MAXIMIZING HEALTH RESEARCH DATA BENEFITS IN PUBLIC HEALTH EMERGENCIES

Research Data Canada Guest Webinar
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WELCOME

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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.
Institutions receiving funds from CIHR

In funds for health researchers and trainees across Canada

Researchers and trainees supported
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.
CIHR is one player in a rapidly changing space.
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’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.
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
• Expectations related to research data management.
• Roles and responsibilities of researchers, communities, institutions and funders.
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 facilities 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.

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

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<th>ACCESS / ETHICS</th>
<th>TIMELINESS / QUALITY</th>
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<td>When lives are at potentially at stake, are patients more willing to let their data be fully accessible?</td>
<td>Is compromising slightly on data quality worth the trade-off to enable more timely access?</td>
<td>How can free and equitable data access be ensured while recognizing costs and commercial potential?</td>
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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 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.
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
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 –

- 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

Considerations –

“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
THANK YOU!

Discoveries for life / Découvertes pour la vie