

Tech Talk

Data Modernization and Equity: Integrated Solutions to Enhance the Research Data Lifecycle

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Today's Learning Objectives

- the importance and challenges surrounding data modernization and data equity in the research lifecycle;
- new trends and solutions in data modernization and equity that can help you improve the movement and use of data throughout the data lifecycle, while promoting DEI in your work;
- how to develop strategies and solutions that can help you achieve your research goals.



Data Modernization and Equity



- Data Modernization is improving the **movement and use of data, enabled by technology, to support decision making** or effective mission implementation throughout the data lifecycle.
- "Equity exists when **intersections of social identities, residence in marginalized communities, and/or experience with oppressive systems do not determine opportunities, access to resources, and outcomes in life**. Achieving equity requires acknowledging, addressing, and dismantling systemic biases in mindsets, practices, and policies" (Venkateswaran et al., 2023).



Moderators



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Framework for Equity-Centered Transformative Research

Holistic framework that supports development of equity-centered practice

Links organizational commitments to DEI to research practice

Integrates multiple approaches and methodologies

Applies to both research and evaluation



Focus on the 3Rs: Researcher, Research, and Researching





Diversity, Inclusion, Equity

Diversity

- *Acknowledging psychological, physical, and social differences as well as differences as a result of systemic cumulative advantages or systemic cumulative barriers to opportunities.*

Inclusion

- *Centering, valuing, and amplifying voices, perspectives, and cultures of those most excluded from power and influence.*

Equity

- *Equity exists when intersections of social identities, residence in marginalized communities, and/or experience with oppressive systems do not determine opportunities, access to resources, and outcomes in life. Achieving equity requires acknowledging, addressing, and dismantling systemic biases in mindsets, practices, and policies.*



Belonging, Transformation and Liberation

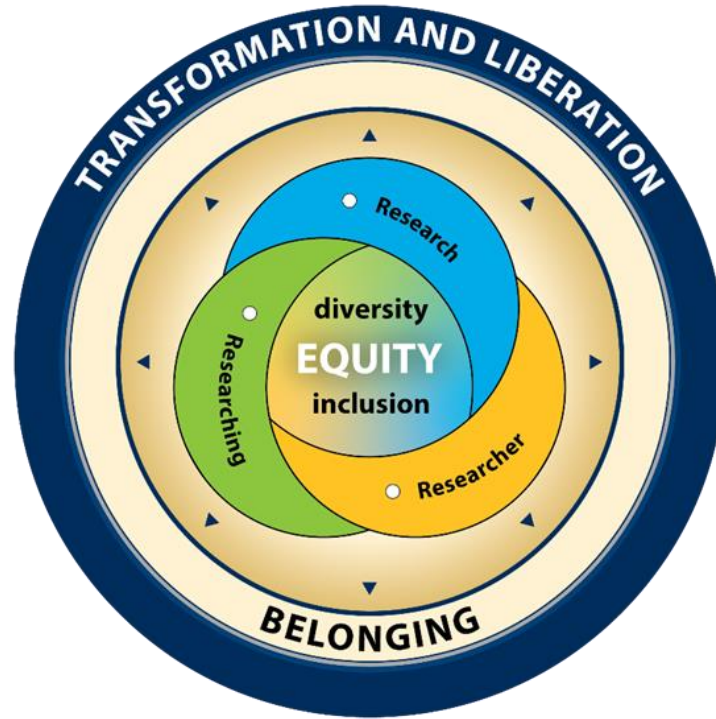
Belonging

- *Belonging is the outcome of using principles of diversity, inclusion, and equity. Belonging is achieved when the research serves those affected by it and the process allows room for multiple modes of knowledge and participation*

Transformation and Liberation

- *Transformation and liberation are the outcome of incorporating principles of diversity, inclusion, and equity in the research. Research should support the creation of systems that transform how the world is envisioned, where all people are free from systems of colonialism and white supremacy, and the voices, perspectives, and experiences of the most marginalized drive the creation of new systems to ensure their well-being.*

Research in Service of Transformation and Liberation



Communities and individuals most affected by the research have ownership of the research process so that they are leading the process towards their liberation

