

Rising Equitable Community Data Ecosystems (RECoDE)

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

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WHY

Why This Work Matters

In the United States, across communities, organizations, governments, and industries, data is increasingly looked at as a powerful lever for change. For any public policy to be impactful and sustainable, it must be informed by high-quality information. This is especially true when it comes to understanding and improving health outcomes, which must take into consideration individual and community health factors. As a result, systems are being modernized to collect, share, analyze, and report more data.

But more data doesn't mean better outcomes.

Data systems built to track housing, health, education, and employment [are largely rooted in racist systems and discriminatory assumptions](#). The COVID-19 pandemic laid bare just how deep those roots go. Platforms and solutions for data collection and distribution have rarely taken deliberate measures to counter those truths, and people have often had little say over how data about them and their neighborhoods are collected, stored, or interpreted. So our RECoDE (Rising Equitable Community Data Ecosystems) project team—made up of curious and committed learners from data.org, Data Across Sectors for Health, Health Leads, and the National Alliance against Disparities in Patient Health—set out to better understand how we can undo those antiquated and dangerous data systems and build in their place an ecosystem that provides all communities power over where, when, and how their data is used to improve individual and community outcomes.

What do we mean by 'community?'

We mean the people living in geographic centers-neighborhoods, cities, towns - as well as those that advocate and work on their behalf at the grassroots level - community advocates, community leaders, and community-based organizations.

What we as a project team learned from our thoughtful and candid community partners—the people closest to the work—is that **we need a common language, a shared vision, and a foundation of trust** in order to build healthy, inclusive community data ecosystems. We share findings from this project not to reveal truths that have long been understood and felt by people impacted by these systems, but rather, with the hope of amplifying voices and presenting recommendations in

a consolidated fashion so that those who hold power to allocate resources at the local, state, and national levels might be able to activate in a way that addresses long neglected issues.

To transform the systems that need to work well in order for everyone to thrive, it's not enough for local officials and organizational leaders to simply agree on a high-level priority like reduced homelessness, for example. Shared priorities must come with shared accountability to be effective, and they must be developed with a diverse set of lived experiences sitting around the table starting on day one and throughout the lifecycle of the initiative. Bringing together these varied stakeholders requires building trust and sharing power, and additional support to ensure that the barriers that too often stand in the way of data access are dismantled.

“ You might be a facilitator, you might be an academic, but you don't study poverty, honey, you experience it. And we need to empower those who have to not carry just the burden, but carry the solution; allow them the space to present the solution.”
— RECoDE Interviewee

These are not radical ideas. But they require radical action.

We prepared our research design ready to tackle important priorities like data standards, technical skills, and data governance. This, we thought, was foundational to advance communities' abilities to build, support, and maintain community data ecosystems focused on achieving health equity for all.

We quickly began to question our preconceived ideas. These elements remain important, but what we heard consistently from participants was that **our initial subject matter was meaningless without something both simple and complex: trust**. Without trust, true partnership is not possible, and without true partnership, we will continue to build systems that perpetuate inequalities and drive health and economic disparities.

As we talk about trust, it is not enough to develop solutions that are trusted. This isn't an exercise in feel-good marketing. We all—our project team and the field more broadly—must build solutions and strategies that are trustworthy: worthy of community trust through long established and sustained relationships.

Through the RECoDE project, nearly 500 people across the country shared their expertise, thoughts, and concerns with us through a survey, interviews, workgroups, and convenings, and they tested our assumptions. Data standards, data collection practices, and technical upskilling did not emerge as primary themes.

Power imbalance and how to right systemic wrongs did, however, over and over again.

As one interviewee said, “There is a reticence to admit that one was ever wrong and that doesn’t fly with communities that have been just very, very plainly shoved aside or disregarded or disrespected. You can’t come in like that, you have to be able to say when you’ve done wrong and if you can’t, that’s just no foundation for trust.”

