Bridging the Research Data Divide:

Rethinking long-term value and access for maternal, infant and child research

Project Team

University of Alberta Libraries

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Community Advisory Committee

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- *Anne Junker*, Scientific Director, MICYRN; Assoc. Professor & Assoc. Head of Faculty Development, University of British Columbia
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- *Christine Wagoner*, Health Information Privacy Advisor, Faculty of Medicine & Dentistry, University of Alberta
- *Rick Watts*, Critical Research Informatics Core (CRIC) Team Lead, Women & Children's Health Research Institute (WCHRI), Faculty of Medicine, University of Alberta

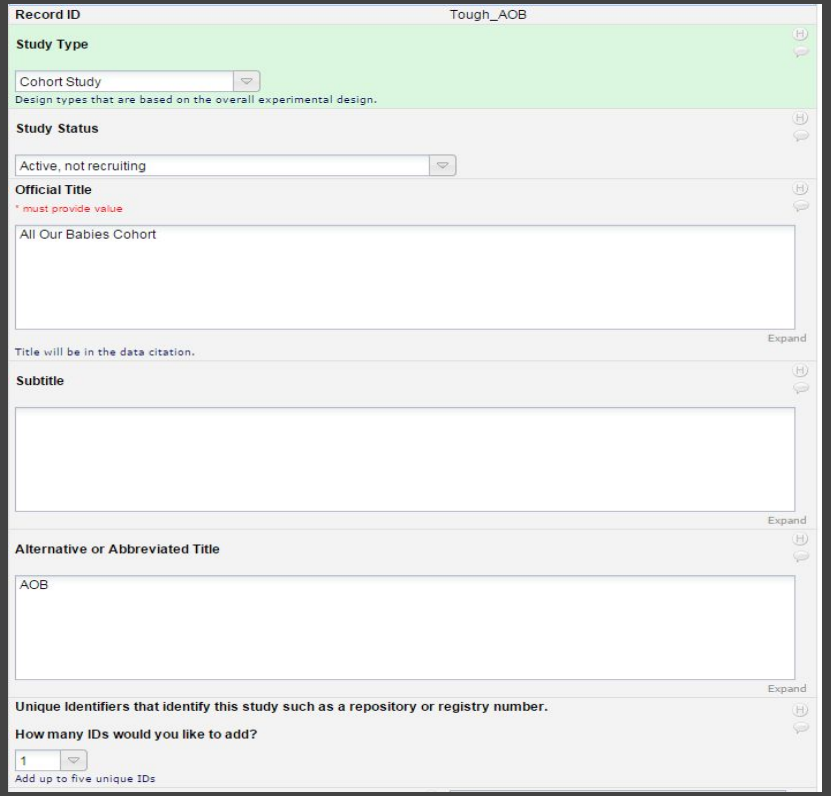
WCHRI Study Catalog Workflow

- Identified studies for inclusion in pilot
- Developed local metadata schema/profile
- Mapped schema to portals/community standards
- Pre-populated metadata schema
- Contacted researchers

