

## Working towards a principled, proportionate, risk-based approach to data access in British Columbia: Summary of stakeholder interviews



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This report provides a summary of interviews conducted by Population Data BC regarding the opportunity to move towards a principled, proportionate, risk-based approach to data access in British Columbia, and will serve as background material for an in-person workshop scheduled to take place in November 2015.

## 1. Background

Existing governance for research data access in BC is a 'one size fits all' approach. The same intensity of review is applied to each application, whether the request is for access to anonymized data or for identifiable data with the intent to contact individuals. This approach is in contrast with the proportional approach used in research ethics<sup>1</sup>, slows the speed of reviews, and affects an ability to scale to increased volume of applications. A second challenge with existing information governance is the 'black box' of reviews: it is not always clear what is being reviewed, what risks or benefits are given the most weight, and what – if any – tradeoffs are considered. The lack of transparency leads to uncertainty for individuals applying for data access and variability among Data Stewards who are adjudicating applications.

These are important issues against a backdrop of a changing research environment in which there is pressure to revisit rules around data access. This includes considering:

- An expansion of users (e.g. from academic users to health authority users to commercial users)
- An expansion of uses (e.g. from hypothesis testing to hypothesis generating questions)
- Changes in how projects are structured (e.g. from specific projects to programs of research)

In British Columbia, we are proposing a principled, proportionate, risk-based approach to data access governance as a means by which these changes can be considered. By principled, we mean that information governance is guided explicitly and transparently by agreed-upon considerations, such as who is making the request for access and in what environment their use of data will take place. Proportionality and risk then refer to the practice of ensuring that the review of data access requests reflects the risk or damages that could arise. A proportionate approach would adjust the extent and stringency of review according to the potential risk posed by the data request, so that higher risk requests receive more scrutiny.

Adopting this type of approach for data access was a key recommendation of the Rawlins Report, a review of the governance and regulation of human health research conducted by the Academy of Medical Sciences at the request of the UK government.<sup>2</sup> Two examples of such a concept in action for data access request reviews are the Scottish Health Informatics Programme (SHIP – now part of the Farr

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<sup>1</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, Retrieved from [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)

<sup>2</sup> That report called for regulation that is symmetrical and proportionate, saying "...approving an inappropriate study is clearly unacceptable, but delaying or prohibiting an appropriate study harms future patients as well as society as a whole." (The Academy of Medical Sciences, 2011; p. 5)

Institute in the United Kingdom) and the now retired precursor to Population Data BC, the British Columbia Linked Health Dataset (BCLHD).<sup>3</sup> Additional information about SHIP and BCLHD are included in Appendix A.

## 2. Developing a framework

### *Population Data BC overview*

Population Data BC is a multi-university, data and education resource facilitating interdisciplinary research on the determinants of human health, well-being and development. Population Data BC serves as a central intake point for applications requesting access to individual-level, de-identified administrative data and coordinates the entire data lifecycle process from pre-application to data destruction on behalf of Data Stewards. While intake and coordination are delegated to Population Data BC, adjudication and decision-making responsibility remain under the authority of Data Stewards. Population Data BC plays a role in policy development and implementation and works closely with Data Stewards via its Data Stewards Working Group to develop harmonized policies and processes related to data access. The Data Stewards Working Group consists of a representative or designate from each organization that retains stewardship over the release of data for which researcher access may be facilitated by Population Data BC, and a member of the Office of the Chief Information Officer for the government of BC. Meetings are chaired by designates from Population Data BC's staff who are ex officio members of the group.

### *Emerging framework overview*

The principles included in the framework were developed by Population Data BC through review and synthesis of all relevant documentation regarding data access, legislation and policy documents of all related parties, current practices in other jurisdictions, and best practice as identified in academic and grey literature. These are:

- Science (scientific merit and impact)
- Approach (questions and analysis)
- Data (granularity, sensitivity and justification for data)
- People (experience, affiliation)
- Environment (technical and network infrastructure)
- Interest (public interest)

The implication is that each request for access would be assessed on each of these principles. A risk-based approach means that for each principle, the request would be judged as having low, medium, high or very high risk. The result is a matrix of principles by risk level, as seen in Appendix B.

