



populationdata^{BC}

A PLATFORM SUPPORTING RESEARCH ON
HUMAN HEALTH, WELL-BEING AND DEVELOPMENT.

POPULATION DATA BC

Privacy in Health Research

Caitlin Pencarrick Hertzman

Population Data BC

University of British Columbia

CFRI, April 2012



OUTLINE

Introduction

Compliance

- Legislation
 - Current
 - 2011 Amendments
- Policies
 - Responsibilities
 - Best Practices

Process

- Data Access Requests
- Data Provision
- Publication, Archiving and Destruction

Take-aways

INTRODUCTION



POPULATION DATA BC OVERVIEW

Population Data BC is a multi-university, nationally active and recognised data and education research resource providing:

- Data linkage, development, and access to what is expected to be the world's most comprehensive data source for research in human health, well-being and development.
- A comprehensive education and training service on how to best use population health data.

Expectation:

Research using these data informs policy-making , leading to healthier communities.

POPULATION DATA BC OVERVIEW

A brief history

- | | |
|-------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1988 | Beginning of the BC Linked Health Database |
| 1996 | Centre for Health Services & Policy Research begins serving the research community |
| 2005 | New funding secured to support: <ul style="list-style-type: none">» Build-out of new space with enhanced physical and electronic security» Adding UBC partners (HELP, SOEH)» Adding non-health care databases |
| 2007 | Additional funding, additional (non-UBC) partners |
| 2008 | Population Data BC is born |
| 2009 | ISAs signed with BC Ministry of Health Services, BC Vital Statistics Agency and WorkSafeBC |

POPULATION DATA BC OBJECTIVE 1:

Broaden and deepen data available supporting research on human health, well-being and development

Current data holdings	Health care & health services	Population & demographic	Occupational & environmental	Early childhood & education
	<p>Medical Services Plan (BC Ministry of Health)</p> <p>PharmaCare (BC Ministry of Health)</p> <p>Hospital Separations (BC Ministry of Health)</p> <p>Home & Community Care (BC Ministry of Health)</p> <p>Mental Health (BC Ministry of Health)</p> <p>Registry Data (BC Cancer Agency)</p>	<p>Consolidation File (Medical Services Registration & Billing) (BC Ministry of Health)</p> <p>Births (BC Vital Statistics Agency)</p> <p>Stillbirths (BC Vital Statistics Agency)</p> <p>Marriages (BC Vital Statistics Agency)</p> <p>Deaths (BC Vital Statistics Agency)</p>	<p>WorkSafeBC Claim Files (WorkSafeBC)</p> <p>WorkSafeBC Firm Level Data (WorkSafeBC)</p>	<p>Early Development Instrument (HELP)</p> <p>Middle Years Development Instrument (HELP)</p>
Future	<p>BC Ambulance (BC Ambulance Service)</p> <p>Cardiac Services (Cardiac Services BC)</p> <p>Physicians & Surgeons File (College of Physicians & Surgeons BC)</p>	<p>Citizenship & Immigration Canada (Citizenship & Immigration Canada (Federal))</p>	<p>WorkSafeBC Exposure Data (WorkSafeBC)</p>	<p>BC K-12 Student Standard Testing School & District (BC Ministry of Education)</p>

LEGISLATION



Scope

Section 3 Scope

- 3 (1) This Act applies to all records in the custody or under the control of a public body, including court administration records, but does not apply to the following:
- (e) a record containing teaching materials or research information of
 - (i) a faculty member, as defined in the *College and Institute Act* and the *University Act*, of a post-secondary educational body,
 - (ii) a teaching assistant or research assistant employed at a post-secondary educational body, or
 - (iii) other persons teaching or carrying out research at a post-secondary educational body;

May exclude primary (researcher-collected) data from FIPPA

- Only if collected for the purposes of teaching or researching as a faculty member, teaching assistant, research assistant etc.
- Must still meet ethics and research agreement obligations as appropriate

Research: FIPPA

Section 33.1 Disclosure inside and outside of Canada

33.1 (1) A public body may disclose personal information referred to in section 33 inside or outside Canada as follows:

(s) in accordance with section 35 [*disclosure for research or statistical purposes*];

Provides authority for disclosure

Research: FIPPA

Section 35 Disclosure for Research for Statistical Purposes

35 (1) A public body may disclose personal information in its custody or under its control for a research purpose, including statistical research, only if

(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form or the research purpose has been approved by the commissioner,

(a.1) subject to subsection (2), the information is disclosed on condition that it not be used for the purpose of contacting a person to participate in the research,

(b) any data linking is not harmful to the individuals that information is about and the benefits to be derived from the data linking are clearly in the public interest,

Data not collected for research purposes can be disclosed for research purposes if:

- The research can't be done without it
- It's not harmful to individuals and is in the benefit of society

Research: FIPPA

Section 35 Disclosure for Research for Statistical Purposes Continued

35 1(c) the head of the public body concerned has approved conditions relating to the following:

- (i) security and confidentiality;
- (ii) the removal or destruction of individual identifiers at the earliest reasonable time;
- (iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body, and

(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.

The Data Steward has responsibilities to review and approve the application

- Security, de-identification, use only for original purpose
- Must be in the form of an agreement – usually a Research Agreement

Research: FIPPA

Section 35 Disclosure for Research for Statistical Purposes Continued

35 (2) Subsection (1) (a.1) does not apply in respect of research in relation to health issues if the commissioner approves

- (a) the research purpose,
- (b) the use of disclosed information for the purpose of contacting a person to participate in the research, and
- (c) the manner in which contact is to be made, including the information to be made available to persons contacted.

Allows one to Request to Contact Individuals as Participants

- Commissioner must approve
- Not a clear or quick method of review yet

Research: E-Health Act

Disclosure

5 A designation order may authorize the disclosure of personal health information only for one or more of the following purposes:

- (a) if disclosure is inside Canada, a purpose set out in section 4 (a) to (f) [*collection and use of personal health information*];
- (b) a planning or research purpose;
- (c) if disclosure is inside or outside Canada, a purpose set out in section 4 (i).

11 The data stewardship committee is solely responsible for managing the disclosure, for a planning or research purpose, of information contained in a health information bank or a ministry database.

Allows for disclosures under s14

- Notes who reviews and approves applications for access

Research: E-Health Act

Section 14 Disclosure for Planning or Research Purposes

14 (1) A person who requires information for a planning or research purpose may request information from a health information bank or ministry database only by submitting to the data stewardship committee

- (a) a request in the form and in the manner required by the data stewardship committee, and
- (b) information required by the data stewardship committee for the purposes of evaluating the request.

Applies only to data in a Health Information Bank

- Only PLIS is in a HIB at this point

Research: E-Health Act

Section 14 Disclosure for Planning or Research Purposes

- 14** (2) The data stewardship committee may approve the request if all of the following apply:
- (a) the request is for a planning or research purpose;
 - (b) in the case of information from a health information bank, the disclosure is authorized under the terms of the designation order;
 - (c) in the case of personal health information requested for a health research purpose, the requirements of section 15 [*disclosure for health research purposes*] have been met;
 - (d) in the case of a request to disclose personal health information outside Canada, there is express consent, in writing, to the disclosure from each person who is the subject of the personal health information.

Requirements for DSC Approval

- Limited to purposes of designation order
- **No disclosure outside of Canada**

Research: E-Health Act

Section 14 Disclosure for Planning or Research Purposes

- 14** (3) If the data stewardship committee approves the request, the administrator may, subject to any conditions set by the data stewardship committee on approving the request, disclose the information to the person who made the request.
- (4) An administrator must not disclose information under subsection (3) except under an information-sharing agreement
- (a) with the person who made the request, and
 - (b) made, whether or not personal health information is disclosed, in accordance with section 19 (2) and (3) [*information-sharing agreements required for disclosure*].

