

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

Alex J. Carlisle, Ph.D.

Chairman & CEO, National Alliance against Disparities in Patient Health (NADPH)  
Lead MPI, NIH Artificial Intelligence/Machine Learning Consortium to Advance Health  
Equity and Researcher Diversity (AIM-AHEAD)

# 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

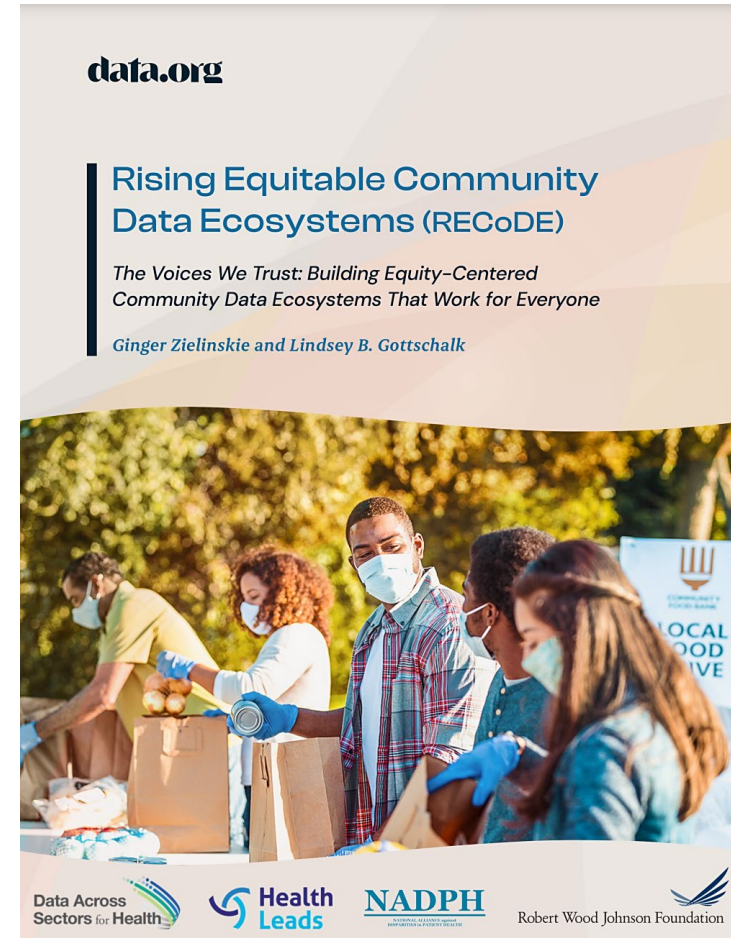
“designing a functional, usable, and accessible resource to serve the future needs of a dynamic, diverse scientific community requires careful consideration of the potential topics and scope of future studies. This design process benefits from the engagement of scientists outside the original team”

.... **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 Qualitative 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...”



# Models for Developing Ethical NAMs Need to Be Engineered

## Approach to Ensure Best Practices and Policies for NAMs Development 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.*



### Overview

Friends of NIMHD w ambitious research e only to the physical,

## Using Automated Research Workflow Environments to Engage a Diverse Researcher Community

Dr. Watson, Dr. Kitani Lemieux, and Jaelyn Stepter at Xavier University of Louisiana.

Jaelyn was the first place winner of this year's Minority Student Research Symposium.



How *All of Us* Engages with Diverse Researcher Communities:

- Creating a pipeline for students: The *All of Us* Minority Student Research Symposium (MSRS)
- Partnerships with HBCUs through



## AIM-AHEAD Ethics & Equity WG Chart

Workgroup Members (51)	Ritu Agarwal	Shilo Anders	Paul Avillach	Warner Barringer	Betina Beech (Chair)	LaTanya Brown-Robertson	Tianxi Cai
David Chapman	You Chen	Elen Clayton	Joseph Coco	Nicole Cook	Priyam Das	Carolyn Diehl	Michelle Dugas
Anne Gagloli	Joyce Harris	Elizabeth Heitman	Rachele Hendricks-Sturup (Chair)	Lethia Jackson	Karuna Joshi	Ioannis Kakadiaris	Junwei Lu
Jessica Lyons	Chris Mader	Simran Makwana	Brad Malin (Chair)	Phuong Nguyen	Laurie Novak	Deepthi Puram	Dan Rubin
Upasna Sagar	Teresa Schmidt	Azizi Seixas	Anil Shanker	Nawar Shara	Melaka Simmons	Rajbir Singh	Casey Overby Taylor
Qingqiao Wang	Gloria Washington	Talitha Washington	Griffin Weber	Weiyl Xia	Chao Yan	Yaacov Yesha	Rui Yin
Zhijun Yin	Azene Zenebe	Huaqing Zhao	Zhigen Zhao				