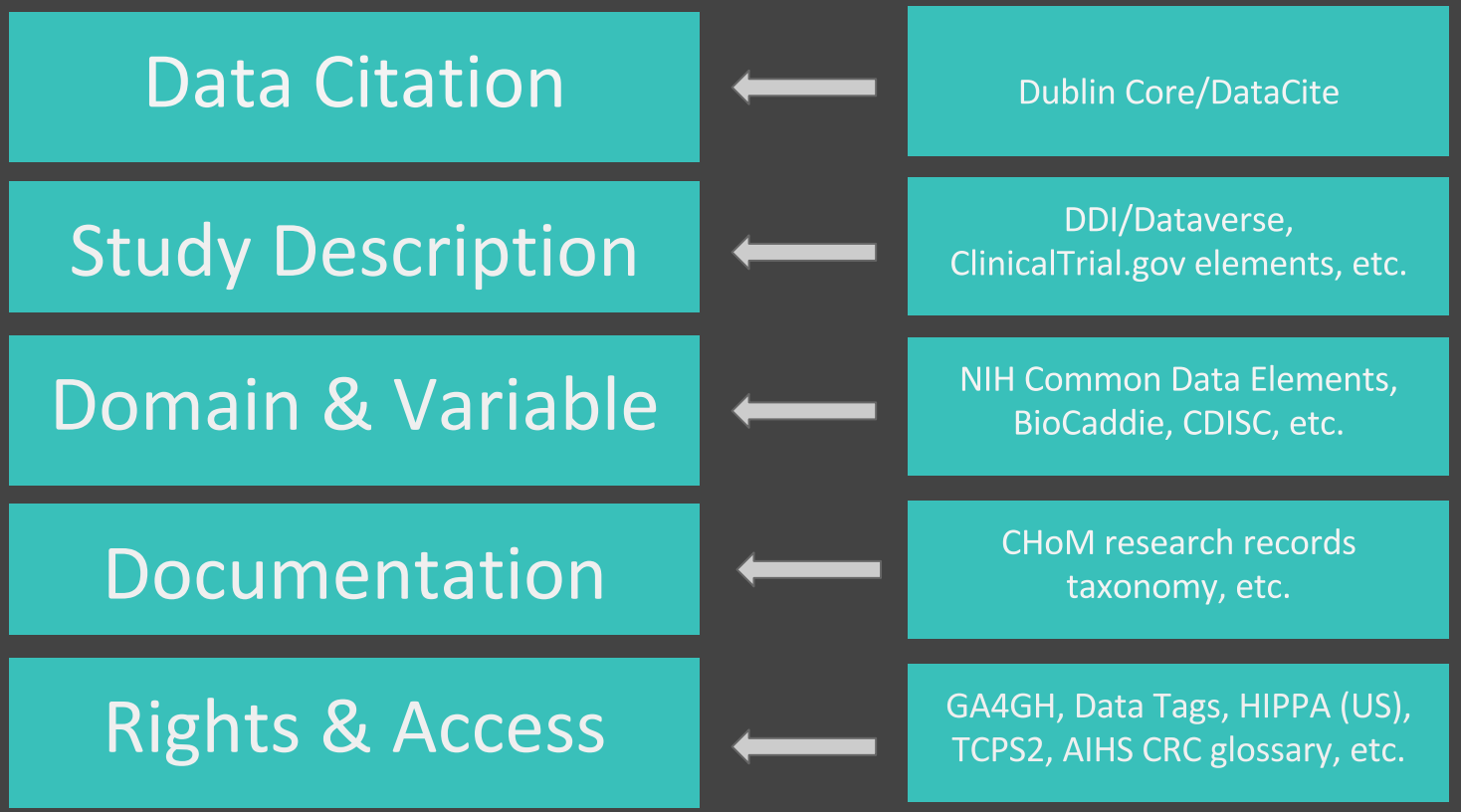
Identified studies for inclusion in pilot

