



CIHR IRSC

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

MAXIMIZING HEALTH RESEARCH DATA BENEFITS IN PUBLIC HEALTH EMERGENCIES

Research Data Canada Guest Webinar

December 8th, 2016



WELCOME



Alison Bourgon

Manager, Knowledge Translation Strategy



Dr. Beate Sander

Scientist, Health Economics



AGENDA

This webinar will examine some of the ways in which CIHR is embracing the data revolution and how data management is being integrated into research practices.



1

CIHR Overview

2

CIHR's Health
Research Data
Activities

3

Zika Virus & CIHR's
Response

4

Data Management in
a Public Health
Emergency

CIHR OVERVIEW

CIHR is the Government of Canada's health research investment agency.

MISSION

To create new scientific knowledge and to enable its application for improved health, more effective health services and products, and a strengthened Canadian health care system.



Knowledge Translation



Global Health



CIHR OVERVIEW

105

Institutions
receiving funds
from CIHR

\$1B

In funds for health
researchers and
trainees across Canada

13K

Researchers
and trainees
supported

CIHR OVERVIEW



Malcolm King
Aboriginal Peoples' Health



Yves Joannette
Aging



Stephen Robbins
Cancer Research



Brian Rowe
Circulatory and Respiratory Health



Anthony Philips
Neurosciences, Mental
Health and Addiction



Cara Tannenbaum
Gender and Health



Paul Lasko
Genetics



Robyn Tamblyn
Health Services and
Policy Research



Shoo Lee
Human Development,
Child and Youth Health



Marc Ouellette
Infection and Immunity



Hani El-Gabalawy
Musculoskeletal
Health and Arthritis



Philip Sherman
Nutrition Metabolism
and Diabetes



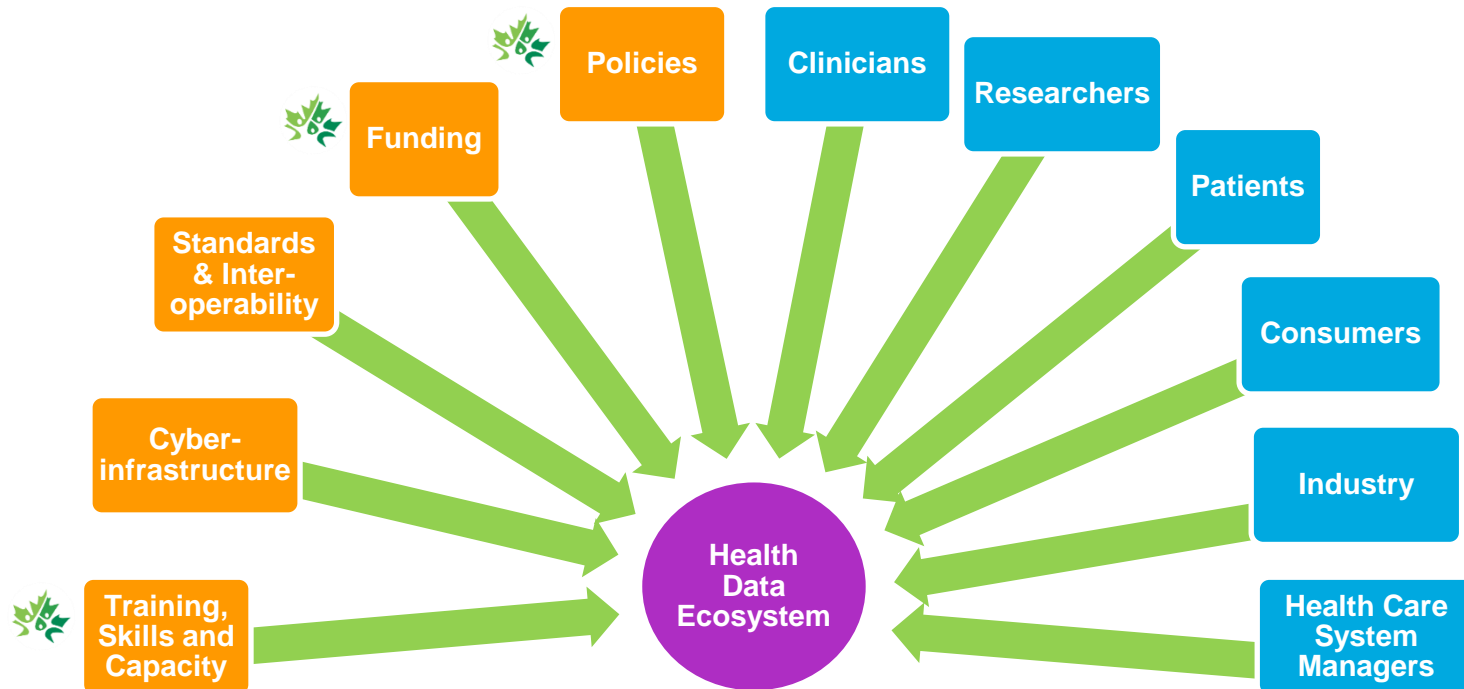
Steven J. Hoffman
Population and Public Health