So, let’s start there. We were wrong.

Our project team was wrong in our assumptions. Healthcare and technology companies were wrong in engaging in democracy theater, repeatedly creating “community advisory councils” that tokenize community voice and experiences without sharing power over decision-making. Academics were wrong in extracting community data for research without generating value for the individuals they researched. Funders were wrong in financially incentivizing CBOs to collect data that suited philanthropic goals versus community stakeholder needs.

As we reflect on the failures of the systems—those we own as a team and those we’ve witnessed—we are trying to understand how we got here and hope our peers and colleagues are experiencing that same journey of discovery to understand how our assumptions

and biases contribute to inequitable systems. It will be a continuous learning and reflection process. For our part, we recognize that we will continue to get things wrong on this journey. But it is important that those of us who have built data solutions, strategies, and incentives that are not worthy of trust commit to learning, connecting, evolving, and always listening so we can set out to make things right.

“I want to name that as a threat in this whole space. There’s a lot of democracy theater out there. And an accountability theater, where it’s going through motions of what seems like it might be accountability, and consultancy, and so on.”

— RECoDE Workgroup Member

What They're Saying: Community Leaders Drive Data Systems Change

“I would really love to see civil rights leaders, black, indigenous, people of color, people with lived experience, really informing the whole design of recreating this process of interoperability of sharing everything.”

— RECoDE Interviewee

“I think that our solutions have to be really paper and pencil, person to person before we build the tech solutions that are actually going to be responsive to the actual day-to-day data needs in our communities.”

— RECoDE Workgroup Member

“Absent an explicit commitment to equity and anti-racism, a CIE plan runs the risk of developing a system that prioritizes the needs of the institution of a single sector, rather than the needs of the community and impacted populations.”

— The CIE® Data Equity Framework

“What the community member has is knowledge of community, and that community person has been in that community, knows that community, knows the key players in the community, knows the politicians that serve that community and are far more productive in running [a] coalition than [someone] who steps foot in the neighborhood once in a while...”

— RECoDE Interviewee

“Representatives from several small CBOs in our study were frustrated about not having enough resources or capacity to be in all the important conversations about health equity, being overlooked in outreach by state and local governments, or being locked out of funding opportunities.”

— Urban Institute – Leveraging Community Expertise to Advance Health Equity

WHAT

What is the Backdrop and Context of This Work?

First, let's reiterate: these ideas are not entirely new. In fact, the insights we are sharing are reinforced across a number of studies and reports. There is a growing body of evidence supporting our argument that data systems must be more inclusive, developing solutions with and not just for communities.

Reports [like Actionable Intelligence for Social Policy's latest toolkit, "Centering Racial Equity Throughout Data Integration,"](#) make a strong case for community engagement. The report from the National Commission to Transform Public Health Data Systems, hosted by the [Robert Wood Johnson Foundation, "Charting a Course for an Equity-Centered Data System,"](#) illustrates with compelling clarity how data are the building blocks for how people understand, describe, and ultimately influence the health of communities. Through the [CIE® Data Equity Framework](#) from Health Leads and 211/CIE® San Diego, and the Urban Institute's recent convening on [Leveraging Community Expertise to Advance Health Equity](#), a playbook begins to emerge. From all the materials we found through our literature review, our collective understanding has grown on the role that the community must increasingly play in multi-sector data sharing to address health equity.

Our work herein builds upon these resources, which were tremendously valuable to us in our research and analysis.

The familiarity of many of these insights and recommendations illustrates that the critical

challenges faced when sharing data for community health and wellbeing are not being addressed. The field has historically talked around the problem rather than shifting focus to collectively do something meaningful or lasting to fix it.

“What do we talk about when we're talking about governance, because I think there's a little bit of an assumption in a lot of places that if you just design the tools and the interfaces, right, and you make sure that everything's legal, then that's governance.”
— RECoDE Workgroup Member

As Dr. Kedar Mate, president and CEO of the Institute for Healthcare Improvement, [aptly put it](#), “Talking about equity, disparities, and the failures of our systems is important, but we must also make meaningful and consistent changes to advance health equity.”

