

Webinar: Sharing your COVID-19 data with the CITF

David Buckeridge, MD PhD FRCPC
Scientific Lead | Data Management and Analysis, CITF Secretariat

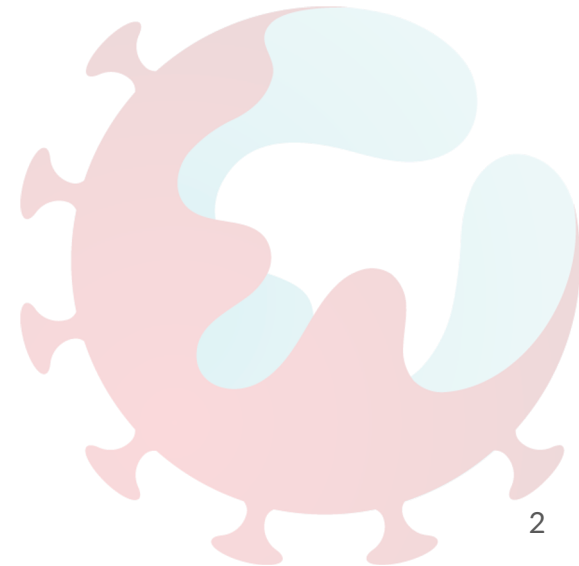


**COVID-19 IMMUNITY
TASK FORCE**

October 8th, 2020

Outline

- Background on CITF
 - Mandate
 - Principles
 - CITF Governance
- Benefits of sharing COVID-19 data
- Sharing your (meta)data with the CITF
 - Study cataloguing
- Data & Data Governance
 - Core Data Elements
 - Data centralization
 - Data sharing & Stewardship
 - Consent & Approvals

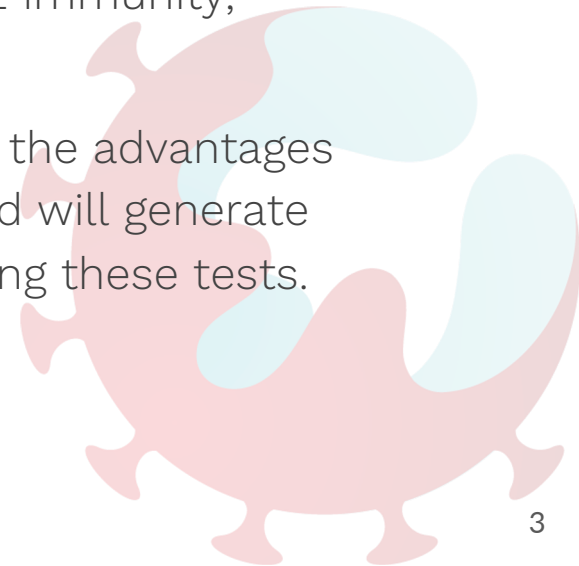


The COVID-19 Immunity Task Force

Helping to Guide Canada's Epidemic Response

The COVID-19 Task Force aims to catalyze, support, and, where appropriate and feasible, harmonize the design and rapid implementation of population-based studies that will generate reliable first estimates of SARS-CoV-2 immunity, overall and in priority populations across Canada.

The Task Force will also support laboratory studies to establish the advantages and limitations of immunity testing and related technologies and will generate practical insights into the optimum ways of using and interpreting these tests.



Background: CITF Mandate

“to track the spread of the virus in both the general population and priority populations in Canada. [...] to shed light on immune responses to SARS-CoV-2 in a diversity of communities, age brackets, populations, and occupational groups across the nation”

– CITF

“to support study implementers across a core set of common logistical challenges ... questionnaire elements, data management, data structures, data models, and data transfers”

