

A large concrete bridge with multiple arches spans a deep valley. The bridge has a decorative railing with arched openings. The valley below is filled with dense green vegetation. In the background, a large, rocky mountain rises under a clear blue sky with some light clouds. The bridge's structure is made of light-colored concrete, and the arches are prominent. The overall scene is a mix of natural beauty and human engineering.

Bridging the Divide

Photo by Mason Jones: <https://unsplash.com/photos/INvs-DWLoEo>

Hidden collections brought to light

“... seeking to improve discovery, access and long-term preservation of maternal, infant, child health research data through the creation of rich metadata.”

“... offering a descriptive approach that can help educate the researchers creating metadata for their studies early in the records lifecycle and inform the practices of archivists and data curators.”



Photo by Seabass Creatives
https://unsplash.com/photos/yIW287G3_U0

Project Partners



University of Alberta Libraries

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Collections

Centre for the History of Medicine

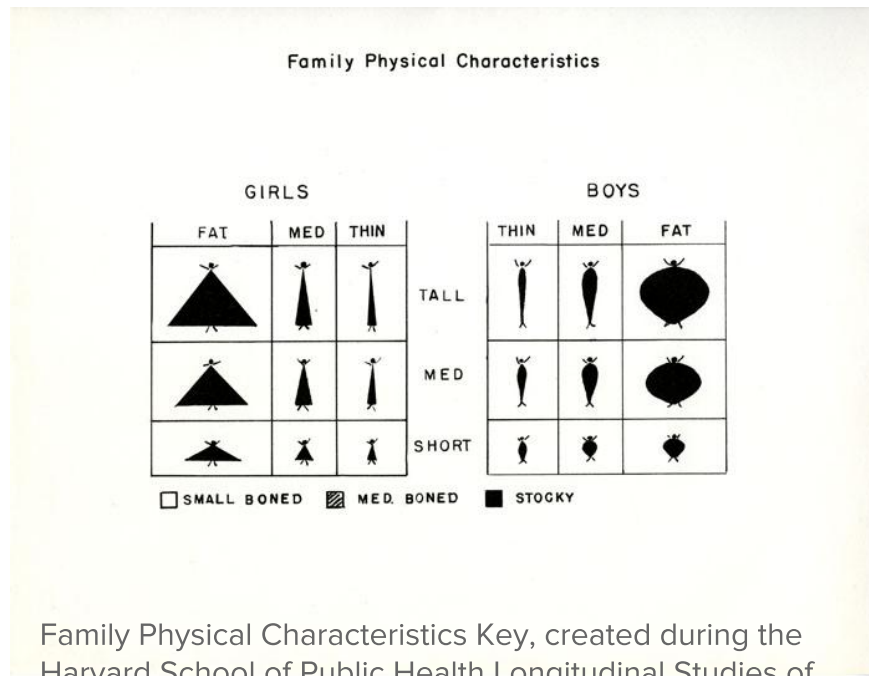
- historical research records (HRR) in which datasets are embedded
- Harvard School of Public Health Longitudinal Studies of Child Health and Development records (1930-1979)
- Early intervention studies from the multisite Infant Health and Development Program in the papers of health services researcher Marie McCormick (1985-2014)
- Anne Becker's social transition and risk for disordered eating in Fiji study (2004-2010)

University of Alberta Libraries

- contemporary, with entirely born digital research data (BDRD)
- selected 36 studies to be included in the pilot
 - 28 clinical trials, 2 cohort studies, 6 others
- variety of statuses:
 - some complete, ongoing, terminated, withdrawn trials.

Overview

- Special Collections Research Data Description
 - Harvard School of Public Health Growth Study Records
 - Special Collections Processing Workflow
 - Anticipated Metadata Workflows
- Contemporary Research Data Description
 - Created REDCap Project
 - Populated Dataverse REDCap Form
 - Contacted Researchers
 - Researcher Documents
 - Researcher Meetings
- Next Steps



Family Physical Characteristics Key, created during the Harvard School of Public Health Longitudinal Studies of Child Health and Development. From the Harvard Medical Library in the Francis A. Countway Library of Medicine.