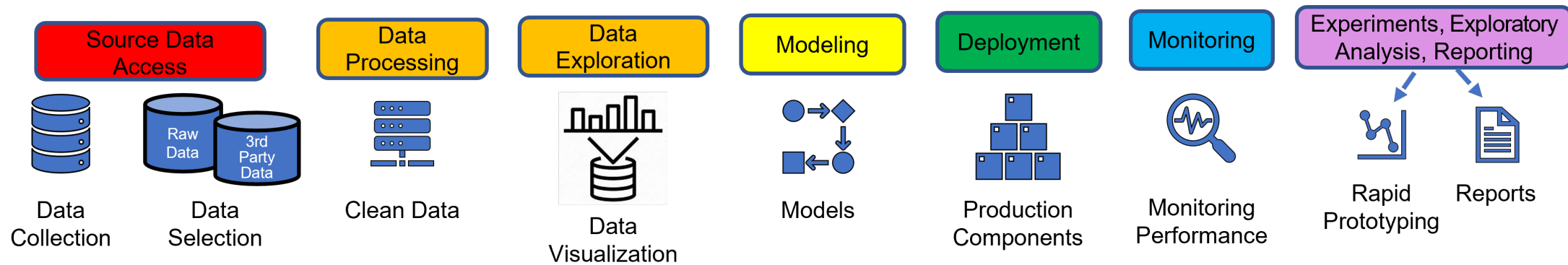


# Engage Community Throughout Entire Development Lifecycle of NAMs

## Comprehensive Workflow AI/ML Analysis



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



## PwLE approach to Providing Infrastructure to Support AIM-AHEAD

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

# 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

AI/ML Capability Maturity Model						
Domain	Subdomain	Level 1: Nascent	Level 2: Emerging	Level 3: Tool Developer	Level 4: Institutionalized	Level 5: Optimized
Focus	NA	Nascent	Tool User	Tool Developer	Integrator	Evolving
	Organizational Commitment	Interested	Invested	Committed	Embedded	Embedded
Environment	Requirements	Might Have knowledge of the current capabilities of AI/ML in their industry. Won't Have in-depth experience using AI/ML products. Must Have some exposure to AI/ML products.	Won't Have expertise and resources to build and maintain general tools, such as Python devs. Must Have a repertoire of tools which they use for their AI/ML projects.	Might Have library, such as general APIs, which can be used more generally across products. Won't Have support with regard to the wider community. Must Have expertise and tools which are supported for the developer.	Might Have tools and libraries which are supported for the wider AI/ML community for general projects, but restricted to a particular platform. Must provide services such as support which are accessible to the wider AI/ML community.	Must Have tools which are not only used by your contemporaries, but more generally across the AI/ML community. Must provide services such as support which are accessible to the wider AI/ML community.
	Workforce	Human Capital	Single (solo) person or support found ad hoc	Multiple people support multiple teams	Distinct teams support the project	Distinct teams support the program
Human-Centered Design	Research	Infrequent - Unstructured qualitative	Ad-hoc - Structured qualitative, findings sometimes influence product decisions	Milestone driven, structured qualitative and quantitative, findings influence product decisions	Integrated into workflow, structured qualitative and quantitative, findings influence enterprise business decisions	Integrated into workflow, structured qualitative and quantitative, findings influence enterprise business decisions
	Design	Unstructured - No documented repeatable process	Self-design style - May have design team follow documented standards, guidelines, patterns.	Genius design style - May have product team follow documented standards, guidelines, patterns.	Activity focused design style - The program follows documented standard guidelines, patterns.	Customer focused design style - The enterprise follows documented standard guidelines, patterns.
ELSI	Measurement	Unaware of importance end-user needs	Aware but not implementing	Implementing but not optimizing	Part of workflow, Optimizing but not sharing	Sharing and seeking greater user experience
	Regulatory	Unaware of legal issues	Has access to IRB and legal counsel	General understanding of legal issues	Incorporates governance processes to identify and monitor ethical concerns	Full compliance with regulatory issues
	Ethical	Minimal understanding of disparities	?	Understanding of factors that contribute to inequity, including social determinants	Incorporates governance processes to identify and monitor ethical concerns	Ability to identify and address many factors that contribute to inequity

“Capacity Bingo”

NADPH