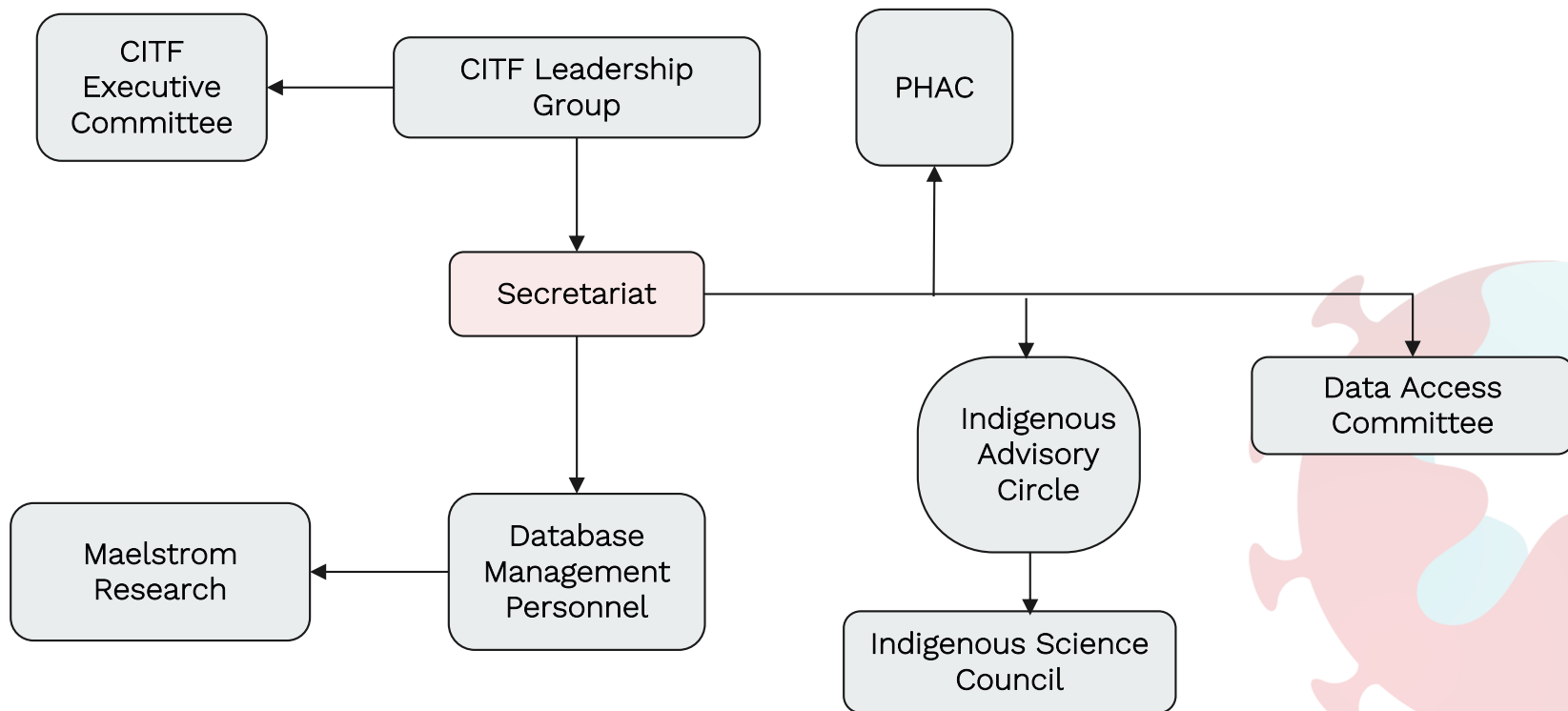
“to provide regular scientific updates on the state of serologic testing, results from studies, and the evolving understanding of immunity related to SARS-CoV-2”

– CITF Secretariat

Background: CITF Principles

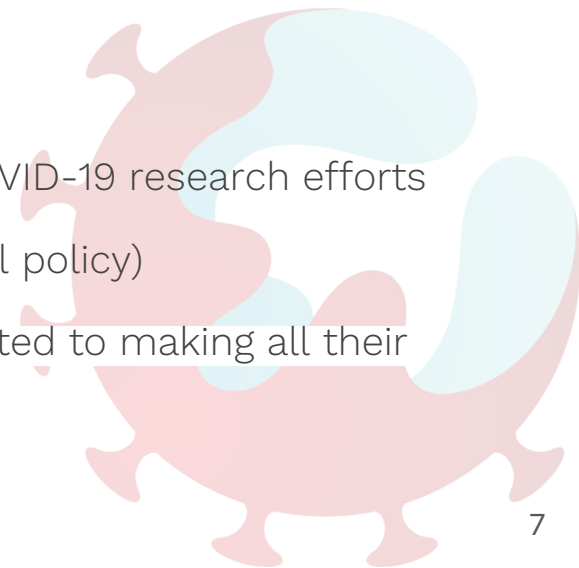
- Partner in all of its work with stakeholders
 - Identify priority issues related to serologic testing and its application
 - Promote **rigorous gathering and rapidly sharing of data** to inform Canadians
 - Mobilize the **best science** and study designs
 - Ensure **protection of privacy in data-gathering**
- Enhance cost-efficiencies and avoid unnecessary duplication
 - **Rapid reporting of results to key audiences**, including decision makers and interested stakeholders
 - Promote ethical and sound participatory practices
 - Adhere to best practices regarding any authorship of scientific publications
 - Liaise with relevant entities in other countries and with international agencies
 - Communicate with openness and **transparency**