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<sup>3</sup> (1) <http://www.scot-ship-toolkit.org.uk/information-page/ship-triage-process>

(2) [http://www.scot-ship.ac.uk/sites/default/files/Reports/SHIP\\_BLUEPRINT\\_DOCUMENT\\_final\\_100712.pdf](http://www.scot-ship.ac.uk/sites/default/files/Reports/SHIP_BLUEPRINT_DOCUMENT_final_100712.pdf)

(3) [http://www.fphscotconf.co.uk/uploads/fph2013\\_presentations/Janet\\_Murray.pdf](http://www.fphscotconf.co.uk/uploads/fph2013_presentations/Janet_Murray.pdf)

To move towards an operational framework, we must determine how to translate where an application falls along the spectrum of risk for each principle on the matrix (the “scoring”), to a required level of scrutiny and review. This is a complex and challenging endeavour.

### **3. Study overview**

Members of Population Data BC’s Data Stewards Working Group and other provincial stakeholders involved in access to data in BC were contacted and invited to participate in a one-hour telephone interview. Upon confirmation of interest in participating, individuals signed a consent form and were provided with a pre-interview documentation package, which included the interview guide of semi-structured interview questions and the proposed framework.

The objectives of the interview were to:

1. Seek clarity in Data Steward roles and responsibilities regarding research data access adjudication
2. Request preliminary feedback and perspectives on the proportionate governance framework
3. Understand additional considerations for operationalizing and implementing the framework

The study team consisted of Kaitlyn Gutteridge, Nancy Meagher, Kelly Sanderson and Kimberlyn McGrail. All interviews included two staff from Population Data BC, one of whom (KG) was involved in all interviews. The interviews were recorded with permission (all interviewees agreed) and transcribed. Debriefing conversations amongst the study team helped to identify common themes and emerging consensus among interviewees, which were clarified and expanded on through review of transcripts (KG).

The consent form indicated that responses would be summarized without attribution and shared with participants, used for public discussion purposes, and may be developed into a paper for publication. The University of British Columbia Behavioural Research Ethics Board provided review and approval for the study. The interview guide is included as Appendix C.

## **4. Results**

### **Overview**

Eighteen individuals from 15 organizations were sent letters of invitation, and 12 interviews were conducted with 17 individuals from 13 organizations (three interviews included two participants; one interview included three participants from two organizations). All interviews were conducted over the telephone save for one, which was in-person.

Of the seventeen individuals, most participated in their capacity as a Data Steward, but other perspectives were represented as well, including data privacy and legislation, information governance, information security architecture, and research ethics (Table 1).

<b>TABLE 1: LIST OF STAKEHOLDERS INTERVIEWED</b>
<b><i>Organizations representing stewardship roles</i></b>
<ul style="list-style-type: none"> <li>• BC Cancer Agency and BC Generations Project</li> <li>• BC Ministry of Children and Family Development</li> <li>• BC Ministry of Education</li> <li>• BC Ministry of Health</li> <li>• BC Vital Statistics Agency</li> <li>• Human Early Learning Partnership</li> <li>• Perinatal Services BC</li> <li>• Vancouver Island Health Authority</li> <li>• WorkSafeBC</li> </ul>
<b><i>Organizations representing other roles relevant to data access</i></b>
<ul style="list-style-type: none"> <li>• BC Ministry of Technology, Innovation and Citizen Services</li> <li>• Office of the Information and Privacy Commissioner of British Columbia</li> <li>• UBC Research Ethics Board</li> <li>• Vancouver Coastal Health Authority</li> </ul>

The sections that follow present summary information in relation to the interview objectives of assessing the level of clarity in the role of Data Stewards, discerning support for a principled, proportionate approach to data access governance, comprehensiveness of the draft framework, and considerations for implementation.

