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

Department	Reference Number	Organizational Scope	ICES Site	IPC Scope
PLO	017-00-00	ICES Network	ICES Network	All Acts
Original Date (YYYY-MM-DD)	**Current Version (YYYY-MM-DD)**	**Review Frequency**	**Next Review (Month YYYY)**	**Supersedes (if applicable)**
2022-06-01	2025-07-30	Triennial	July 2028	N/A
Authority (Title)	Chief Privacy and Legal Officer			
Policy Owner (Title)	Director, PLO			
Required Reviewers (Titles)	Sr. Director, Strategic Partnerships and Digital Services			
	Director, DAS			

Please refer to the glossary for terms and definitions.

Provisions highlighted in grey are not yet in effect and are subject to review and approval by the Information and Privacy Commissioner.

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.

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")**, in accordance with the *Privacy Impact Assessment Policy*, 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 the *Risk Management Policy*.

(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, as applicable:

(A) *Personal Health Information Protection Act* ("*PHIPA*") and its regulations; and

(B) The *Coroners Act* and its regulation;

(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 policies, standards, procedures, 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 the *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 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 in accordance with the *Risk Management Policy*.

4.2.2 Chief Coroner consent for PI disclosure for research purposes

(a) Prior to disclosure of RRCD containing PI that ICES initially collected as a **Prescribed Entity** under the *Coroners Act*, 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 Identified risks and exceptions

(a) Any conditions, restrictions, or risks identified in a PIA and/or Research Agreement must be addressed in accordance with the Risk Management Policy.

(b) Any exceptions to ICES' policies, standards, and procedures must be approved in accordance with the *Change Management and Exceptions Policy.*

4.2.5 Secure Transfer

(a) All disclosures of RRCD to Third Party Researchers must be conducted in accordance with *Secure Collection, Disclosure, and 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 accordance with the *Third Party Research Data Disclosure Procedure.*

4.3 Research Agreements

4.3.1 ICES shall maintain a log of all executed Research Agreements with, at minimum, the information set out in Appendix A.

4.3.2 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");

4.3.3 All Research Agreements are maintained by the ICES Director, DAS or delegate; and

4.3.4 All Certificates of Destruction are maintained by the ICES Director, DQIM or delegate.

4.4 Communication related to approved or not approved disclosures of RRCD

4.4.1 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).

4.5 Disclosing De-Identified Data

4.5.1 ICES may disclose De-Identified Data in the form of Publishable Data for research purposes in the following circumstances:

(a) To **Knowledge Users**, such as policy-makers; and

(b) For incorporation of results of an **ICES Project** into **Reports**.

4.6 Requirements prior to disclosing De-Identified Data for research purposes

4.6.1 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 the *Use of ICES Data Policy*.

4.6.2 If the use of PHI/PI to create the De-Identified Data is permitted under the *Use of ICES Data Policy*, then such disclosures are permitted pursuant to this Policy.

4.6.3 All disclosures of De-Identified Data must first be reviewed in accordance with the *De-Identification and Aggregation Policy.*

5.0 RELATED DOCUMENTATION

5.1 Policies

5.1.1 *Change Management and Exceptions Policy*

5.1.2 *Privacy Impact Assessment Policy*

5.1.3 *Risk Management Policy*

5.1.4 *Use of ICES Data Policy*

5.1.5 *De-Identification and Aggregation Policy*

5.2 Standards

5.3 Procedures

5.3.1 *Secure Collection, Disclosure, and Transfer Procedure*

5.3.2 *Third Party Research Data Disclosure Procedure*

5.4 Tools

5.5 Guidelines

6.0 TRAINING AND COMMUNICATION

6.1 Policies, standards, and procedures are available on the **ICES Intranet**.

6.2 This policy and any related standards and/or 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's **Owner**.

6.3 Once new policies, standards, and procedures are published to the **ICES Intranet**, they are communicated to **ICES Agents** on the **ICES Intranet** and through ICES' weekly email with the organization's internal updates.

7.0 COMPLIANCE AND ENFORCEMENT

7.1 **ICES Agents** must comply with all applicable policies, standards, and procedures.

7.2 **ICES Agents** must notify a Privacy and/or Security **Subject Matter Expert ("SME")** at the first reasonable opportunity if they breach or believe there has been a breach of ICES' privacy and security policies, standards, or procedures in accordance with applicable policies and standards, including:

7.2.1 *Privacy Breach Management Policy*

7.2.2 *Security Incident Management Standard*

7.3 Enforcement of compliance with this policy is the responsibility of the the **ICES Agent** identified as the Authority of this policy.

7.4 All violations of policies, standards, and procedures may be subject to a range of **Disciplinary Actions** in accordance with applicable policies, including:

7.4.1 *Discipline and Corrective Action Policy*

7.4.2 *Termination of Employment Policy*

7.4.3 *Discipline and Corrective Action in Relation to ICES Data Policy*

7.4.4 *Termination or Cessation of Employment or Contractual Relationship in Relation to ICES Data Policy*

7.5 Compliance is subject to audit in accordance with applicable policies, including:

7.5.1 *Privacy and Security Audit Policy*

8.0 EXCEPTIONS

8.1 Any exceptions requested pursuant to this policy must be in accordance with applicable policies, including:

8.1.1 *Ongoing Review of ICES' Policy Suite Policy*

8.1.2 *Change Management and Exceptions Policy*

8.2 Exceptions cannot relieve ICES of its legal requirements, including but not limited to those established under:

8.2.1 *Personal Health Information Protection Act, 2004 ("PHIPA")* and its regulation;

8.2.2 *Coroners Act* and its applicable regulations;

8.2.3 *Child, Youth and Family Services Act, 2017 ("CYFSA")* and its applicable regulations; and

8.2.4 The **IPC Manual, Coroners Addendum,** and **CYFSA Addendum**.

9.0 CHANGE TABLE

Change Date (YYYY-MM-DD)	Change Notes
2025-07-30	■ Reviewed for compliance with ICES' obligations as a Prescribed Entity: ○ **IPC Manual:** ▪ Policy, Procedures, and Practices for Disclosure of Personal Health Information for Research Purposes and the Execution of Research Agreements ▪ Log of Research Agreements ○ **Coroners Addendum:** ▪ Policy, Procedures and Practices for Disclosure of Personal information for Research Purposes and the Execution of Research Agreements ▪ Log of Research Agreements ■ Reviewed and revised as part of ongoing review of ICES' Policy Suite activities ■ Revised to reflect updated template and standardized language in Sections 6.0 to 9.0

Appendix A

Research Agreement – Log Requirements	
At minimum, the log of Research Agreements must include the following information:	
	1. The name of the Third Party Research Project
	2. The name of the principal Third Party Researcher to whom the PHI/PI was disclosed pursuant to the Research Agreement
	3. 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
	4. For PI disclosure, the date that the Chief Coroner consented to the disclosure of the PI for research
	5. 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
	6. The date that the approval to disclose the PHI/PI for research purposes was granted by ICES
	7. The date that the Research Agreement was executed
	8. The date that the PHI/PI was disclosed
	9. The retention period for the PHI/PI as set out in the Research Agreement
	10. 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
	11. 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
	12. 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