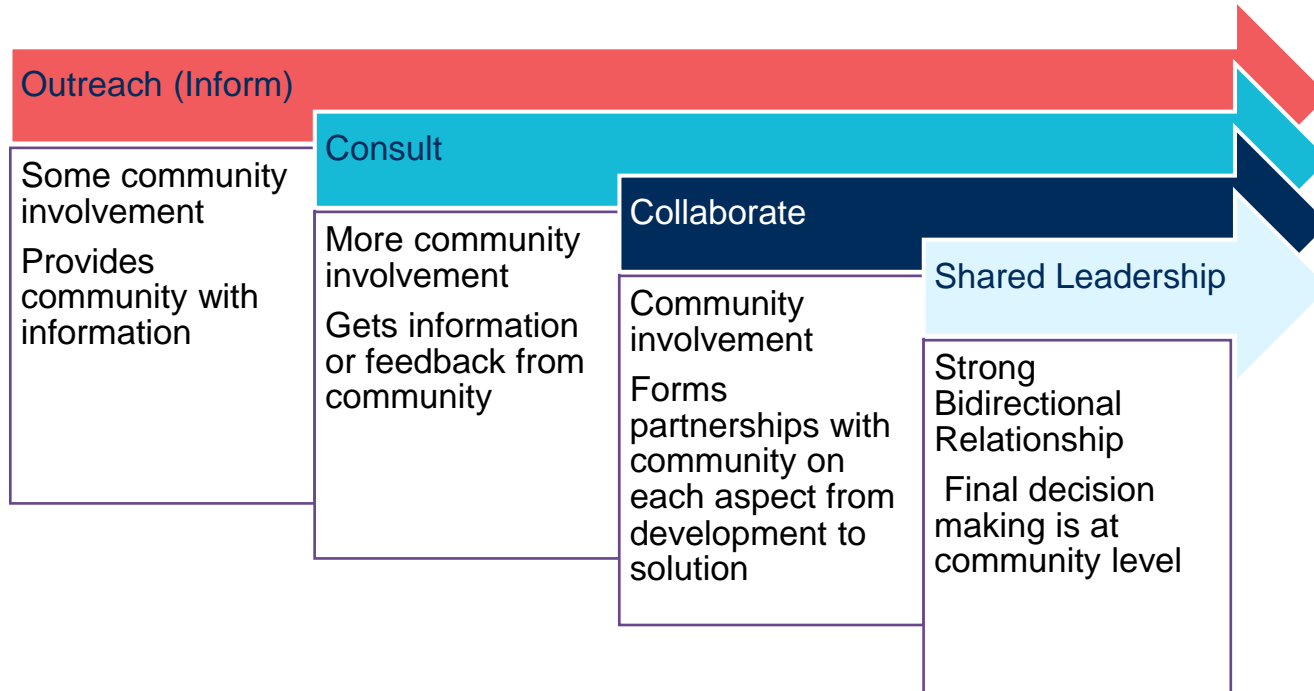
	Diversity	Inclusion	Equity	Belonging	Transformation and Liberation
Researcher	Researcher understands the importance of acknowledging and reflecting on their own biases and assumptions that influence research	Researcher values authentic partnerships with communities most affected by research, understands the power dynamics inherent in the researcher-participant relationship and possesses knowledge of how to create an inclusive collaborative environment when engaging in partnerships.	Researcher possesses values and beliefs oriented towards anti-racism and anti-oppression and understands how research can be used both as a tool for oppression and social justice	Researcher's sense of self expands to include values and beliefs of communities who serve as authentic partners in the research	Researcher undergoes their own individual transformation to support the transformation and liberation of others
Research	Research acknowledges how social and political factors shape experiences of individuals who do not reflect the dominant culture or norm	Research acknowledges the social and political context and culture of communities where the research is conducted	Research aims to dismantle the root causes of systemic inequities	Research findings provide value to those most affected by the conditions being researched.	Research is in service of the creation of new systems that dismantle oppressive, white supremacist and colonial systems.
Researching	Research approach privileges theories, methodologies, and approaches in the research process that are rooted in groups that have been most marginalized and/or based in the culture of the participants and/or communities in the research	Research process is grounded in intentional and authentic partnership with research participants and communities most affected by the research	Use of anti-racist or anti-oppressive research methods throughout the research process	Research is conducted so that all expressions of knowledge and participation styles are valued throughout the process	Communities and individuals most affected by the research have ownership of the research process so that they are leading the process towards their liberation