**Clarity and concerns in Data Stewards’ roles and responsibilities (Survey section 1)**

On a scale of one (not clear) to five (very clear), participants reported feeling quite clear (mean: 4, range 2-5) in respect to the scope of their responsibility when reviewing a data access request. Factors that influenced this clarity include:

- Documentation available to support their understanding. The majority of participants referenced consulting internal policy and procedural documents, legislation (e.g. BC’s *Freedom of Information and Protection of Privacy Act, E-Health Act*) and public body specific legislation (e.g. *Workers Compensation Act, Health Authorities Act*) during their review of access requests.
- Clear designation of one’s role as a Data Steward, whether in the form of a committee appointment, or as articulated in one’s job description.

Of note, a strong sentiment of personal responsibility for protecting data was voiced, and as one participant noted, the viewpoint of a Data Steward is often internalized as “my data” versus “data stewarded on behalf of individuals”.

When asked about the main concerns while reviewing data access requests, participants consistently referred to the request meeting requirements of section 35 of the BC *Freedom of Information and Protection of Privacy Act* (FIPPA). Upon further exploration, additional concerns in adjudication included:

- Granularity of data released to the researcher, including data sensitivity and risk of re-identification
- Data storage environment and related technical infrastructure
- Reputational risk for the organization
- Researcher’s track-record, their involvement in past privacy events and the Data Steward’s ability to “trust” the researcher
- Operational capacity required to review the request and create data extracts

Of the list above, only two of the concerns reflect specific section 35 requirements (data storage environment and data granularity).

While there was general agreement that the expected roles were clear, there was also acknowledgement that more could be done to improve the adjudication process itself. This was not a topic of direct inquiry, but interviewees consistently offered up suggestions for improving the process, pointing to a need for further clarity. These suggestions include:

- Standardization of policies and procedures across organizations, as most documentation reflects internal requirements
- Clear demarcation of the components of the data request that are reviewed by research ethics boards, Data Stewards and funding agencies
- Guidance around the interpretation of terminology including personal information, de-identified data and re-identification
- Better support for and management of Data Stewards’ sentiment of personal responsibility for safeguarding data

## **Perspectives on the Proportionate Governance framework (Survey section 2)**

### *Overall response*

Overall, the framework was very well received, and the following were enthusiastically supported:

- The relevance and opportunity for proceeding with a proportionate governance framework in BC
- The comprehensiveness of the current draft framework

- The framework’s structured, logical and scientific articulation of existing but undocumented processes

At the same time, a few participants felt a tiered review system was not entirely necessary given the scope and scrutiny of their review is already limited and their review timelines are short (hours to days).

*Gaps*

Despite broad support for the framework, two aspects were identified as potential gaps:

- The need for contextual knowledge in adjudication, particularly for newer forms of data (other than administrative, transactional data). Semi-structured data, such as Electronic Medical Records (EMRs) and Health Records (EHRs) as well as unstructured data (e.g. genomics data) require understanding of the context in which they are collected and this may need to be taken into account in adjudication.
- Consideration of potential reputational risk associated with the approval of a project. This concern related to risks that flow from a researcher’s improper use or disclosure of data.

*Importance and relevance of the six draft framework principles*

During preliminary discussion of the framework, participants were asked to assign 100 points to the six principles of review (**Science; Approach; Data; People; Environment;** and **Interest**), where the higher numerical values represent increased interest and value in the relevance of the principle. Some respondents opted to rank rather than assign points, so for results, the points were converted to a ranking (see Table 2).

