CHEO RESEARCH INSTITUTE
INSTITUT DE RECHERCHE

# Research Data Management Strategy

## Intro/Background:

In the spring of 2021, Canadian research funding agencies launched the Tri-Agency (Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC)) Research Data Management Policy. As part of the Tri-Agencies ongoing commitment to Canadian research excellence, the objective of this policy is to promote sound Research Data Management (RDM) and data stewardship practices (1).

As part of the policy, post-secondary institutions, and research hospitals eligible to hold Tri-Agency funding are required to develop an institutional research data management strategy that will provide its researchers with an environment that enables and supports sound data management practices. Notably, to support Indigenous data sovereignty, the policy specifically calls for a distinction-based approach when collecting, using, storing, or sharing Indigenous data (1).

While the mandate to implement an organizational research data management strategy comes from the Tri-Agencies, one of the main strategic goals of the Children's Hospital of Eastern Ontario Research Institute (CHEO RI) is to further integrate technology to streamline communications, work processes, and facilitate research using digital means (2) and, therefore, is already working to expand its digital research infrastructure.

Sound data management is essential to all research and the purpose of this strategy is to outline how the CHEO RI will improve and implement RDM best practices across the organization.

## **Scope**:

This strategy applies to all CHEO RI research data collected, used, shared, and stored and all CHEO RI researchers, staff (paid and unpaid), and trainees.

## Future Vision for Research Data Management at CHEO RI:

The CHEO RI aims to establish a culture where all researchers, staff and trainees are proficient with RDM best practices; where all have access to cohesive RDM solutions and support.

CHEO RI acknowledges the history of colonialism within Canadian research. CHEO RI is committed to ensuring that the voices, rights, and self-determined preferences of First Nations, Inuit and Métis Peoples are respected, affirmed, and implemented in the CHEO RI RDM best practices.

Further, the CHEO RI is committed to becoming a leader in RDM; exploring and adopting new RDM technologies, as they become available, to ensure continued research excellence.

## Current State and Institutional Readiness

In May of 2022, a CHEO RI Research Data Management Advisory Taskforce was assembled and includes key stakeholders in Research Data Management. Membership consists of representatives from

- CHEO RI Operations
- CHEO RI Quality Assurance Office
- CHEO RI Grants Office
- Clinical Research Unit
- REDCap Administration
- CHEO Research Ethics Board (REB)
- CHEO RI Research Informatics Core
- CHEO Privacy Office
- Bio-Med Research Group
- CHEO RI Researchers

The Taskforce was charged with assessing the current RDM landscape, raising awareness of RDM policies and requirements, proposing a roadmap for improvement, formalizing RDM practices, and creating the CHEO RI RDM strategy.

Through further stakeholder engagement, internal review, and assessment via a RDM landscape survey, the Taskforce found that while the CHEO RI supports researchers, staff, and trainees on a wide range of RDM services, including data collection, capture, extraction, and analysis, the organization lacks cohesive solutions and supports for data curation, storage, and long-term archival practices. As a result, researchers, staff, and trainees have been left to leverage a wide range of practices and solutions on their own.

In 2021 the CHEO RI underwent an Information Technology (IT) review to assess current gaps in IT capabilities and gather requirements on the future needs of research teams, investigators,

and operational teams within the CHEO RI. The review identified data storage and archiving capabilities as well as remote access as key needs for RI stakeholders to effectively manage their research data.

Additionally, to better serve Indigenous and diverse communities, Team CHEO (CHEO, CHEO Foundation and CHEO RI) established an EDII (Equity, Diversity, Inclusion, and Indigeneity) Taskforce to develop a roadmap for systemic change across the three organizations. The Taskforce identified five overarching goals to guide this change (3), and implementation is underway. This work will further set the stage for thoughtful discussions around Indigenous data sovereignty and equity within data management.

