Webinar:
Sharing your COVID-19 data with the CITF

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COVID-19 IMMUNITY TASK FORCE

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Outline

- Background on CITF and data sharing
- Process for sharing your (meta)data with the CITF
- Governance of data managed by CITF

The COVID-19 Immunity Task Force

Helping to Guide Canada's Epidemic Response

Catalyze, support, and harmonize the design and rapid implementation of population-based studies

Generate reliable estimates of SARS-CoV-2 immunity, overall and in priority populations across Canada

Support laboratory studies to establish the advantages and limitations of immunity testing and related technologies

Generate practical insights into the use and interpretation of 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"

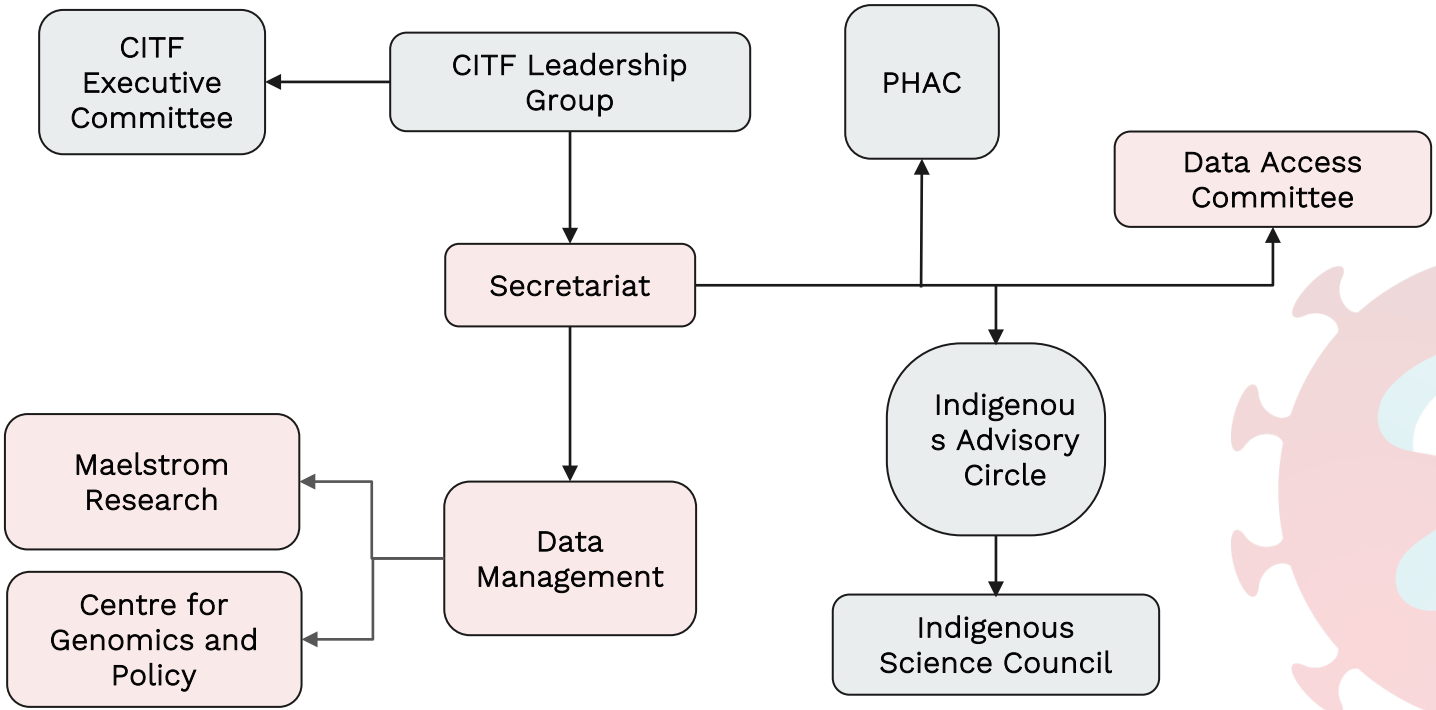
"to provide regular scientific updates on the state of serologic testing, results from studies, and the evolving understanding of immunity related to SARS-CoV-2"

– 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 rapid 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
- 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