<b>TABLE 2: VALUE AND RELEVANCE OF SIX PRINCIPLES PER ORGANIZATION (N=13)*</b>	
<b>Principle</b>	<b>Response Ranking (1 = most; 6= least important)</b>
	<i>Mean (Range)</i>
Data	1.5 (1-3)
Approach	3.6 (2-5.5)
Environment	3.7 (2-6)
Interest	3.9 (2-6)
People	4.1 (1-5.5)
Science	4.2 (2-6)

\*Five of 13 organizations did not use the scale proposed by the question; the results have been combined in manner that best represents the range of responses.

While **Data** emerged as a clear front-runner, this does not negate the importance of the other principles. When participants were subsequently asked to list their top three concerns, **Data**, **Environment** and **Approach** were consistently noted, which aligned with the ranking exercise. **People** also emerged here as an element that was generally considered in one way or another, often with reference to trust (more on this below).

The assessment of **Data** was considered a “grounding mechanism”, whereby additional levels of protection offered by other controls would be modified to account for the risk associated with **Data** (requirement for additional levels of control increases when sensitivity of data rises).

For the four principles indicated as main concerns (**Data**, **Environment**, **Approach** and **People**), primary considerations that arose from the interviews are provided in Table 3.

<b>TABLE 3: FOUR PRIMARY PRINCIPLES OF CONCERN AND RELATED CONSIDERATIONS OF INTEREST</b>	
<b>Principle</b>	<b>Considerations</b>
Data	<ul style="list-style-type: none"> <li>• Need to justify data requested</li> <li>• Sensitivity of data requested</li> <li>• Granularity of data requested</li> <li>• Re-identification risk / lack of de-identification standards</li> </ul>
Environment	<ul style="list-style-type: none"> <li>• Technical infrastructure for data storage</li> <li>• Mechanisms for monitoring and managing the data lifecycle</li> </ul>
Approach	<ul style="list-style-type: none"> <li>• Researcher’s intended use of data, and understanding of the uses</li> <li>• Non-traditional research – data mining, hypothesis generating</li> </ul>
People	<ul style="list-style-type: none"> <li>• Ability to proceed through research ethics approval process</li> <li>• Past experience with the data requested</li> <li>• Trust in the researcher</li> <li>• Relationship with industry and source of funding</li> </ul>

*Immediate rejection of an application*

Over half of the participants (62%) reported there were no risks present along the spectrum of risk that would elicit an immediate rejection of an application. Instead, participants felt high risk(s) should be considered within the context of the application’s overall level of risk across all six principles.

Of those who did indicate that there would be circumstances under which they would consider immediate rejection of an application, no single principle was identified as being the trigger; this varied by respondent. Concerns included applications with no external peer review (High; **Science**), data mining (Very High; **Approach**), intent to contact individuals (Very High; **Data**), non-academic and non-experienced users or previous users that were involved in a data breach or violation (High; **People**), new, non-vetted environments (High; **Environment**) and commercial access to data (High and Very High; **Interest**).

#### *Review required for low risk rating*

Perspectives on how to handle requests that ranked low in all six principles (or medium for **Data** and low for everything else) were discussed during the interviews, and mixed ideas for a minimal review stream were presented. Of those who expressed uncertainty about implementing a minimal risk review stream, the reasons given were legislative authority, organizational oversight responsibility, and possibility of organizational risk. Some regarded any applications with record level data, even if appropriately de-identified, as a trigger for Data Steward review and approval.

#### **SUMMARY: STAKEHOLDER CONSIDERATIONS FOR REVIEW OF LOW-RISK PROJECTS**

- Common policies and procedures to enable consistent implementation and operationalization of low risk reviews
- Designate a centralized body to review and approve low-risk applications, or alternately develop a minimal set of items for Data Steward review (e.g. only review **Data** and **Environment**)
- Define low risk criteria up front and have researchers justify where they fit within the criteria and engage them in the first round of risk classification
- Develop datasets that would fall under low risk that are not privacy sensitive – use those as key criterion for risk of **Data**

While not a topic of direct inquiry, delegating review of applications to another organization was raised by many participants. There was a difference of opinion around legislative authority to delegate review and approval of applications under section 35 of FIPPA to a party outside of the head of the public body. Some felt it was not currently possible under FIPPA and (for example) the current governance structure in place at Population Data BC, and others suggested that FIPPA explicitly permits this type of delegation, possibly in the context of a common set of policies and procedures. Even in the case of a potential delegated review process, the majority of participants were interested in being aware of low-risk projects and providing some level of sign-off.