THE GLOBAL “DATA REVOLUTION” IS HAVING A PROFOUND IMPACT ON HEALTH RESEARCH.

As a publicly funded organization, CIHR believes that the results of the research we fund, including data, **should be as openly accessible as possible.**

HEALTH RESEARCH DATA - ECOSYSTEM

CIHR is one player in a rapidly changing space.

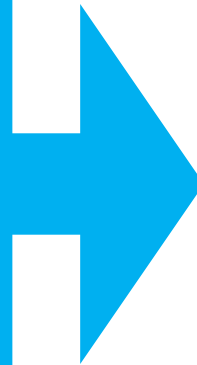


HEALTH RESEARCH DATA - CIHR

Working with key partners, we are currently leading and contributing to many data-related activities.

CIHR ACTIVITIES

- Strategies
- Policies
- Platforms
- Initiatives
- Funding opportunities
- Workshops / events



FOCUS AREAS

- Data management
- Data access
- Data linkage and integration
- Data skills
- Data infrastructure
- Data use and reuse

CIHR HEALTH RESEARCH ROADMAP II

CIHR's strategic plan includes a commitment to **“embrace the data revolution”**.

- Advance data-intensive research
- Seize the transformative power of information and communication technologies.

A strong foundation...
but a more targeted and coordinated approach was needed.

CIHR HEALTH RESEARCH AND HEALTH-RELATED DATA FRAMEWORK

VISION

Health research and health-related data in Canada are effectively accessed, analyzed, linked, integrated, used, reused, stored and preserved to advance knowledge, expand research opportunities, and improve health services, products and outcomes.

INTEGRITY

STEWARSHIP

VALUE

DISCOVERABILITY

SUSTAINABILITY

PROACTIVITY



CIHR HEALTH RESEARCH AND HEALTH-RELATED DATA FRAMEWORK

1

COLLECTIVE CULTURE
FOSTERED

2

REQUIRED RESOURCES
AVAILABLE

3

RELEVANT SKILLS
EXPANDED

4

ACCESS, LINKAGE, USE &
REUSE ENABLED

TRI-AGENCY STATEMENT OF PRINCIPLES ON DIGITAL DATA MANAGEMENT

- Expectations related to research data management.
- Roles and responsibilities of researchers, communities, institutions and funders.

DATA MANAGEMENT PLANNING

CONSTRAINTS & OBLIGATIONS

ADHERENCE TO STANDARDS

COLLECTION & STORAGE

METADATA

PRESERVATION, RETENTION & SHARING

TIMELINESS

ACKNOWLEDGEMENT & CITATION

EFFICIENT & COST EFFECTIVE



PUBLIC HEALTH EMERGENCY (PHE)

An occurrence or imminent threat of an illness or health condition, caused by bio terrorism, epidemic or pandemic disease, or a novel and highly fatal infectious agent or biological toxin, that poses a substantial risk of a significant number of human fatalities or incidents or permanent or long-term disability.

- World Health Organization



ZIKA VIRUS

Mosquito-born virus.

Most humans are asymptomatic when infected or have mild symptoms.

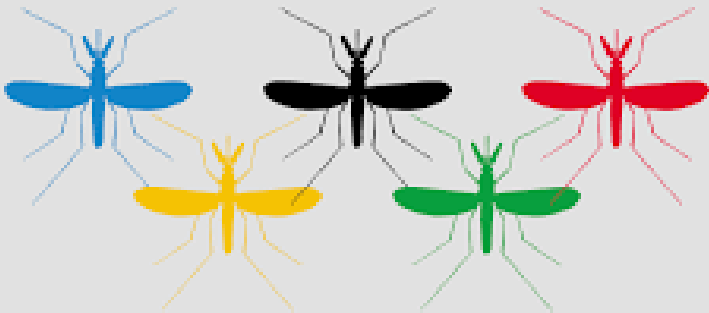


During the current outbreak, there has been a relationship observed between the virus and:

- Rare development of neurological complications in adults
- Birth of babies with smaller heads (microcephaly)

ZIKA VIRUS

In February, outbreak declared a PHE of international concern.