Administrator is at the Ministry of Health

- Most likely the Secretariat
- Requires an ISA

Research: E-Health Act

Section 15 Disclosure for Health Research Purposes

15 If a request for personal health information under section 14 [*disclosure for planning or research purposes*] is made for a health research purpose, the data stewardship committee may approve the request only if all of the following criteria are met:

- (a) the health research purpose cannot reasonably be accomplished unless personal health information is disclosed;
- (b) personal health information is disclosed on condition that it not be used for the purpose of contacting a person to participate in the health research, unless the commissioner approves
 - (i) the health research purpose,
 - (ii) the use of disclosed personal health information for the purpose of contacting a person to participate in the health research, and
 - (iii) the manner in which contact is to be made, including the information to be made available to persons contacted;
- (c) any record linkage is not harmful to the individuals who are the subjects of the personal health information and the benefits to be derived from the record linkage are clearly in the public interest;
- (d) the data stewardship committee has imposed conditions relating to
 - (i) security and confidentiality,
 - (ii) the removal or destruction of individual identifiers at the earliest reasonable time, and
 - (iii) the prohibition of any subsequent use or disclosure of personal health information without the express authorization of the data stewardship committee.

History of Amendments

Process

Who was involved?

- *Special Committee to Review the Freedom of Information and Protection of Privacy Act*
- 118 submissions were received from a variety of stakeholders
- 11/35 recommendations were made to the previous special committee in 2004
- Invited written submissions, public hearings and consultation

<http://www.oipc.bc.ca/pdfs/public/Rpt-FOI-39-2-Rpt-2010-MAY-31.pdf>

Timeline:

- Special Committee formed 2009
- Report 2010
- First Reading October 4
- October 4 2011 Commissioners lends approval
- Second Reading Oct 19
- Committee, Report and Third Reading Oct 25
- Royal Assent Nov 14

Amendments Affecting Research

Section 3 Scope

- 3 (1) This Act applies to all records in the custody or under the control of a public body, including court administration records, but does not apply to the following:
- (e) a record containing teaching materials or research information of
 - (i) a faculty member, as defined in the *College and Institute Act* and the *University Act*, of a post-secondary educational body,
 - (ii) a teaching assistant or research assistant employed at a post-secondary educational body, or
 - (iii) other persons teaching or carrying out research at a post-secondary educational body;

More clear and broad definition of who may hold research information

Amendments Affecting Research

Section 36.1 Data Linking Initiatives

36.1 (1) A public body participating in a new or significantly revised data-linking initiative must comply with the regulations, if any, prescribed for the purposes of this subsection.

(2) If all the participants in a new or significantly revised data-linking initiative are a health care body, the ministry of the minister responsible for the administration of the *Ministry of Health Act* or a health-related organization as prescribed, then subsection (1) does not apply to the participants.

Entirely New Section

- Definitions of Data Linking and Data Linking Initiative in Schedule 1 of the Act
- Regulations to be promulgated by the Ministry of Labour, Citizen Services and Open Government
- Carves out “health only” projects

Amendments Affecting Research

Section 69 General information respecting use of personal information

69 (1) In this section:

(5.3) The head of a public body that is not a ministry must conduct a privacy impact assessment in accordance with the directions of the minister responsible for this Act.

(5.4) **The head of a public body that is not a ministry**, with respect to a proposed system, project, program or activity, **must submit**, during the development of the proposed system, project, program or activity, the **privacy impact assessment**, if it addresses a **common or integrated program or activity or a data-linking initiative**, to the commissioner for **the commissioner's review and comment**.

(5.5) The head of a public body must **notify** the commissioner of a data-linking initiative or of a common or integrated program or activity at an early stage of developing the initiative, program or activity.

For every project:

- **Conduct** a PIA

For a Data Linking Initiative:

- **Notify** the commissioner at an early stage
- **Submit** your PIA to the OIPC for review and comment

Amendments Affecting Research

Section 69 General information respecting use of personal information

- 69 (5.6) If all the participants in a data-linking initiative are either a health care body, the ministry of the minister responsible for the administration of the *Ministry of Health Act* or a health-related organization as prescribed, then
- (a) subsections (5.3), (5.4) and (5.5) do not apply with respect to a participant that is a **health care body or a health-related organization** as prescribed, and
 - (b) subsections (5), (5.1) and (5.5) do not apply with respect to a participant that is the **ministry of the minister responsible for the administration of the *Ministry of Health Act***.