## **Considerations for moving forward; operationalizing and implementing the framework (Survey section 3)**

Participants reiterated their support for a proportionate governance framework in BC. The framework was considered a mechanism for advancing a coordinated, streamlined and transparent approach to data access. Population Data BC was considered a trusted organization, which would be well positioned to participate in the preliminary review and assessment of applications.

Support for moving ahead with the framework was reinforced by stakeholders in their willingness to galvanize the appropriate internal support required to pursue a proportionate governance model, and educate stakeholders within their realm of influence. Stakeholders noted the benefit of engaging in opportunities and relationships that can instill province-wide trust and ownership in the proportionate governance process as a key area for consideration when implementing the framework.

Nevertheless, it was recognized that there is still a lot of work to be done in terms of operationalizing something of this nature. Some foundational considerations for moving forward are considered in the next section.

## **5. Summary and recommendations**

Participants were committed to moving ahead with a proportionate and principled approach to data access in the province. The relevance and utility of the current framework's six principles and their associated spectrum of risk resonated with participants. The proposed framework was considered generally comprehensive and well-structured, with some considerations for further discussion.

The following are the major themes that have emerged from this work:

- **Unanimous support for the concept of principled proportionate governance;** the main question that remains is how to operationalize and implement it.
- **Transparency and harmonization are seen as priorities and major features of this framework;** there is a desire for harmonized policies and procedures and harmonization was seen as an essential tool for reducing subjectivity across varying areas of concern.
- **“Data” is a significant principle for all;** granularity of data requested will have a major influence on review.
- **Trust as a general concept figures prominently;** of people and policies and procedures, creating a path towards trust needs to be considered.
- **Defining risk needs more work;** there was a range of opinion about the limits of what ought to be allowed, and more importantly how to translate the placement of a project in the framework to a required level of review. This is a fruitful area for further discussion.

There are other remaining uncertainties that would benefit from further discussion as well. While **Data** emerged as the most important principle and area of concern, it was not clear whether the ranking provided by participants considered underlying assumptions about the role of other review bodies (e.g.

research ethics boards) in the process. For example, **Science** may have ranked as a principle of lower concern, either because it is not a true concern amongst participants, or because they feel that **Science** is covered by another body (e.g. peer review committee). This speaks to the need to take a step back to consider the roles and responsibilities of all parties involved in data access requests, including peer review committees and research ethics boards. Clear understanding and integration of the varying parties' scope of review could be more explicit in future iterations and in finalizing the risk assessments.

The overall goal of a principled, proportionate, risk-based approach to data access governance is to identify a standardized set of requirements for assessing the risk associated with an application, align controls to mitigate the overall risk of an application, and ensure appropriate levels of review and involvement from Data Stewards in the process.

The interviews discussed in this report provide a clear mandate to proceed with development of this framework, and in particular its operationalization in BC. What follows are recommendations to this end, for discussion at our workshop on November 6, 2015.

## **Recommendations**

### **1. Finalize the framework**

- Finalize the choice of principles to be included: There were ideas put forward about new types of data and reputational risk that need to be considered by all Data Stewards.
- Formally support the framework: All interviewees expressed their support of the framework and interest in ongoing participation, and we recommend making this formal at our meeting. This is with the understanding that it will always be a living document and can be modified over time.
- Identify other areas that could be developed to support risk mitigation: For example researcher accreditation, development of more in-depth metadata, and clearer definition of the role of de-identification in this process.