“*Marginalization doesn’t happen with groups who have power. We’ve seen that pattern over and over again. To those in power or those who have the power to create technology...I think trying to frame and reframe that ‘why’ over and over again to them helps.*”

— RECoDE Interviewee

The current context has brought to light just how urgent the situation has become. COVID-19 and its economic fall-out have underscored the structural racism that exists in many systems in our country, including in local data systems. It’s not enough to collect data. It’s not even enough to make it transparent.

Numerous trackers, models, platforms, and [solutions are being](#) used to create, connect, and in some cases commoditize health, public health, and social services data. Healthcare organizations, payers, and private businesses are finding increased value in community-driven supports to improve health outcomes. Coupled with the speed of innovation and the influx of private equity investment, the community data systems landscape is changing rapidly.

The technology and funding exist, but they are not being applied to maximum—or equitable—efficacy.

As [AISP](#) reports, “cross-sector data sharing and integration enable the transformation of individual-level information into actionable intelligence that can be used to understand urgent and long-term community needs; improve services, systems and practices; develop innovative policies and interventions; and ultimately build stronger communities. Yet, the way that cross-sector data are used can also reinforce legacies of racist policies and produce inequitable resource allocation, access, and outcomes.”

If marginalized communities and stakeholders are not a meaningful part of the initial data ecosystem design, their perspectives are too often overlooked. This

work is rapidly evolving, and data ecosystem leaders need to make a deliberate effort to ensure that these models are co-created with community partners and evolve in ways that are responsive to and aligned with the needs of the people they serve.

“How do we know that the work that’s happening is impactful and isn’t just a service that doesn’t result in anything? That it actually has an impact on someone long term, that it’s sustainable, and that it’s sticky?”
— RECoDE Workgroup Member

This is the context in which data.org and our partners began this effort. Through a year-long learning journey built around the principles of trust, humility, and authentic collaboration, data.org, Data Across Sectors for Health, Health Leads, and the National Alliance against Disparities in Patient Health convened a series of conversations focused on answering fundamental questions about how we access and leverage resources to ensure that data ecosystems are accountable to the community.

How might we do so while staying focused on improving health outcomes and well-being, inclusive of under-resourced communities?

What are community data ecosystems?

Community data ecosystems are made up of the what, the who, and the how that enables data sharing and collaboration within a community. They include data infrastructure, tools, user capabilities, standards, and policies used to manage cross-organization data sharing.

HOW

Methods, Activities, and Inputs to Inform Equitable Data System Design

The RECoDE project launched in 2020 as an initiative to engage people involved with and touched by every part of the ecosystem and its lifecycle, with particular attention on the needs and stories of the people who are most impacted by inequitable data systems.

The project consisted of:

- 1.** The creation of a consortium called the “[Learning Council](#),” comprised of individuals from organizations across the U.S. with interest and expertise in health and community data sharing. Learning Council members were tasked with ensuring diverse voices and stakeholders were represented in project activities, providing subject matter expertise, and bringing local, regional, and national perspectives to the table.
- 2.** A national survey on the field of multi-sector data sharing for community health in the U.S., with an increased focus on equity in data sharing. The survey was the second iteration of the All In National Inventory, an initiative of Data Across Sectors for Health (DASH) and All In. The 2021 survey drew from existing questions about collaboration and partnership, reflected barriers and facilitators to data sharing that DASH has identified through five years of experience working with communities, and was adapted from the previous iteration to have an increased focus on equity in data sharing.
- 3.** A series of 50 1:1 virtual interviews with individuals—from community organizations and social enterprises to data stewards and healthcare providers—aimed at discerning barriers and facilitators in the data ecosystem. A focus group was additionally conducted with a