If all participants are a health care body, Minister or related organisation:

- You don't have to provide notice to the OIPC or CIO
- You don't have to conduct a PIA
- You don't have to send your PIA to the OIPC or CIO if you write one anyways

Next Steps

- Promulgation of regulations
- Ministerial orders
- Templates, guides and instructions
- Public body's policies & procedures
- PIA workshops and resources

Working in Multiple Jurisdictions

What legislation applies and when?

International:

- EU Directive
- PATRIOT Act

Federal:

- PIPEDA
- Privacy Act

Provincial:

- FIPPA, E-Health, PIPA (BC)
- PHIA, FOIP, PIPA (AB)
- FIPPA, MFIPPA, PHIPA (ON)

Substantively similar provincial legislation preempts PIPEDA.

- All legislation applies unless it specifically specifies otherwise
- Researcher's responsibility to determine which legislation applies

POLICIES AND BEST PRACTICES



APPLICATIONS

Responsibilities

Principal Investigator

- Ensuring application provides details and information required by DAR, legislation etc

Research Ethics Board

- Having reviewed the application for ethical, privacy and confidentiality concerns

Data Steward

- Ensuring that the disclosure and subsequent use, storage and access are consistent with requirements of FIPPA

Population Data BC

- Provide support, information and process and requirements
- Coordinating the application with all Data Stewards, ensuring it is complete and accurate

Applications can become an addendum to legal documents such as Research Agreements

MONITORING

Responsibilities

Principal Investigator

- Behaviour and access of entire research project team

Research Ethics Board

- Amendments

Data Steward

- Responding to incident notices, expiries, extensions and amendments

Population Data BC

- Monitoring for compliance with legislation, ethics and agreements
- Monitoring for expiries
- Managing incidents
- Coordinating amendments and extensions

Monitoring is the weakest piece of the puzzle – until recently.

