Achieving Good Ethics and Equity in the Development and Application of Novel Technologies

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Technology Should Be Accessible and Understandable to All Stakeholders

How A Field Built on Data Sharing Became A Tower of Babel

dbGAP
"I personally do not download dbGaP data, I just go straight to the researchers and ask if they want to collaborate," **……..."Even logging into dbGaP can be a pain. It's just not researcher-friendly,"**

> —Ruth Loos, Genetic Epidemiologist, Icahn School of Medicine at Mount Sinai

TOPMed
A precision-medicine program run by the NIH's National Heart, Lung, and Blood Institute. Consists of more than 155,000 research participants across more than 80 studies and shares its data in several repositories, including dbGaP and some university-based portals.

"It's a remarkable resource," says Mathias. But **it's cumbersome for an outsider to find all the pieces of available data and request access**, she says. They **must often provide detailed proposals and letters of support**. **"It's unnecessarily difficult."**

> —Rasika Mathias, Genetic Epidemiologist, Johns Hopkins University
> Powell, K. Nature. 590,198 – 201 (2021)

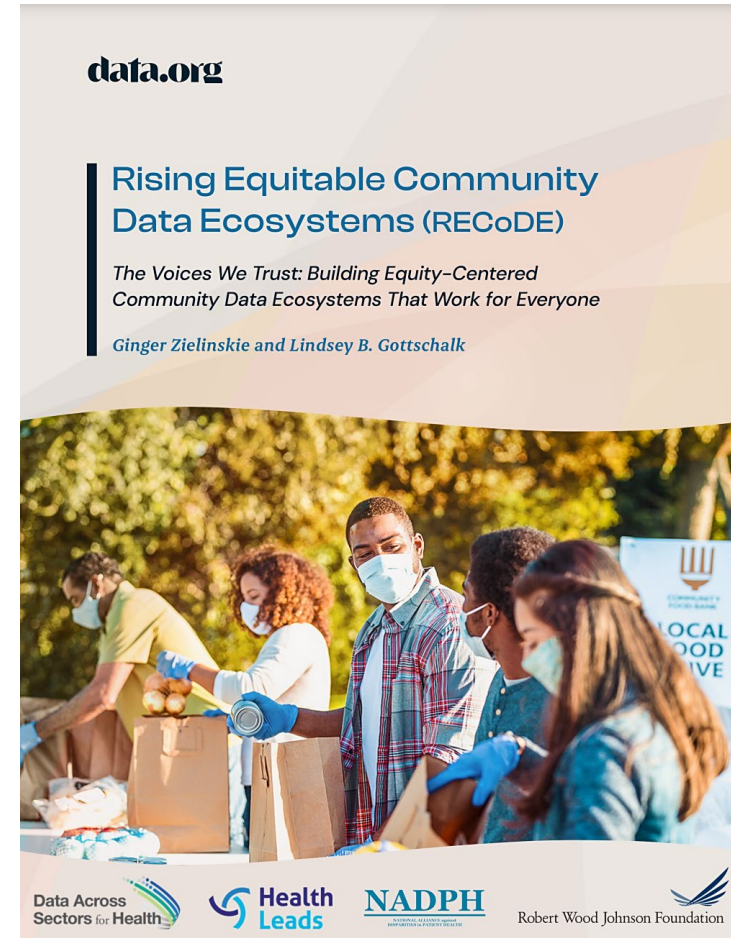**Addressing Challenges in Converting Grant-Funded Infrastructures to Broadly Used Research Resources**
"designing a functional, usable, and accessible resource to serve the future needs of a dynamic, diverse scientific community requires careful consideration of the potential topics and scope of future studies. This design process benefits from the engagement of scientists outside the original team"

…. *Experts in the field of human-centered design can build user-friendly interfaces and tools designed to make exploring and accessing resources less burdensome*. We suggest that domain scientists and **funders identify and support experts who can facilitate the creation of useful and usable research resources."**

> —Roland, B. and Geiger, A. M. Cancer Epidemiol Biomarkers Prev. 28, 1559–62 (2019)

Deep Engagement and Qualitive Assessment Are Necessary to Understand Impact of Technology on Communities