### **2. Translate risk assessment to review**

- Pursue ideas of minimal risk review, delegated review and a centralized review body, and determine what is and is not legally possible and practically feasible in BC.
- Identify a common understanding of "low risk" requests and create a specific plan or pilot for expediting this type of request.
- Identify areas of persistent disagreement that will require further discussion, e.g. assessment of what constitutes "high" or "very high" for a given principle or requests that may never be considered.
- Establish a preliminary understanding of the variety of request scenarios that would not meet "low risk" criteria and the necessary assessment and potential controls considered when defining the level of review required.
- Develop a plan for public engagement to provide input to the areas defined above.

### **3. Monitoring and harmonization**

- Approve a timeline for reporting on the implementation of the new approach to reviewing low risk projects.
- Document – and make public – these discussions, the framework, and the pilot and review process.
- Develop a vision and action plan for moving forward with a common set of policies and processes that govern the operationalization of the framework.

## Appendix A: Scottish Health Informatics Programme and BC Linked Health Database Case Studies

### Case Study A: The British Columbia Linked Health Database (BCLHD) (1996-2002)<sup>4</sup>

The British Columbia Linked Health Database, a precursor to Population Data BC, initially brought together core data on health care services utilization and vital events for the province's residents from 1985 onwards. Adjudication of research data access requests was guided by review of five key issues (domains). The first four had to be met. The fifth determined the potential risk.

1. Scientific merit of the research question and method: Met either by success in a peer review process for grant funded research, or for a student by peer review and approval by his/her supervisory committee.
2. Ethical acceptability of the research question and method: Met with approval from an institutional Research Ethics Board
3. Public interest value of the research: Met with success in peer review from a public funding agency (taken as implying public interest), but also justified by the researcher
4. Security of data: Met by showing care of data would be in accordance with government standards and agreements outlining conditions for data use, return or destruction
5. Potential identifiability of data:
  - i. No person-specific information required (aggregate data release)
  - ii. Person-specific information but without personal identifiers, detailed birth date or detailed postal code
  - iii. Person-specific information and potential identifiers (e.g. detailed birth date and/or postal code) but with subsequent contact with individuals and individuals not directly affected by the research
  - iv. Person-specific information and potential identifiers included in the data, no subsequent contact with individuals but potential for research findings to indirectly affect individuals in the future
  - v. Person-specific information and identifiers included in the data with the intent to use information for subsequent contact

Applications were triaged into two categories for review and approval: fast-track review and full review. Fast track applications were those falling under "potential identifiability of data" categories one and two; all others were subject to full review. In practice, the data access coordinator worked with

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<sup>4</sup> The BCLHD transitioned to Population Data BC in 2009. Population Data BC aims to build on BCLHD's past success and is engaged in efforts to greatly expand its existing data holdings to include educational, occupational, environmental and socioeconomic information. Over time, Population Data BC aims to become the world's most comprehensive data resource on factors that influence human health, well being and development (<https://popdata.bc.ca>)

researchers to move their requests down into category two as much as possible; the vast majority of applications ultimately fell into this category.

**Limitations of this model:** This model functioned well for many years, but was essentially a risk-minimization approach. It did not consider strategies other than data de-identification for mitigating risk.

## **Case Study B: The Scottish Health Informatics Programme (SHIP) (2012 - present)**

The Scottish Health Informatics Programme is a Scotland-wide research platform that provides research access to linked Electronic Patient Records held by NHS Scotland. Adjudication of research data access requests uses SHIP's guiding principles and best practices, which are operationalized through four key benchmarks (domains) each of which includes a spectrum of risk. The domains and optimal (i.e. lowest risk) criteria are:

### **1. Safe People:**

- Everyone in contact with the data is trained in information governance (training materials are vetted)
- Applicant can demonstrate formal track record with administrative data (publications, affiliation with an academic institution, previous application)

### **2. Safe Environment:**

- Level of information security assessed with intended access through a SHIP Safe Haven considered optimal