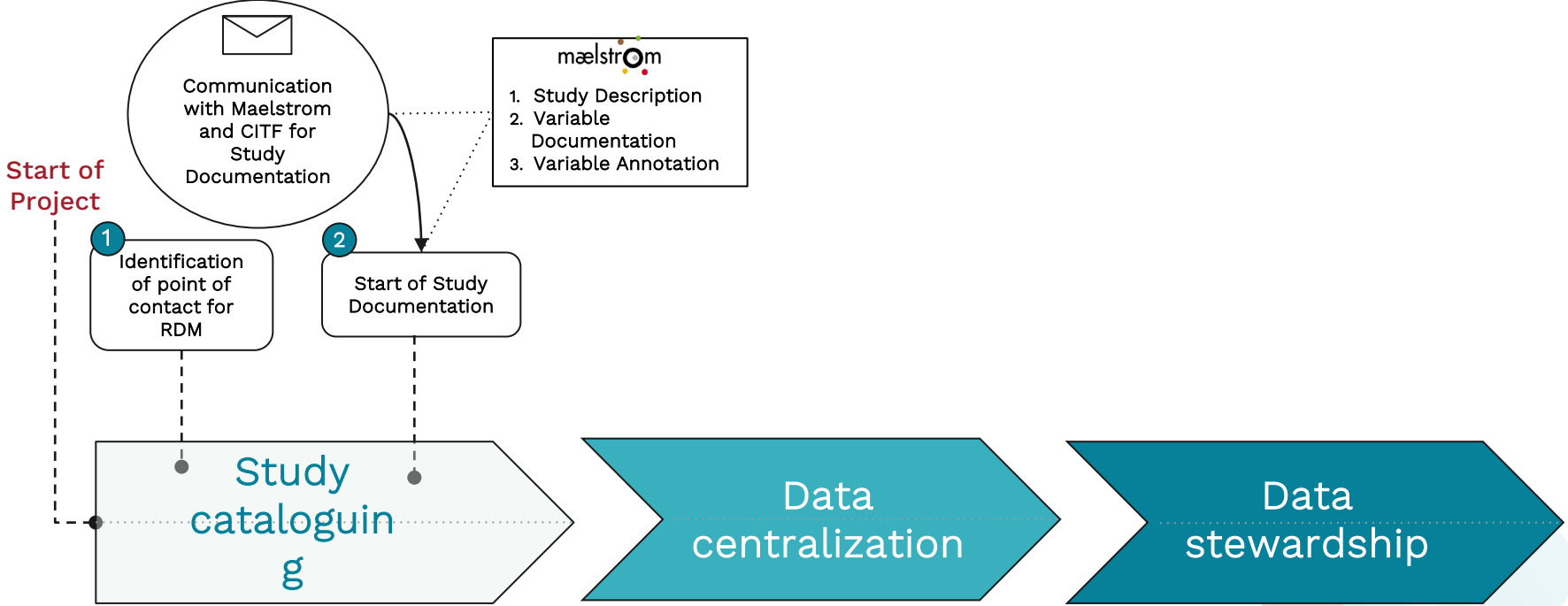
CITF Organizational Structure



Benefits of sharing COVID-19 data

- Sharing data in general and for COVID-19
  - Over 30 leading publishers have committed to making all COVID-19 publications and data accessible in PubMed Central
  - Contributes to openness and transparency in COVID-19 research efforts
  - Funders increasingly expect sharing to obtain maximal value (upcoming Tri-Council policy)
  - Experience, frameworks and tools exist to enable legal and ethical sharing of research data
- Benefits in the context of CITF
  - Enable cross-study analyses of Core Data Elements to inform pandemic planning efforts
  - Potential to enrich individual CITF studies through comparative analyses
  - Allows CITF data to be contributed to international COVID-19 research efforts

Process for Sharing (meta)data with CITF


Communication with Maelstrom and CITF for Study Documentation
mælstrom
1. Study Description
2. Variable Documentation
3. Variable Annotation
Start of Project
1
Identification of point of contact for RDM
2
Start of Study Documentation
Study cataloguing
Data centralization
Data stewardship

Study Metadata to be Catalogued

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.