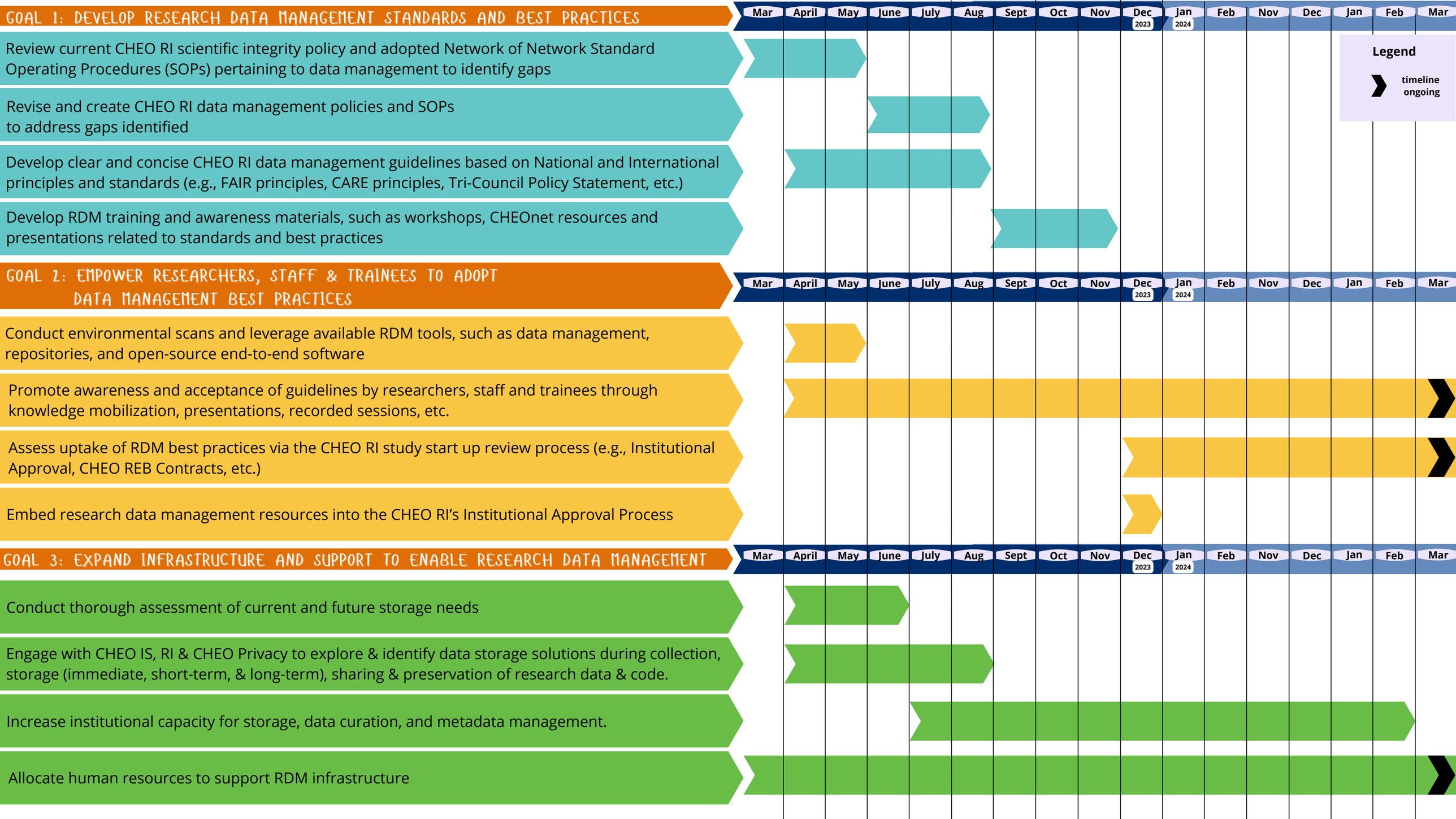
CHEO RI leadership, researchers, staff, and trainees recognize the need for improvement and are keen to see new supports and services available, while taking into consideration the policies and guidelines of our collaborators, i.e. the University of Ottawa, the Ottawa Hospital Research Institute, etc. Given our researchers are often cross-appointed to multiple organizations, it is paramount that we align. To this effect, some members of the Taskforce have joined a regional RDM Taskforce to ensure successful collaboration.