Researching

- Research conducted in the traditional paradigm can result in bias, tension with community partners, issues with data quality and validity, and perpetuation and intensification of marginalization
- Community engagement improves cultural validity. Members of the community can identify data patterns, mechanisms that shape these patterns, and potential risks and implications for research findings and resulting policy.
- Other benefits include:
 - Mutual capacity-building
 - Connections made between institutions and communities

Community Engagement Continuum



Adapted from. Citation: Clinical and Translational Science Awards Consortium. "Community engagement key function committee task force on the principles of community engagement." *Principles of community engagement* (2011).

Community Engagement Research

	Outreach (Inform)	Consult	Collaborate (Partnership)	Shared Leadership (Community Ownership)
Research questions	Based on funding priorities and are shared	Community provide input in identifying locally relevant issues	Researchers and Community both identify issues of importance	Full participation of Community in identifying issues of greatest importance.
Research design	Design based entirely on scientific rigor and feasibility without input of the community. Community is informed of the plan.	Researchers share design with Community and ask for feedback.	Researchers work with Community to ensure study design is tailored to context.	Community intimately involved with study design.
Instrument design	Instruments adopted/adapted from other studies or created by researchers. Shared with Community, but not for feedback.	Researchers develop instruments and share with Community for feedback.	Researchers co-develop instruments with Community to ensure alignment with context.	Creation of data collection instruments are led by Community and grounded in cultural context.
Data collection	Conducted by researchers or individuals w/no connection to the Community	Community provide input on aspects data collection, but not involved with data collection.	Community involved in some aspects of data collection.	Conducted by members of the community, to the extent possible based on available skill sets. Focus on capacity building.
Analysis & Interpretation	Researchers own the data, conduct analysis, interpret the findings and develop recommendations.	Researchers share results of analysis with community members for comments.	Data is shared; Community & researchers work together to interpret results and develop recommendations.	Community leads analysis, interpretation of results and development of recommendations, with researcher support.
Dissemination	Results given and directed towards main client.	Results disseminated to the Community.	Community assist researchers to identify appropriate venues to disseminate results and appropriate formats.	Community leads in the creation of deliverables and dissemination venues.



Consult

	Consult
Research questions	Community provide input in identifying locally relevant issues
Research design	Researchers share design with Community and ask for feedback.
Instrument design	Researchers develop instruments and share with Community for feedback.
Data collection	Community provide input on aspects data collection, but not involved with data collection.
Analysis & Interpretation	Researchers share results of analysis with community members for comments.
Dissemination	Results disseminated to the Community.



Shared Leadership

	Shared Leadership (Community Ownership)
Research questions	Full participation of Community in identifying issues of greatest importance.
Research design	Community intimately involved with study design.
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Sample Community Engagement Strategies by Project Type

Project	Sample Community Engagement strategies
Quantitative	<ul style="list-style-type: none">• Identify community most impacted by surveys• Create advisory board to help inform instrument development• Identify a community champion• Leverage existing networks to support data collection
Qualitative	<ul style="list-style-type: none">• Partner with community-based organization to recruit community members to participate• Train community members to conduct interviews/focus groups• Train community member on qualitative data analysis



Bringing Data Modernization to the Community

- Data is used to drive decisions. Communities are using data and need data to inform decision-making on issues to address equity.
- In the absence of available data, community members build stories based on their experience. The data exists, but it is not available to communities.
- How can communities know that data is available and what type of data is available?
- How can communities more easily access data?



Leading the way to data modernization

Building, scaling and supporting **community-driven data ecosystems**

Transforming data to evidence and practice to policy through **clinical informatics and digital health policy solutions**

Advancing adoption of **data standards**

Solving real-world problems with innovations in **data science**

Our Data Modernization Approach



At its heart, our work is **people-centric**. The technology succeeds when it meets the needs of the community it was built for.

We aim to meet users where they are, understanding that partnership and understanding the user landscape is key.

Successful efforts to bridge data-technology gaps engage local, state, national and international forums, even if that slows down implementation.



