



# Disclosure of ICES Data for Research Purposes and Execution of Research Agreements Policy

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Chief Privacy and Legal Officer		Director, PLO		
Required Reviewers (Titles)				
Sr. Director, Strategic Partnerships and Digital Services		Director, DAS		

Please refer to the [glossary](#) for terms and definitions.

## 1.0 PURPOSE

- 1.1 This **Policy** defines the rules for the disclosure of **Risk Reduced Coded Data (“RRCD”)**, a type of **Personal Health Information (“PHI”)** and **Personal Information (“PI”)**, by **ICES Agents** to **Third Party Researchers** for research purposes to ensure consistency with the mandate of ICES, in accordance with applicable laws and other legal requirements, including **Data Minimization** principles.
- 1.2 This **Policy** confirms ICES’ commitment to not disclose **RRCD** if other information, such as **De-Identified Data**, will serve the identified research purpose, and not disclose more **RRCD** than is reasonably necessary to meet the identified research purpose of the disclosure.
- 1.3 This **Policy** confirms that except for **RRCD**, ICES does not disclose any other types of **PHI/PI**, including **Fully Identifiable Data** and **Coded Data**, to **Third Party Researchers** for research purposes.

## 2.0 SCOPE

- 2.1 This **Policy** applies to all **ICES Agents** when disclosing **RRCD** to **Third Party Researchers**.

## 3.0 ROLES AND RESPONSIBILITIES

- 3.1 ICES **Chief Privacy and Legal Officer (“CPLO”)** is accountable for this **Policy** to ensure all disclosures of **RRCD** are in compliance with applicable laws and any other legal requirements.
- 3.2 ICES Director, **Data & Analytic Services (“DAS”)** is responsible for ensuring that all **Policies, Procedures, and Practices** relating to the disclosure of **RRCD** for authorized research purposes are in compliance with this **Policy**.



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## 4.0 DETAILS

### 4.1 Authority for Disclosure of RRCD

4.1.1 All disclosures of **RRCD** for research purposes must be assessed in a **Privacy Impact Assessment** (“**PIA**”) to determine whether the disclosure of **RRCD** is lawful. The decision for a particular disclosure of **RRCD** to a **Third Party Researcher** must also take into consideration ICES’ *Risk Management Policy* and ICES’ *Risk Management Standard*.

#### a. **ICES as a Corporation**

- i. Any disclosure of **RRCD** for research purposes must be in accordance with ICES’ authority as a not-for-profit corporation and, specifically, as permitted by ICES’ **Corporate Objects**.

#### b. **Authority as Permitted or Required by Law**

- i. ICES will disclose **RRCD** for research purposes only where permitted or required by law, including Ontario’s *Personal Health Information Protection Act* (“**PHIPA**”), the *Coroners Act*, and their applicable regulations;
- ii. ICES may disclose **PHI** to **Third Party Researchers** for the purpose of s.44 of **PHIPA** as if ICES were **Health Information Custodian** (“**HIC**”), which is permitted by s.18(4) of Ontario Regulation 329/04 to **PHIPA**;
- iii. ICES may disclose **Personal Information** (“**PI**”) to **Third Party Researchers** in accordance with s.5 of Ontario Regulation 523/18 to the *Coroners Act*; and
- iv. Any disclosure of **RRCD** must be assessed and approved in accordance with all other applicable ICES **Policies, Procedures, Practices**, and legal agreements executed by ICES.

#### c. **Authority Under Contracts**

- i. Any disclosure of **RRCD** to **Third Party Researchers** for research purposes must be consistent with the executed **Data Sharing Agreement** (“**DSA**”) under which the applicable **ICES Data** was initially collected by ICES from the **Data Provider** because the executed **DSA** governs the collection, use, and disclosure of such **ICES Data** by ICES.

### 4.2 Requirements prior to disclosing RRCD

#### 4.2.1 Privacy Impact Assessments

- a. Prior to any disclosure of **RRCD**, ICES must be satisfied that a **PIA** has been conducted by an ICES Privacy **Subject Matter Expert** (“**SME**”) in accordance with *ICES’ Privacy Impact Assessment Policy* which sets out the requirements that must be satisfied and the criteria that must be considered in determining whether to approve or deny a



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request for disclosure of **RRCD** for research purposes. These requirements and criteria include but not limited to ensuring that:

- i. The disclosure is permitted or required under applicable laws, regulations, and other legal requirements, and that any and all conditions or restrictions set out in the applicable statutes and their regulations have been satisfied;
  - ii. The **RRCD** does not contain any additional identifying information not necessary or relevant to the purpose of the disclosure;
  - iii. There is a written application, a written research plan, and a copy of the decision of the **Research Ethics Board** (“**REB**”) approving the written research plan, and that the written research plan complies with the requirements in the applicable statutes and their regulations;
  - iv. The **RRCD** being requested is consistent with the **RRCD** identified in the written research plan that was approved by the **REB**;
  - v. Other information, such as **De-Identified Data**, will not serve the identified research purpose for the disclosure; and
  - vi. No more **RRCD** is disclosed than is reasonably necessary to meet the identified research purpose.
- b. An analysis must be set out in the applicable **PIA** and communicated in written format to the requester; and
  - c. If any **Risks** are identified in the applicable **PIA**, such **Risks** must be escalated pursuant to ICES’ *Risk Management Standard* and associated **Procedures**.

## 4.2.2 Chief Coroner consent for PI disclosure for research purposes

- a. Prior to disclosure of **RRCD** containing **PI**, the Chief Coroner must consent to the disclosure for the specific research purpose and said research purpose must be related to the health or safety of the public or any segment of the public.

## 4.2.3 Research Agreement

- a. A **Research Agreement** must be executed between ICES and the **Third Party Researcher** prior to disclosure of **RRCD** for research purposes; and
- b. The **Research Agreement** must be executed in accordance with this **Policy** prior to any disclosure of **PHI/PI** for research purposes.

## 4.2.4 Exceptions and Risks Identified

- a. Any conditions, restrictions, or **Risks** identified in a **PIA** and/or **Research Agreement** must be addressed pursuant to *Ongoing Review of Privacy and Security Policies, Procedures, Practices and Exceptions Policy*, ICES’ *Risk Management Policy*, ICES’ *Risk Management Standard*, and ERM **Procedures** as applicable.



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## 4.2.5 Secure Transfer

- a. All disclosures of **RRCD** to **Third Party Researchers** must be conducted in accordance with ICES' *Secure Transfer of PHI/PI Procedure*

## 4.2.6 Secure Return or Destruction

- a. ICES **Data Quality and Information Management ("DQIM")** personnel are responsible for ensuring that **RRCD** disclosed to a **Third Party Researcher** is either securely returned or securely disposed of, whichever method is specifically identified in the **Research Agreement**, following the retention period outlined in the **Research Agreement**; and
- b. If the **RRCD** is not securely returned or a certificate of destruction is not received by ICES within a reasonable period of time following the date of termination **Research Agreement**, or the retention period identified in the **Research Agreement**, such findings must be reported to the ICES **CPLO** to advise on next steps.

## 4.2.7 Documentation related to approved or not approved disclosures of RRCD

- a. All documentation related to the receipt, review, approval, or denial of requests for the disclosure of **RRCD** for research purposes must be logged in ICES' **Log of Third Party Researcher Disclosures**;
- b. ICES shall maintain a log of all executed **Research Agreements** with, at minimum, the following content included:
  - i. The name of the research study;
  - ii. The name of the principal **Third Party Researcher** to whom the **PHI/PI** was disclosed pursuant to the **Research Agreement**;
  - iii. The date(s) of receipt of the written application, the written research plan, and the written decision of the **Research Ethics Board ("REB")** approving the research plan;
  - iv. For **PI** disclosure, the date that the Chief Coroner consented to the disclosure of the **PI** for research;
  - v. For **PI** disclosure, the specific purpose of the research and confirmation that the purpose of the research is related to the health or safety of the public or any segment of the public;
  - vi. The date that the approval to disclose the **PHI/PI** for research purposes was granted by ICES;
  - vii. The date that the **Research Agreement** was executed;
  - viii. The date that the **PHI/PI** was disclosed;
  - ix. The retention period for the **PHI/PI** as set out in the **Research Agreement**;
  - x. Whether the **PHI/PI** will be securely returned, securely disposed of, or de-identified and retained by the **Third Party Researcher** following the retention period set out in the **Research Agreement**;



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- xi. The date by which the **PHI/PI** must be securely returned, a certificate of destruction be received, or written confirmation of de-identification be received from the **Third Party Researcher**; and
- xii. The date the **PHI/PI** is securely returned, a certificate of destruction is received, or written confirmation of de-identification is received from the **Third Party Researcher**.
- c. All written applications, written research plans, copies of the **REB** approval decisions, and other documentation required to assess and approve or not approve the request for disclosure of **RRCD** will be maintained by the ICES Manager, Privacy in the shared drive of the ICES **Privacy and Legal Office** (“**PLO**”);
- d. All **Research Agreements** are maintained by the ICES Director, **DAS** or delegate; and
- e. All Certificates of Destruction are maintained by the ICES Director, **DQIM** or delegate.