## Oversight and Review:

In March of 2023, the Research Data Management Taskforce will expand to include additional interested parties and will formally transition to the CHEO RI Data Management Advisory Committee (D-MAC).

As new RDM best practices and tools evolve, this strategy may be revised as needed. At minimum, a formal review will be done annually, by the CHEO RI D-MAC, in accordance with the committees Term of Reference (to be developed).

The CHEO RI CEO and Scientific Director will hold the D-MAC committee accountable for implementation and shall approve all changes prior to implementation.

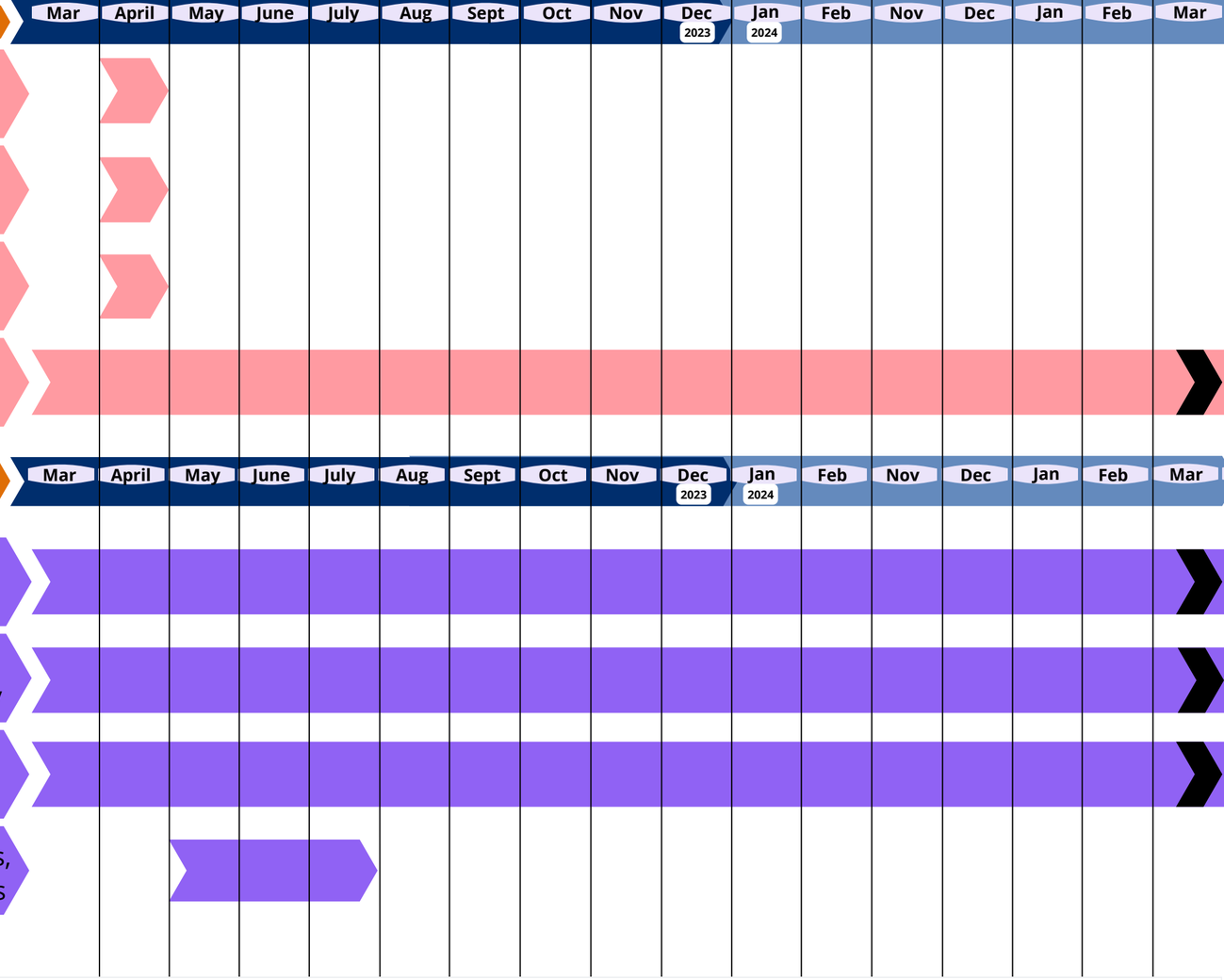

GOAL 1: DEVELOP RESEARCH DATA MANAGEMENT STANDARDS AND BEST PRACTICES
Mar
April
May
June
July
Aug
Sept
Oct
Nov
Dec
2023
Jan
2024
Feb
Nov
Dec
Jan
Feb
Mar
Legend
timeline
ongoing
Review current CHEO RI scientific integrity policy and adopted Network of Network Standard Operating Procedures (SOPs) pertaining to data management to identify gaps
Revise and create CHEO RI data management policies and SOPs to address gaps identified
Develop clear and concise CHEO RI data management guidelines based on National and International principles and standards (e.g., FAIR principles, CARE principles, Tri-Council Policy Statement, etc.)
Develop RDM training and awareness materials, such as workshops, CHEOnet resources and presentations related to standards and best practices
GOAL 2: EMPOWER RESEARCHERS, STAFF & TRAINEES TO ADOPT DATA MANAGEMENT BEST PRACTICES
Conduct environmental scans and leverage available RDM tools, such as data management, repositories, and open-source end-to-end software
Promote awareness and acceptance of guidelines by researchers, staff and trainees through knowledge mobilization, presentations, recorded sessions, etc.
Assess uptake of RDM best practices via the CHEO RI study start up review process (e.g., Institutional Approval, CHEO REB Contracts, etc.)
Embed research data management resources into the CHEO RI's Institutional Approval Process
GOAL 3: EXPAND INFRASTRUCTURE AND SUPPORT TO ENABLE RESEARCH DATA MANAGEMENT
Conduct thorough assessment of current and future storage needs