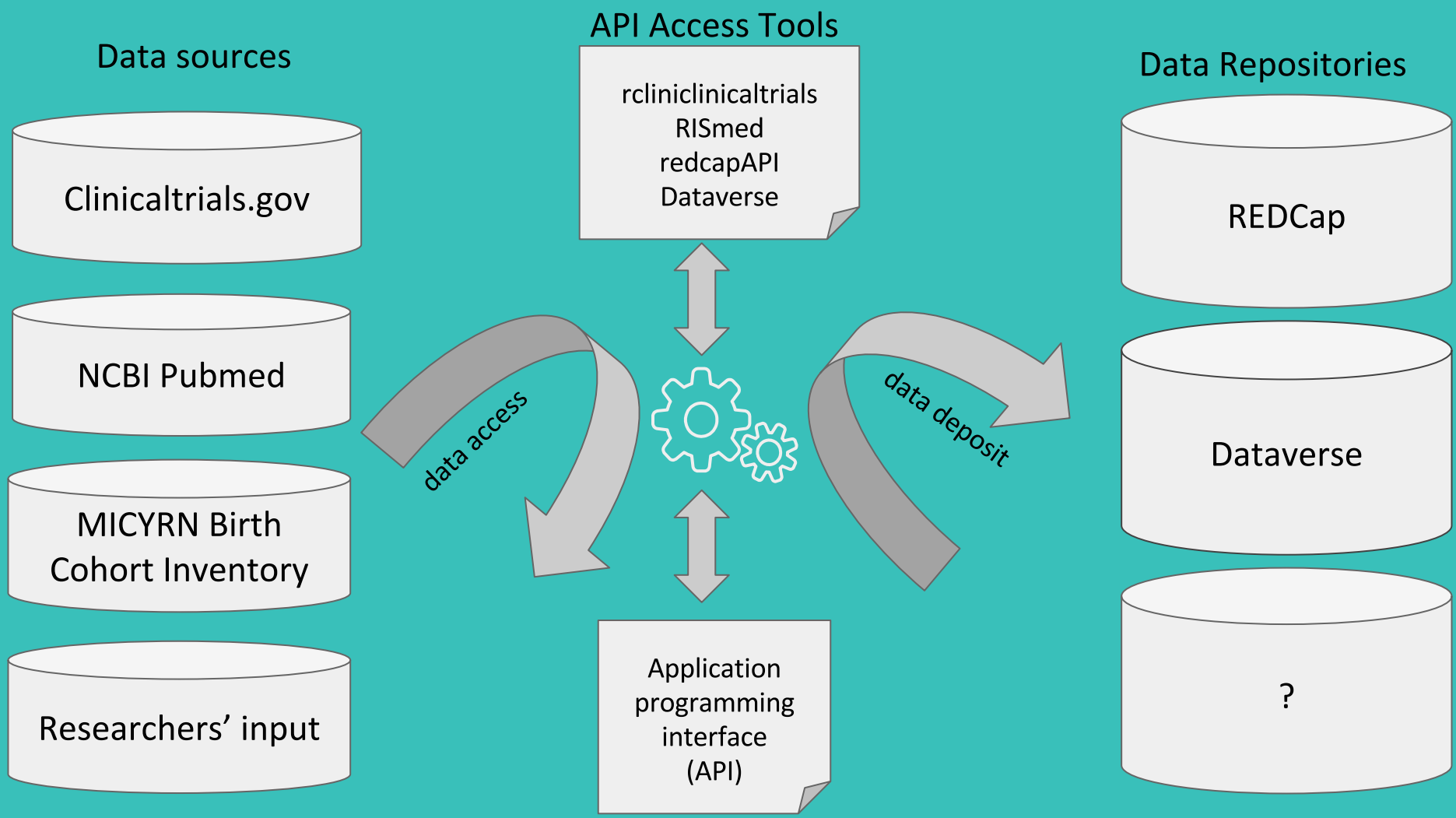
- sent out an opt out survey/promoted in WCHRI newsletter
- selected 33 studies to be included in the pilot
  - 28 clinical trials, 2 cohort studies, 3 others
  - variety of studies:
    - some complete, ongoing, terminated, withdrawn trials.
    - some with multiple sites, PIs from different universities, etc.

Metadata schema/collection form

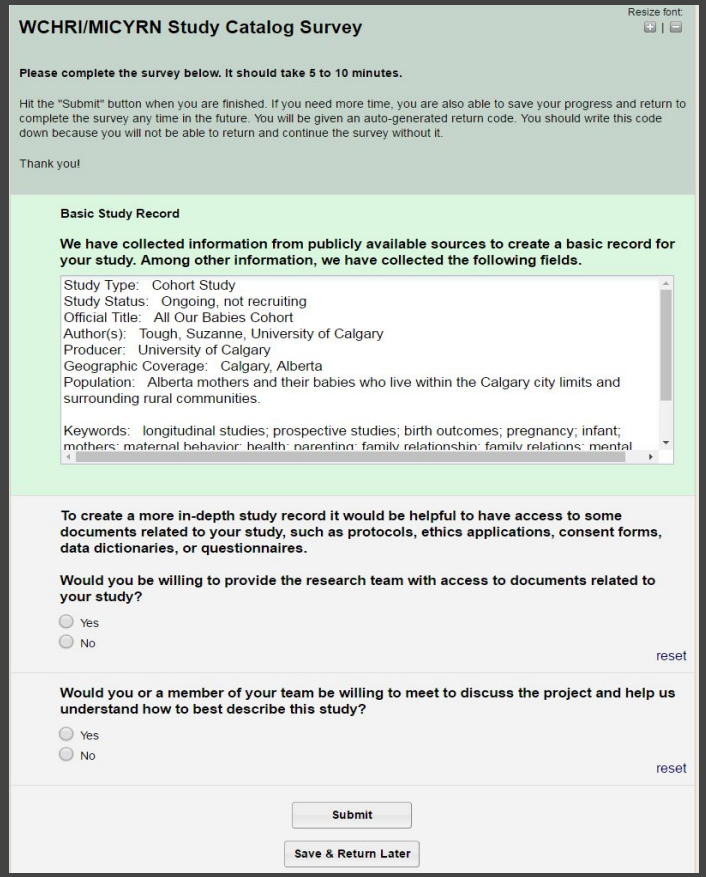


Dataverse/DDI-based metadata schema




Data sources
Clinicaltrials.gov
NCBI Pubmed
MICYRN Birth Cohort Inventory
Researchers' input
API Access Tools
rcliniclinicaltrials
RISmed
redcapAPI
Dataverse
data access
data deposit
Application programming interface (API)
Data Repositories
REDCap
Dataverse
?