While Zika has not yet been found in Canada, the virus could spread to Canadians through:

- Having sex with infected partners or
- Traveling to affected countries.

CIHR'S RESPONSE



POLICY

Joint international statements



PARTNERSHIPS

Global Research Collaboration for Infectious Disease Preparedness (GloPID-R)



FUNDING

CIHR-IDRC partnered Zika Virus Research Program

CIHR'S RESPONSE - POLICY

CIHR is a signatory on two international joint statements promoting the need for data sharing in PHEs.

Statement on data sharing in public health emergencies

We've joined other global health bodies to call for all research data gathered during the Zika virus outbreak, and future public health emergencies, to be made available as rapidly and openly as possible.

<https://wellcome.ac.uk/what-we-do/our-work/statement-data-sharing-public-health-emergencies>

CIHR'S RESPONSE - PARTNERSHIPS

GLPID-R

A network of research funding organizations that facilitate an effective research response to new or re-emerging infectious disease outbreaks with pandemic potential.



CIHR'S RESPONSE - FUNDING

In the spring of 2015, CIHR and IDRC partnered to launch a Canada-Latin America and Caribbean Zika Virus Research Program.

\$3M

Grantees were required to...

Include at least one member with **expertise in data management and responsible data sharing**

Provide a **data management plan** for how data will be shared with the team and international collaborators

Agree to share quality-assured interim and final data as **rapidly and widely as possible**

Three collaborative teams have now been funded

DATA MANAGEMENT IN A PHE

CIHR is a member of the **GloPID-R Data Sharing Working Group**.

Aim is to develop a system for data sharing in PHEs.

Activities include:

- Defining data of interest
- Mapping data sharing in past PHEs
- Developing core principles for data sharing in PHEs



DATA MANAGEMENT IN A PHE

The core principles are still being refined. Special consideration is being given to balancing access, ethics, timeliness, quality and equity.

ACCESS / ETHICS

When lives are at potentially at stake, are patients more willing to let their data be fully accessible?

TIMELINESS / QUALITY

Is compromising slightly on data quality worth the trade-off to enable more timely access?

EQUITY

How can free and equitable data access be ensured while recognizing costs and commercial potential?

DATA MANAGEMENT IN A PHE

From November 30th to December 2nd, researchers from around the world who are studying the Zika virus met in Brazil to explore opportunities to collaborate, including how to share data.



SCIENTIST PERSPECTIVE



OUR PROJECT

Assessing ZIKV transmission dynamics and mitigation strategies.
A multidisciplinary approach.

Our objective is to characterize the ecological transmission dynamics of ZIKV and design integrated ZIKV intervention approaches. To attain this objective, we have ***two specific aims***:

- (1) To characterize ZIKV vector populations, viral genetic diversity and ecological transmission dynamics in three different eco-epidemiological settings (Argentina, Colombia, Ecuador), and predict areas at risk for ZIKV transmission across the LAC region; and
- (2) To identify a range of integrated ZIKV intervention strategies and assess their comparative effectiveness, economic impact and cost-effectiveness using computer simulation.