- RECoDE report published March 2022 : https://data.org/wp-content/uploads/2022/02/ReCode-Report.pdf

- RECoDE recommendations have been codified/embedded into AIM-AHEAD Ethics and Equity Principles

- "More work is needed on regulation, especially with an increased interest in social determinants of health data and an explosion of new tools to collect, analyze, and profit from non-healthcare data. Procurement policies could be a powerful lever for setting guidance on how to ethically work with social determinants of health and other community-level data..."

data.org

Rising Equitable Community Data Ecosystems (RECoDE)

The Voices We Trust: Building Equity–Centered Community Data Ecosystems That Work for Everyone

Ginger Zielinskie and Lindsey B. Gottschalk

Data Across Sectors for Health · Health Leads · NADPH · Robert Wood Johnson Foundation

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Models for Developing Ethical NAMs Need to Be Engineered

Approach to Ensure Best Practices and Policies for NAMs Developent and Application

Apply best practices for engagement, human-centered design approaches and overall qualitative research methodology.

Develop workgroups to embed discussions and thought leadership around ethical, legal, and social implications (ELSI) for proposed NAMs.

Look to achieve synergies and economy of scale by consolidating efforts from various groups and initiatives.

Develop a set of ethics and equity principles, and a framework to guide NAMs constituents and collaborators now and into the future.

The charge is to *Ensure ethics and fairness are at the front and center of NAMs applications to build equity in biomedical research and healthcare practices.*

Engage Community Throughout Entire Development Lifecycle of NAMs

Comprehensive Workflow AI/ML Analysis

We want to be able to access data and analyze in an environment suitable to our needs.

Source Data Access	Data Processing	Data Exploration	Modeling	Deployment	Monitoring	Experiments, Exploratory Analysis, Reporting

Data Collection   Data Selection

Clean Data

Data Visualization

Models

Production Components

Monitoring Performance

Rapid Prototyping   Reports
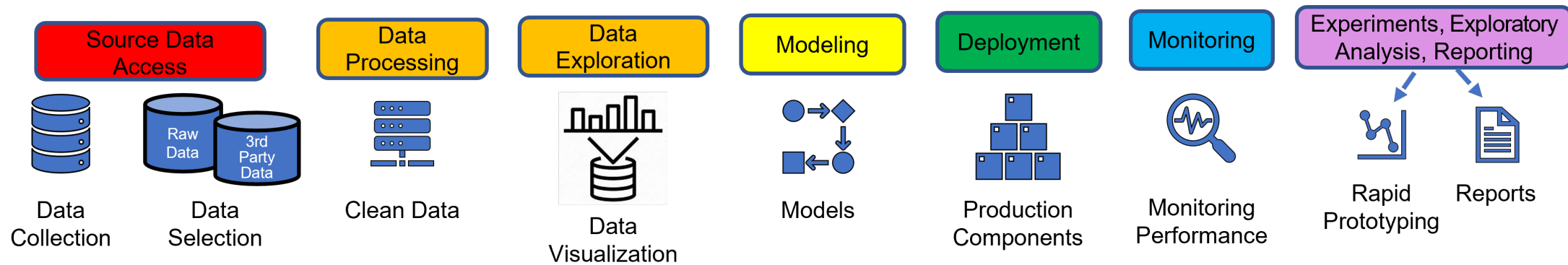
PwLE approach to Providing Infrastructure to Support AIM-AHEAD

- Engage PwLE (AIM-AHEAD Survey & Self-Assessment)
  - Gather critical input requirements
  - Co-design/Co-Create Technology

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No Group Is Monolithic - Expect Heterogeneity in Populations

Artificial Intelligence (AI) & Machine Learning (ML) Self-Assessment Tool

This assessment will enable NADPH to gauge your organization's current comfort & maturity with respect to AI/ML technology by answering questions spanning eight sections.

Start press Enter ↵

🕐 Takes 2 minutes

Institutional Capability Matrix:
A self-assessment tool for stakeholders to assess their organizational capabilities.

* Self-Assessment tool to support scalable program (automation qualitative assessment)

5 Levels
- Nascent
- Emerging
- Tool Developer
- Institutionalized
- Optimized

"Capacity Bingo"

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