Interviewee community representation* (n=59)	Proportion (percentage %)
Community-based or social sector organizations	18%
Data stewards	8%
Disabilities community	4%
Government	2%
Healthcare provider or system	12%
Historically underrepresented ethnic-racial or gender group	14%
Multi-stakeholder	28%
Neutral broker, philanthropy, or funder	6%
Rural communities	2%
Underserved community	6%

*self-identified

group of nine commercial health insurance payor representatives. Individuals who could speak to their perspectives of being affected by inequitable data systems were prioritized in the recruitment; the Learning Council and trusted national and community-based organizations aided recruitment efforts. See adjoining tables for the self-reported communities and occupations represented by interviewees.

4. A series of five workgroups held over two weeks in September 2021. Each workgroup was assigned a different theme developed by the Learning Council: community governance; data purpose and use; money, measurement, and power; policy change; and technology and talent.
5. A two-day virtual convening in December 2021 that included approximately 50 people. All individuals who were engaged in interviews, workgroups, and the Learning Council were invited to participate in order to discuss the project findings and offer input on follow-on actions.

Interviewee Occupation* (n=59)	Proportion (percentage %)
Clinical professional	5%
Disabilities advocate	2%
Faith-based organization	2%
Food systems representative	2%
Healthcare system leader	19%
Local health advocate	3%
Public health or epidemiology	14%
Racial justice advocate	5%
Researcher or academic	7%
Social enterprise or sector representative	41%

**self-identified*

Over the course of a year, across all project activities, we heard from nearly 500 people representing communities across the United States.

The survey was distributed across RECoDE partner networks, such as the All In network, which includes thousands of individual members working in over 150 communities, as well as additional 25+ national networks that distributed the survey through their existing communication channels. Respondents represented a range of lived experiences, with professional expertise in academia, healthcare, social services, advocacy, and beyond.

Survey data helped inform the research plan for subsequent workgroups, assigning a “How Might We” statement to each thematic area, which is used in Human Centered Design to reframe insights into opportunities for action. This is what we know; how do we use that to inform what we do? Seven underlying questions emerged; if you’re involved in using healthcare, public health, and community data to improve outcomes and advance social good, these questions can help guide your work, too.

Questions to Identify Opportunities for Action

- 1** *What needs to be true to create equitable, accessible community data ecosystems?*
- 2** *What are the possible areas for quick wins?*
- 3** *What needs the most attention?*
- 4** *Where do you want to know more?*
- 5** *What topics are most pressing?*
- 6** *What voices belong at the table?*
- 7** *What influencers should we prioritize in crafting recommendations?*

Insights to Inform: Sharing What We Heard and What We Learned

Talking the Talk

Informed by the survey and interviews, the Learning Council helped craft a data dictionary for our workgroups. Starting with a common vocabulary helps to reach a shared understanding and create a shared language with terms that are digestible and valuable. This exercise allowed participants to build consensus around language and terms, and also gave them the ability to build upon or argue against that language as it relates to its appropriateness, accuracy, and relevance from their own lived experience.

“Communication and translation skills are needed on so many levels.”
— RECoDE Workgroup Member

Again, the field must be willing to reflect and reconsider that ‘the way we’ve always done it’ may not be the only way, the best way, or the most equitable way.

Systems should be designed by and for the people that they intend to serve. There must be a balance to protect data security and maintain quality while also giving people control over their own data. Both perspectives are valuable, and the best way to preserve and advance both is to increase collaboration to develop the skills and expertise to be the best data stewards possible.

Walking the Walk

There are many points of failure within the data lifecycle, especially when it comes to who is making decisions. More than 400 survey participants were asked about their involvement of people with lived experience—those who carry the burden of inequitable outcomes—in various stages of the data lifecycle. The majority of these survey participants came from either the non-profit sector (55%) or government agencies and public institutions (35%), with others coming from faith-based organizations, private companies, and beyond.

