Webinar: Sharing your COVID-19 data with the CITF

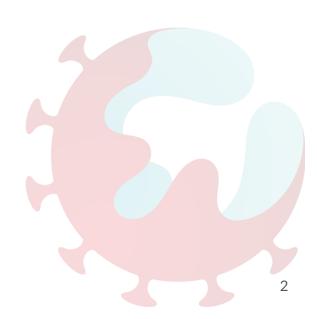
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October 8th, 2020

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" "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

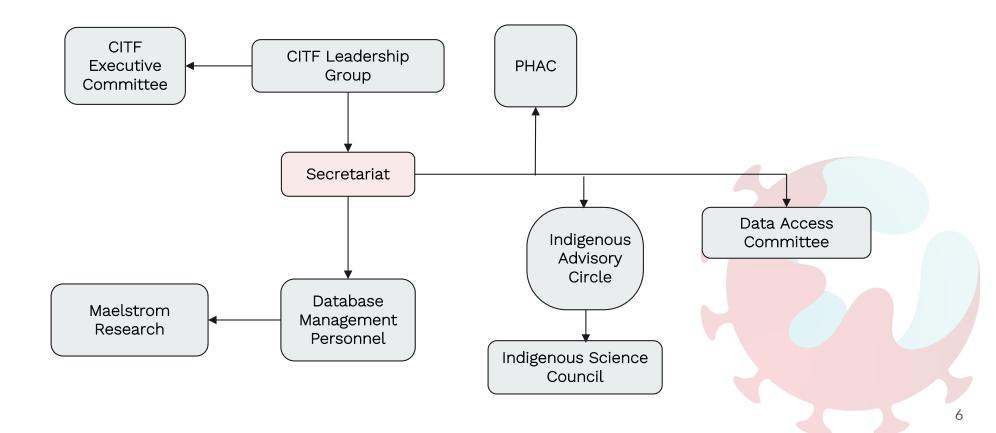
- CITF

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 datagathering

- 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

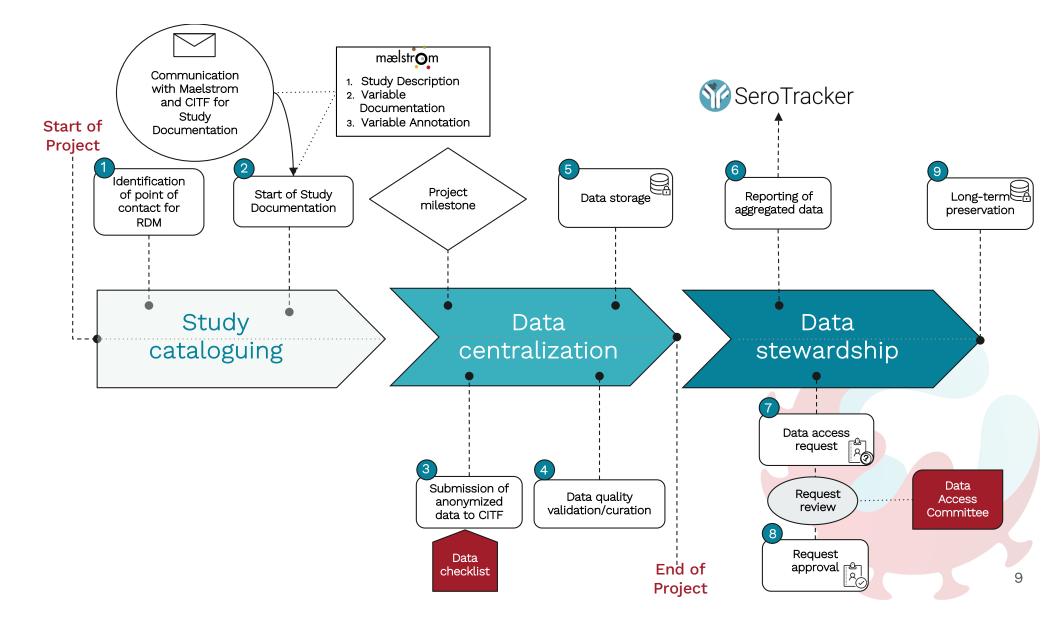


Benefits of sharing COVID-19 data

- 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





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

🗕 🔍 🌒 👔 Networks Mae	elstrom research × +							
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	Integrative Analysis of Longitudinal Studies of Aging and Dementia							
	The Integrative Analysis of Longitudinal Studies of Aging and Dementia (IALSA) research network (NIH/NIA P01AG043362) was formally established in 2005 to facilitate interdisciplinary, cross-national research on							
	Read more							
	124 Individual Studies	75 Individual Studies with Variables	725,930 Individual Study Variable	s				
	1 Harmonization Study	72 Harmonization Study Variables						
	Research Advancement through Cohort Cataloguing and Harmonization							
	More and more Canadians are affected by chronic diseases such as cancer, cardiovascular disease, chronic obstructive lung disease, diabetes, and mental illnesses. Many of these conditions have their origins in early life (conception, pregnancy, in							
	Read more							
	26 Individual Studies	24 Individual Studies with Variables	185,334 Individual Study Variables	ן ו				
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	Quebec Study Catal	oque						
mælstr O m	The Quebec Study Catalogue is a Maelstrom Research initiative aiming to document and promote the scientific usage of large scale epidemiological studies in Quebec. The catalogue is established to: give the opportunity to researchers from different							
	Read more							
	25 Individual Studies	11 Individual Studies with Variables	86,601 Individual Study Variables					
			J					
	Cohort Studies of Memory in an International Consortium							
Cosmic	Ageing is intricately connected with cognitive decline, and there is an increasing proportion of life lived with cognitive impairment as the lifespan increases. If an impact is to be made on this disability burden, we must understand the risk and							
	Read more							
	23 Individual Studies	15 Individual Studies with Variables	88,451 Individual Study Variables					
	Ageing Trajectories	of Health: Longitudinal Opport	unities and Synergies					
🙀 ATHLOS	Ageing Trajectories of Health: Longitudinal Opportunities and Synergies The objective of the ATHLOS Project is to achieve a better understanding of ageing by identifying patterns of healthy ageing pathways or tuning their in the determinents of them retified and the united algorithm is finance and and the provide and the and the and the set of the advisory of the transformer of the set of the							