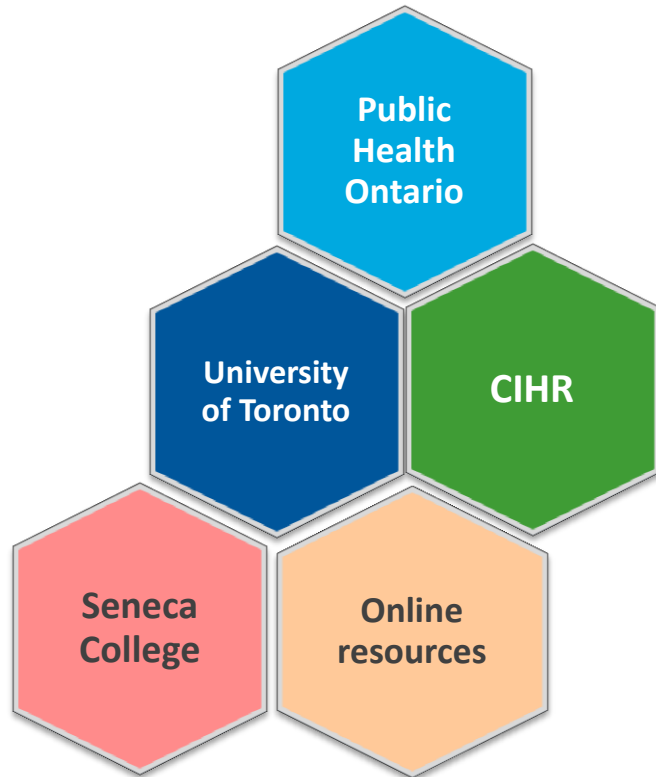
OUR PROJECT

CIHR/IDRC Requirements

- Include at least one member with expertise in data management and responsible for data sharing.
- Provide a data management plan for how data will be shared with team and international collaborators.
- Agree to share quality-assured interim and final data as rapidly and widely as possible.

DATA MANAGEMENT PLAN – DEVELOPMENT

First experience creating a data management plan to apply for a funding opportunity.



- ✓ Library information specialists
 - PHO, UofT
- ✓ Document and Records Management
- ✓ Webinar: Elsevier Publishing Campus, Dutch Techcenter for Life Sciences
- ✓ CIHR guidelines
- ✓ Consultation: Seneca College technology/informatics
- ✓ Online resources: DMP tools, checklists
- ✓ Previous data transfer, privacy assessments

PRINCIPLES OF DATA MANAGEMENT

The FAIR Guiding Principles for scientific data management and stewardship.



Findable: Globally unique and persistent identifier

Accessible: Retrievable by their identifier using a standardized communications protocol

Interoperable: Formal, accessible, shared, and broadly applicable language for knowledge representation

Reusable: Richly described with a plurality of accurate and relevant attributes

DATA MANAGEMENT PLAN – COMPONENTS

Guided by: Tri-Agency Statement of Principles on Digital Data Management

1. Types of data and information created:

Vector / laboratory / environmental / demographic / human surveillance data

2. Formats:

Team specific (Excel, R, SAS) converted to csv for data sharing

3. Metadata:

“Readme file” will be provided with each dataset

4. Data sharing:

Data sharing agreements between all investigators. Collaborating researchers to submit a data request to the site-specific data custodian to gain access to vector data.

5. Open Access Policies on Publications / Data Preservation

- Where? Zika Open-Research Portal (or similar data sharing platform)
- Open access publications

SOME GENERAL THOUGHTS

Purpose of data sharing:
An important distinction –

Considerations –

- Secondary (new/different) use of existing data
 - Routinely collected (e.g., surveillance data, patient records)
 - Collected for research project
- To increase power/relevance of study, i.e., pool data
 - ↑ sample size
 - ↑ geographic coverage

- “Standard” data sharing
- Privacy / Privacy Impact Assessment
 - Ethics approval
 - Data custodian
 - Data sharing agreements

Harmonisation / Standardization
→ study protocol, data management plan
“Standard” data sharing
Publications

SOME GENERAL THOUGHTS

Scientists are generally interested in sharing data, but we . . .

- Need help and tools to draft data management plans
- Need venues to connect early, prior to data collection, e.g., GLoPID-R
- Need frameworks and general principles of data sharing
 - Taking into account purpose of data sharing
 - Acknowledging challenges (individual and shared publications)
 - Providing incentive to share data which requires additional resources for data cleaning/conversion/metadata, e.g., publishing data similar to publication

SOME GENERAL THOUGHTS

First steps for Zika project . . .

- Collaboration to use primary data collected by other teams for secondary use (i.e., data from cohort studies to inform computer simulation).
- Working group to harmonize data collection and analysis protocols for vector studies (mosquito collection, surveys, laboratory testing, etc.) to enable future data sharing across research teams.

MORE INFORMATION

For more information on CIHR's activities related to data management and data-intensive research, please:

- Visit our Health Research Data webpage
- Contact us at researchdata@cihr-irsc.gc.ca



For more information on CIHR's activities related to the Zika virus or PHEs, please contact us at the:

- CIHR [Institute of Infection and Immunity](#)
- CIHR [Institute of Population and Public Health](#)





CIHR IRSC

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



THANK YOU!