Contacted researchers



Resize font:

WCHRI/MICYRN Study Catalog Survey

Please complete the survey below. It should take 5 to 10 minutes.

Hit the "Submit" button when you are finished. If you need more time, you are also able to save your progress and return to complete the survey any time in the future. You will be given an auto-generated return code. You should write this code down because you will not be able to return and continue the survey without it.

Thank you!

Basic Study Record

We have collected information from publicly available sources to create a basic record for your study. Among other information, we have collected the following fields.

Study Type: Cohort Study
Study Status: Ongoing, not recruiting
Official Title: All Our Babies Cohort
Author(s): Tough, Suzanne, University of Calgary
Producer: University of Calgary
Geographic Coverage: Calgary, Alberta
Population: Alberta mothers and their babies who live within the Calgary city limits and surrounding rural communities.

Keywords: longitudinal studies; prospective studies; birth outcomes; pregnancy; infant; mothers; maternal behavior; health; parenting; family relationship; family relations; mental

To create a more in-depth study record it would be helpful to have access to some documents related to your study, such as protocols, ethics applications, consent forms, data dictionaries, or questionnaires.

Would you be willing to provide the research team with access to documents related to your study?

- Yes
- No

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Would you or a member of your team be willing to meet to discuss the project and help us understand how to best describe this study?

- Yes
- No

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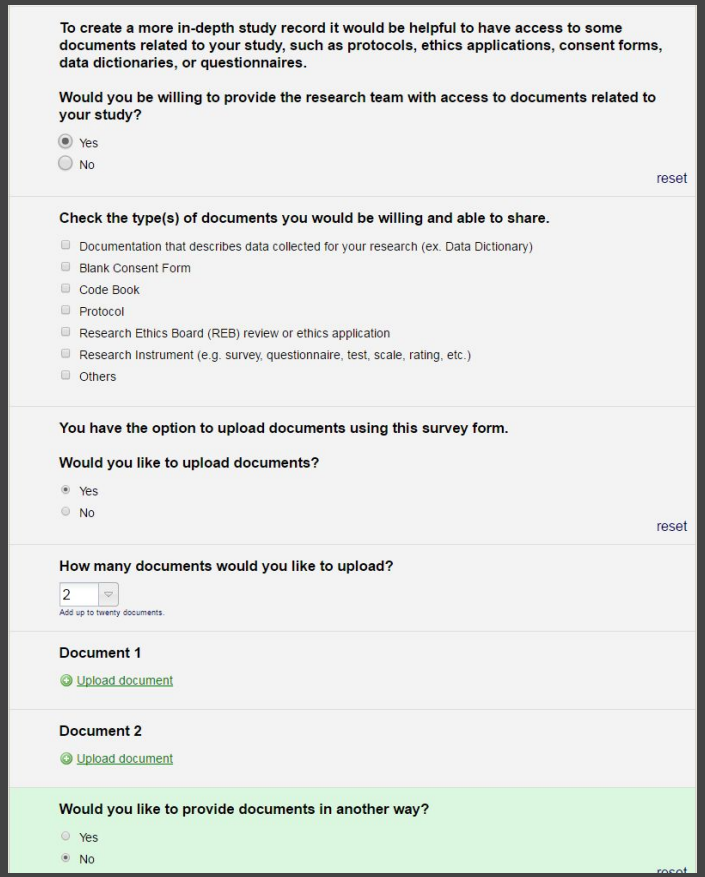
Submit

Save & Return Later



To create a more in-depth study record it would be helpful to have access to some documents related to your study, such as protocols, ethics applications, consent forms, data dictionaries, or questionnaires.

Would you be willing to provide the research team with access to documents related to your study?

- Yes
- No

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Check the type(s) of documents you would be willing and able to share.

- Documentation that describes data collected for your research (ex. Data Dictionary)
- Blank Consent Form
- Code Book
- Protocol
- Research Ethics Board (REB) review or ethics application
- Research Instrument (e.g. survey, questionnaire, test, scale, rating, etc.)
- Others

You have the option to upload documents using this survey form.

Would you like to upload documents?

- Yes
- No

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How many documents would you like to upload?

2

Add up to twenty documents.

Document 1

Upload document

Document 2

Upload document

Would you like to provide documents in another way?