CITF Governance



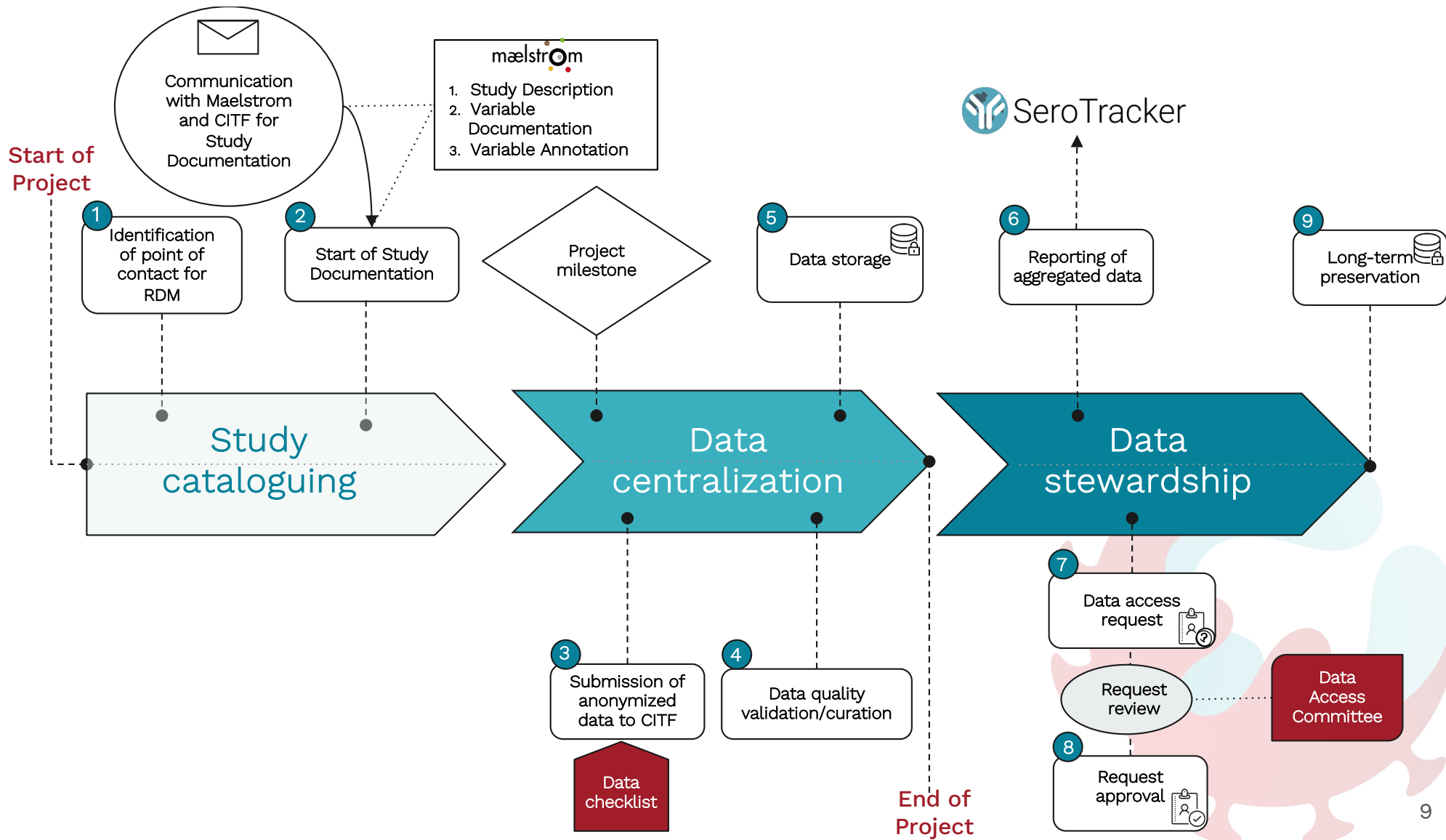
Benefits of sharing COVID-19 data

- Experience, frameworks and tools exist to enable legal and ethical sharing of research data
- Enable CITF cross-study analyses of Core Data Elements to inform COVID-19 research and pandemic planning efforts
- Potential to enrich CITF studies through comparative analyses
- Contributing CITF data to international COVID-19 research efforts
- Demonstrating the highest level of openness and transparency in COVID-19 research efforts
- Funders' expectations to obtain maximal value (upcoming Tri-Council policy)
- Community response: more than 30 leading publishers have committed to making all their COVID-19 publications and data accessible in PubMed Central.