Overwhelmingly, people with lived experience are not actively engaged or making decisions within multisector data initiatives.

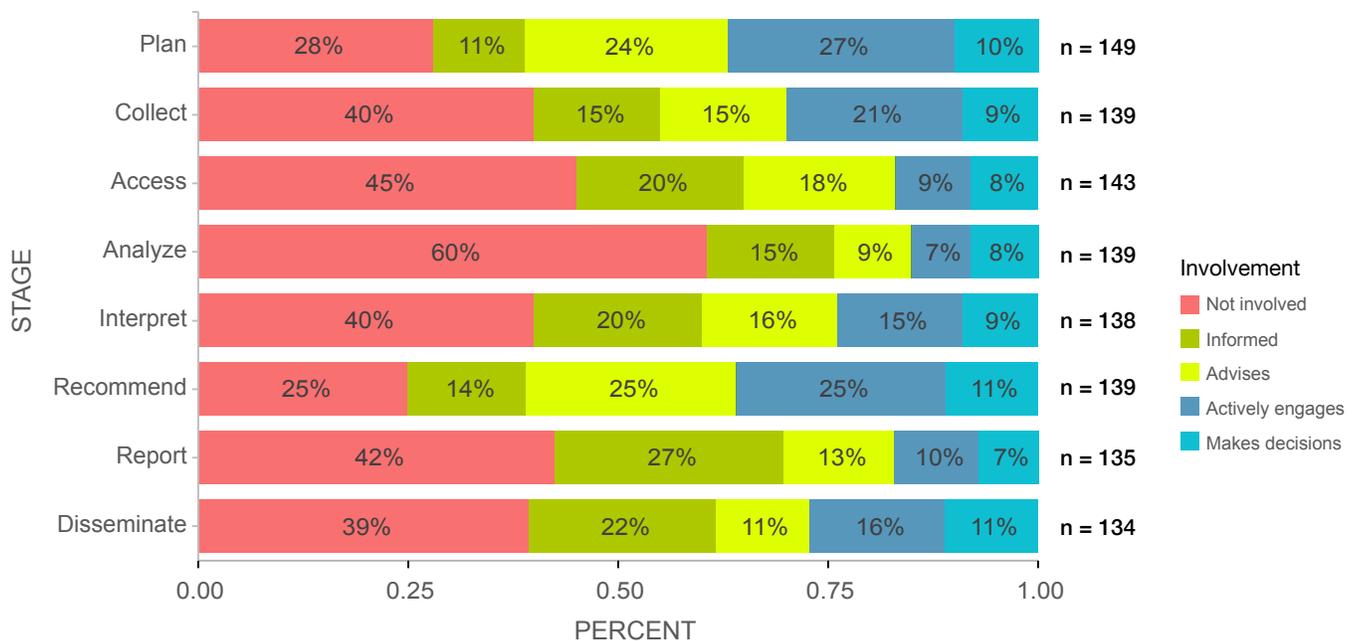
This lack of participation poses critical risks at every stage in the data lifecycle. If trusted people are not collecting data within communities, the likelihood of distrust and refusal to share information is high. On the

other end of the cycle, a major gap exists in data analysis. Without relevant lived experience, the risk of misinterpretation of data or making false assumptions is high. Data infrastructure and solutions must be local, and must be informed by and supported by the local community in order to be meaningful and sustainable.

“Engaging communities is a long-term process that includes both addressing immediate challenges and thinking strategically about longer-term leadership development and capacity building so community members can effectively advocate for their needs and lead health equity initiatives. Forming authentic relationships with communities therefore requires considerable time and patience.”

— Urban Institute – Leveraging Community Expertise to Advance Health Equity

Involvement of Persons with Lived Experience in the Data Life Cycle



Those with the deepest knowledge of community have the least power over the data systems that attempt to describe that community. They are the ones who understand best what needs to happen to improve outcomes.

