Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Data Access Support Hub (DASH)
Webinar

January 28, 2021

Presenters:
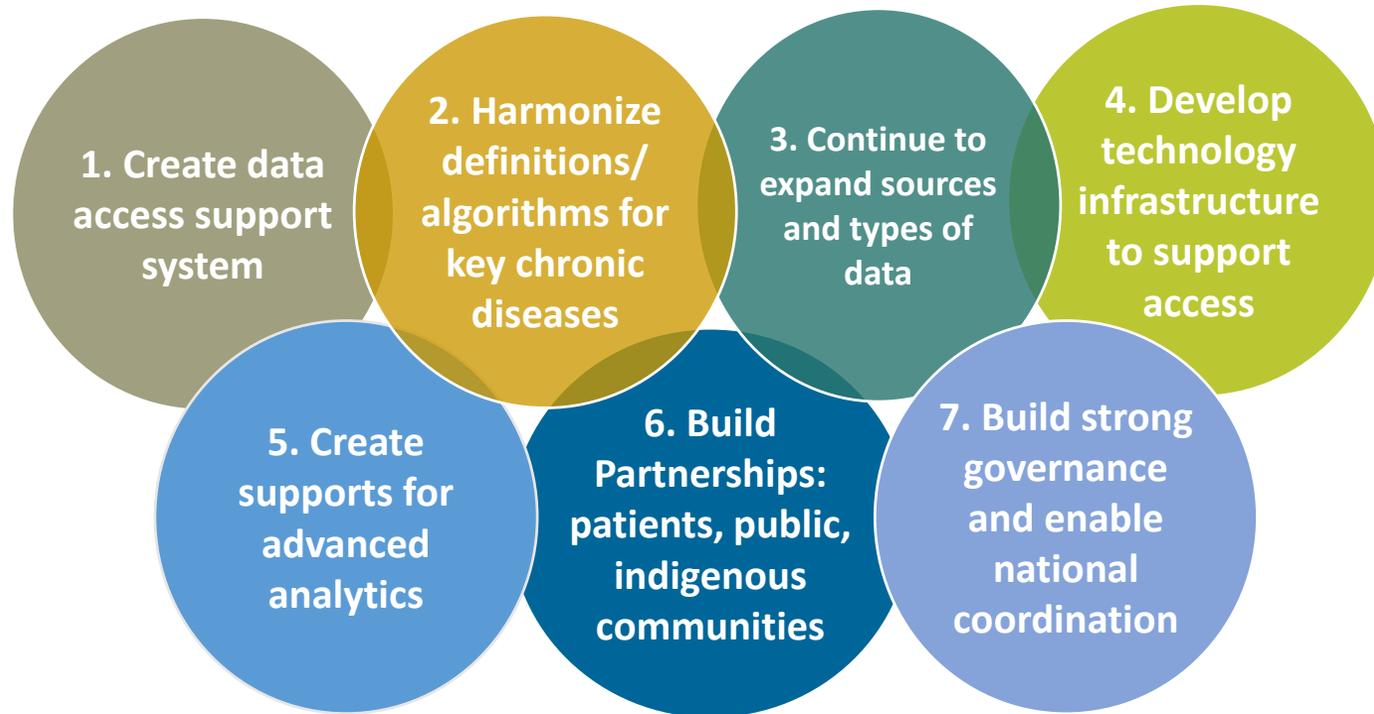Juliana Wu, Site Lead, DASH
Marie-Chantal Ethier, Lead, DASH

Agenda

➢ Overview of HDRN Canada

➢ Overview of DASH

➢ DASH Accomplishments and Activities

➢ Upcoming DASH Activities and Opportunities

➢ Questions

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Health Data Research Network (HDRN) Canada

Objectives:

1. Create data access support system

2. Harmonize definitions/ algorithms for key chronic diseases

3. Continue to expand sources and types of data

4. Develop technology infrastructure to support access

5. Create supports for advanced analytics

6. Build Partnerships: patients, public, indigenous communities

7. Build strong governance and enable national coordination

HDRN Canada Principles:

- ✓ Distributed network with distributed funding

- ✓ Respect for local context, policy environment, and existing jurisdictional responsibilities for delivery of health and social care

- ✓ Leverage and share existing assets (infrastructure, data, human and technical capacity)

- ✓ Openness to ideas, input, and new collaborations

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HDRN Canada Organizations

HDRN Canada is comprised of provincial, territorial, and pan-Canadian organizations with decades of experience managing health data

Each HDRN Canada Organization brings its established relationships, including with their ministries of health and local data providers.

Data Access Support Hub (DASH)

DASH is a single access portal providing coordinated, "concierge" service for researchers

- Services provided by multi-centre coordination team
- Facilitates access to data in provincial/territorial and pan-Canadian data centres in a distributed manner; connect and support meeting jurisdictional requirements
- Excludes: multi-jurisdictional requests that can be met solely by pan-Canadian data assets held at CIHI or STATCAN

DASH Objectives

- Make local processes **transparent** and comprehensible to requestor
- Provide **coordinated support** to requestor throughout request process as much as possible
- **Harmonize** aspects of data access processes across data centres over time
- **Streamline** and progressively **automate** the DASH central request process

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DASH Website

Resources available through DASH:

- 380+ datasets available for request

- 140+ multi-jurisdiction algorithms from 34 existing validation or feasibility studies

- Inventory of data access requirements and procedures at HDRN Canada partner centres

- Online request intake form

- COVID-19 Resources

Data Assets Available via DASH

- Traditional sources of **administrative** data (e.g. physician payment information, hospital separations), drug claims, patient assessments in long-term care and home care

- Other clinical data, including data from electronic medical records (EMRs)

- **Data Asset Inventory** provides overview of information of data holdings that can be requested through DASH: https://www.hdrn.ca/en/inventory/

- Overtime, will integrate **new data sources** including expanded EMR/clinical data, data collected directly from patients, and social data when available

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Data Access via DASH

- Data access is in accordance to each partner organization's access policies and procedures

- Legislative or policy limitations in many Canadian jurisdictions related to:

  ➢ Disclosure of patient-level data

  ➢ Transfer and/or sharing of data across jurisdictional boundaries for research use

Impacts ability to pool data in one location for analysis

- Researchers are encouraged to connect with DASH early in the research design phase, on topics that can impact data access such as linkage, disclosures, hosting and access to linked data, informed consent and data sharing agreements

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DASH Service Model

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┌─────────────┐                    ┌─────────────┐  ┌─────────────┐
│  Requestor  │                    │  Requestor  │  │  Requestor  │
│   submits   │                    │   accepts   │  │   submits   │
│   central   │                    │  letter +   │  │ Data Access │
│ DASH Intake │                    │    cost     │  │   Request   │
│    Form     │                    │  estimate   │  │             │
└─────────────┘                    └─────────────┘  └─────────────┘
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| Initial Consultation with requestor | Confirm Eligibility & Feasibility of request with data centres | Liaise with data centres to develop cost estimate | Prepare consolidated DASH Feasibility Letter and cost estimate | Central Data Access Request Submission | | Ethics, Privacy & Data Steward Reviews | Contracts & Agreements | Data Extraction/ Analysis | Data Release data cuts/access environments | Invoicing |

Efficiency gains through DASH:

- ✓ Central intake process
- ✓ Coordinated eligibility and feasibility assessments
- ✓ Meeting coordination with data centres and requestor, and prepare consolidated feedback and cost estimates
- ✓ DASH staff support requestor in populating data request forms

In the short term:

- DASH staff supporting requestor through these highly localized steps
- Timelines will remain quite variable based on complexity of data request, various review times and researcher response time

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DASH Accomplishments and Activities Completed To-Date

Coordinated Support

- **DASH Launch** in Feb 2020 and began central intake
- Receipt of 37 **DASH requests** since launch

