

**WAY
FORWARD**

**ADVANCING
HEALTH EQUITY
THROUGH DATA**

ICES Data & Analytic Services

Jacob Etches, Minnie Ho, Refik Saskin

Approaches to accessing population level health data in Canada Workshop

Agenda

- 1** Overview of Data & Analytic Services
- 2** Public Sector Research
- 3** Private Sector Research

A person wearing headphones is seated at a desk in a modern office, working on a laptop. The desk is equipped with multiple large monitors. The office has large windows overlooking a cityscape. The entire image is overlaid with a blue tint.

Overview of Data & Analytic Services

■ A Little Bit of History

ICES was founded in 1992 to study the health care system and promote effective, efficient and equitable health care in Ontario.

Originally known as the Institute for Clinical Evaluative Sciences, ICES was created as an independent, not-for-profit research institute and given unprecedented access to the health records of Ontarians.

ICES' original focus on hospital-based services has expanded to include community-based health services, health policy, Indigenous health, the social determinants of health, and data science.

Our Mission and Values

Our mission is translating data into trusted evidence that makes policy and health care better and people healthier.



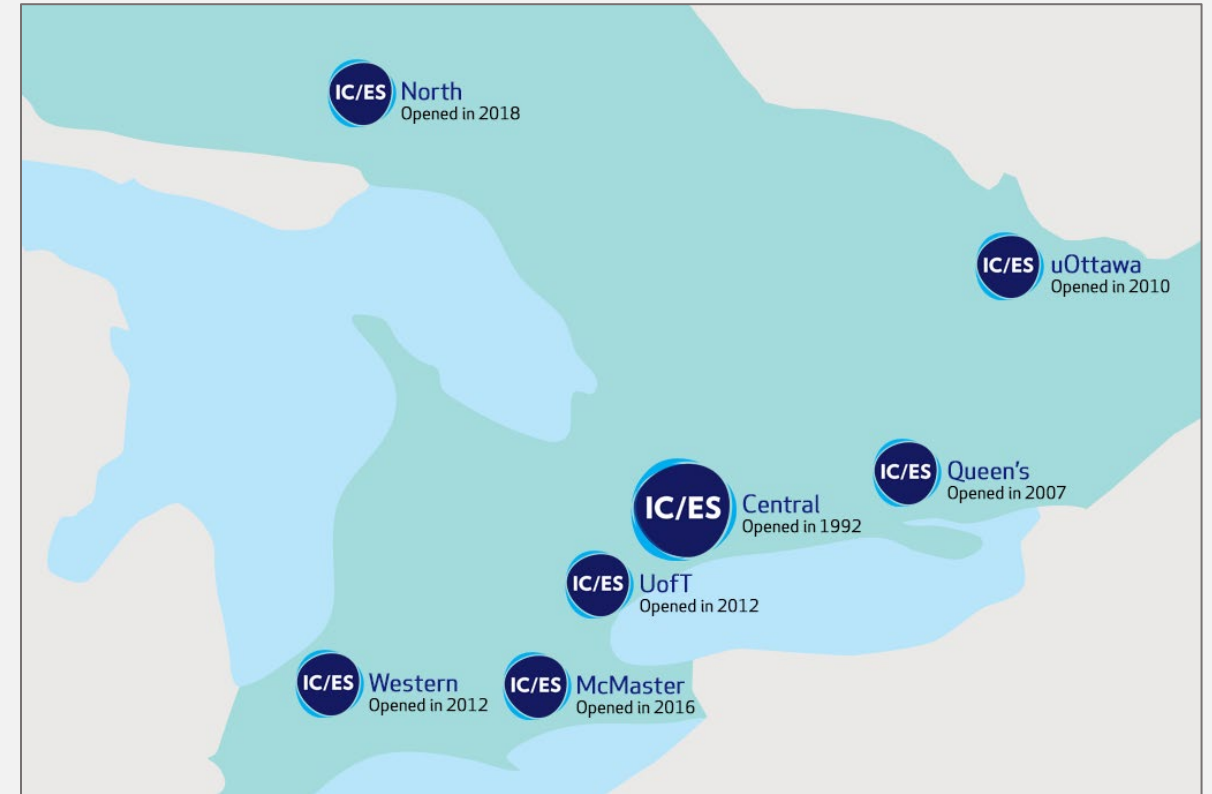
Our values

- **We strive for excellence** – demonstrated by the quality, innovation and rigour for our work.
- **We behave with integrity** – expressed through independence, transparency and impartiality.
- **Our work is relevant** – by providing actionable and timely analyses that lead to improved health equity, outcomes and value and are responsive to health priorities.
- **We collaborate** – through effective partnerships, accessible data and a spirit of openness.
- **We are respectful** – exemplified by inclusiveness and appreciation of each other, trusted data stewardship, meaningful public engagement and alignment with Ontarian's values and accountability for our funding.

■ Who Are We?

More than **800 research, data and clinical experts** spanning a network of **8 research programs and 7 sites** across Ontario.

Governed by a volunteer board of directors and guided by a scientific advisory committee and a public advisory council.



As a prescribed entity under provincial privacy legislation, ICES is a trusted steward of the health records of over 20 million Ontarians, including past and present health card holders.

 **750 billion**
data points



18 billion
individual records (lines of data)



20 million

patient life histories
Over 25 contiguous years and
growing quarterly

Training & mentorship

Policy

Engagement



100+ structured and semi-structured
linked data resources

Partnerships

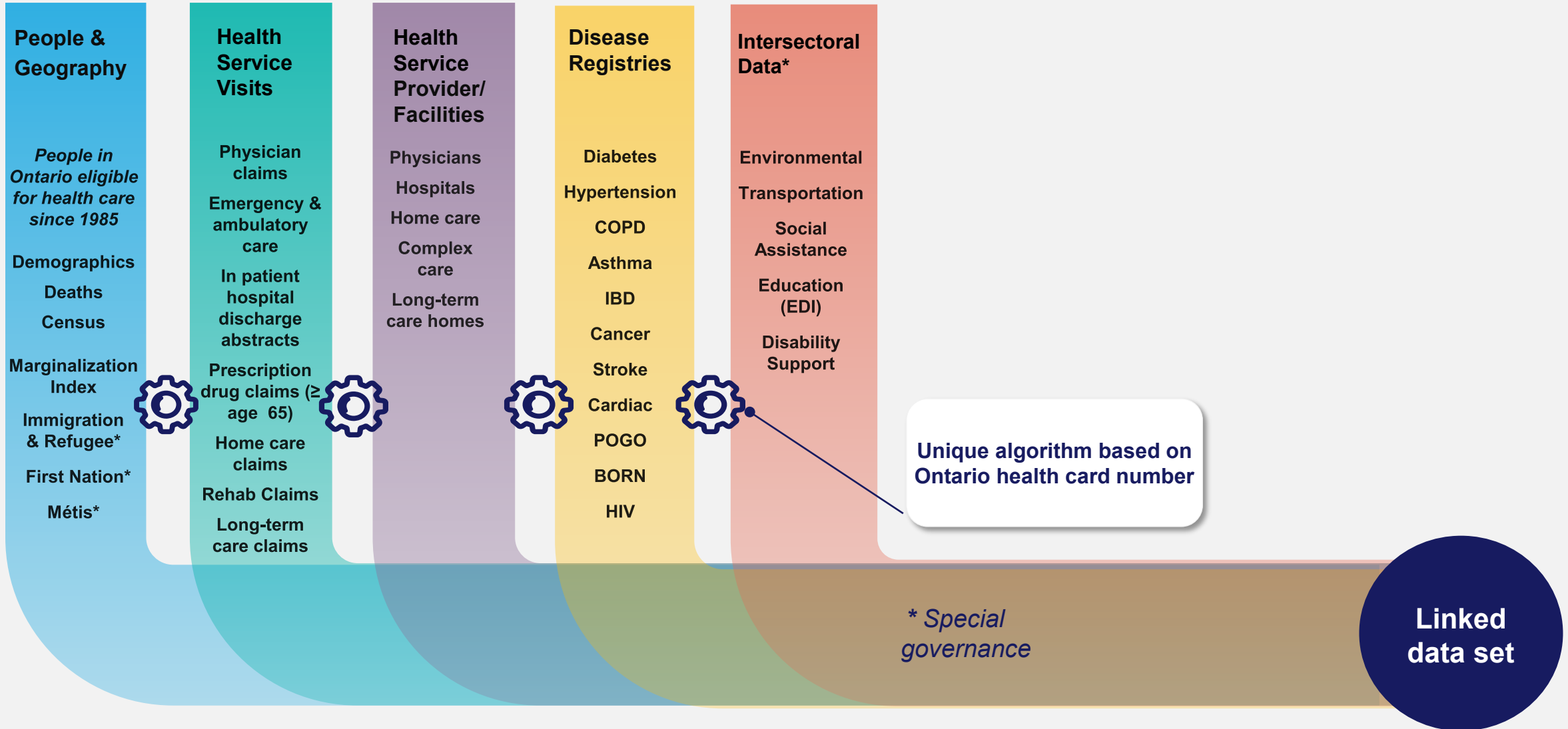
Plus unstructured data

Free-text electronic medical records of



>500,000
primary care patients

ICES Core Data Repository: De-identified and Linkable



■ Data & Analytic Services



The ICES Data & Analytic Services (DAS) platform was **launched in March 2014** as part of the **Ontario SPOR Support Unit**.