BEST PRACTICES

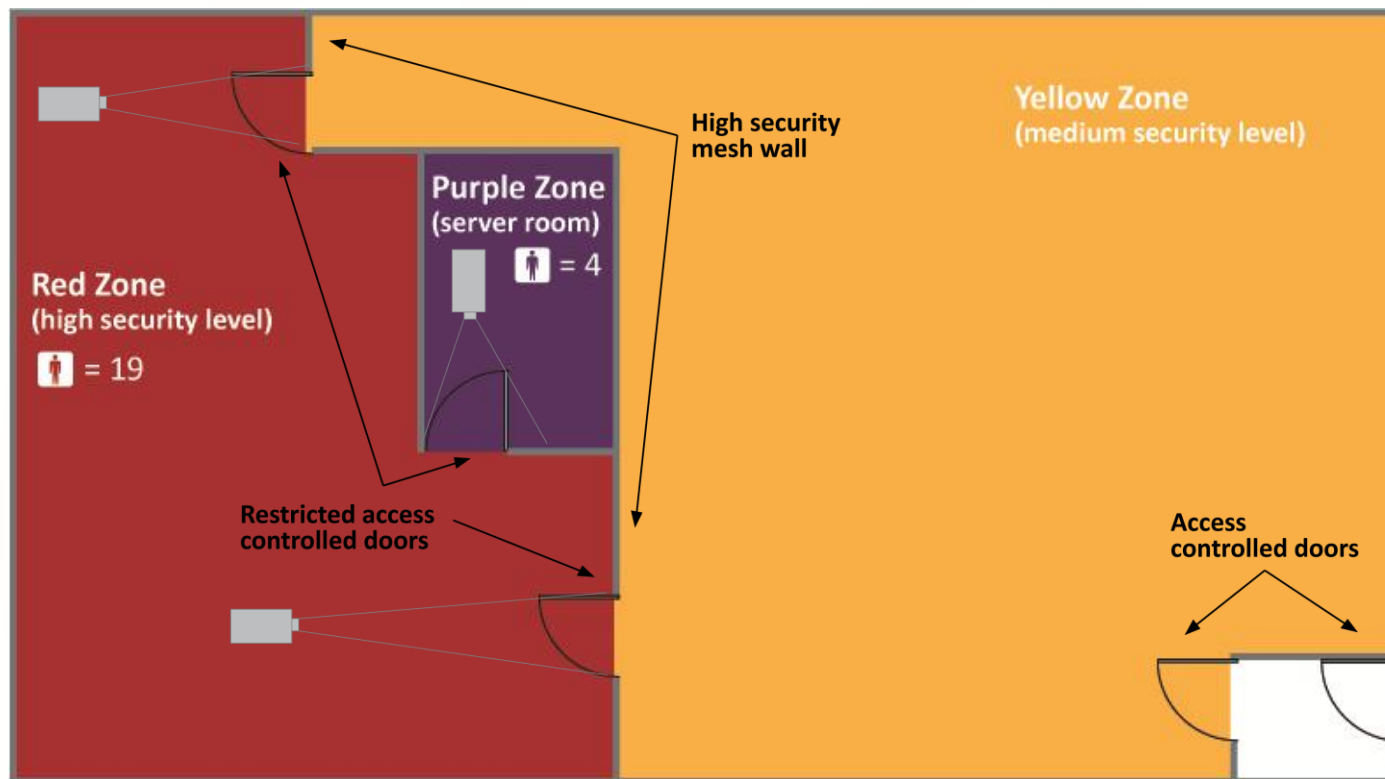
Physical

- Physical zoning with fobbed access and alarms
- Video Surveillance
- Fortification of walls
- Sign-in and escorts for visitors

Privacy by Design Principles: Preventative Controls, Privacy by Default, Embedding Privacy into Design

