Cross-Cohort Collaboration
March 5, 2016

Data Harmonization & Data Sharing

Questions to Address

- What is the objective of data harmonization and sharing for the CCC?
- What are the steps involved in data harmonization?
- What are the resources required for successful data harmonization?
- What resources are already available?
- What type of data access and control is desirable?
- What ought to be the next steps in data harmonization for the CCC?
  - Short term
  - Long term

What is the Objective of Data Harmonization & Sharing for the CCC?

Objective of Data Harmonization & Sharing

- Facilitate opportunities to address questions that require larger sample sizes, and more diverse populations and/or expertise
  - E.g., studies of rare outcomes, complex interactions, and mediations
- Using inferentially similar, high quality data for valid synthesis

What Are the Steps Involved in Data Harmonization?

Steps in Data Harmonization

- Cataloguing the characteristics of each cohort study (e.g. design, sample size) in a systematic way.

- Defining the 'target variables' - set of variables to be generated from the harmonization process.
  - 'target' variables determine the data information content that is required from each study to generate compatible (i.e. harmonized) variables.

Steps in Data Harmonization

- Each cohort determining its potential for generating 'target variables'
  - Each cohort evaluates study-specific questionnaires, standard operating procedures and data dictionaries, the potential for each cohort study to generate the target variables can be determined.

- Each cohort working with the data to transform their data locally into a common harmonized format.
  - Use standard algorithms

What Are the Resources Required for Data Harmonization?

Resources Required for Data Harmonization

Step/Process	Resources Required
Cataloguing characteristic of each cohort	Teams to develop standard data collection tools, complete data forms, and catalogue descriptive information
Defining 'target' variables (exposures, outcomes, covariates) and quality criteria	Team of researchers knowledgeable about data needs and their cohorts; workshops/meetings; reports
Determining the potential for generating target variables	Team within each cohort to review data collection tools, SOP, data dictionaries, and qa/qc documentation
Transforming cohort data into a harmonized dataset	Algorithms, team of information scientists within each cohort

Resources Required for Harmonization

- Time
- Provisions for updating data
- Resource management / coordination
  - Retrospective harmonization
  - Prospective harmonization

What Resources are Available?

Resources Available for Data Harmonization

- Experience and data from other consortia
  - CHARGE
  - The Cardiovascular Disease Lifetime Risk Pooling Project
  - Epidemiology of Non-fracture Fall Injuries: Cross-cohort Study of Medicare Outcomes
  - Duke BioLINCC Data Harmonization Project
  - TOPMed
- International Harmonization Initiative

International Harmonization Initiative

- Schema for selection of variables and classification of quality of harmonization
- Web-based platform for harmonization
  - https://www.maelstrom-research.org
  - http://www.obiba.org

What Type of Data Access & Control is Desirable?