Special Collections

Research Data Description

Special Collections Processing Workflow

- Rehousing
- Preservation
- Folder listing
- Identifying sensitive information
- Logging audio & audiovisual recordings
- Logging and imaging electronic records
- Rearrangement
- Finding aid and catalog record creation



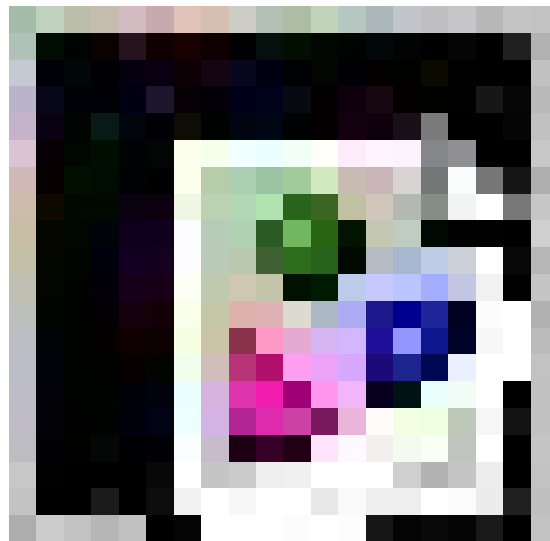
Harvard School of Public Health Growth Study Records



- Founded by Harold Coe Stuart (center), with members of the HSPH Department of Maternal and Child Health.
- Multiple Studies:
 - Original (c. 1930-1957)
 - 30-year follow-up (c. 1960-1969)
 - 40-year follow-up (c. 1970-1979)
 - 50-year follow-up (c. 1970-1979)
- ~200 cubic feet of research data, administrative records, and publications
- Raw data (measurements, surveys, medical test results, physical examination records, interviews)
- Summarized data
- Assessment data (subject rankings and scores based on interpretation of raw data)
- Coded data
- Analyzed data (charts, graphs, calculations)
- Imaging records (photographs, negatives, x-rays)
- Regulatory records (protocols, methodologies, codebooks)
- Subject recruitment records
- Grant funding records
- Reports

Anticipated Metadata Workflows

- Anticipating multidisciplinary use
- Research Data Lifecycle
- Mapping existing archives and records management descriptive standards and metadata schemas to Dataverse
- Metadata gap analysis
- HMS Data Management Working Group



(UK Data Service's Data Lifecycle Model)