Transforming access to ICES data:

- Access to research ready individual level data for researchers

- Custom linkages with external research data

- Access to aggregate research data

Data & Analytic Services (DAS)

Ontario Health Quality (OHQ)

PM: Anahita Carbonneau
Staff Sci: Michael Campitelli

Applied Health Research Question (AHRQ)

PM: Natasha Fortin
PM: Diana An (on leave)
Staff Sci: Lesley Plumptre
ahrq@ices.on.ca

Third Party Research (TPR) for Public Sector

PM: Stefana Jovanovska
Staff Sci: Refik Saskin
das@ices.on.ca

Third Party Research (TPR) for Private Sector

PM: Keresa Arnold
Staff Sci: Jacob Etches
das.privatesector@ices.on.ca

Indigenous

PM: Sarah Deck
PM: Jessica Jordao (on leave)
Staff Sci: Graham Mecredy
Staff Sci (MNO): Sarah Edwards
Staff Sci (WAHA): Beth Rachlis
indigenous@ices.on.ca

Ontario Health Data Platform (OHDP)

PM: Raquel Duchon
Staff Sci: Luke Mondor
Staff Sci: Maria Koh (on leave)
ohdp@ices.on.ca

Access to data

Analytics & reporting (research)

Analytics and reporting (EPM)

Support for longitudinal cohort studies

Access to data

Analytics and reporting (EPM)

SERVICES AVAILABLE

■ Available Services

For Researchers

[Information for Public Sector Researchers \(ices.on.ca\)](https://ices.on.ca)

[Information for Private Sector Researchers \(ices.on.ca\)](https://ices.on.ca)

I. ACCESS TO ICES DATA

Researchers, students, policy makers or knowledge users who are affiliated with a publicly funded, not-for-profit organization and who want to obtain and analyze ICES data to answer a research question may submit a request to ICES DAS. DAS staff will contact the requestor to discuss the project's feasibility, timeline and cost. Projects requesting access to data require the approval of a research ethics board.

DAS staff work with requestors to design a research-ready data extract from the ICES data repository using an algorithm that de-identifies data in a way that provides researchers with individual-level data while meeting all privacy standards. Requestors are provided with access to the linked, de-identified data extract on a secure, online research environment, where they can perform analyses and create reports. To ensure privacy policy compliance, linked data cannot be copied or removed from the environment.

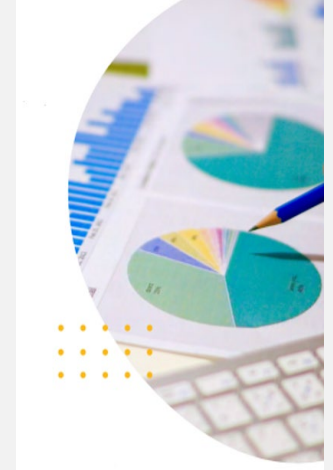
DATA PLATFORM



ICES Data & Analytic Virtual Environment (IDAVE)



Data Safe Haven (DSH)



II. ANALYTIC SERVICES AND REPORTS – RESEARCH

In cases where the requestor is not seeking access to individual-level data, DAS can provide analytic services, including results reports based on analysis of ICES data. DAS staff and scientists will perform the analyses that generate the results report, in accordance with specifications provided by the requestor. Projects requesting analytic services for the purposes of research require the approval of a research ethics board.

■ Available Services

For Researchers

[Information for Public Sector Researchers \(ices.on.ca\)](https://ices.on.ca)

[Information for Private Sector Researchers \(ices.on.ca\)](https://ices.on.ca)

III. ANALYTIC SERVICES AND REPORTS – SYSTEM EVALUATION

Health system policy makers and providers looking to obtain research evidence to inform planning, policy, and program development for the benefit of the entire Ontario health care system are also eligible to submit requests for DAS analytic and reporting services. Requestors will receive results reports that include summary results (e.g., the number of people with a particular medical condition in Ontario in a specific time period, or the number of hospitalizations associated with that condition). DAS staff and scientists will work with the requestor to perform the analyses that generate the results report. Requests for non-research analytic services do not require research ethics board approval.



IV. SUPPORT FOR COHORT AND LONGITUDINAL FOLLOW-UP STUDIES

Researchers interested in receiving a cohort list of applicable individuals for the purposes of conducting publicly funded research may submit a request. ICES DAS may only provide a cohort list for the following purposes, subject to ethics board approval and other conditions that may apply: 1) to abstract or examine data from existing data sources (including but not limited to medical records, disease registries, human biological materials or genetic databases); or 2) to contact physicians or institutions for recruitment in research. DAS staff and scientists will work closely to work with the requestor to ensure the secure provision of minimal information as required to conduct the research.

Available Services

For Knowledge Users

The Applied Health Research Question (AHRQ) program, an initiative of the Ontario Ministry of Health, is also managed through DAS.

[Applied Health Research Question Overview \(ices.on.ca\)](https://ices.on.ca)



ICES is an independent, not-for-profit research institute made up of a community of research, data and clinical experts. We work with Ontario's health-related data and aim to inform health system policy and planning to improve the health of all Ontarians. Our organization receives core funding from the Ontario Ministry of Health.

THE APPLIED HEALTH RESEARCH QUESTION PROGRAM

How we support health system organizations

Many organizations across the province rely on research findings to improve the services they provide to their community. The Ministry of Health created the Applied Health Research Question (AHRQ) Program to help Ontario-based organizations connect with health data institutes that provide tailored analytics and information services.

What are AHRQs?

AHRQs are research questions posed by health system organizations to obtain evidence that can benefit Ontario's health care system. These organizations, called "Knowledge Users," can submit an AHRQ to ICES and our team completes an analysis for them using our Data Repository. Knowledge Users typically submit an AHRQ to better understand the population they serve, inform health system planning, or develop a policy or program.

You could be eligible if

- You represent a "Knowledge User": an Ontario-based, publicly funded organization seeking data to inform planning, provision of health care services, policy or program development.
- Your question addresses a specific information need or gap that will benefit health care service delivery or policy in Ontario.*
- Your request to conduct research is not readily fundable through other research funding opportunities.

*Requests to support specific advocacy positions are neither in scope nor appropriate for the AHRQ program.

Representatives from Indigenous communities or organizations who would like to inquire about AHRQs should contact indigenous@ices.on.ca.



Approval Process

- ✓ Is the requestor an eligible Knowledge User?
- ✓ Is ICES the most appropriate research provider to answer the question?
- ✓ Can the AHRQ be answered using ICES data?
- ✓ Does the AHRQ identify a gap that will benefit health care service delivery or policy in Ontario?
- ✓ Is the scope reasonable, considering the needs of other Knowledge Users?

HOW TO APPLY

You can find the application form with submission details [here](#). Requests can be submitted at any time and are evaluated monthly. AHRQ requests must be approved in writing by a senior decision-maker within the Knowledge User's organization.

STAY CONNECTED



How Third Party Researchers Access ICES “Data”

Who am I

Third-Party Researcher
(Private)

Third-Party Researcher
(Public)