### **3. Safe Data:**

- Privacy risk assessment has been undertaken by all projects
- Data are reviewed in accordance with sensitivity and relation to vulnerable populations
- Risk of disclosure from linked output file from analysis assessed low (e.g. no full dates, no rare conditions) - high risk (e.g. rare conditions, detailed geographic area)
- General addressing of the privacy and ethical concerns associated with the application
- Data not used to contact individuals
- Linkage previously approved for similar purposes
- Subjects are aware their data may be used for these purposes/permissions are in place for use

### **4. Public Interest:**

- Applicant demonstrates understanding of context and contribution of the project to the state of public health knowledge
- Study design and methods noted in application meet objective of the study
- Public interest not outweighed by commercial interest
- Formal external peer review undertaken or internal review by an academic institution

In the SHIP model, a research coordinator reviews the project and assigns a risk score (low, medium, high) for each benchmark. Applications are triaged into four categories based on the total risk score. The four categories are:

- "Category 0" public domain data is only requested and no risks are present;
- "Category 1" risks are minimal and outputs are non-sensitive (e.g. the linkage was previously approved and a safe haven system used for access and storage);

- “Category 2” issues are flagged during the review of the application including privacy and security risks and requests for multiple linkages;
- “Category 3” the application fails considerably to meet an acceptable risk score for a least one of the benchmark.

Applications in Categories 0 and 1 are reviewed only by a research coordinator, Category 2 applications receive fast-tracked advisory board review, and Category 3 applications require full advisory board review.

**Limitations of this model:** This model is currently limited to researchers affiliated with an academic institution, does not allow for exploratory analyses or hypothesis-generating methods and limits projects to those where public interest outweighs commercial interests.

## Appendix B: Proportionate Governance Framework

### Classification of Ethical, Privacy and Security Risks for Data Requests: A Foundation for Principled Proportionate Governance

The table below proposes a means by which the level of potential risk can be assessed for data access requests. The overall assessment of risk across all domains (the rows) can then be used to determine the level of scrutiny or review each project requires. This is the essence of applying a proportionate review process to requests for access to data, in which those that pose higher risk require a higher level of review.

Category	Spectrum of Risk			
	Low	Medium	High	Extra High
<b>Science</b>	<ul style="list-style-type: none"> <li>Peer reviewed</li> <li>Tri-council funding in place</li> </ul>	<ul style="list-style-type: none"> <li>Peer reviewed</li> <li>No funding in place or non Tri-council funding in place</li> </ul>	<ul style="list-style-type: none"> <li>No peer review or funding in place;</li> <li>Internal review may be in place</li> </ul>	
<b>Approach</b>	<ul style="list-style-type: none"> <li>Defined questions</li> <li>Hypothesis testing</li> </ul>	<ul style="list-style-type: none"> <li>Defined questions with additional exploratory analysis proposed</li> </ul>	<ul style="list-style-type: none"> <li>Exploratory analysis</li> <li>Hypothesis generating</li> </ul>	<ul style="list-style-type: none"> <li>Data mining</li> </ul>
<b>Data</b>	<ul style="list-style-type: none"> <li>Aggregated data</li> </ul> OR <ul style="list-style-type: none"> <li>Record-level information but derived variables and/or anonymized information</li> <li>Anonymization software may be used</li> </ul>	<ul style="list-style-type: none"> <li>Record-level information</li> <li>Requested variables tailored to / justified by defined research need</li> </ul>	<ul style="list-style-type: none"> <li>Record-level, sensitive information and reasonable risk of identifiability</li> <li>General justification for data use(s) provided; not variable specific</li> </ul>	<ul style="list-style-type: none"> <li>Record-level sensitive information with the intent to contact individuals</li> </ul>
<b>People</b>	<ul style="list-style-type: none"> <li>Experienced academic-affiliated user</li> </ul>	<ul style="list-style-type: none"> <li>New academic users</li> </ul> OR <ul style="list-style-type: none"> <li>Experienced non-academic users</li> </ul>	<ul style="list-style-type: none"> <li>Non-academic and non-experienced user</li> </ul>	
<b>Environment</b>	<ul style="list-style-type: none"> <li>Population Data BC's Secure Research Environment (SRE)</li> </ul>	<ul style="list-style-type: none"> <li>Environment with vetted privacy and security controls</li> </ul>	<ul style="list-style-type: none"> <li>New non-vetted environment</li> </ul>	
<b>Interest</b>	<ul style="list-style-type: none"> <li>Public interest</li> <li>No commercial interest</li> </ul>	<ul style="list-style-type: none"> <li>Public interest</li> <li>Some commercial interest</li> </ul>	<ul style="list-style-type: none"> <li>Commercial interest</li> <li>No short term public interest but potential for longer-term public value.</li> </ul>	<ul style="list-style-type: none"> <li>Commercial interest</li> <li>No public interest</li> </ul>