Sharing your (meta)data with CITF



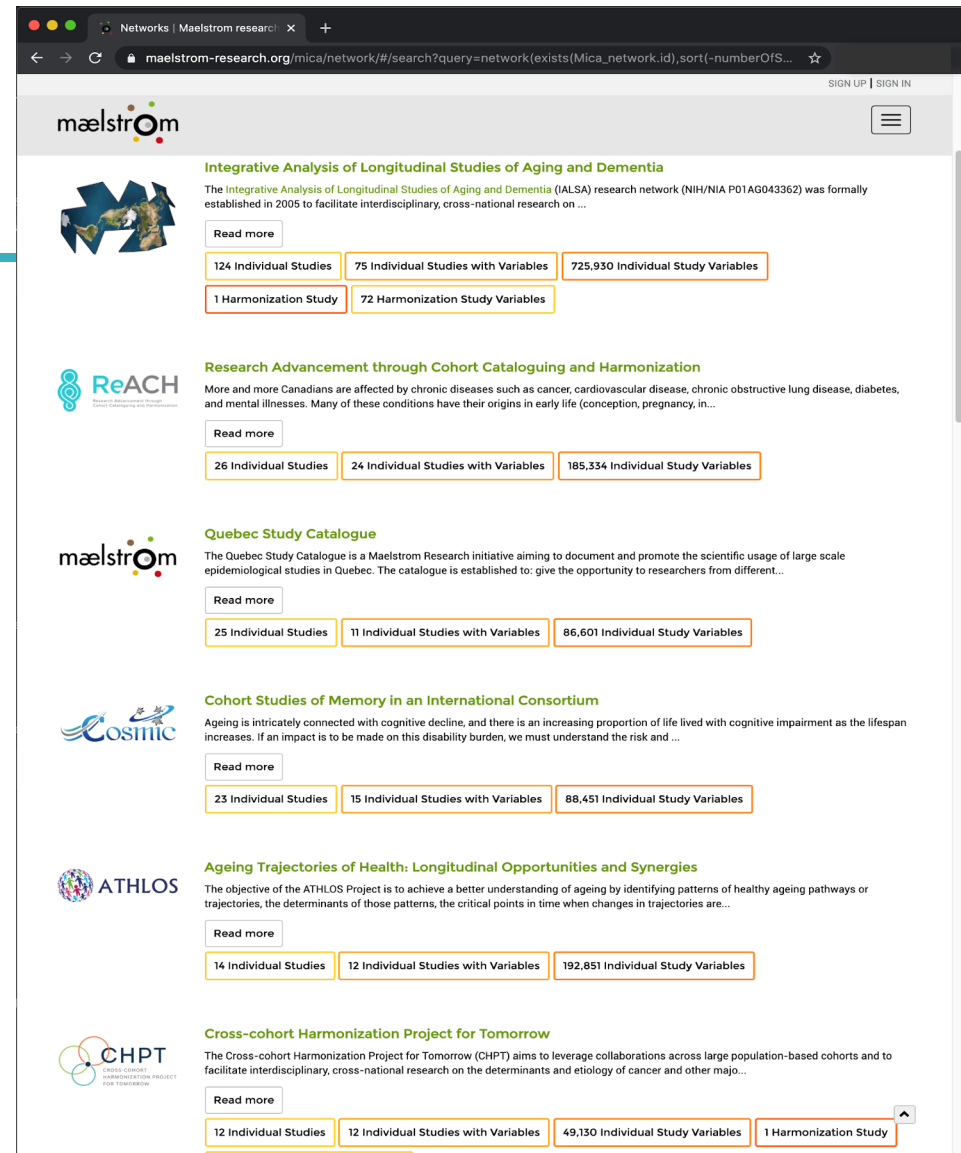
RI-MUHC: maelstrom

Maelstrom is a research group based at the RI-MUHC that has developed a standard approach to documenting and disseminating epidemiological study metadata.

Led by Prof. Isabel Fortier, Maelstrom has ~15 staff (Data analysts, scientists, programmers) + 8 investigators.

To date, Maelstrom supports:

- 19 networks
- 230 individual studies
- 5 harmonization studies



The screenshot displays the maelstrom-research.org website, which lists various research networks and their associated study counts. The website features a navigation bar with the maelstrom logo and a search bar. The main content area lists several research networks, each with a logo, a brief description, and a table of study counts.

Network	Individual Studies	Individual Studies with Variables	Individual Study Variables	Harmonization Study	Harmonization Study Variables
