

## **ICES Project Information Guide for CHEO**

### **What is ICES?**

The Institute for Clinical Evaluative Sciences (ICES) is a not-for-profit research institute. ICES Central is located in Toronto, with satellite sites in several Ontario cities including Ottawa. ICES securely hosts a vast array of Ontario's health-related data (e.g. administrative health records, population-based health surveys, anonymous patient records and clinical data) to answer important questions impacting the health of Ontarians. ICES projects integrate data from several administrative health databases through data linkage based on health card numbers. ICES houses data on the entire Ontario population, with some datasets spanning 25+ years.

### **ICES Publications Directory**

A list of ICES publications is available at: <https://www.ices.on.ca/Publications>.

These publications demonstrate the types of research utilizing ICES data.

### **ICES Data Dictionary**

The ICES Data Dictionary includes all datasets housed at ICES, along with a list of variables and definitions for each: <https://datadictionary.ices.on.ca/Applications/DataDictionary/Default.aspx>

### **ICES Scientists**

Every ICES project must have the involvement of a full ICES scientist. These scientists have completed a 3-year probationary period and are able to fully support ICES projects. Each scientist is affiliated with a specific ICES research program. The list of ICES scientists can be found at: <https://www.ices.on.ca/About-ICES/ICES-Scientists>.

Note that any scientist can support a project, regardless of geographical location. The following ICES scientists are based in Ottawa, if you are interested in working with a local researcher:

Eric Benchimol	Lise Bjerre	Larry Chambers	Virginie Cobigo
Eric Crighton	Simone Dahrouge	DeShayne Fell	Alan Forster
Jeremy Grimshaw	Steven Hawken	William Hogg	Claire Kendall
Tetyana Kendzerska	Doug Manuel	Daniel McIsaac	Beth Potter
Manish Sood	Louise Sun	Peter Tanuseputro	Kednapa Thavorn
Carl Van Walraven	Kumanan Wilson		

## ICES Project Application Process

ICES projects start with a research proposal, designed by the research team that outlines the study’s objective(s) and analysis strategies. Before gaining access to ICES data, ICES requires you to complete five main steps to initiate a project.

### 1. Your own institution (e.g. CHEO) REB approval

Ethics approval is needed before you can access ICES datasets. If REB approval has not been obtained when submitting the ICES application, the REB application may be submitted; once REB approval is granted, confirmation of approval must be sent to ICES.

### 2. Project Activation Worksheet (PAW)

The PAW is required to initiate an ICES project. This document includes the study objectives, budgeting and billing information and is used to assign a project (TRIM) number to the application. This form would also indicate whether a project is funded through OCHSU.

### 3. Privacy Impact Assessment (PIA)

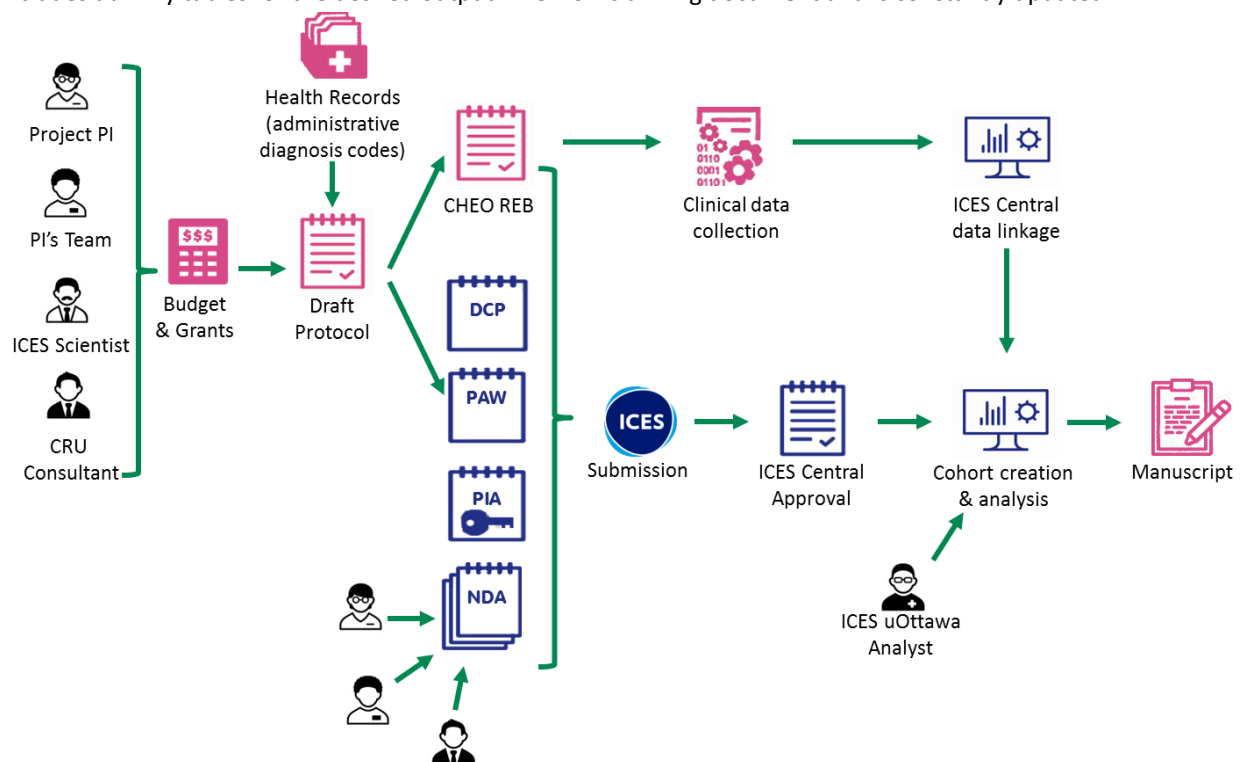
The PIA identifies all datasets that are required to conduct the ICES project. It identifies research questions, requests data holdings, requests approval for project-specific data linkage, and identifies project team members. Any changes to project information must be submitted to the ICES privacy office as a PIA amendment.

