

Secure Island Data Repository (SIDR) Data Release Committee - Terms of Reference

Purpose

The SIDR Data Release Committee (DRC) provides three main functions:

1. Review and provide feedback on applications from researchers who are seeking access to administrative data sets held in, or intended to be transferred to, the data repository.
2. Receive and review proposed publications in accordance with the *SIDR Dissemination of Research Findings Procedure*.
3. Provide a forum to discuss dataset transfers, data linkage procedures, and other relevant issues.

Role and Activities

The Committee is responsible for:

1. Ensuring the data requested is appropriate and specific to the research objectives and methodology.
2. Protecting the confidentiality of personal health information in the custody of SIDR and the privacy of the individuals who are the subject of that information.
3. Ensuring that conditions pursuant to the SIDR Originating and Master Data Sharing Agreements with the Department of Health and Wellness; Health PEI and other Data Providers for access to data have been met.
4. Upholding standards of data access consistent with the highest levels of security, confidentiality and privacy in Canadian legislation, namely:
 - To maximize the protection of individual privacy.
 - To approve access to linked data files only to researchers involved in specific, approved research projects.
 - To approve access by researchers that is limited to the minimum datasets required for their specific project.
 - To assure Data Providers that their data will be used appropriately, and that confidentiality and security obligations will be met.
 - Ensuring that any proposed record linkage is not harmful to individuals or providers and the benefits derived from the record linkage are clearly in the public interest.

Membership

Core members of this committee include:

- SIDR Manager
- Research representative (expertise in administrative data)
- UPEI Privacy Officer (or designate)
- DHW representative
- Health PEI representative
- Public representative
- Administrative support (minute taker/non-voting)

The research representative may include the SIDR Director or other SIDR scientists or analysts with appropriate expertise. At the discretion of the SIDR Director, additional committee members may be added on an as needed or ongoing basis:

- Other data provider representative(s) when projects are requesting data that is not provided by Health PEI or the Department of Health and Wellness
- Individuals with subject matter expertise (e.g., scientific peer-reviewers, people with lived and living experience, community representatives, health care professionals, etc.)
- Other representatives as appropriate/required

Membership terms are two years. Membership will be staggered to ensure maintenance of expertise. New members may be invited to observe at meetings prior to taking up their membership.

Flexible Participation for Public Partners and People with Lived/Living Experience

SIDR recognizes that meaningful participation requires flexibility. Public partners and people with lived and living experience may participate in DRC processes in the manner that is most comfortable and accessible for them. This may include attending meetings, providing input in writing, meeting separately with SIDR staff, or using alternative communication methods. SIDR will work collaboratively with partners to ensure their perspectives are incorporated into the review in ways that support their comfort, safety, and preferred engagement style.



Quorum and Participation

Quorum consists of 50% of core membership. If a core DRC member cannot attend a meeting, they may participate by:

- submitting questions, comments, or their position in writing in advance of the meeting; and/or
- sending an alternate representative from their organization.

Written or asynchronous input will be considered equivalent to in-meeting participation for the purposes of consensus decision-making. As mentioned, SIDR may also meet separately with public partners or people with lived and living experience to gather feedback in a manner that is comfortable and appropriate for them. Input received through these alternative methods will be incorporated into the consensus process and documented in the meeting record.

Conflict of Interest

Should any member of the DRC be involved in the research project being reviewed, they cannot participate in the review.

In the case that the SIDR Manager is involved in the research project, SIDR will be represented by a delegate from UPEI's Office of Research Services.

In the event that the Data provider DRC representative is involved in the research project, another suitable person from within that public body or organization must be selected to attend the DRC review.

Governance

The Chair of the Committee will be the SIDR Manager. The Vice-Chair position will rotate between a representative of DHW and a representative of Health PEI on a two-year basis. The Vice-Chair is responsible for fulfilling Chair duties when the Chair is not available.

Subcommittees may be formed to review: (i) draft reports produced as outputs from research that has made use of data in the SIDR Repository and/or (ii) proposed publications in accordance with the *SIDR Dissemination of Research Findings Procedure*.



Operations and Documentation

The DRC will be scheduled to meet monthly (as required), with the exceptions of July and August where there will be one meeting for both months. Researcher applicants will be invited to attend DRC meetings to provide a brief (5-10 minute) overview of their project and answer any questions from DRC members.

Minutes will be taken at each meeting, documenting: (i) research projects reviewed; (ii) the Committee's decisions and comments; and (iii) any other relevant discussions/decisions. An administrative assistant from SIDR will attend meetings to record minutes.

The UPEI Privacy Officer's completed Project Application Privacy Review Form will be provided to the Committee and form part of the record of a project's review. The privacy review may be conducted by the UPEI Privacy Officer or a designate.

Accountability

The Data Release Committee is accountable to the UPEI Vice President Academic and Research.

Confidentiality

Data Release Committee members may be privy to private and confidential personal information, business and/or research project information in the course of their duties with SIDR. Committee members are expected to hold this information in confidence and safeguard it using a reasonable degree of care. This duty to maintain confidentiality is to continue even after membership on a committee ends.