	trajectories, the determinants of those patterns, the critical points in time when changes in trajectories are							
	14 Individual Studies	12 Individual Studies with Variables	192,851 Individual Study Variables					
			-					
	Cross-cohort Harmonization Project for Tomorrow							
	The Cross-cohort Harmonization Project for Tomorrow (CHPT) aims to leverage collaborations across large population-based cohorts and to facilitate interdisciplinary, cross-national research on the determinants and etiology of cancer and other majo							
FOR TOMORROW	Read more							
	12 Individual Studies	12 Individual Studies with Variables	49,130 Individual Study Variables	1 Harmonization Study				
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Study cataloguing

1. Study description

2. Variable documentation

Information: Targeted population(s), and data collection events.

Description will be done using published papers and study websites, and subsequently validated with PIs. Information: Data dictionaries and questionnaires.

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

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Networks / CITF - COVID-19 Immunity Task Force

CITF - COVID-19 Immunity Task Force

Task Force (CITF) was launched to track the spread of the virus in both the general population and priority populations in Canada



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

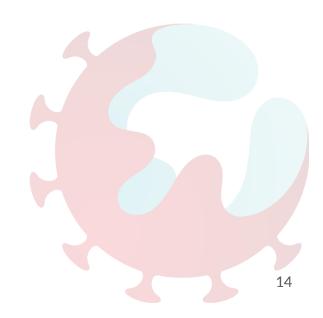
Data annotation:

CDISC and LOINC standards

CITF Doma	omain Visit		t	#	Element	Question	Туре	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	
DEMOGRAPH	IC	Basel	ine	4	Sex	What is your sex now	Categorical	MALE/FEMALE/PREFER TO SELF- DESCRIBE/PREFER NOT TO ANSWER	
CITF Domain		#	El	ement	Туре		Technical	specs	
SEROLOGY		1		Test rdered	Categorical	LOINC code for test		for test	
SEROLOGY		2)evice entifier	Categorical	D	DI or unique trade name		
SEROLOGY		3	Tes	st resul	t Categorical				
SEROLOGY		4	Tes	st resul	Numerical				

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

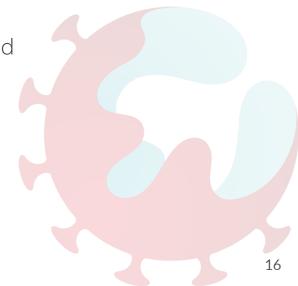
- All CITF data will be shared with the international research community
- Timelines for sharing between projects & outside CITF to be discussed
- Acknowledgement in publications & mechanisms to facilitate collaboration with study investigators
- Data will be shared either openly or through restricted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

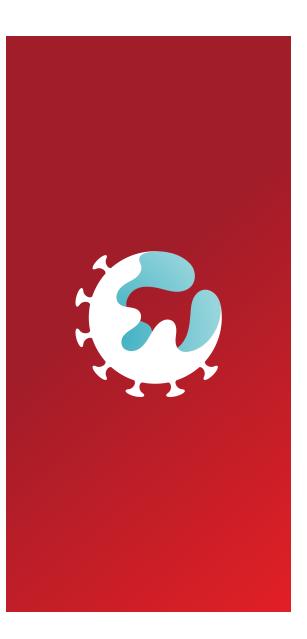




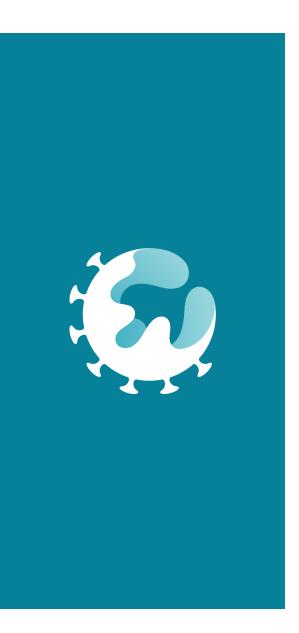


- Consent guidance and "templates" to assist CITF studies in preparing consent materials that allow for data sharing
- Guidance on the inclusion of data from past collections
- Data submission form / checklist to confirm approvals and data de-identification





Thank you



Questions?

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