PHYSICAL

Security of the Population Data BC physical environment



BEST PRACTICES

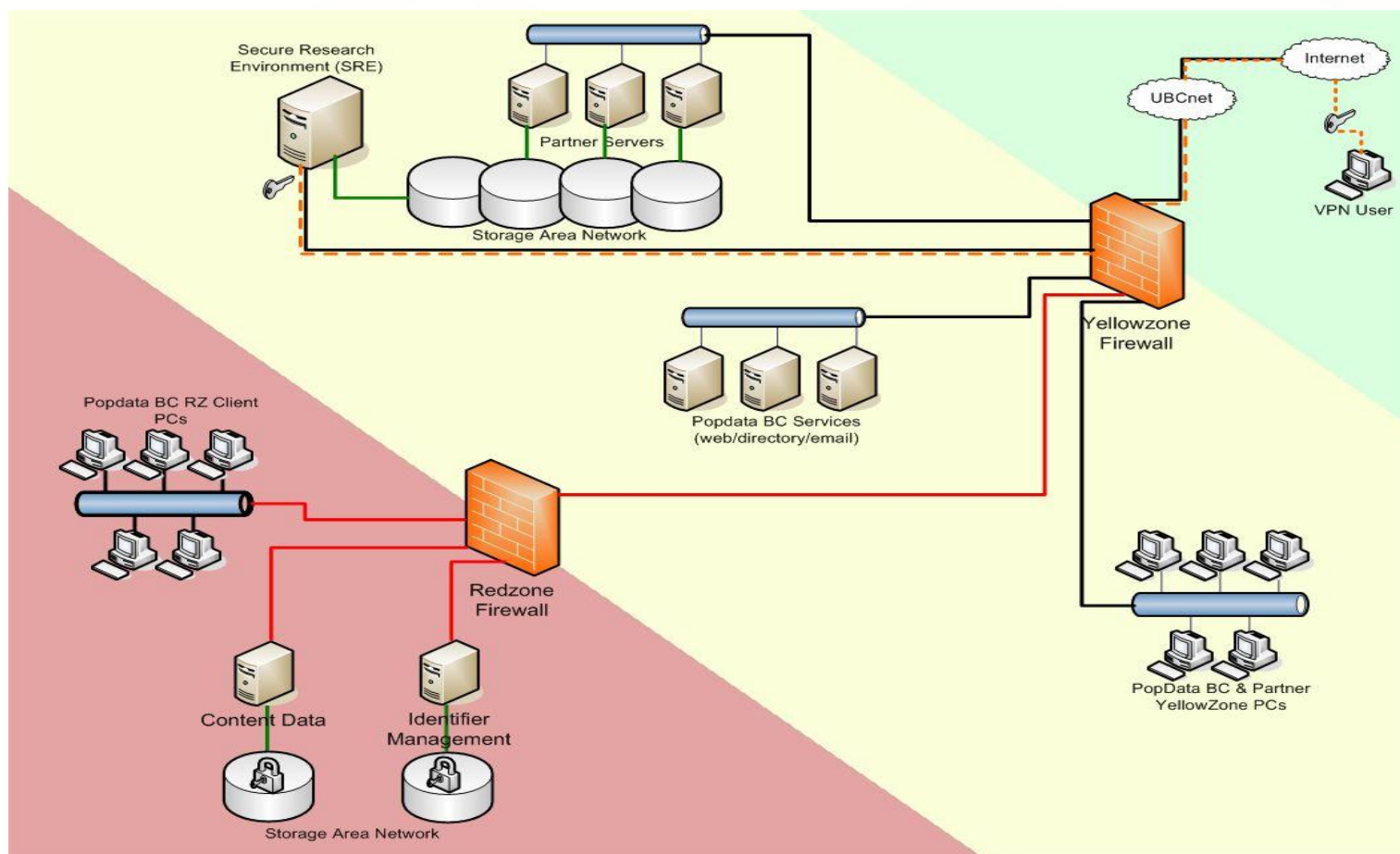
Technical

- Network Zoning with two-factor authentication
- Dummy Terminals
- Separation of identifiers from content
- Proactive linkage
- Auditing/Logging/Monitoring
- Secure Research Environment
- Encryption
- Data Destruction Methods

Privacy by Design Principles: Preventative Controls, Privacy by Default, Embedding Privacy into Design, Positive Sum Approach, Full Lifecycle Protection

TECHNICAL

Security of the Population Data BC network environment



BEST PRACTICES

Policy

- External Auditing
- Data Access Request (DAR)
- Research Data Access Framework (RDAF)
- Agreements
- Privacy Policy, Incident Response Policies and more
- Privacy Impact Assessment (PIA)
- Privacy Training (researcher and staff)
- Criminal Record Checks
- Limited, Need to Know access
- Education, literature reviews and close working relationships with OIPC and OCIO

Privacy by Design Principles: Preventative Controls, Positive Sum Approach, Respect for User Privacy