## 4.2.8 Communication related to approved or not approved disclosures of RRCD

- a. All decisions for whether to approve or deny the request for the disclosure of **RRCD** for research purposes and the reasons for the decisions will be communicated by an ICES Privacy **SME** to the applicable ICES **Research Program Manager** (for **DAS**) or ICES **Research Program Coordinator** (for **DAS**).

## 4.3 ICES may disclose Publishable Data for research purposes in the following circumstances:

- 4.3.1 To **Knowledge Users**, such as policy-makers; and
- 4.3.2 For incorporation of results of an **ICES Project** into publications and reports.

## 4.4 Requirements prior to disclosing De-Identified Data for research purposes

- 4.4.1 Prior to the disclosure of **De-Identified Data**, ICES Agents must satisfy themselves that the use of **PHI/I** to create the **De-Identified Data** is permitted under ICES' *Use of ICES Data Policy*.
- 4.4.2 If the use of **PHI/PI** to create the **De-Identified Data** is permitted under ICES' *Use of ICES Data Policy*, then such disclosures are permitted pursuant to this **Policy**.
- 4.4.3 All disclosures of **De-Identified Data** must first be reviewed in accordance with ICES' *De-Identification and Aggregation Policy*.

## 5.0 RELATED DOCUMENTATION

- 5.1 *Ongoing Review of Privacy and Security Policies, Procedures, Practices, and Exceptions Policy*
- 5.2 *Change Management Policy*
- 5.3 *Privacy and Security Audit Policy*
- 5.4 *Termination or Cessation of Employment or Contractual Relationship in Relationship to ICES Data Policy*
- 5.5 *Discipline and Corrective Action in Relation to ICES Data Policy*
- 5.6 *Privacy and Security Incident Breach Management Policy*



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- 5.7 *De-Identification and Aggregation Policy*
- 5.8 *Use of ICES Data Policy*
- 5.9 *Risk Management Standard*
- 5.10 *Secure Transfer of PHI/PI Procedure*
- 5.11 *Risk Management Policy*
- 5.12 *Privacy Impact Assessment Policy*

## 6.0 TRAINING AND COMMUNICATION

- 6.1 **Policies** and **Procedures** are available on the **ICES Intranet**.
- 6.2 This **Policy** and any administrative **Procedures** are communicated to all **ICES Agents** across the **ICES Network** during onboarding and on a yearly basis. **Policy** awareness is also supported and promoted by the **Policy Owner**.
- 6.3 Once new **Policies** are published to the **ICES Intranet**, they are communicated to **ICES Employees** in ICES OnTap, the weekly email with the organization's internal updates.

## 7.0 COMPLIANCE AND ENFORCEMENT

- 7.1 **ICES Agents** must comply with all applicable ICES **Policies** and **Procedures**.
- 7.2 **ICES Agents** must notify an ICES Privacy **Subject Matter Expert** ("SME") or ICES Security **SME** at the first reasonable opportunity if they breach or believe there has been a breach of ICES' Privacy and Security **Policies** or **Procedures**, in accordance with ICES' *Privacy and Security Incident Breach Management Policy* and associated **Procedures**, as set out in the framework posted on the PLO/Cybersecurity Intranet site.
- 7.3 All other violations under ICES Privacy and Security **Policies** and **Procedures** may be subject to a range of **Disciplinary Actions** including warning, temporary or permanent loss of **Access Privileges**, legal sanctions and/or termination of employment for cause, or contract with ICES pursuant to *ICES' Discipline and Corrective Action in Relation to ICES Data Policy* and *ICES' Termination or Cessation of Employment or Contractual Relationship in Relationship to ICES Data Policy* and associated **Procedures**.
- 7.4 Compliance is subject to annual audit by an ICES Privacy **SME** or ICES Risk & Compliance Analyst pursuant to the **Annual Audit Schedule** established under ICES' *Privacy and Security Audit Policy*.

## 8.0 EXCEPTIONS

- 8.1 Any exceptions requested pursuant to this **Policy** must be in accordance with ICES' *Ongoing Review of Privacy and Security Policies, Procedures, Practices, and Exceptions Policy* and ICES' *Change Management Policy*.