- Yes
- No

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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

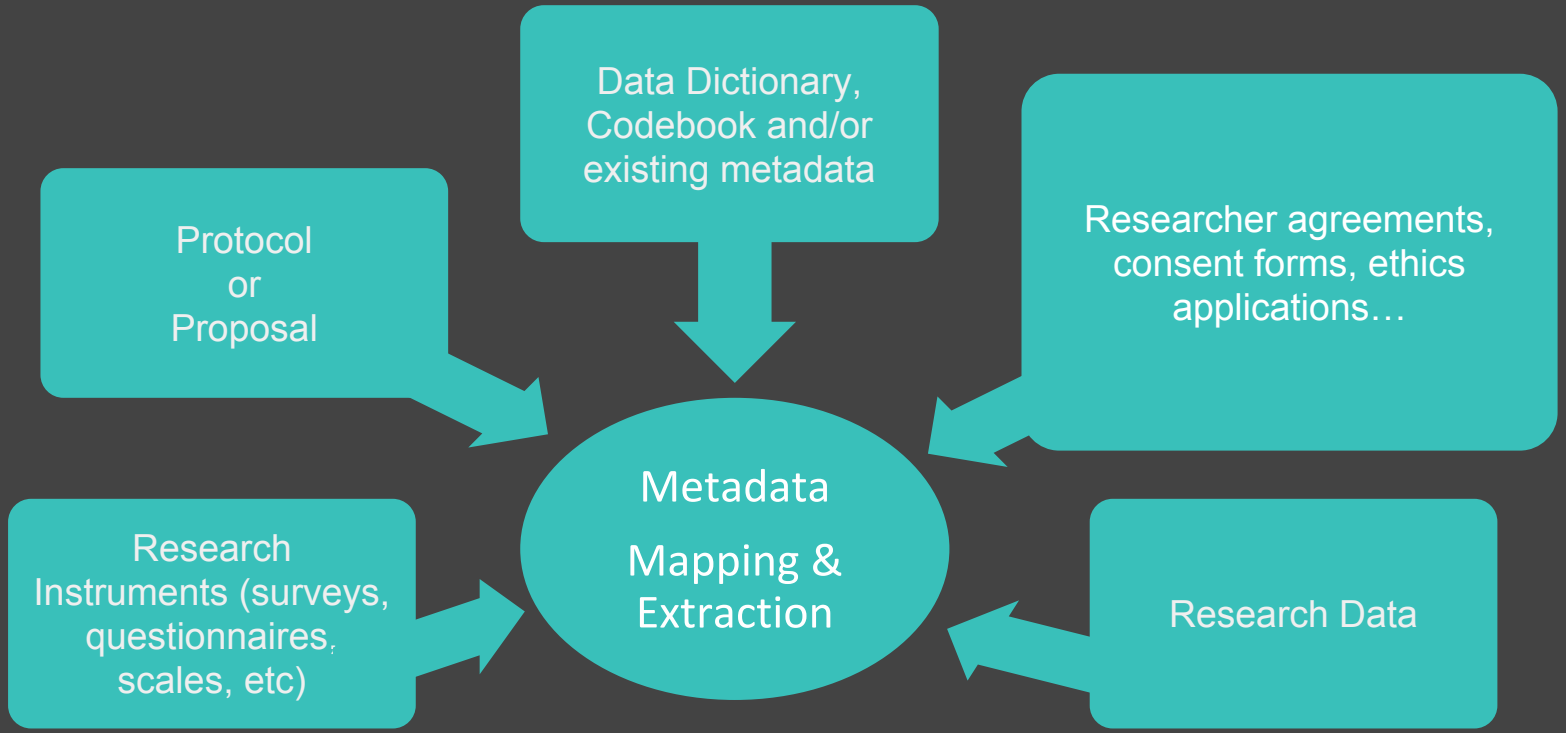
Arrange meeting, go through form, update study record in REDCap

Discuss metadata

Follow up on missing information

Rich study record with research documents in Dataverse, if approved

Research Documents



Meeting with researchers

- Validate/add to the study record
- See whether they are willing or able to share research data (terms of use, restrictions, access, etc).
- Gain the researcher's perspective on the metadata elements we've chosen
  - what information would help you find or understand data?
  - where would you look?

Next steps

- analyse feedback about metadata, finalize local metadata schema to reflect feedback (while maintaining standards)
- explore other platforms (DataCite, CDCA, Maelstrom, Labkey, disciplinary repositories,???)
- document workflow and best practices learned from pilot