Who can help me

ICES Staff Scientist

ICES Analyst / Epidemiologist

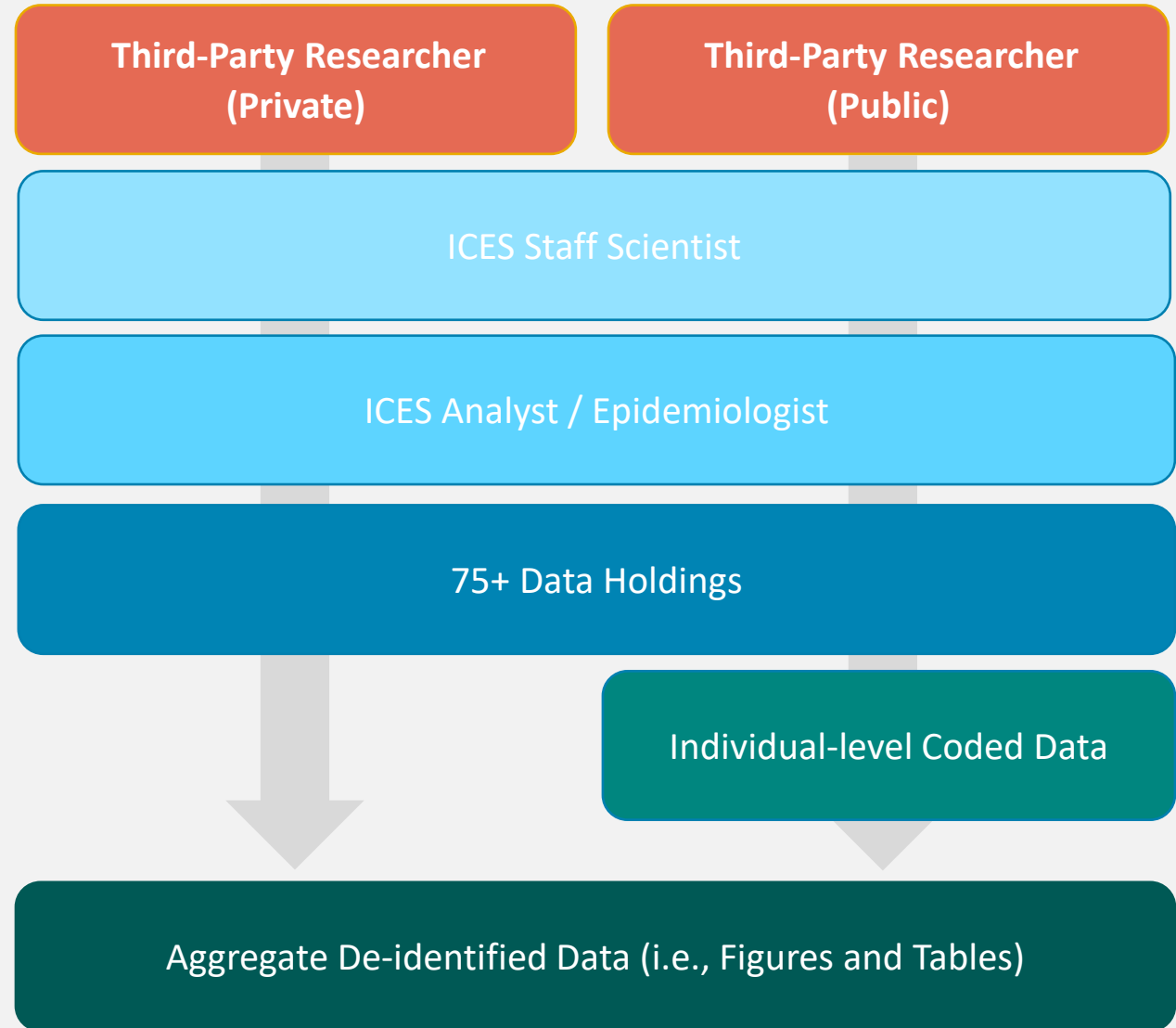
What can I access

75+ Data Holdings

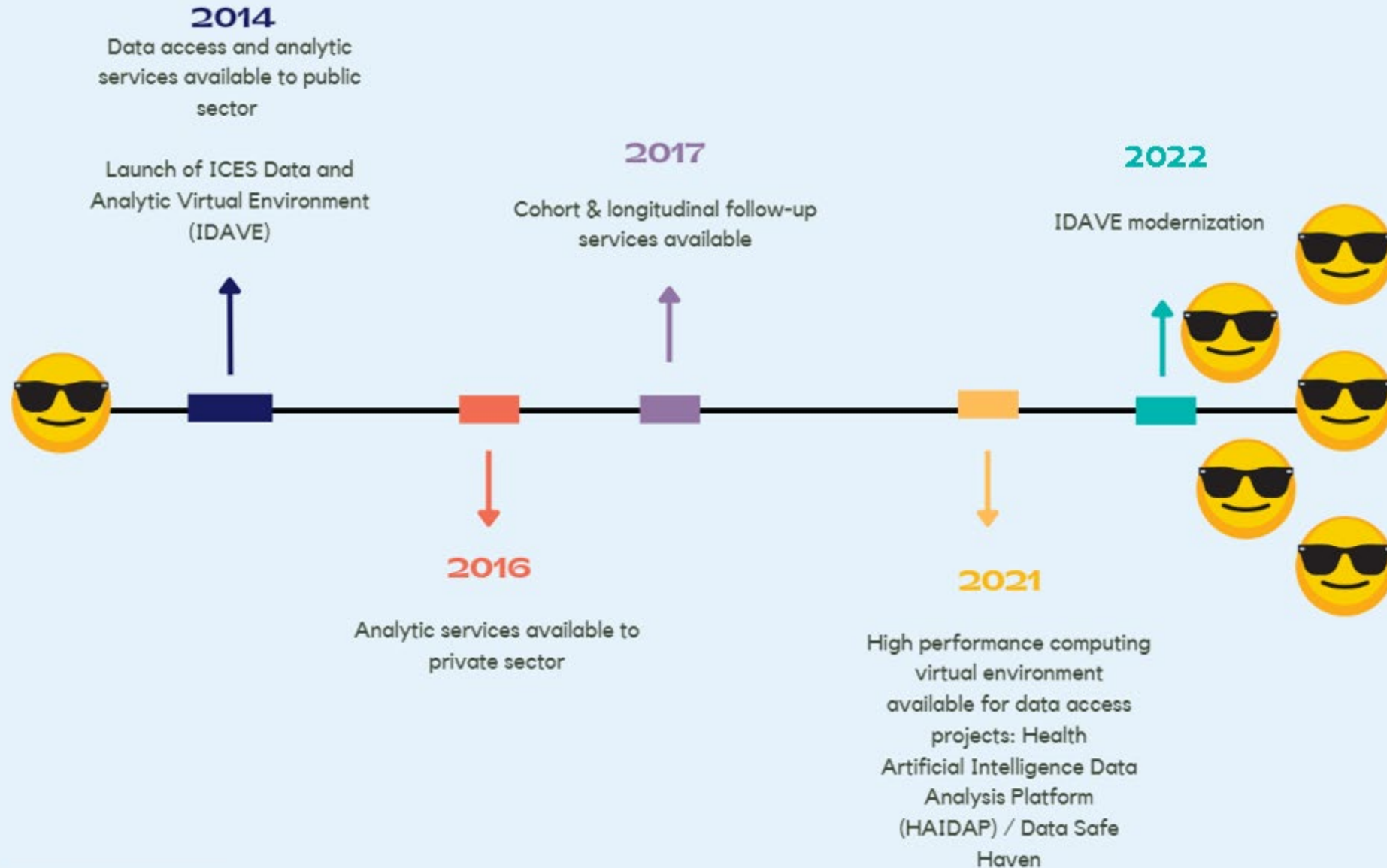
What do I receive

Individual-level Coded Data

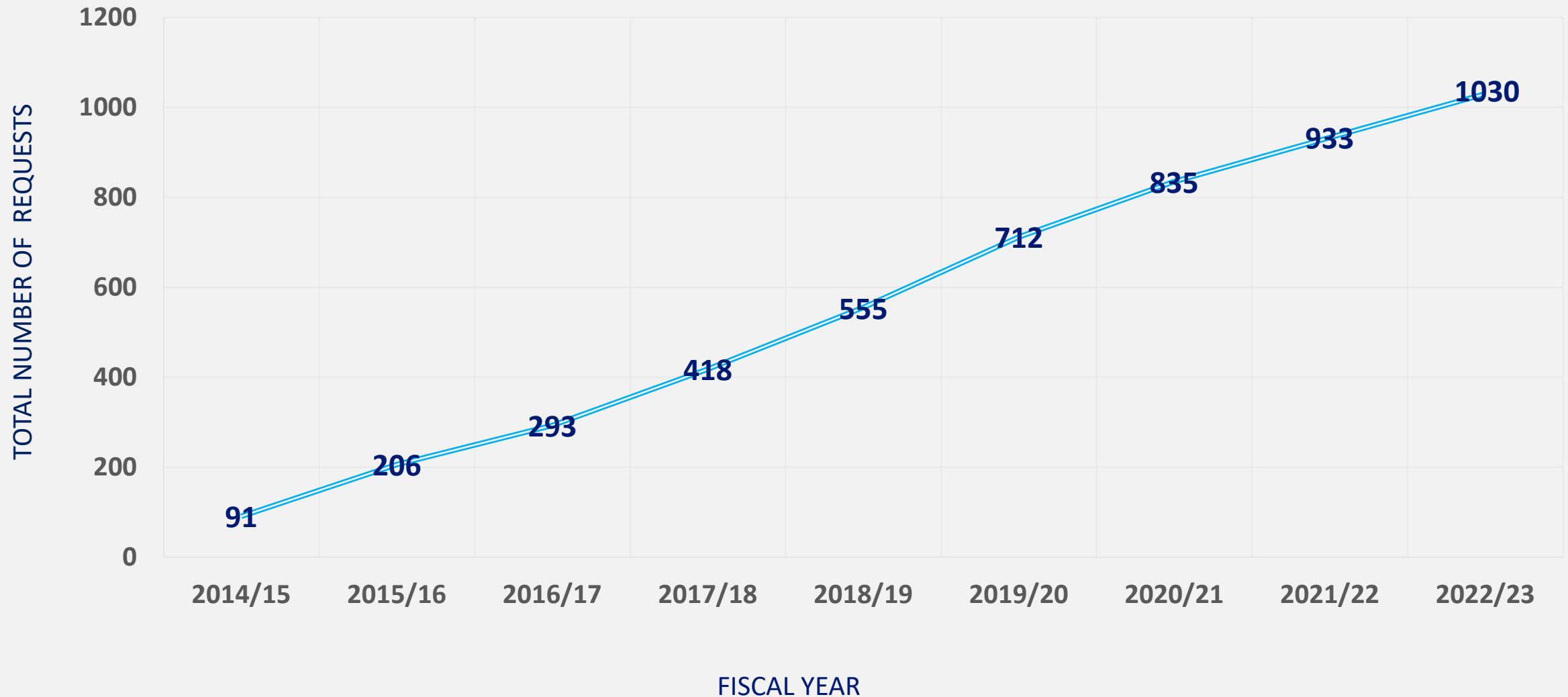
Aggregate De-identified Data (i.e., Figures and Tables)



■ Nine Years Young



Steady growth over the years





PROJECTS

Powered by ICES Data

DATA & ANALYTIC SERVICES TEAM

A person wearing headphones is seated at a desk in a modern office, working on a laptop. The desk is equipped with multiple computer monitors. The office has large windows overlooking a cityscape with tall buildings. The entire image is overlaid with a blue tint.