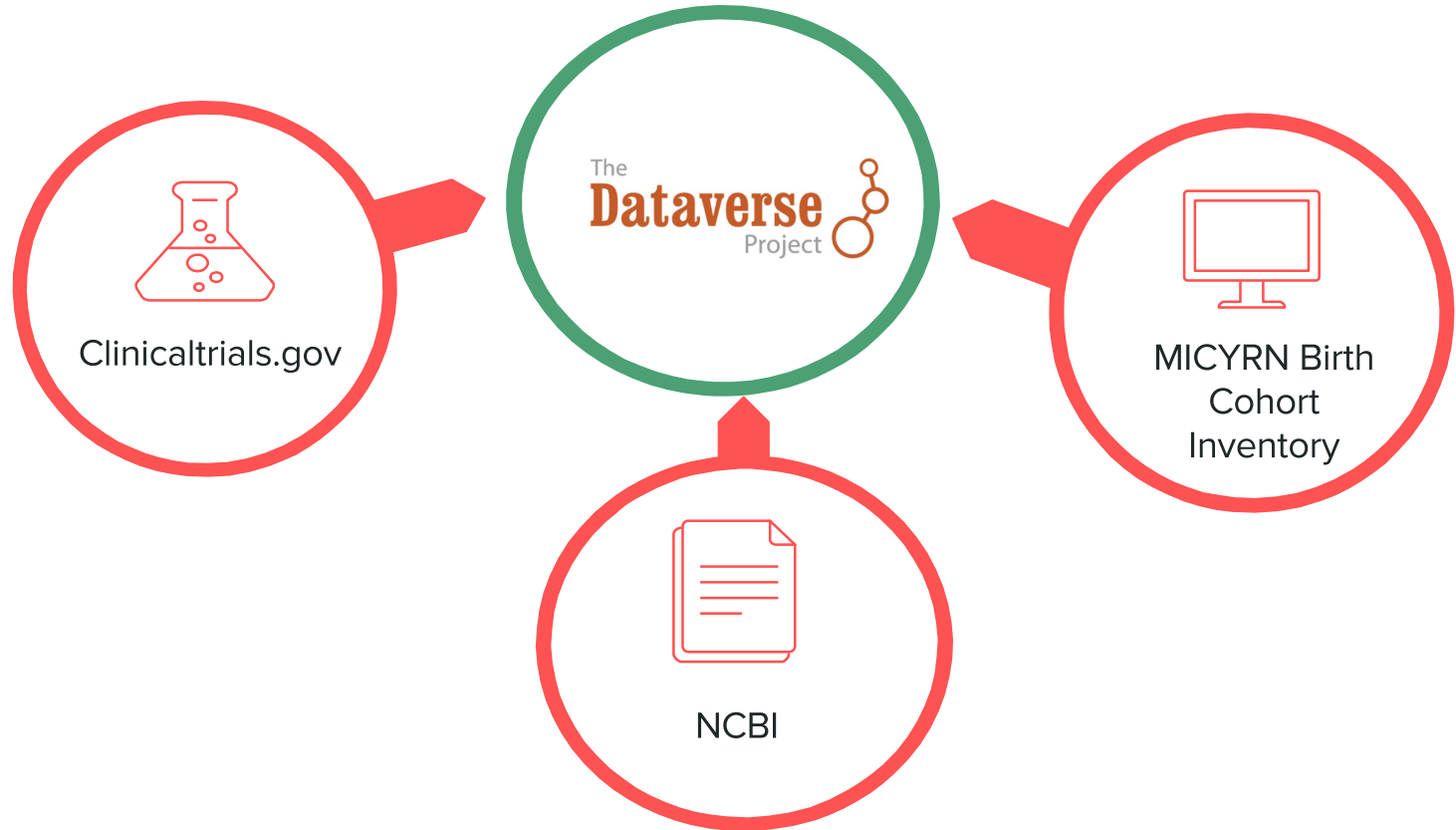
<https://www.ukdataservice.ac.uk/manage-data/lifecycle>

Contemporary Research Data Description

Created REDCap Project

Record ID	Richer_NCT01596166
Study Type	
Randomised Controlled Trial	
Design types that are based on the overall experimental design.	
Study Status	
Completed	
Official Title	
* must provide value	
Efficacy of Combination Therapy with Intravenous Ketorolac and Metoclopramide for Pediatric Migraine Therapy in the Emergency Department	
Title will be in the data citation.	
Subtitle	
Alternative or Abbreviated Title	
Intravenous Ketorolac and Metoclopramide for Pediatric Migraine in the Emergency Department	