Integrative Analysis of Longitudinal Studies of Aging and Dementia	124	75	725,930	1	72
ReACH	26	24	185,334		
Quebec Study Catalogue	25	11	86,601		
Cohort Studies of Memory in an International Consortium	23	15	88,451		
ATHLOS	14	12	192,851		
CHPT	12	12	49,130	1	

Study cataloguing

1 . Study description

Information:

Targeted population(s),
and data collection
events.

Description will be done
using published papers
and study websites, and
subsequently validated
with PIs.

2. Variable documentation

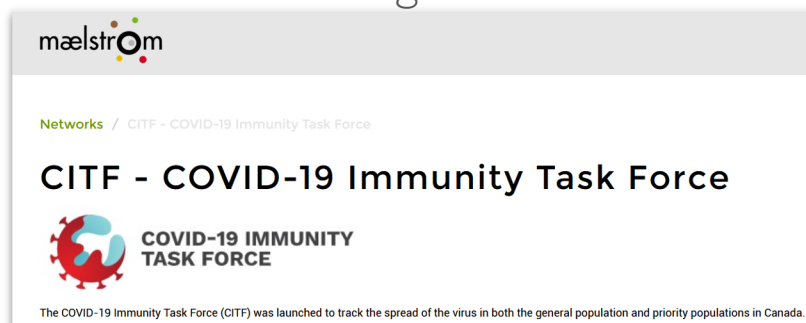
Information:

Data dictionaries and
questionnaires.

Variables should have a name,
a label, and if applicable,
codes and labels for
categories.

3. Variable annotation

General study
characteristics, targeted
populations, data
collection events, and
data dictionaries will be
made available on
Maelstrom's website.





Data & Data Governance

Core Data Elements

6 domains:

- Demographic
- COVID-19
- Symptoms
- Exposure
- Health & Health behaviours
- Serology

Data annotation:

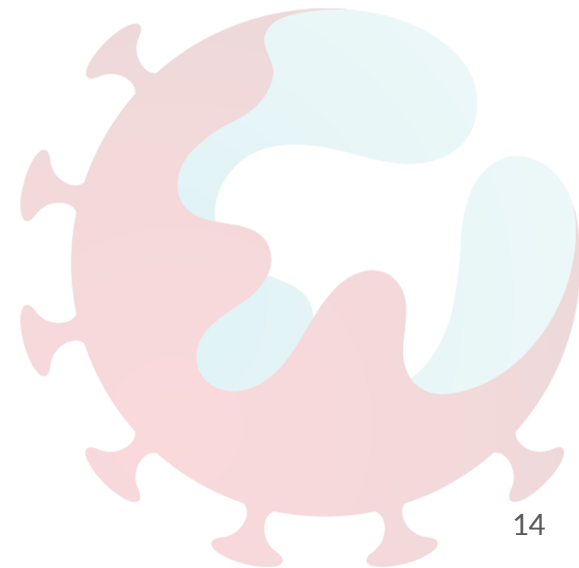
CDISC and LOINC standards

CITF Domain	Visit	#	Element	Question	Type	Technical specs
DEMOGRAPHIC	Baseline	1	Date of interview	Date of interview	Date	DD/MO/YR
DEMOGRAPHIC	Baseline	2	Age	What is your age	Numerical	YEARS
DEMOGRAPHIC	Baseline	3	Sex	What was your assigned sex at birth	Categorical	MALE/FEMALE/PREFER TO SELF-DESCRIBE/PREFER NOT TO ANSWER
DEMOGRAPHIC	Baseline	4	Sex	What is your sex now	Categorical	MALE/FEMALE/PREFER TO SELF-DESCRIBE/PREFER NOT TO ANSWER

CITF Domain	#	Element	Type	Technical specs
SEROLOGY	1	Test ordered	Categorical	LOINC code for test
SEROLOGY	2	Device Identifier	Categorical	DI or unique trade name
SEROLOGY	3	Test result	Categorical	SCT code: positive(10828004) / negative (260385009)
SEROLOGY	4	Test result	Numerical	mg/mL

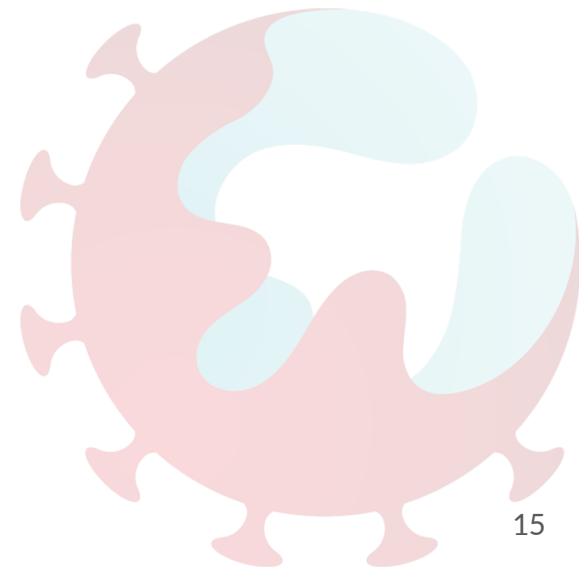
Data centralization: Submitting data to the CITF database

- Requirement to submit Core Data Elements (to extent possible)
 - May be possible to accept other data types
- Study/data cataloguing complete (Maelstrom)
- Secure upload & storage to CITF Secretariat
- Timelines for data submission to be discussed
- Quick Guide to Data Sharing available



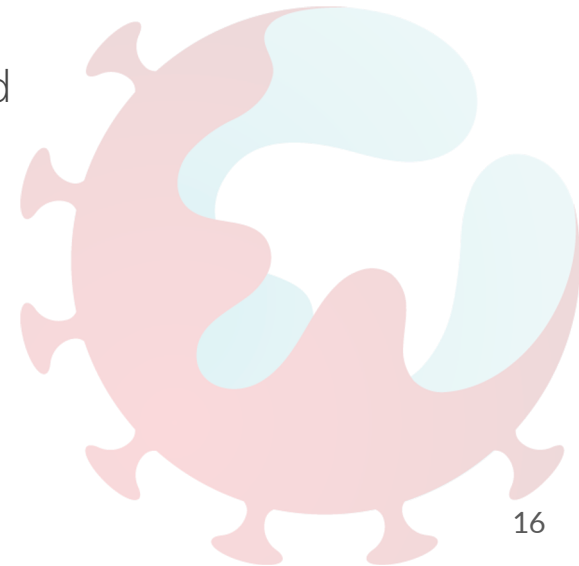
Data sharing & stewardship

- All CITF data will be shared with the international research community
- Timelines for sharing between projects & outside CITF to be discussed
- Acknowledgement in publications & mechanisms to facilitate collaboration with study investigators
- Data will be shared either openly or through restricted access models depending on privacy risks
- CITF Data Access Committee will oversee equitable access procedures



Consent & approvals

- Consent guidance and “templates” to assist CITF studies in preparing consent materials that allow for data sharing
- Guidance on the inclusion of data from past collections
- Data submission form / checklist to confirm approvals and data de-identification





Thank you



Questions?

David Buckeridge
david.buckeridge@mcgill.ca