Public Sector Research

■ Eligibility

University, college or hospital-affiliated researchers or students

Publicly-funded, not-for-profit health care agencies

Policy makers

Other knowledge users including not-for-profit organizations

■ Available Services

Access to highly risk-reduced coded data

- Available through secure “Virtual Desktop Infrastructure”: IDAVE or DSH
- Client performs analyses using analytics software and produces reports
- Re-identification risk assessment is conducted on all research results

Full analytic services

- Data set creation and analysis according to client requirements
- Report generation

Linkage of ICES data holdings with external project-specific data

- Data sharing agreement required

Requests by researchers based outside of Canada are supported

Step 1 The Requestor submits the DAS Request Form.

Step 2 ICES DAS assesses eligibility and project feasibility. If acceptable, the Requestor is invited to a consultation to review project objectives and timelines.

Step 3 During the consultation, ICES DAS will gather information to develop a preliminary project plan. Following the consultation, ICES DAS will provide the Requestor with a Confirmation of Feasibility that includes a cost estimate of the services requested.

Step 4 The Requestor seeks research ethics board approval for the project and satisfies any other conditions that must be met prior to project initiation, as specified in the Confirmation of Feasibility.

Step 5 The ICES Privacy Office reviews the submission to the research ethics board and corresponding approval.

Step 6 ICES DAS provides the Requestor the DAS Agreement for signature.

Step 7 ICES DAS works with the Requestor to develop and finalize the data set creation plan.

Step 8 ICES DAS completes cohort creation and uploads the customized research-ready data to the secure virtual server, the ICES Data & Analytic Virtual Environment (IDAVE).

Step 9 ICES DAS grants Authorized Researchers access to the IDAVE, where analyses will be performed by the Requestor's project team.

Step 10 The Authorized Researchers complete analyses, including creation of manuscript-ready output, within the IDAVE.

Step 11 ICES DAS assesses requested files for re-identification risk, as per ICES policies. Files cleared of re-identification risk are e-mailed to the Requestor.

■ ICES Data & Analytic Virtual Environment (IDAVE)

Part of the secure ICES network

Microsoft Office, SAS 9.4, R 4.2.2, Stata 17

IDAVE is fully compliant with IPC requirements:

- Strong password and two-factor authentication are required
- Data cannot be directly copied or transferred out of IDAVE by the end-user
- External peripherals (printers, USB devices, etc.) connected to the user's local computer cannot be used within IDAVE
- Communications with the server are encrypted
- End-users can only access resources they are authorized to access
- No access to the internet within the environment, significantly reducing the probability of malware

■ Data are on IDAVE. Now what?

We check-in if needed to ensure the datasets are as expected

If changes are required we will arrange for the revisions

We continue to offer advice on:

- Data elements
- Definitions of exposures or outcomes
- Analytic and modelling strategies

■ Project examples

Neighbourhood factors and Covid-19 case rates

Vaccine distribution approaches for at-risk populations during COVID-19

Long-term impacts of affordable housing

Pneumococcal vaccination in adults with underlying medical and social conditions

Inequalities in lung cancer stage at diagnosis

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Private Sector Research



**Who is
private sector?**





**What extra
restrictions?**

■ Principles

1. Alignment with the ICES mission, vision and values
 - There must be public benefit
2. Transparency
 - Full results reports posted 1 year after delivery
 - Full DCP posted 1 year after delivery
 - Identify of clients posted during and after project
3. DAS private sector work cannot detract from other ICES research

■ Data

1. Certain data not permitted for use by private sector
 - e.g., ORGD, CCHS, CIC, TARGET, OHS
2. Certain user fees are different for private sector
3. Analytics only
 - Private sector clients currently cannot access data through IDAVE/DSH
 - DAS clients cannot receive cells smaller than 6



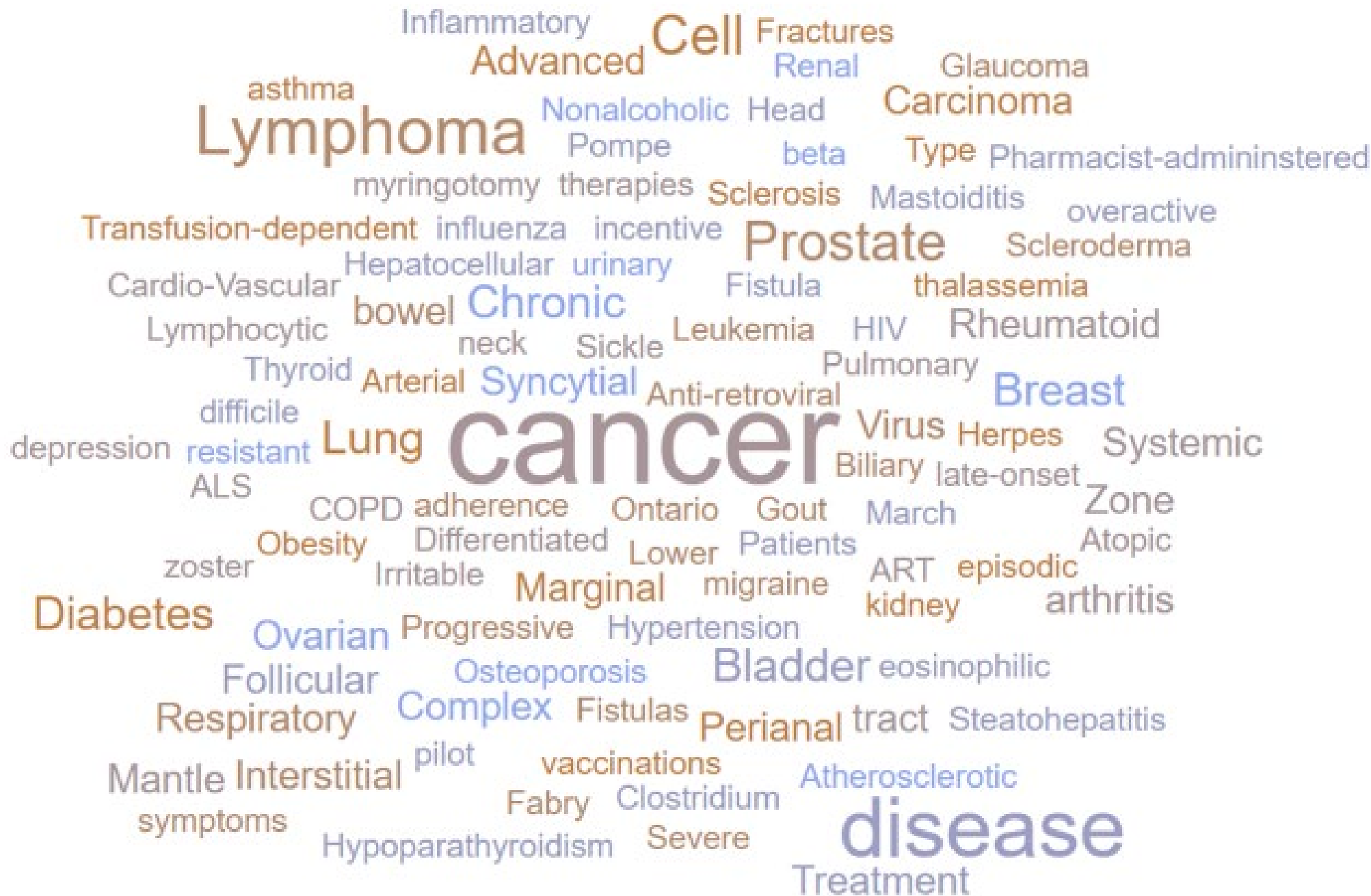
What process?

■ Phases of a private sector project

1. First conversation
2. Basic feasibility checks
3. Protocol
4. Confirmation of feasibility
5. Services agreement
- 6. REB approval**
7. Analysis
8. Quality control
9. Sign-off & debrief
10. 1 year later: post all results and DCP publicly



**What kinds
of projects?**



■ Typical private sector study tables

1. Exclusions
2. Incidence and prevalence
3. Baseline sociodemographic and clinical characteristics
4. Matching
5. Treatment pathways, lines of therapy & patterns of care
6. Health care resource utilization
7. Health care costs
8. Clinical outcomes
9. Overall survival
10. Adjusted models of key outcomes
11. Stratifications by age, severity, type, comorbidities, follow-up time etc.