Populated Dataverse REDCap Form



Contacted Researchers



No Response or Declines

Basic study record in REDCap

Notify researcher via email, offer contacts if they want to follow up



Documentation

Use documents to complete record metadata in REDCap

Follow up on missing information

Rich study record with research documents in Dataverse, if approved



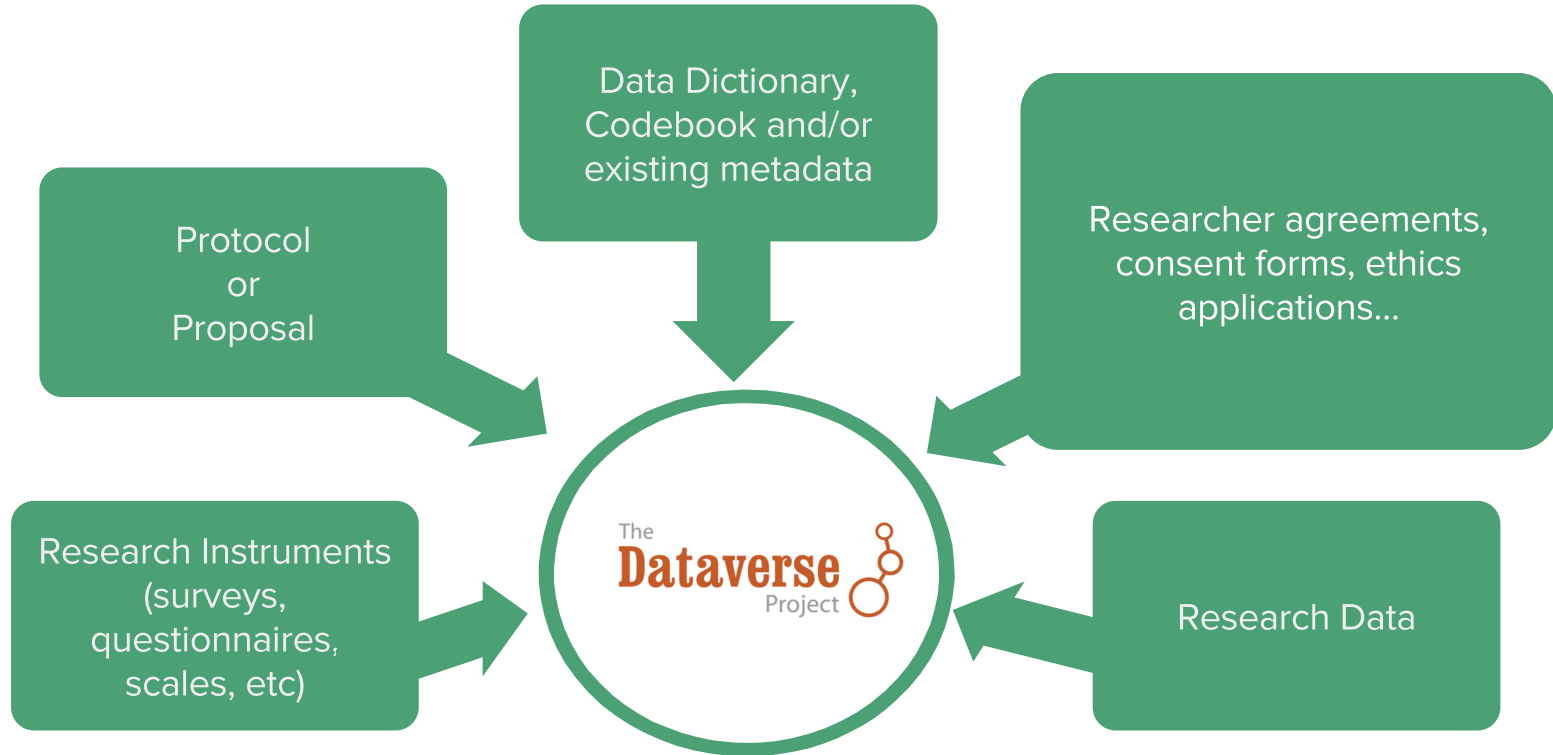
Meeting

Arrange meeting, go through form, update study record in REDCap

Discuss metadata
Follow up on missing information

Rich study record with research documents in Dataverse, if approved

Researcher Documents



Researcher Meetings

- Validate and add to the study record
- Researcher feedback on metadata
 - What do they need and want?
 - What information would help them find or understand data?
 - When they need data where do they go? where would they look?
 - Are they using any standards already?
 - Will Dataverse work for these studies?
 - What's missing? What's irrelevant?

Next Steps

- Enhance DDI-based metadata
- Analyse and incorporate feedback
- Schema gap analysis
- Best practices



Photo by Darylgio Agoncillo
https://unsplash.com/photos/PQvRco_Snpl

Any Questions?

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Photo by Evan Dennis
<https://unsplash.com/photos/i--IN3cvEjg>