Process Transparency

- Developed **Data Access Process Inventory**
- Summarized **Indigenous Data Access Processes**
- Developed **Research Study Design** considerations for researchers

Process Harmonization

- Developed **Access Workflow Model**
- Developed **Linkage Models**
- Developed draft **DASH Data Access Request (DAR) Form**
- Identified criteria for looking at **Private Sector Requests**

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Indigenous Data Access

Goal: to understand and make transparent Indigenous data access policies and processes at HDRN Canada partner organizations

- ✓ Consulted with partner organizations and summarized processes

- ✓ Adapted our workflow model to reflect variation in local processes

- ✓ Make processes transparent to researchers and community on DASH website (target: March 2021)

Key observations

> *"Nothing About Us Without Us"*

- ✓ Early engagement of Indigenous communities in the research project is necessary

- ✓ Approval of research project by Indigenous groups is required in most jurisdictions

- ✓ Local variation in processes exists to ensure OCAP® principles and others are respected and reflect diversity across Indigenous groups
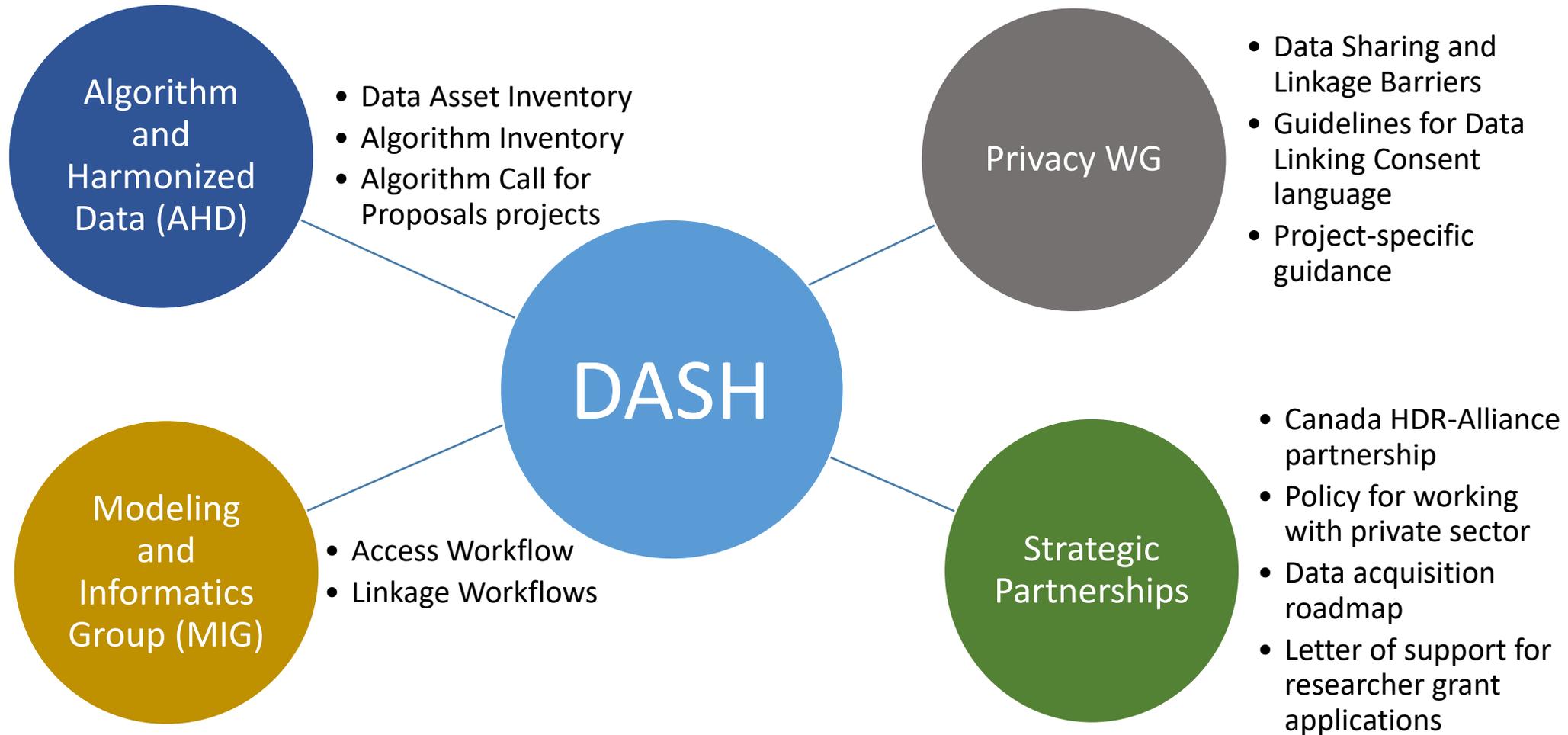
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Strategic Partnerships