Oncology

Real-World Treatment Patterns, Survival, and Costs for Ovarian Cancer in Canada: A Retrospective Cohort Study Using Provincial Administrative Data

Manjusha Hurry¹, Shazia Hassan², Soo Jin Seung^{2*}, Ryan N Walton¹, Ashlie Elnoursi¹, Jacob D McGee³

Received: 29 Sept
DOI: 10.1111/dorm

ORIGINAL ARTICLE

¹AstraZeneca Canada, Mississauga, Canada
²Sunnybrook Research Institute, Toronto, Canada
³London Health Sciences Centre, London, Canada

A retrospective observational population-based study to assess the prevalence and burden of illness of type 2 diabetes with an estimated glomerular filtration rate < 90 mL/min/1.73 m² in Ontario, Canada

Wally Rapattoni BPharm, MSc¹ | David Zante MBA¹ | Marko Tomas PharmD¹ |
Varun Myageri MEng² | Shane Golden MSc² | Perna Grover PhD² |
Ali Tehrani BA² | Brad Millson MBS² | Sheldon W. Tobe MD³ | Jennifer B. Rose PhD¹

¹Janssen Inc., Toronto, Ontario, Canada
²IQVIA, Kirkland, Quebec, Canada
³Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada

OXFORD
Current Oncology

Article

Examining Treatment Patterns and Real-World Outcomes in Chronic Lymphocytic Leukemia Using Administrative Data in Ontario

Soo Jin Seung^{1,*}, Manjusha Hurry², Shazia Hassan¹, Ashlie Elnoursi², Krystin A. B. Scheider², Dennis Wagner², Jonathan J. Edwin² and Andrew T. W. Aw³

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² AstraZeneca Canada, Mississauga, ON L4Y 1M4, Canada; manjusha.hurry@astrazeneca.com (M.H.); ashlie.elnoursi@astrazeneca.com (A.E.); Krystin.Scheider@astrazeneca.com (K.A.B.S.); dennis.wagner83@gmail.com (D.W.); jonathan.edwin@alumni.ubc.ca (J.J.E.)
³ The Ottawa Hospital General Campus, Ottawa, ON K1H 8L6, Canada; aaw@toh.ca
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WILEY



OXFORD

JNCI Cancer Spectrum (2021) 5(6): pkab082
doi: 10.1093/jncics/pkab082
First published online 1 October 2021
Article

Real-World Use of Androgen-Deprivation Therapy: Intensification Among Older Canadian Men With de Novo Metastatic Prostate Cancer

Christopher J. D. Wallis¹, MD, PhD, FRCSC,^{1,*} Shawn Malone, MD, FRCPC,² Ilias Cagiannos¹, MD, FRCSC,³ Scott C. Morgan¹, MD, MSc, FRCPC,² Robert J. Hamilton, MD, MPH, FRCSC,⁴ Naveen S. Basappa, MD, FRCPC,⁵ Cristiano Ferrario, MD,⁶ Geoffrey T. Gatto, MD, MPH, FRCSC,⁷ Ricardo Fernandes, MD, FRCPC,⁸ Tamim Niazi, MDCM, FRCPC,⁹ Krista L. Noonan, MD, FRCPC,¹⁰ Fred C. FrCP(C),¹² Huang Hew, MSc,¹³ Katherine F. Y. Chan, MD, FRCSC¹⁴



Current Oncology

Article

Estimating the Burden of Illness of Relapsed Follicular Lymphoma and Marginal Zone Lymphoma in Ontario, Canada

John Kuruvilla^{1,2}, Emmanuel M. Ewara^{3,*}, Julia Elia-Pacitti⁴, Ryan Ng⁵, Maria Eberg⁵, Atif Kukaswadia⁶ and Arushi Sharma⁷

¹ Department of Medical Oncology and Hematology, Princess Margaret Cancer Centre, 610 University Avenue, Toronto, ON M5G 2C1, Canada; john.kuruvilla@uhn.ca
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⁵ Market Access, Janssen Canada Inc., 19 Green Belt Drive, North York, ON M3C 1L9, Canada
⁶ Medical Affairs, Janssen Canada Inc., 19 Green Belt Drive, North York, ON M3C 1L9, Canada
⁷ Medical Affairs, Janssen Canada Inc., 19 Green Belt Drive, North York, ON M3C 1L9, Canada



ELSEVIER

Contents lists available at ScienceDirect

Journal of Affective Disorders

journal homepage: www.elsevier.com/locate/jad

Research paper

Burden of Treatment Resistant Depression (TRD) in patients with major depressive disorder in Ontario using Institute for Clinical Evaluative Sciences (ICES) databases: Economic burden and healthcare resource utilization

Roger S. McIntyre^{a,*}, Brad Millson^b, G. Sarah Power^b

^a Department of Psychiatry, University of Toronto, Toronto, ON, Canada; Department of Psychopharmacology Unit, University Health Network, 399 Bathurst Street, Toronto M5T 2S8, ON, Canada
^b IQVIA, Health Access and Outcomes, Kirkland, Quebec, Canada



A group of people, including a man with glasses and a woman with a tattoo, are shown with their hands stacked in a high-five gesture. The entire image is overlaid with a blue tint. The text "Thank you!" is centered over the hands.

Thank you!

Contact:

Data & Analytic Services (<https://www.ices.on.ca/DAS>)

Data Analytic Services

das@ices.on.ca

DAS Private Sector

das.privatesector@ices.on.ca



Accessing Data through the Ontario Ministry of Health

Michael Hillmer
Assistant Deputy Minister
Digital and Analytics Strategy Division

ICES Research Forum
May 11, 2023

Our organization

The Ontario Ministry of Health's **Digital and Analytics Strategy Division** (DASD) is responsible for providing a full suite of data and analytics capabilities to enable the mandates of the Ministry of Health and the Ministry of Long-Term Care.

DASD also provides the government with advice on health system data and digital strategy and works with delivery partners and stakeholders to implement strategic direction and ensure value for money.

Five business branches focused on:

- Health data management
- Health analytics and insights
- Advanced analytics and data science
- Digital strategy
- Information management strategy and policy

Data access and collaboration – Research community

DASD supports and collaborates with the research community through a range of measures including providing access to data platforms, fulfilling direct data requests and engaging in research collaborations with individuals, academic institutions and health care organizations.

Four of our most significant supports include:



IntelliHealth Ontario

IntelliHealth is a repository that has a combination of administrative and clinical data from multiple sectors of the Ontario healthcare system.

Available products, services and supports

- Allows users to access data, create dashboards, reports and query system data.
- Data is available to healthcare organizations supporting reporting and analysis.
- A wide range of data is available to all users in categories such as hospital services, home care, vital statistics and population.
- Other data is offered to specific user groups using access-controlled environments.

Getting access

- Established process where authorized user with an affiliation from an approved organization with a standardized IH user agreement that outlines permitted uses of data. (1000 + current users)
- Detailed information and a link for registration is available on the IntelliHealth website.

Website/Contact [IntelliHealth Ontario \(gov.on.ca\)](https://www.intellihealth.on.ca) / IMSupport@ontario.ca

IntelliHealth utilization

Authorization

- IntelliHealth has an established process whereby an authorized user with an affiliation from an approved organization with a standardized IH user agreement that outlines permitted uses of data
- Widely used by diverse group of authorized users to facilitate strategic and operational insights

Data Management Processes

- Data is modeled to include useful calculations, filters and aggregated measures to support ease of use
- IntelliHealth has established data management process linking, de-identification, storage, release of data

Platform As A Service

- Users have the ability to create advance reports and dashboards to support benchmarking and trending.
- User support services (drop-in session, training services, help desk)

Data Processing

- IntelliHealth receives authoritative data from multiple data sources and renders the data in a singular platform

Available data

IntelliHealth

Clinical & Administrative Data

- Inpatient Discharges (DAD)
- Ambulatory Visits (NACRS)
- Complex Continuing Care/Long-Term Care (CCRS)
- Inpatient Rehabilitation (NRS)
- Inpatient Mental Health (OMHRS)

Hospital

- Daily Bed Census
- Bed Segmentation

Home Care

- Episodes, Services, Admissions, Assessments

Medical Services

- Medical Services
- Billing Providers

Population

- Estimates
- Projections
- Population Grouper
- Births and Deaths

Financial

- Ontario Healthcare Financial Statistical (MIS)
- Case Costing

Reference Tables

- Postal Codes mapping to various geographies
- Institution Number Listing
- Ontario Registered Persons (ORP) from RPDB
- Reference Code Tables (ICD-10 CA)

COVaxON

- Dosage and Client information
- Socio-demographic information

CPRO

- Waitlist & placement data

Subrogation

- Search report

Restricted Access due to PHI

IntelliHealth features



Easily Navigate to different Clinical, Administrative, and Demographic Datasets



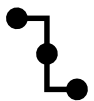
Access to Ministry created Standard and Ad-Hoc Reports