Types of Data Access & Control

- Centralized / data commons
- Federated infrastructure

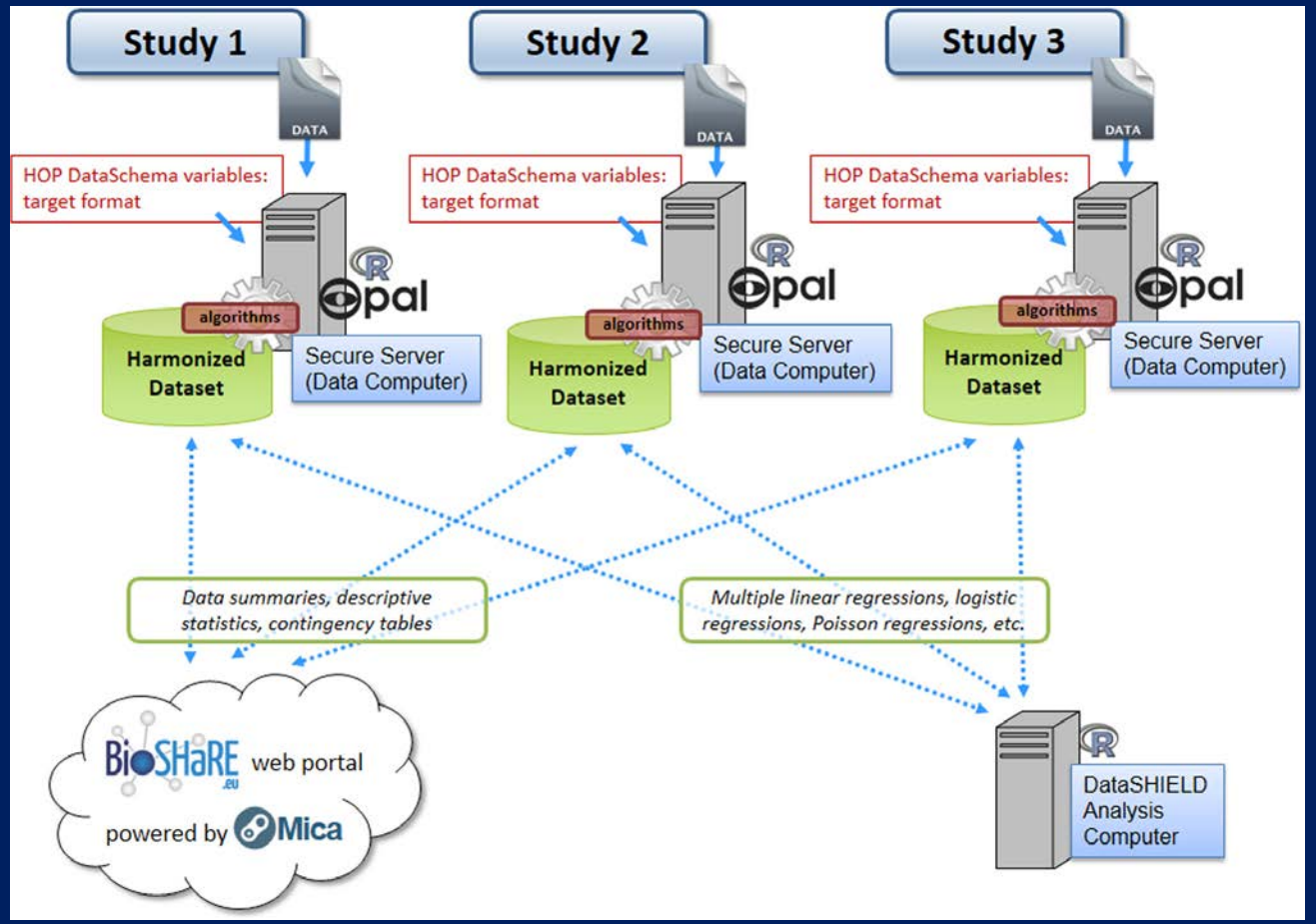
Centralized / Data Commons Questions?

- Where would the Coordinating Center for data harmonization be located?
- What management infrastructure would be required?
- What resources are there to support such infrastructure?
- What kind of data sharing procedures would be needed?
- What would be the roles and responsibilities of the publications committee? time and effort required?
- What are the ethical-legal considerations for each cohort / for the CC?
  - Who would be held accountable in case of a data breach / hacking?
- Would there be a common data use agreement?
- How many cohorts would be included/excluded?
- Is this feasible in the short term ?
  - Sometimes - Cardiovascular Disease Lifetime Risk Pooling Project

Federated Infrastructure Questions

- Data access and control would remain with each cohort after endorsement of the concept of the project by the CCC Executive Committee
- Data sharing procedures would be those of each cohort / in place
- Likely to be more feasible in the short term

Data harmonization and federated infrastructure for three Healthy Obesity Project studies



Doiron *et al. Emerging Themes in Epidemiology* 2013, 10:12
http://www.ete-online.com/content/10/1/12

What ought to be the next steps in promoting / supporting data harmonization in the CCC?

- Short term

- Long term

References

- Doiron et al. Data harmonization and federated analysis of population-based studies: the BioSHaRE project. Emerging Themes in Epidemiology 2013 10:12. doi:10.1186/1742-7622-10-12
- Fortier et al. Is rigorous retrospective harmonization possible? Application of the DataSHaPER approach across 53 large studies. International Journal of Epidemiology 2011;40:1314–1328. doi:10.1093/ije/dyr106
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