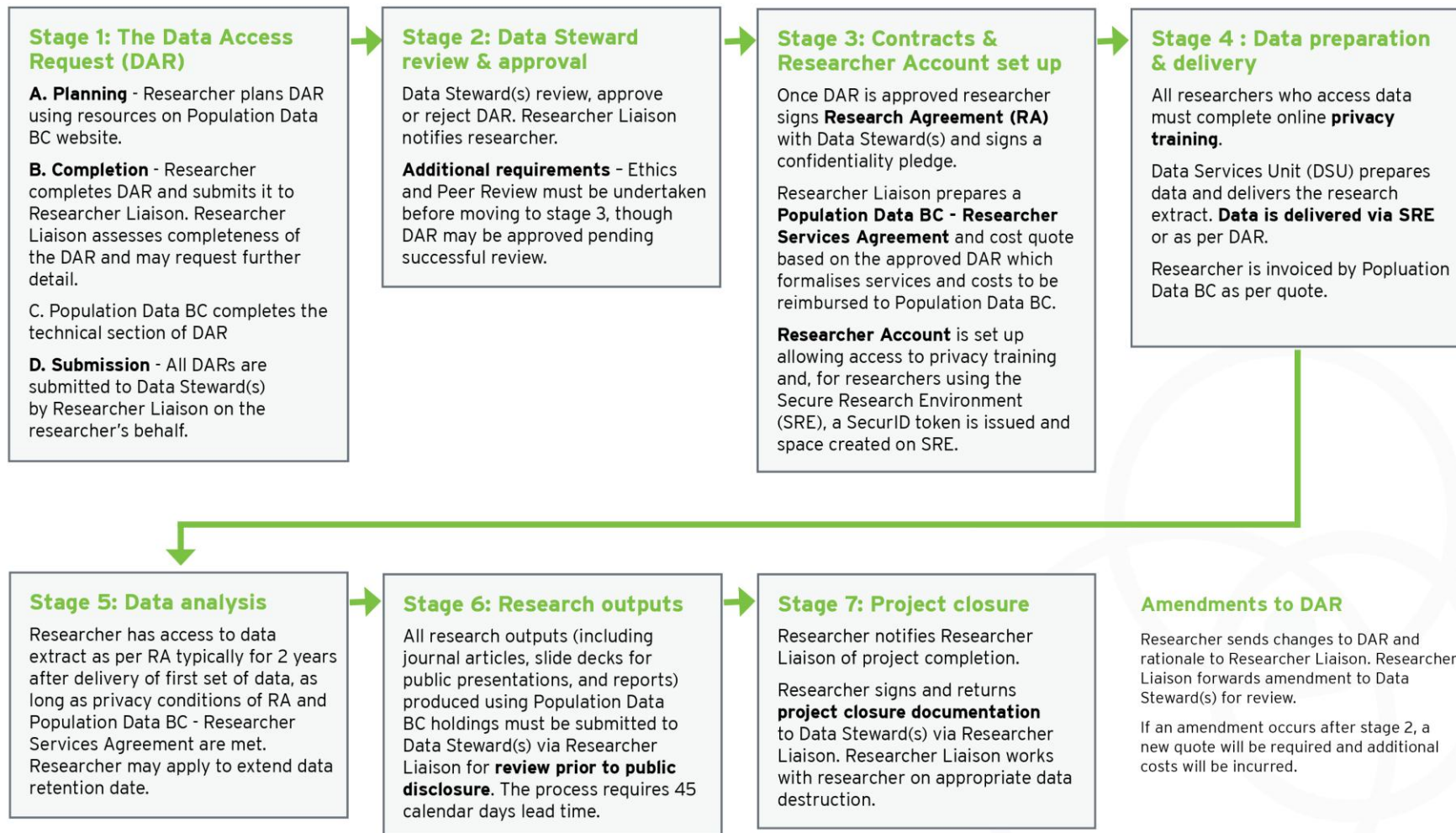
DATA ACCESS PROCESS



POPULATION DATA BC OBJECTIVE 3:

Streamlining access to data

Data Access Process Overview



DATA ACCESS PROCESS

Processing times

Working with Data Stewards we aim to reduce processing times by:

- Developing strong agreements, policies and frameworks clarifying the roles and processes involved in application receipt and approval
- Moving the coordination and intake of applications to Population Data BC so that there is a single hub of communication
- Development of a single application form for all public bodies party to Population Data BC
- Providing researchers with technical support in defining study populations
- Developing policies and support systems to aid researchers in the completion of DARs prior to submission

DATA ACCESS PROCESS

The Secure Research Environment

The SRE is a central server accessible only via:

- an encrypted Virtual Private Network (VPN) through a firewall
- use of a SecurID token for authentication.

The SRE provides:

- Secure storage and backup
- Centralized location for access and processing of research data
- A range of software for use in data analysis
- Security standards that meet Data Steward requirements

TAKEAWAYS

- Legislation is decided by where the data is coming from and where it is going to
- Researchers are responsible, but head of the public body is liable
- Amendments have critical impact on research – PIA submission
- Contact rlu@popdata.bc.ca for any questions on the data access process
- Contact caitlin.hertzman@popdata.bc.ca for more information on privacy and population health research

Researchers cannot rely on ethics review and an approved DAR, they must know their responsibilities and maintain compliance while working with the data. READ YOUR AGREEMENTS, KNOW YOUR OBLIGATIONS.



populationdata^{BC}

A PLATFORM SUPPORTING RESEARCH ON
HUMAN HEALTH, WELL-BEING AND DEVELOPMENT.

CONTACT INFORMATION

Caitlin Pencarrick Hertzman, CIPP/C

Lead, Privacy and Policy

Population Data BC

604-822-6514

www.popdata.bc.ca

caitlin.hertzman@popdata.bc.ca