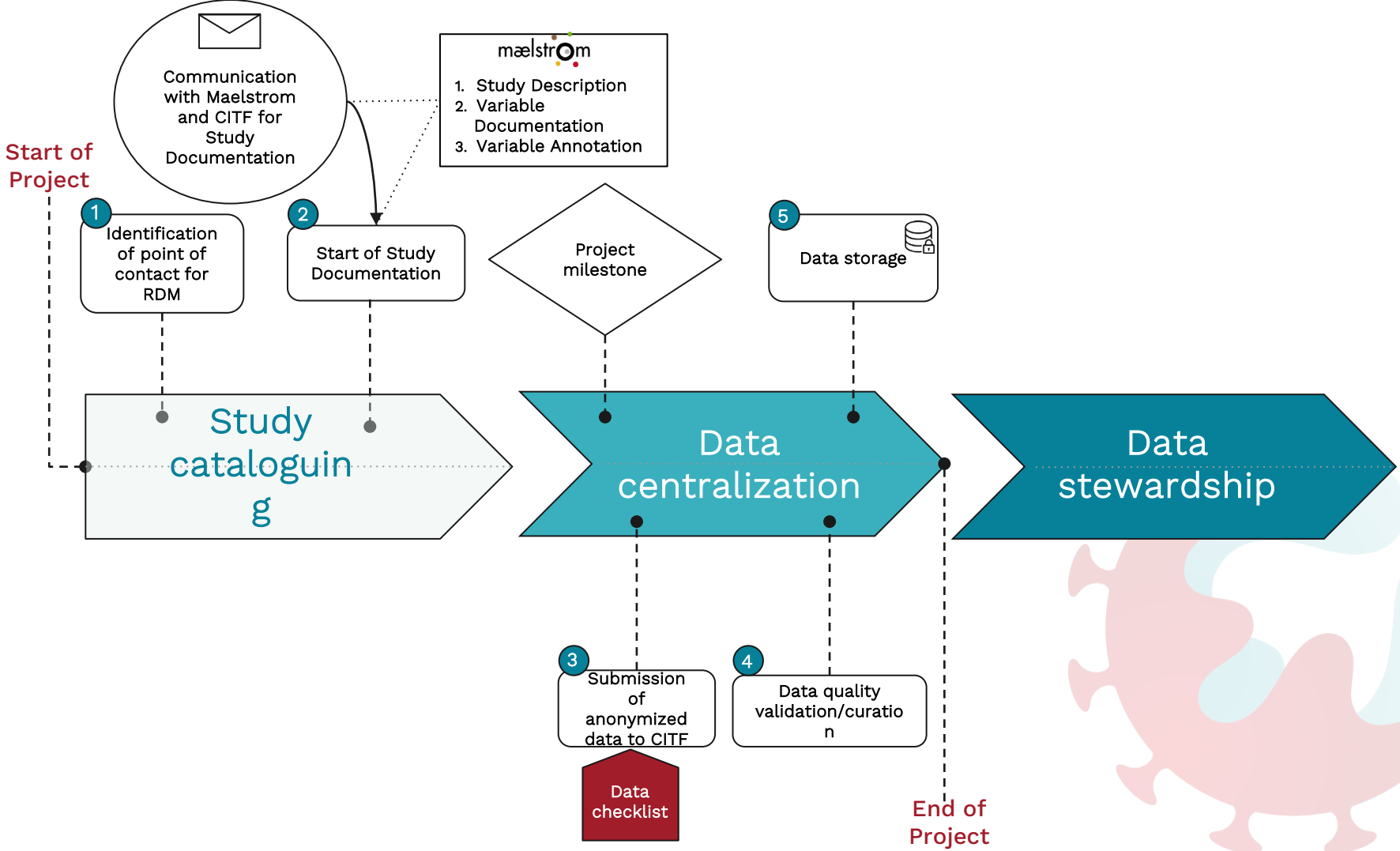
2. Variable documentation

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.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1. Study Description
2. Variable Documentation
3. Variable Annotation
Start of Project
1
Identification of point of contact for RDM
2
Start of Study Documentation
Project milestone
5
Data storage
Study cataloguing
Data centralization
Data stewardship
3
Submission of anonymized data to CITF
4
Data quality validation/curation
Data checklist
End of Project

Core Data Elements to be Shared

Core data elements identified in six domains by Task Force:

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

Standard encodings defined for data elements:

- Data model: CDISC
- Laboratory: LOINC
- Other: align with international efforts