Access to Shared Folders for collaborative reporting



Ability to create customized extracts, reports, and dashboards



Link across the continuum of care (e.g., Patients in Ambulatory and Inpatient)

Feature – IntelliHealth custom reporting



Users can search for reports or fields



Reports can be scheduled



Reports can be set to run in the background and emailed upon completion



Reports and settings can be managed through a preference tab



Users can print specific selections or criteria of a report



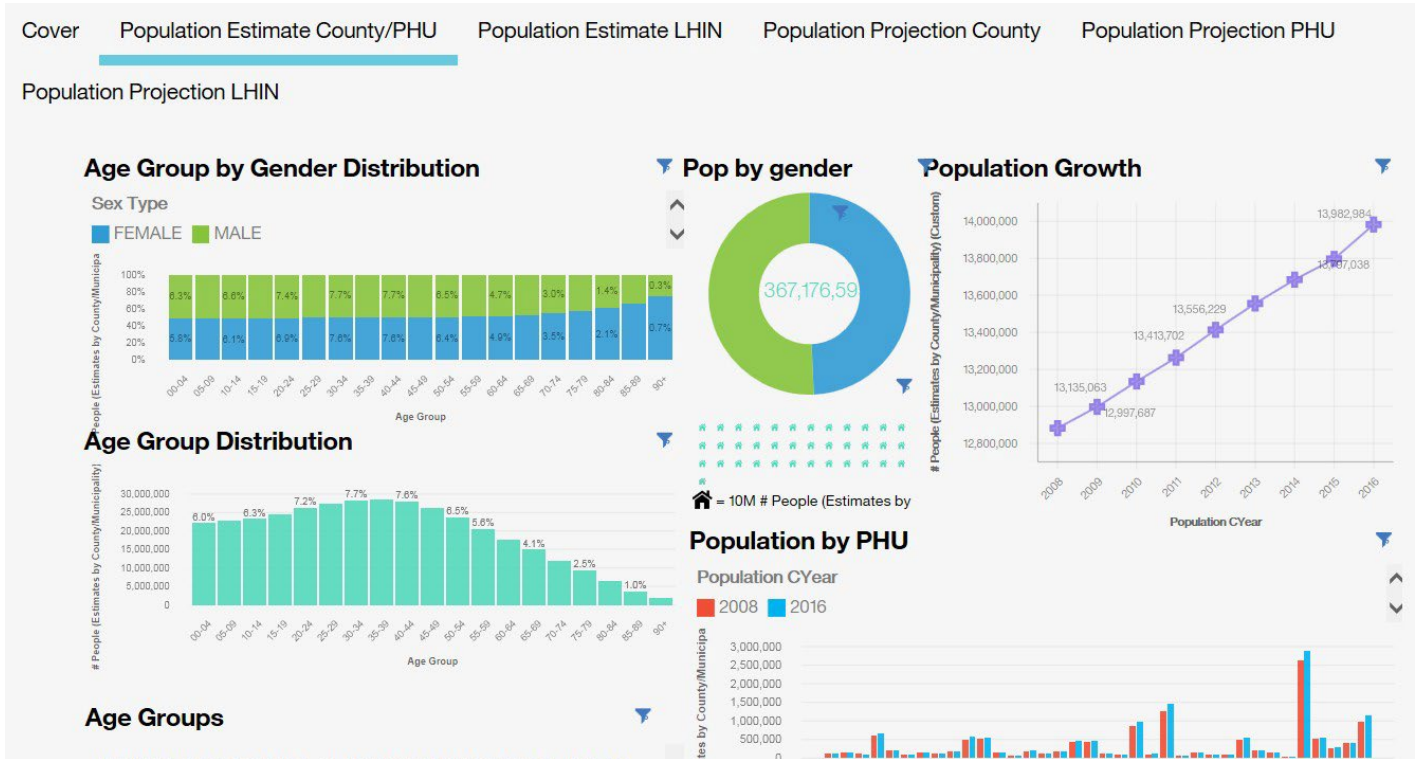
Users can export data quick and reliably into varying formats (i.e. CSV, Excel)



Reports can be saved in a public folder for peer collaboration

Feature – IntelliHealth custom dashboards

The **Dashboard** feature of IntelliHealth allows users to create multiple visual representations of data that are concise, interactive, and modern *sample visualizations available:*



The Ontario Health Data Platform

The Ontario Health Data Platform (OHDP) has been built to benefit Ontarians. The platform provides data access to researchers to better detect, plan and respond to the COVID-19 pandemic. This is a collaborative effort by leading public sector organizations to accelerate research and analytics within Ontario to help the province better manage and respond to the pandemic.

[Learn More](#)

Ontario Health Data Platform

The Ontario Health Data Platform (OHDP) COVID-19 is a federated high-performance computing environment for secure, accurate, and privacy-protective linkage of large health datasets that are currently held across various organizations.

Platform allows for big data analytics, including machine learning, that will strengthen evidence for Ontario's ongoing response to COVID-19 and its related impacts.

Products, services and supports

- **Data Visitation Model** Institution(s) User/Researcher with an affiliation with approved institute and approved REB access data as a service for research and analytics. No data is removed from the platform.
- **Platform as a Service** Authorized organizations/users can bring their own data and use the platform with all the capabilities.

User profile

- OHDP users include researchers from Ontario-based research and healthcare institutions, knowledge users from organizations i.e., Toronto Public Health, MOH, Office of the Chief Medical Officer of Health, etc.

Ontario Health Data Platform

Getting access

Researcher approval and access provision process in place that includes

- **Researcher submits research application online** that includes a research ethics board (REB) approved research plan/protocol
<https://redcap.ohdp.ca/surveys/?s=YRY3TMXFWL>
- **Thereafter, the MOH leads the application evaluation process** from the lens of research priority, computing needs, security and intellectual property
- Once approved, **OHDP Research and Privacy Agreement** between sponsoring institution/researcher and the MOH is formalised and access to OHDP is provided to the researcher

User profile

OHDP users

include researchers from Ontario-based research and healthcare institutions and knowledge users from organizations (i.e., Toronto Public Health, MOH, Office of the Chief Medical Officer of Health etc.)

Website

<https://ohdp.ca>

Contact

info@ohdp.ca

Information Management Support Centre data requests

DASD's **Information Management Support Centre** (IMSC) coordinates over 3000 data requests per year, covering a broad range of health-related topics, that are used to support policy decisions, audits, communications, and the overall management and function of the provincial health system.

Products, services and supports

- Data reports and feeds sourced from Ministry and CIHI data holdings including, OHIP claims, health card and registration data, hospital data, long-term care waitlist and occupancy data, and financial/statistical data.
- IMSC also facilitates registration and access to Intellihealth along with user support and troubleshooting.

User profile

- OPS staff, Auditor General, College of Physicians and Surgeons of Ontario (CPSO), Law enforcement, Health Service Providers, Researchers, Service Ontario, Media (via Comms), Prescribed Entities (e.g., CIHI, ICES) & Registries (e.g., CorHealth, BORN).

Profile of data request activity

Law Enforcement

Missing persons
Court orders

CPSO

Complaint investigations,
Compliance with conditions

MOH & MLTC

Program areas
Program planning & evaluation
Service utilization
Audits

Researchers

Data sharing to support health research and health system planning and evaluation

Office of the Chief Coroner

Coroner's inquests
Death investigations

Other Clients

MAG—Jury Roll
Elections Ontario
ServiceOntario
MCCSS

OH

CCO, TGLN data feeds
LTC home waitlists & placements
Home care

Media Requests

FIPPA & PHIPPA requests

Information Management Support Centre

Getting access

Contact IMSupport@ontario.ca to complete a data application form; our team will help to refine requests as needed and advise on data availability and timelines.

Requirements vary depending on purpose for use and the type of data requested:

- Aggregate data generally does not require a data sharing agreement (DSA), whereas record-level data usually does
- Researchers may be required to submit Research Ethics Board approval and sign a DSA with the Ministry
- Law enforcement are typically required to submit production orders/coroners warrants to authorize MOH access to and disclosure of Personal Health Information

Contact

IMSupport@ontario.ca

Research collaborations

DASD works to establish and develop **partnerships with internal and external stakeholders** in healthcare and analytics to cultivate innovation, research, and collaboration.

We aim to align research with policy, decision and implementation priorities of Ontario's ministries of health and long-term care.

Collaboration, services and supports

- DASD supports research projects in several ways, including participating in projects as researchers or knowledge users, providing letters of support, offering expedited access to data through IntelliHealth, and/or providing analytic support with data processing if required.

Accessing support

- The main requirement is that proposed research is aligned with the government priorities.
- Research ethics board approval is also required.

Contact

- DASD's Assistant Deputy Minister's Office and Health Data Science Branch
- E-mail alan.moon@ontario.ca for appropriate referral.

Research collaborations – Select current projects

There are several **active research projects** involving collaborations with researchers and major universities, hospitals and other health care organizations.

Projects generally explore issues of **relevance to the provincial health policy agenda**.