### 4. Non-Disclosure Agreements (NDA)

NDAs are necessary to uphold ICES privacy standards. Each member of the project team not affiliated with ICES must sign an NDA form, which is included with the PIA.

### 5. Dataset Creation Plan (DCP)

The DCP is a detailed plan for the creation of the study dataset and the analysis strategy. This document outlines variables (e.g. ICD diagnosis codes, fee codes), inclusion criteria and statistical tests. It is used to help estimate the cost of a project. The DCP identifies which datasets are relevant to meet the objectives outlined in the PIA, and includes dummy tables for the desired output. The DCP is a living document and is constantly updated.



## **ICES Project Flow**

The PAW is typically approved within two weeks. The PIA review takes one to two weeks from the time of receipt of the complete application. PIA approval takes a minimum of three weeks, depending on the complexity and requirements of the project. Upon approval, the ICES uOttawa analyst is granted access to the data and can begin your project.

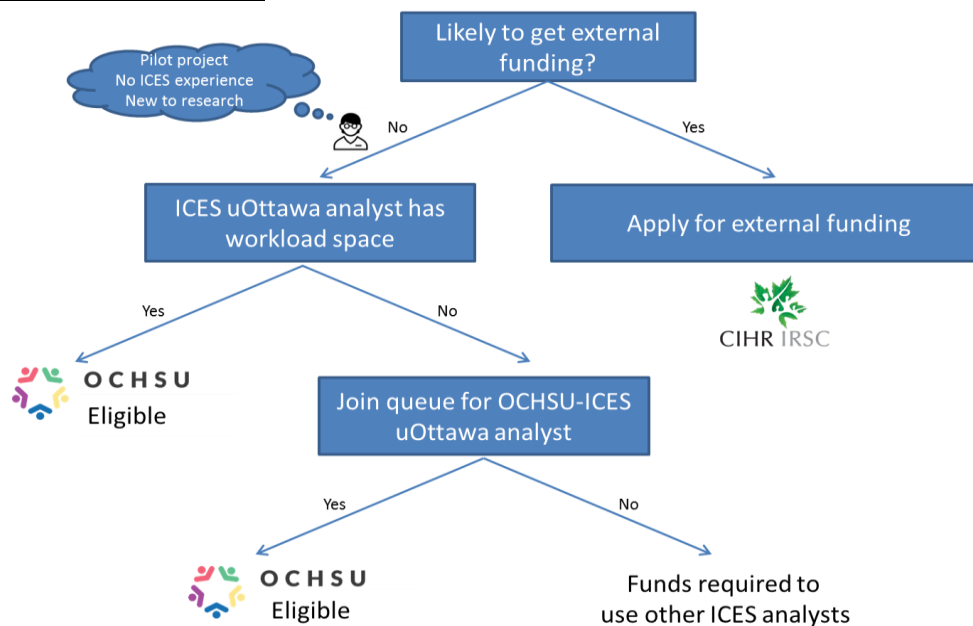
## **Linking External Data to ICES**

A team at ICES Central is able to link external project-specific data to ICES, by linking OHIP numbers to unique ICES Key Numbers. Institutional REB approval is required to link your dataset, and a Data Sharing Agreement (DSA) must be developed between ICES and the external data custodian. The PIA (or amendment) must request for data linkage, and only variables listed in the PIA will be linked. Note that OCHSU does not cover data linkage costs.

## **The OCHSU – ICES Relationship – Obtaining Support through the CHEO CRU**

The Ontario Child Health Support Unit (OCHSU) is aimed at optimizing child health outcomes and setting standards for child health research. OCHSU is funded by CIHR and the Ministry of Ontario, and provides research consulting and services to investigators interested in the health of Ontario children. OCHSU employs an ICES analyst to facilitate projects using ICES data. If you are eligible for an OCHSU-ICES analyst, some ICES costs may be subsidized.

## **OCHSU ICES Project Eligibility**



If you are interested in starting an ICES project, book a CHEO [Clinical Research Unit consult](https://redcap.cheori.org/surveys/?s=62CfDv) through REDCap at <https://redcap.cheori.org/surveys/?s=62CfDv>

## **Contact Details**

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