





FREQUENTLY ASKED QUESTIONS DATA SHARING STANDARDS IN PRIMARY HEALTH CARE









FREQUENTLY ASKED QUESTIONS

Data Sharing Standards in Primary Health Care

INTRODUCTION

DC	ata sharing for secondary use purposes is coming to Primary Health Care (PHC)!
htt	ps://www.albertadoctors.org/leaders-partners/clinic-patient-privacy/tools-and-resources.The
Do	ata Sharing Standards provide guidance on data sharing and matching of individually
	entifying health information for secondary use purposes in Primary Health Care.
	vill enable and align with various provincial initiatives:
_	Home to Hospital to Home Guideline (H2H2H)
	Home to Hospital to Home Transitions Alberta Health Services PMH – Patient's Medical Home
_	http://www.cfpc.ca/uploadedFiles/Resources/Resource Items/PMH A Vision for Canada.pdf
	https://actt.albertadoctors.org/PMH/Pages/default.aspx
	CII/CPAR (Community Information Integration /Central Patient Attachment Registry)
	https://www.albertanetcare.ca/learningcentre/CII-CPAR.htm
	https://actt.albertadoctors.org/PMH/panel-continuity/CII-CPAR/Pages/default.aspx
	PCN Evolution – Primary Care Network Evolution
	Learn more about PCN Evolution (2.0) Alberta Medical Association (albertadoctors.org)
	http://pcnevolution.ca/SiteCollectionDocuments/PCNe%20Overview/PCN%20Evolution%20Vis
	on%20and%20Framework.lrg.pdf
	Healthcare Quality Improvement
	http://www.ihi.org/resources/Pages/Measures/default.aspx
	CDM – Chronic Disease Management
	https://www.albertadoctors.org/services/media-publications/newsletters-
	magazines/digest/digest-archive/multidisciplinary-chronic-disease-mgmt
	https://www.albertahealthservices.ca/info/page11934.aspx
	,
	https://www.albertahealthservices.ca/assets/info/hp/phc/if-hp-phc-phcin-hthth-measures.pdf
	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_https://open.alberta.ca/publications/6862113
	PHC Panel Reporting (HQCA)
	http://hqca.ca/health-care-provider-resources/physician-panel-reports/
	Attachment and Continuity
	http://www.topalbertadoctors.org/toolsresources/patientsmedicalhome/#pmhevidence
	Paneling
	http://www.topalbertadoctors.org/file/guide-to-panel-identification.pdf
	HAP – Health Analytics Portal https://extranet.ahsnet.ca/hap/Pages/default.aspx
	Population Health
	https://open.alberta.ca/dataset?g=%22Primary+health+care+-

+community+profiles%22&sort=title string+asc&dataset type=publications

Interactive Health Data Application (gov.ab.ca)







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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!". In this case 'real-time' includes care when patient is 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." "Secondary uses of the information are necessary to support the effectiveness, efficiency, and sustainability of the health system."

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

¹ 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 ACTT: 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).

<u>Primary Provider</u> - 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 <u>signed agreement</u> 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 they 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]"

http://www.health.alberta.ca/services/primary-health-care.html

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

^[1] 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.

Alberta Health. Primary health care [Internet]. Edmonton, Alberta, Canada: Government of Alberta; 2013 [cited 2013 Nov 26]. Available from:







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 Care² 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 ACTT 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.

² 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







5. What do we do if an individual choses 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.

Note: The custodian's duty is to consider an expressed wish along with any other relevant factors. Therefore, the right to have an expressed wish considered does not equate to a right to veto the disclosure of health information where a disclosure is authorized without consent in the legislation.

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 CII/CPAR (Community Information Integration /Central Patient Attachment Registry)?

"CII/CPAR is the chosen vehicle to integrate community EMRs with two-way data flow. Community Information Integration (CII) is a system that transfers select patient information between community Electronic Medical Records (EMRs) and other members of the patient's care team through Alberta Netcare. The Central Patient Attachment Registry (CPAR) is a provincial system that captures the confirmed relationship of a primary provider and their paneled patients."

Retrieved from https://www.albertanetcare.ca/learningcentre/CII-CPAR.htm

Commonalities:

CII/CPAR and Data Sharing Standards guide Identify relationships between patients and their primary providers.