Data solutions that move the needle on data modernization aims



Build the Right Foundation

- Expand foundational infrastructure
- Modernize and connect key surveillance systems and sources
- Transform legacy systems, processes, and activities



Accelerate Data into Action

- Increase interoperability through data standards
- Advance forecasting and predicting analytics
- Promote health equity



Support and Extend partnerships

- Ensure partner alignment and collaboration
- Support policies for data exchange



Develop a State-of-the-Art Workforce

- Identify workforce needs
- Increase data science capacity
- Facilitate state, tribal, local and territorial (STLT) data science upskilling



Manage Change and Governance

- Govern policies, planning, and resources
- Manage culture change
- Streamline acquisition processes

We build community capacity to connect to data with fit-for-purpose scalable, extensible, digital data ecosystems using the Data Commons approach.



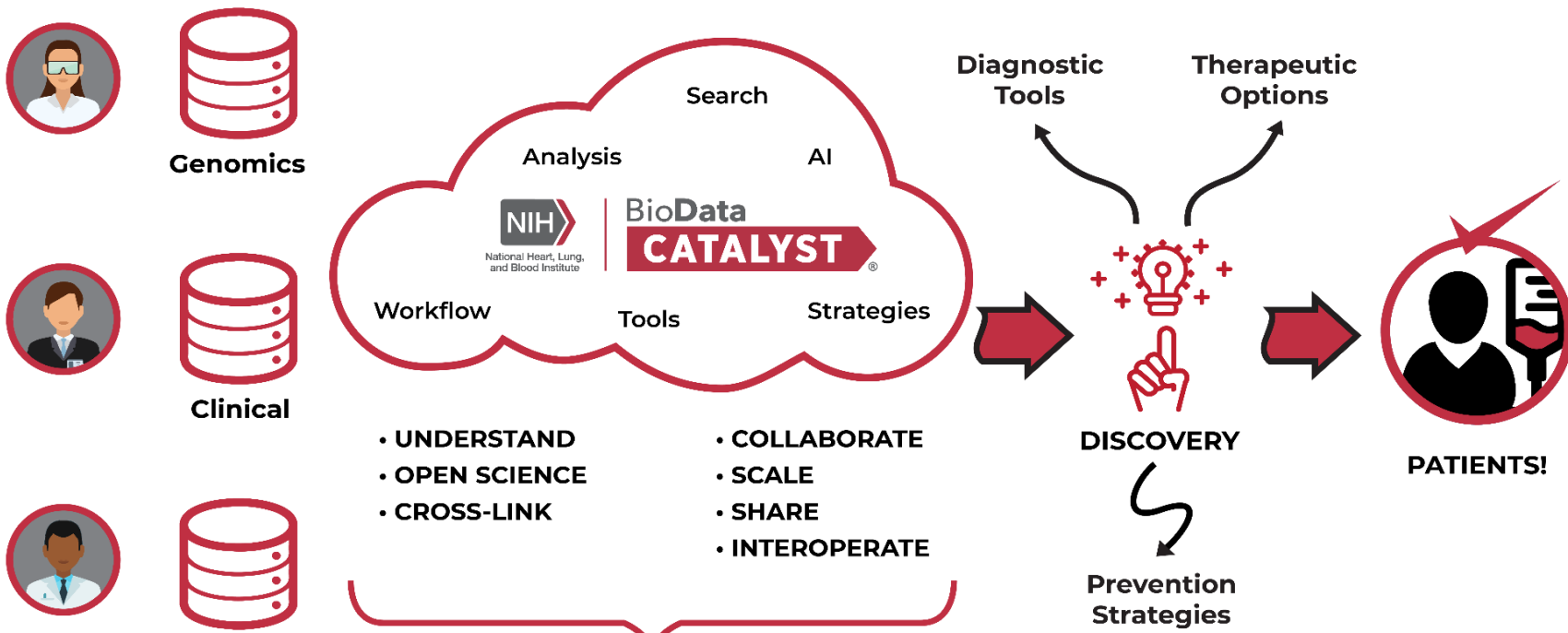


NIH BioData Catalyst

Connecting Researchers to FAIR Data
and Innovative Compute Tooling

Community-Driven Mission

The **mission** of BioData Catalyst is to develop and integrate advanced cyberinfrastructure, leading edge tools, and FAIR data to support the NHLBI research community.





