within the context of a specific practice or setting” with no expectation that the results will be applicable elsewhere, the project is likely quality improvement or evaluation. **Quality improvement** is typically undertaken to improve service delivery “with a particular focus on eliminating waste, reducing variation or improving reliability.”<sup>1</sup> **Evaluation** uses information about “program activities, characteristics, and outcomes to make judgments about the program, improve program effectiveness, and/or inform decisions about future programming.”<sup>1</sup>
- ❖ **Research** is defined as “an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation.”<sup>2</sup> The primary purpose of

research is to obtain facts, principles or knowledge that can be “*applied broadly beyond the specific site, unit, or program under investigation*” (i.e., concept of generalizability). Research projects include specific design features that increase the confidence that that the resulting knowledge will be generalizable across a wide variety of contexts and not dependent on local variables or practices.

#### References:

<sup>1</sup> Alberta Project Ethics Community Consensus Initiative (ARECCI). ARECCI Project Ethics Course Reference. Edmonton: Alberta Innovates, 2015.

<sup>2</sup> Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2014.

[http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS\\_2\\_FINAL\\_Web.pdf](http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf)

## **APPENDIX A: ABBREVIATIONS**

**AH** – Alberta Health

**AHS** – Alberta Health Services

**EMR** – Electronic Medical Record

**HIA** – Health Information Act

**HQCA** – Health Quality Council of Alberta

**IMA** – Information Management Agreement

**ISA** – Information Sharing Agreement

**PCN** – Primary Care Network

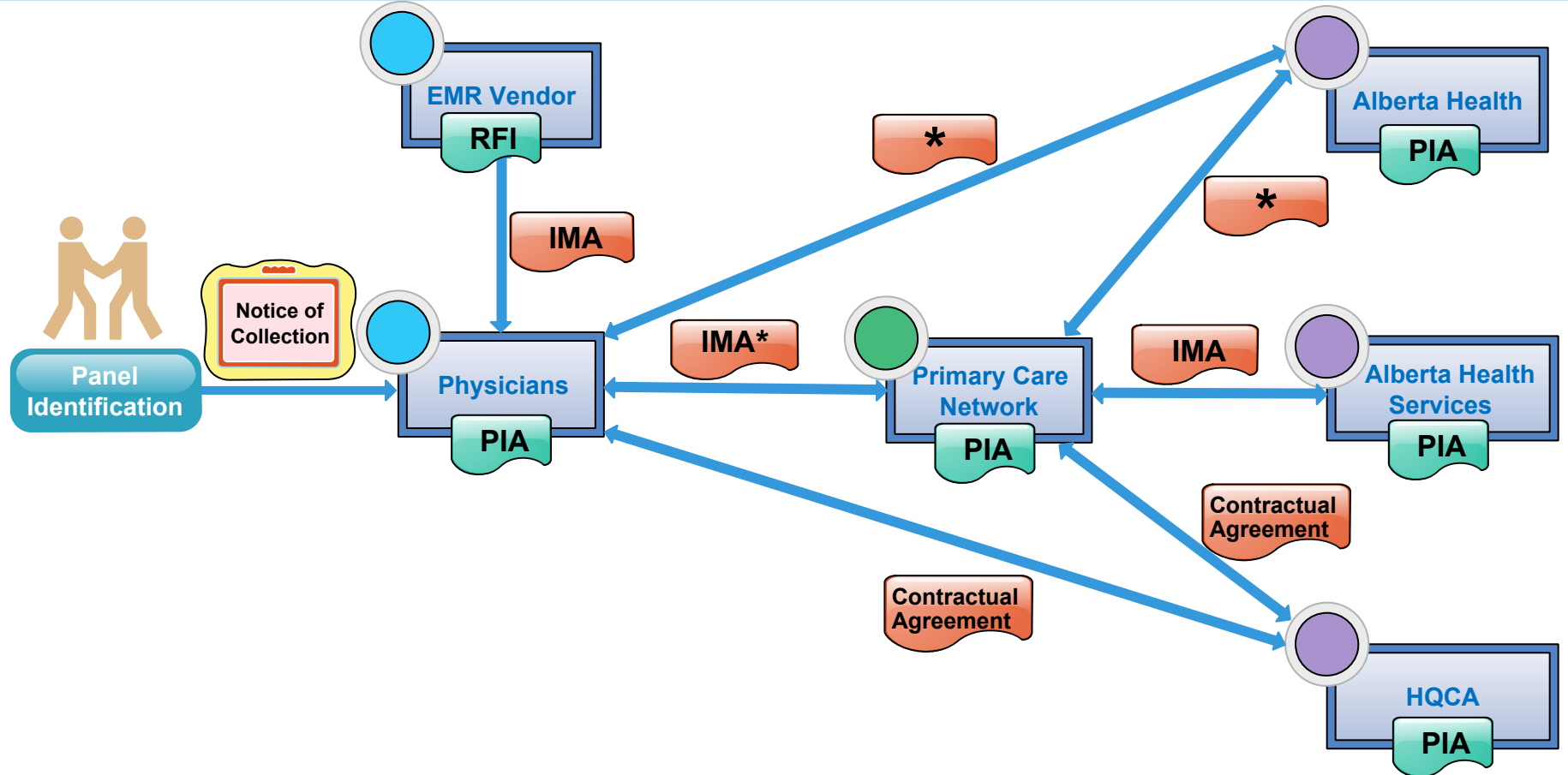
**PHC** – Primary Health Care








**PIA** – Privacy Impact Assessment

**TOP** – Toward Optimized Practice

APPENDIX B:

Privacy Requirements for Sharing Patient-Identifiable Health Information in Primary Health Care  
Secondary Use of Data (Quality Improvement, Business Planning, Evaluation, etc.)



-  - **Notice of Collection** of patient health information must be posted in the waiting areas of physician clinics.
-  - **Privacy Impact Assessment** for managing patient-identifiable data;  - **Request for Information**.
-  - **Information Management Agreement**.
-  - IMA should include a clause or mechanism that **authorizes a PCN to exchange** patient-identifiable data provided by physicians on their behalf with AH, AHS & HQCA .
-  - **Contractual Agreement** (can contain ISA or IMA elements).
-  - **TBD** . Nothing in place at this time.

### APPENDIX C: REVISION HISTORY

<b>Document Status (Version)</b>	<b>Date of Revision</b>	<b>Changes or Additions</b>