- The Canada HDR-Alliance facilitates HDRN Canada to work with external data partners to expand sources and types of data available to researchers in a coordinated way

- The Canadian Partnership for Tomorrow's Health (CanPath) is the first member of the Canada HDR-Alliance

DASH role in supporting the Alliance:

- ✓ Establish joint data access workflow and review processes

- ✓ Support multi-jurisdictional research projects

- ✓ Support future work with other pan-Canadian cohorts and networks where linkages not currently existing

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DASH Collaborations within HDRN Canada

Algorithm and Harmonized Data (AHD)
- Data Asset Inventory
- Algorithm Inventory
- Algorithm Call for Proposals projects

DASH

Privacy WG
- Data Sharing and Linkage Barriers
- Guidelines for Data Linking Consent language
- Project-specific guidance

Modeling and Informatics Group (MIG)
- Access Workflow
- Linkage Workflows

Strategic Partnerships
- Canada HDR-Alliance partnership
- Policy for working with private sector
- Data acquisition roadmap
- Letter of support for researcher grant applications

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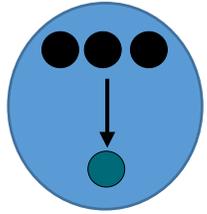
Overcoming Data Sharing Issues in Canada

- Often researchers would like data from multiple jurisdictions to be pooled in one location – but this is not always feasible

- Legislative review underway to understand what is possible in current state

- Statistical review underway to determine what analyses are feasible in a distributed data environment

- Secure environment review underway to assess best practices and potential for environments to be connected for distributed analysis

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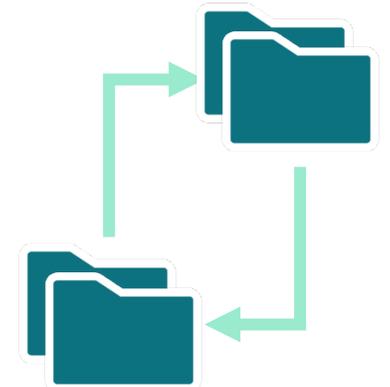
Upcoming DASH Activities

➢ Implement DASH Data Request Form

➢ Publish Indigenous Data Access Processes on DASH webpage

➢ Support projects as part of Algorithm Call for Proposals

➢ Integrate project tracking mechanism into DASH researcher portal

➢ Support policy development for private sector research/access requests

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Opportunities

➢ Identify additional focus areas of harmonization within data access process (e.g. dataset creation plan, data de-identification, training/orientation, etc.)

➢ Tackle barriers for data sharing and linkage across jurisdiction

➢ Continue to build relationships within HDRN Canada as well as with external partners and researchers to support our objectives and enhance our services

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Questions and How to Reach Us

For more information about **DASH**

Contact: dash@hdrn.ca

Visit: https://www.hdrn.ca/en/dash

For more information about **HDRN Canada**

Contact: info@hdrn.ca

Visit: https://www.hdrn.ca/

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