**PROPORTIONATE GOVERNANCE  
STAKEHOLDER INTERVIEWS**  
Interview Guide

## Interview Guide

### Part One: Opening questions

1. On a scale of one through five, where one is not clear at all and five is very clear, in your role as a (insert role), do you feel like you are clear with respect to the scope of your responsibility?
2. What do you feel are your responsibilities in the adjudication of the data access request?
  - a. Are there specific documents / policies / legislative requirements that inform your responsibilities?
3. What are your main concerns about the data access request during the review?
  - a. Do you have any specific privacy and/or security concerns?
  - b. Do you have any concerns related to those accessing the data?
  - c. Do you have concerns in regards to the data requested and proposed analysis of said data?
4. What are the challenges you encounter while reviewing access requests?

### Part Two: Proportionate Governance model

*Proportionate Governance involves an approach to governance that is based on understanding both what the categories or domains are that contribute to risk (the principles) and how the risk assessment maps to the resulting process for adjudication (the proportionality). Proportionality is the practice of ensuring that the review of research data access requests and the disciplinary mechanisms where requirements are not met reflect the perceived risk or damages that may arise. A proportionate approach would adjust the extent and stringency of review according to the potential risk posed by the data request, so that higher risk requests receive more scrutiny.*

*Requests for access to data are reviewed by multiple stakeholders, each of which may have a different lens (or lenses) for adjudication. To account for the varying privacy, security and ethical lenses, we propose six categories of risk (principles) with a spectrum of risk for each ranging from low to very high, as a means by which the level of potential risk can be assessed. The six categories are:*

- *Science: scientific merit and potential impact*
- *Approach: questions and analyses*
- *Data: granularity, sensitivity and justification for the data requested*
- *People: experience, affiliation*
- *Environment: technical and network infrastructure*
- *Interest: public and societal interest*

*The overall assessment of risk across all domains (the rows) can then be used to determine the level of scrutiny or review each project requires. This is the essence of applying a proportionate review process to requests for access to data, in which those that pose higher risk require a higher level of review.*

1. Do you have any initial comments / feedback / perceptions regarding the model?
2. If you were to have a total of 100 points to assign between the six principles, where the higher numerical values represent increased interest in and value in the relevance of the principle, what value would you allocate to each of the six principles?

3. Is there anything missing from the principles addressed that should be considered during the review? Is this model comprehensive?
4. Of the six principles addressed in the model, which three are the most concerning for you?
5. Are there any specific levels of risk outlined in the spectrum for each category that would represent an immediate rejection of the application should it present said risk? If so, which one and why?
6. From your perspective, if everything ranks low (or one over from aggregate in data), what would be the proportionate level of review for this type of application?

**Part Three: Proportionate Governance model: implementation**

- 1) From your perspective, is it feasible to implement this type of model for data access in British Columbia? Why or why not?
- 2) What would you / your public body need to do to further progress this initiative?
- 3) Do you have any questions for us that should be addressed during the full-day session?