Engage with CHEO IS, RI & CHEO Privacy to explore & identify data storage solutions during collection, storage (immediate, short-term, & long-term), sharing & preservation of research data & code.
Increase institutional capacity for storage, data curation, and metadata management.
Allocate human resources to support RDM infrastructure

## GOAL 4: ESTABLISH ORGANIZATIONAL STRUCTURE FOR RESEARCH DATA MANAGEMENT

- Transition the RDM Taskforce into the Data Management Advisory Committee (D-MAC)
- Engage additional stakeholders, such as family and community advisors with an interest in data management, ensuring diversity and equity in membership
- Develop Terms of Reference for the committee
- Ensure the long-term sustainability of RDM at the CHEO RI

## GOAL 5: ADOPT RESEARCH DATA MANAGEMENT PRACTICES THAT RESPECT INDIGENOUS DATA SOVEREIGNTY

- Follow and adopt Indigenous led RDM initiatives in Canada (e.g., First Nations OCAP™ principles and Guiding Inuit Qaujimajatuqangit Principles)
- Create opportunities for CHEO RI researchers, staff & trainees to request consultations from First Nations, Inuit, & Métis peoples around RDM, by aligning with CHEO's Indigenous Engagement Strategy
- Ensure CHEO RI RDM resources, standards and policies incorporate and respect Indigenous ownership and stewardship
- Establish data management solutions throughout the project lifecycle which allow for proficient access, control, & removal of Indigenous data as per each individual community's self-determined preferences





**References:**

1 Communications and Marketing Branch. (2021, March 15). Tri-Agency Research Data Management Policy - Science.gc.ca. Government of Canada. Retrieved April 22, 2022, from https://science.gc.ca/eic/site/063.nsf/eng/h_97610.html

2 CHEO Research Institute. (2022, October 23). Welcome and Strategic Overview. CHEO Research Institute. Retrieved April 22, 2022, from https://www.cheoresearch.ca/aboutus/strategic-overview/

3 Equity, Diversity, Inclusion and Indigeneity. (n.d.). CHEO. Retrieved January 11, 2023, from https://www.cheo.on.ca/en/about-us/equity-diversity-inclusion-and-indigeneity.aspx