Some examples of research subjects include:

- Cannabinoid poisonings among elderly
- Covid mortality analysis
- Risk factors and prevalence of concussion due to pandemic
- Prevalence and impact of osteoporosis care gap in Ontario
- Vitamin D analysis
- CMOH study to compare RSV data from I9 and DAD
- Data synthesization

DASD

Digital and Analytics
Strategy Division



Thank You

HDRN Canada's Data Access Support Hub (DASH)

A coordinated service for accessing multi-region data

Jordan Hunt | Manager, Data Access Support Hub
May 11, 2023



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

Session Overview

- Overview of Health Data Research Network Canada's Data Access Support Hub (DASH) service and process
- DASH resources and tools available to researchers
- Tips for requestors



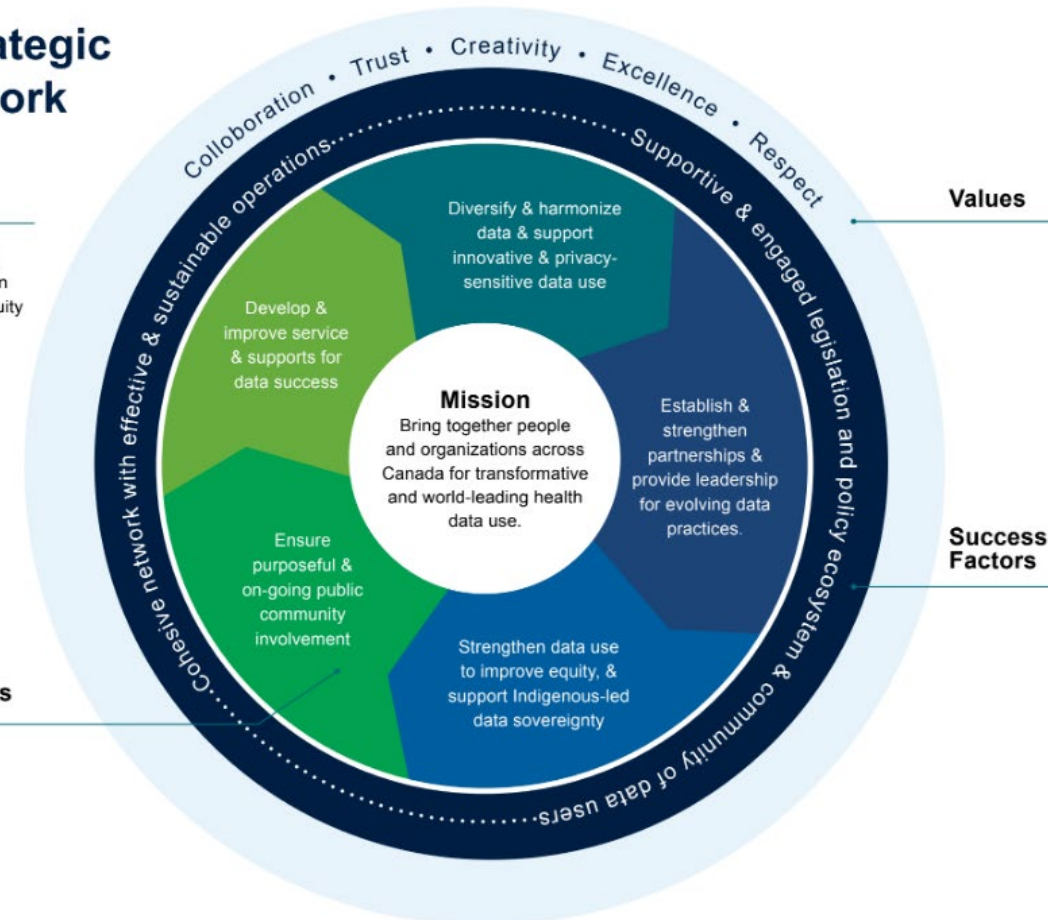
Health Data Research Network Canada (HDRN Canada)

Our Strategic Framework

Vision

Data across Canada drive improvements in health and health equity

Strategic Goals



Data Access Support Hub (DASH)

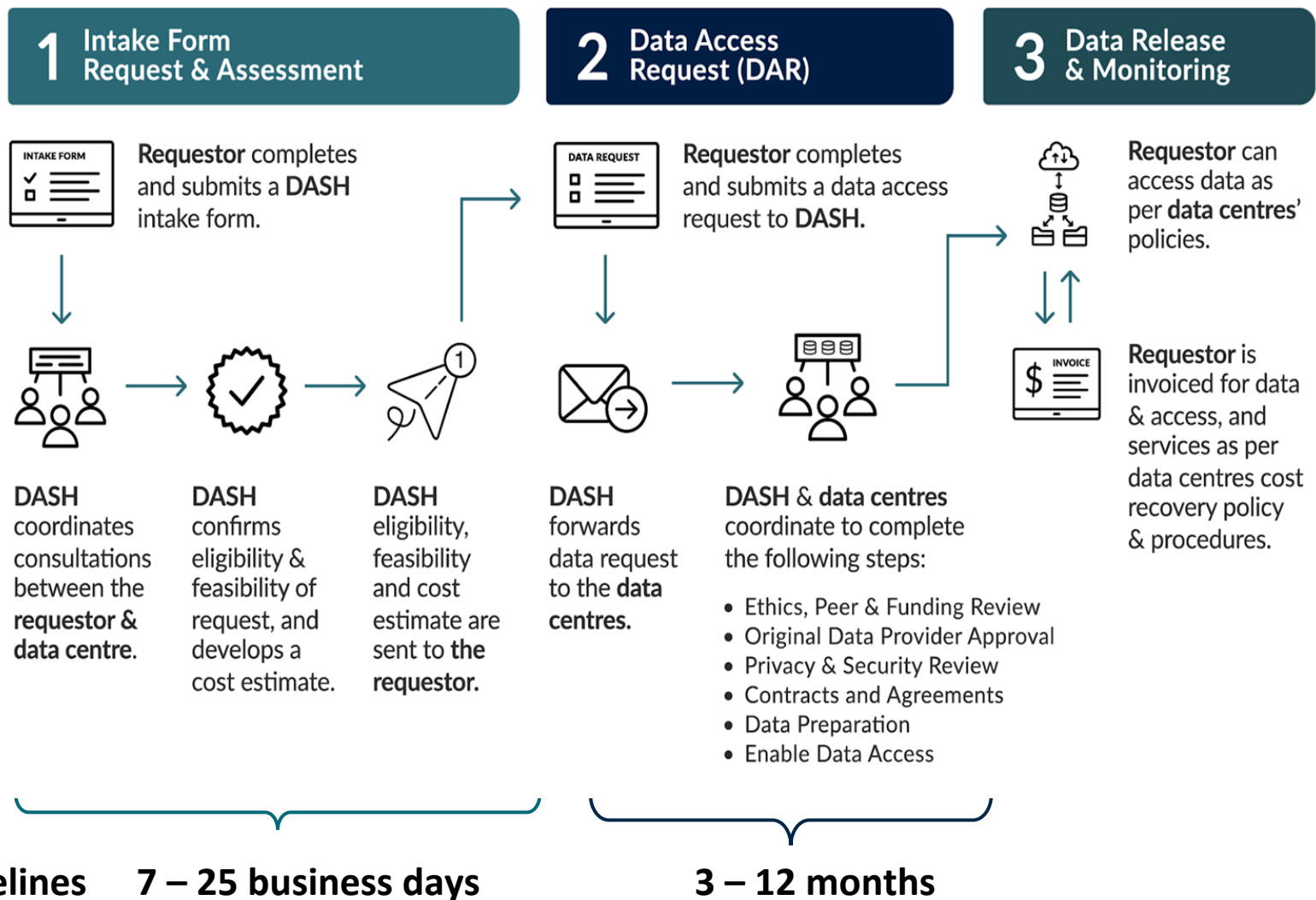
- DASH is a service for researchers conducting multi-regional research
 - Service provided by coordination team of representatives from 13 organizations across Canada
 - Facilitate inquiries re: data access in provincial/territorial and pan-Canadian data centres and help navigate local requirements
 - DASH does not hold data; data resides at the data centres



DASH (continued)