Distinctions:

"CII/CPAR enables sharing of important healthcare information between the patient's family physician and other providers in the patient's **circle of care.**"

Retrieved from https://actt.albertadoctors.org/PMH/panel-continuity/CII-CPAR/Pages/default.aspx

The Data Sharing Standards guide outlines the privacy **principle** of data sharing (correct information to the correct provider) for **secondary purposes** (evaluation, quality improvement, etc.) to enable primary care providers to access or match patientidentifiable data from other organizations for their confirmed patient panel (or access aggregate data if panel is not confirmed) to address a specific question that primary care providers want to study about their patient populations.

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"³. 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.

³ 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 Notice to be provided at the time of collection, and does not set out a particular method.

For example, it could be

- posters displayed in clinic in areas where health information is being collected (e.g., in waiting areas).
- notice statements may also be provided through other means such as audio recordings on phone lines or they may be included on forms patients are filling out.

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









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 <u>individually identifying</u> 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 <u>data matching</u> 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 s66:

"(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, or (c) provides information management or information technology services in a manner that requires the use of health information but does not include an individual employed by a custodian who performs any of the functions listed in clauses (a) to (c)."⁴

⁴The Health Information Act (PDF) - Alberta. Retrieved from http://www.qp.alberta.ca/documents/Acts/H05.pdf

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. ⁵

⁵Alberta Health. *Health Information Regulation*. Retrieved from 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). 5 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.6
- 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.

⁶ 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







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 Regulation⁷, 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."

⁷http://www.gp.alberta.ca/documents/Regs/2001 070.pdf

8 http://www.health.alberta.ca/documents/HIA-Guidelines-Practices-Manual.pdf







SECTION C: DATA SHARING TERMINOLOGY

22. What is "data matching"?

"<u>Data Matching</u> 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." 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."
- Research is defined as "an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation."² 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:

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

² 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







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

ACTT – Accelerating Change Transformation Team

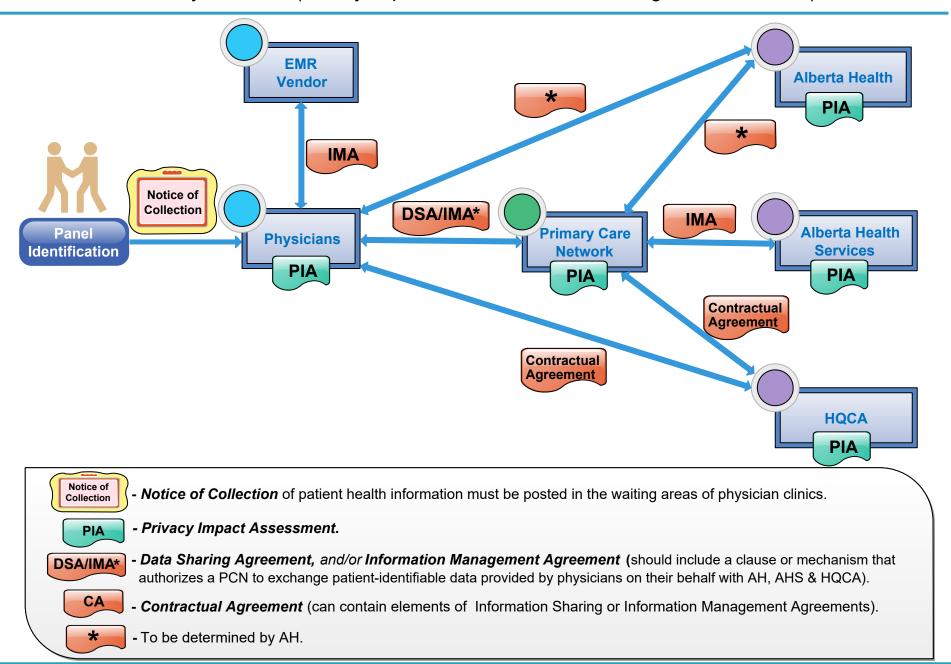






Privacy Requirements for Sharing Patient-Identifiable Health Information in Primary Care

Secondary Data Use (Quality Improvement, Business Planning, Evaluation, etc.)









APPENDIX C: REVISION HISTORY

Document Status (Version)	Date of Revision	Changes or Additions
Version 1.0	June 2017	The first copy was published
Version 2.0	March 2021	The second copy has updated links on p.2, question#5 on p.8, and question#9 on p.9, question #11 on p.10, question#14 on p.12, Appendix A and diagram on p. 19