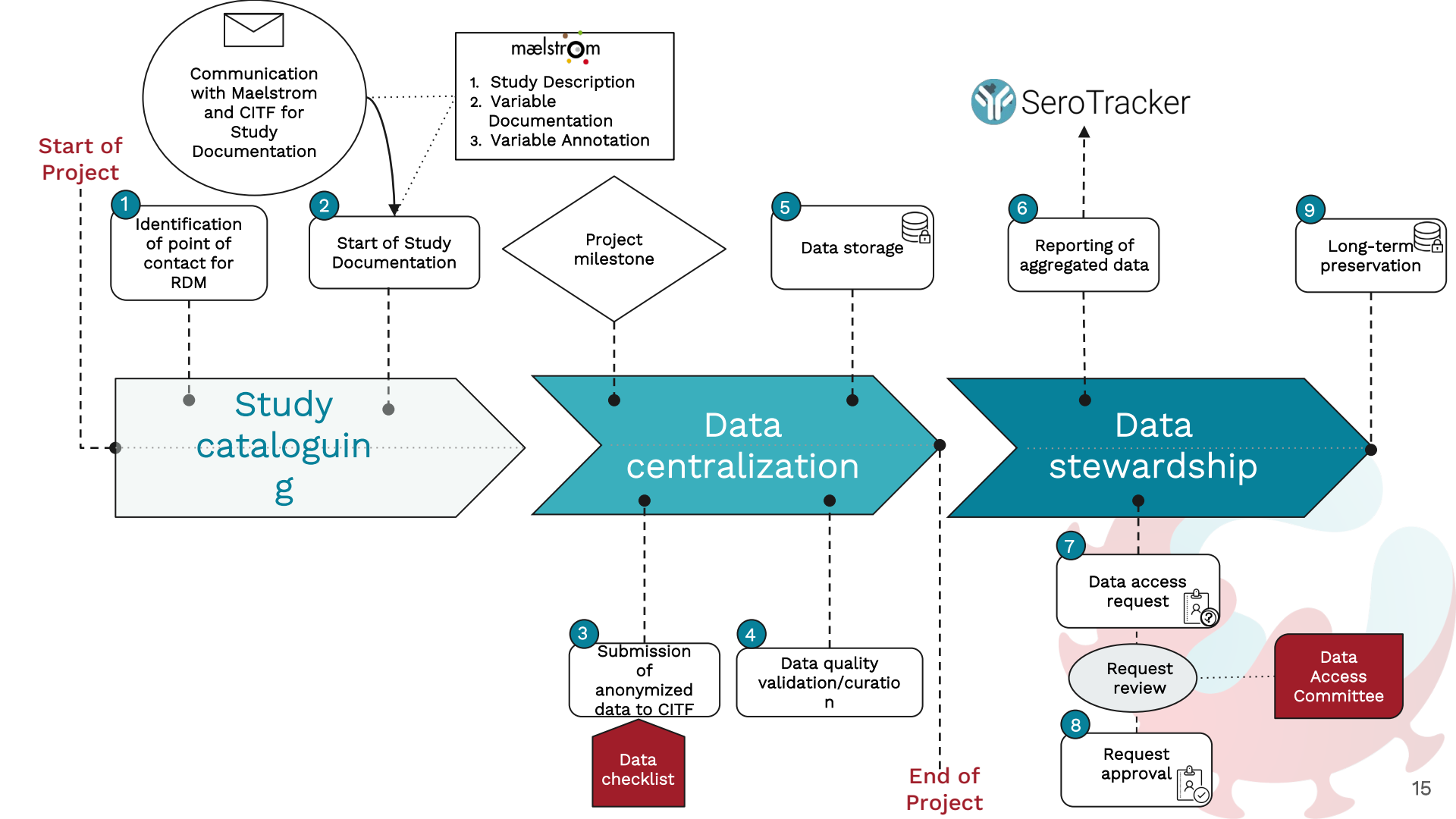
CITF Domain	Visit	#	Element	Question	Type	Technical specs
DEMOGRAPHIC	Baseline	1	Date of interview	Date of interview	Date	DD/MO/YR
DEMOGRAPHIC	Baseline	2	Age	What is your age	Numerical	YEARS
DEMOGRAPHIC	Baseline	3	Sex	What was your assigned sex at birth	Categorical	MALE/FEMALE/PREFER TO SELF-DESCRIBE/PREFER 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
LABORATORY	1	Test ordered	Categorical	LOINC code for test
LABORATORY	2	Device Identifier	Categorical	DI or unique trade name
LABORATORY	3	Test result	Categorical	SCT code: positive(10828004) / negative (260385009)
LABORATORY	4	Test result	Numerical	mg/mL

Data centralization: Submitting data to the CITF database

- Submission of Core Data Elements
  - To extent possible (e.g., retrospective samples, previous consent)
  - Secure upload & storage to CITF Secretariat
  - Timelines for data submission to be defined
- Tools available
  - Prospective and retrospective consent guidance
  - Quick guide to data sharing
  - Upload checklist

Data Governance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SeroTracker
Start of Project
1 Identification of point of contact for RDM
2 Start of Study Documentation
Project milestone
5 Data storage
6 Reporting of aggregated data
9 Long-term preservation
Study cataloguing
Data centralization
Data stewardship
3 Submission of anonymized data to CITF
Data checklist
4 Data quality validation/curation
End of Project
7 Data access request
Request review
Data Access Committee
8 Request approval

Data governance and access

- Data will be made available through restricted and controlled access models, depending on privacy risks
- CITF Data Access Committee will oversee equitable access procedures
- Acknowledgement of contributing studies in publications & mechanisms to facilitate collaboration with study investigators
- Centralized data will be shared with the international research community

Thank you

Questions?

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