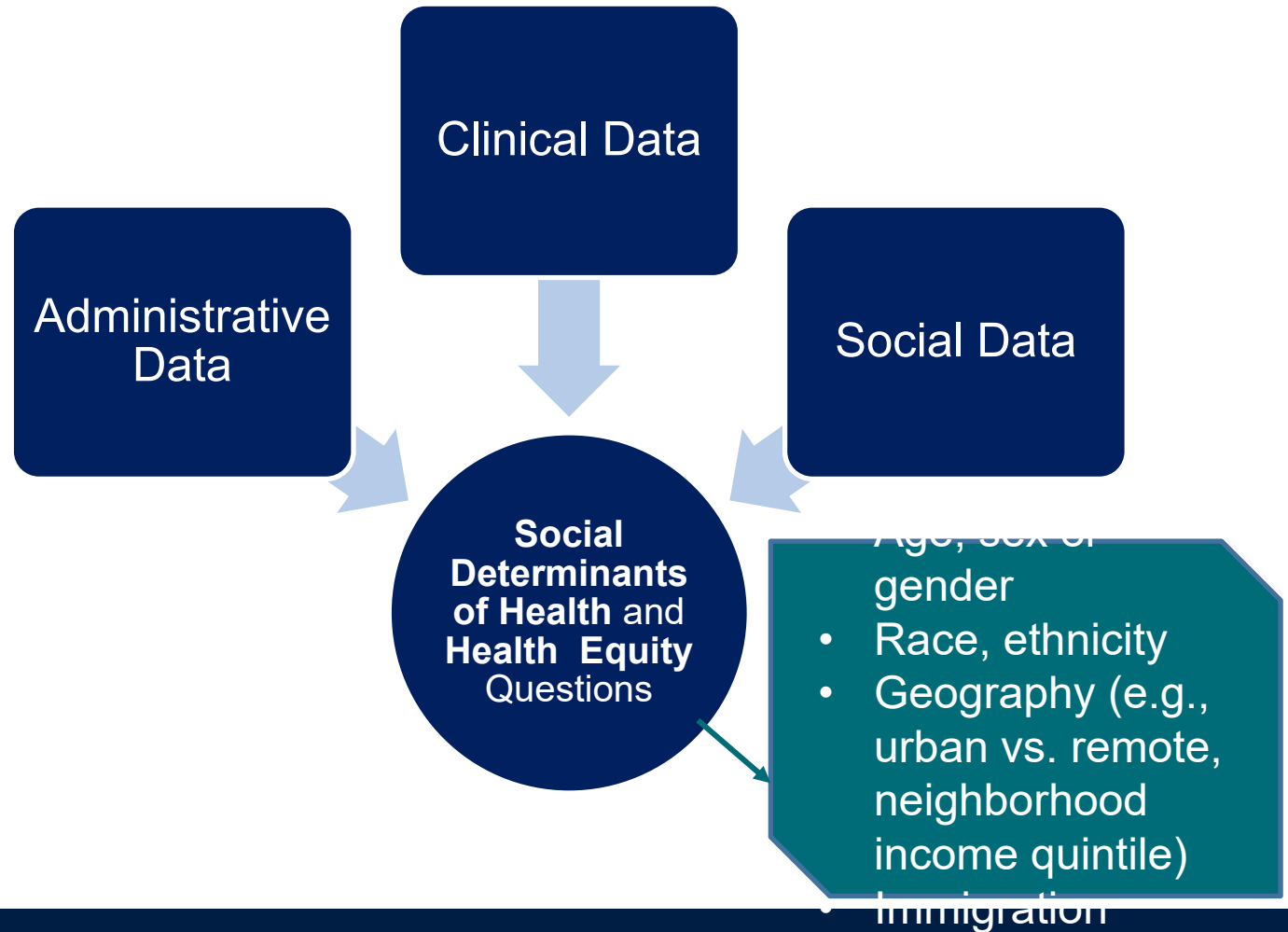
- **DASH simplifies the data access process by:**
 - *Providing navigational support and coordination* throughout data access request process
 - *Offering centralized resources and tools*
 - *Harmonizing aspects of data access processes* across data centres
 - *Integrating technological solutions* to streamline and progressively automate the DASH request process

DASH Process Overview



Data Assets Available via DASH

- **Data Asset Inventory** provides overview of data holdings available
- **New data sources** being updated on regular basis
- Opportunities for **linking researcher collected data** to administrative data



Innovative Resources

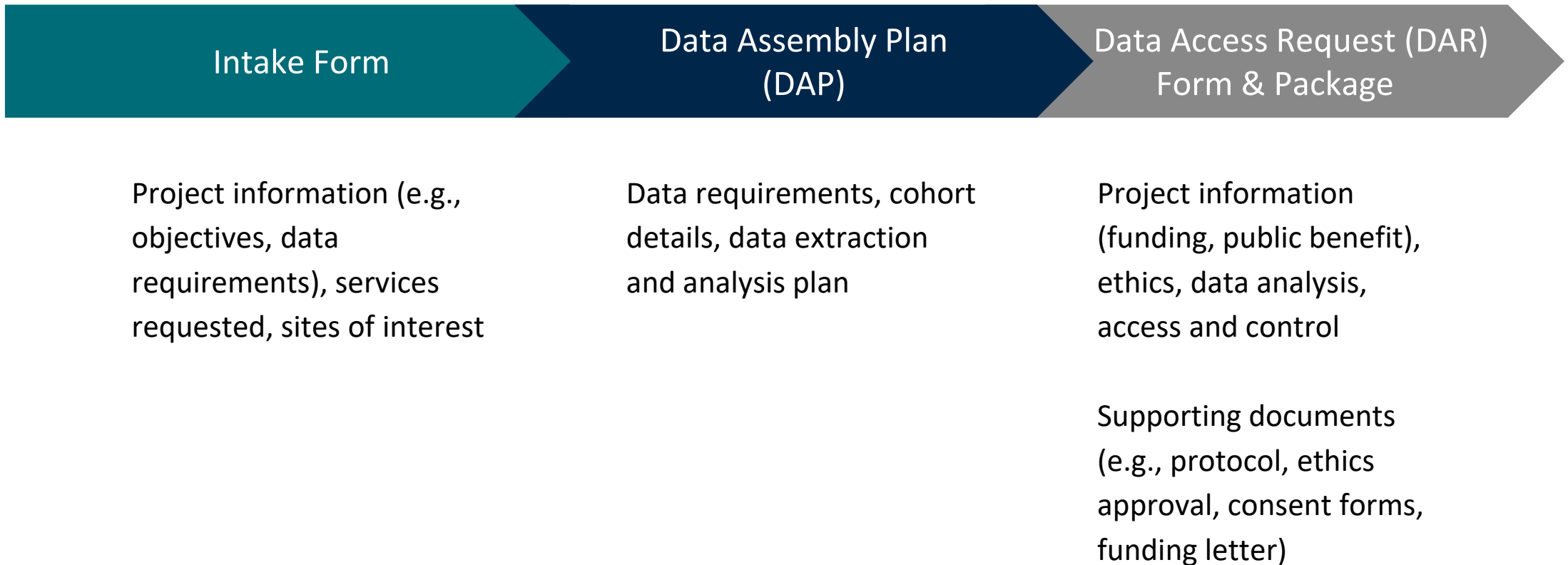
- **Data Assets Inventory**
(<https://www.hdrn.ca/en/inventory/>)
- **Algorithm Inventory**
- **Privacy, Ethics and Study Design Considerations**
- **Web portal with centralized forms**

The screenshot displays a search interface for the Data Assets Inventory. At the top, there is a search bar with the text 'laboratory' and a search icon. Below the search bar, there are three filter panels: 'Region', 'Data Categories', and 'Site'. Each panel has a search icon, a close icon, and a refresh icon. The 'Region' panel lists Alberta (AB) with 2 results, British Columbia (BC) with 1 result, Manitoba (MB) with 3 results, Newfoundland (NL) with 1 result, and Ontario (ON) with 2 results. The 'Data Categories' panel lists demographics (7), diagnosis (2), geographic location (7), healthcare encounter (8), healthcare facility (4), and lab evaluation requests (8). The 'Site' panel lists Alberta SPOR SUPPORT Unit (2), Institute for Clinical Evaluative Sciences (2), Manitoba Centre for Health Policy (3), Newfoundland and Labrador Centre for Health Info... (1), and Population Data BC (1). Below the filters, there is a 'Show Availability' button and a table of datasets. The table has columns for Name, Region, and Description. The datasets listed are 'Covid Test Lab Data' (BC), 'COVID19 Integrated Testing Data (C19INTGR)' (ON), and 'CPL - Cadham Provincial Laboratory' (MB).

Name	Region	Description
Covid Test Lab Data	BC	Information on test results for COVID tests, extracted from Provincial Laboratory Information Solution (PLIS).
COVID19 Integrated Testing Data (C19INTGR)	ON	The COVID-19 Integrated Testing Dataset is derived from 3 data sources: 1) Ontario Laboratories Information System (OLIS) contains COVID-19 testing ep ...
CPL - Cadham Provincial Laboratory	MB	Cadham Provincial laboratory (CPL) provides a range of services, including public health laboratory services and reference services for identification ...

Centralized Tools

DASH web portal integrates forms that are required throughout the data access process



Tips for requestors

- ✓ Review DASH website resources
- ✓ Become familiar with legislation/policy for disclosure of patient level data, and to the transfer and/or sharing of data across regional boundaries for research use
- ✓ Ensure you have appropriate authority/consent to link researcher collected or external data (if applicable)
- ✓ Have well defined study objectives and data needs
- ✓ **Consult with DASH as early as possible for guidance on the above**

Thank you!

- Get in touch: dash@hdrn.ca
- Visit: <https://www.hdrn.ca/>
- Follow-us:  @hdrn_rrds



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada



CIHR
IRSC
Canadian Institutes of
Health Research
Instituts de recherche
en santé du Canada





Questions?