This Approach Adds Extraordinary Value to Data and Brings People Together



- Access to **hundreds of terabytes** of heart, lung, blood, and sleep data (based on data access approvals)
- **Team collaboration** on data
- Users bring data, tools, and workflows **to the data**
- Hundreds of optimized plug-and-play tools, allowing researchers to **focus on science**, not technology
- **Democratizes** access to data and compute resources
- More done in less time: **faster computing** in the cloud
- **Support**, tutorials, and documentation to help users navigate the system
- **Discounted cloud** to new users of the system
- Continues to evolve according to **user community needs!**

Community Engagement

For the Community:

- Offers early-career researchers **funding for novel and innovative research**
- Brings a diverse scientific focus to data-driven questions **that can be answered** using BioData Catalyst
- Advances career and training opportunities by providing support for analysis toward **publications**

For the System:

- **Improves the ecosystem** based on user feedback
- **Contributes to the functionality** of the ecosystem
- Contributes to **diversity** across fields of study, institutions, geography, and investigators



**Alexander Bick,
MD, PhD**

CHIP expansion and
CVD



**Melissa Cline,
PhD**

Genetics of
Cardiomyopathies



**Jacqueline Dron,
PhD**

Genetics CAD
Lifecourse



**Einat Granot-
Hershkovitz, PhD**

Ancestry-enriched
Variants and CVD



**Jamie Murkey,
MPH**

Psychosocial stress
and CVD



**Yaling Tang,
MD**

Transcriptomics in
Heart Failure

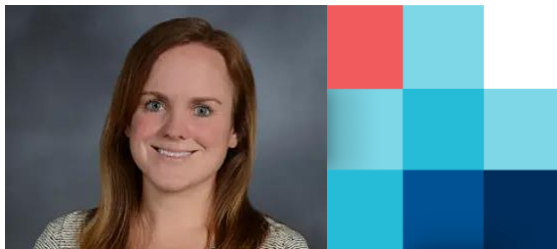


**Xuefang Zhao,
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Structural Variants
and Lipids



Panelists



Natalie Benda, PhD

Assistant Professor of Health Informatics,
Columbia University School of Nursing



Lissette M. Saavedra

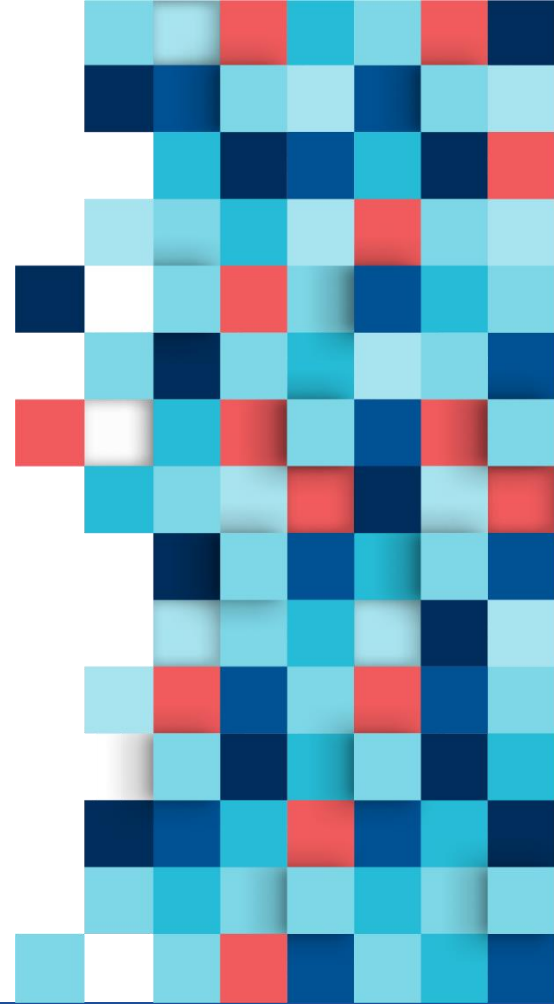
Senior Research Psychologist, RTI
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Panelists Q&A



Tech Talk

Questions and
Discussion