Throughout interviews and workshops, we heard over and over again that this work requires trust, transparency, empathy, and humility. When those with power don't share it, nothing changes. Until data systems are overseen and owned by community, the systems who have power over these data ecosystems must begin to share and cede power back to that community.

“ We need to do a better job of engaging in the communities that we are trying to connect to, about what the purposes are for our own data collection, and how we're using that to improve services and really drive towards policy change”
— RECoDE Workgroup Member

Creating the Conditions

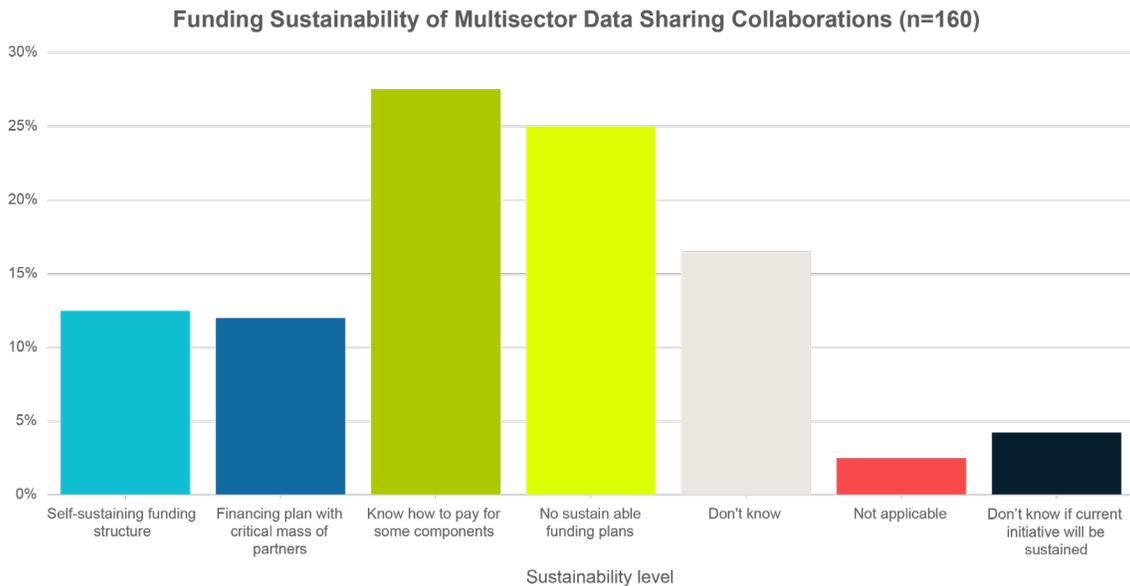
First Comes Funding

To leverage data effectively, you need sufficient resources. That includes both money and people.

When it comes to financial support, data systems are too often developed for what funders want, not what communities necessarily need. And while 86 percent of survey respondents—an overwhelming majority—agreed that their organizational leaders have a clear idea of how data can be used to drive decisions beyond justification of funding, many—54 percent—indicated that funding requirements still define what data they choose to collect.

86% of survey respondents agree that organizational leaders have a clear idea of how data can be used to drive decisions beyond justification of funding
54% indicated that funding requirements still define what data they choose to collect

Disproportionate time is spent checking boxes to meet reporting requirements, especially for organizations whose funding streams cross reporting systems in local, state, federal, and private domains. With this loss of control over what and how data is collected, community-based organizations and the communities they serve simultaneously lose power to dismantle the racism and oppression that persist in data ecosystems.



A vicious cycle begins, with the pursuit of funding taking precedence, as most multi-sector data sharing collaborations do not have a sustainable source of funding. Short two- to three-year funding cycles further exacerbate the problem, standing in the way of longer-term planning and bolder, more innovative approaches.

Moreover, when funding is available, it is often accessible for execution, but less consistently available for planning, and particularly when it comes to the role of partnership and coordination among community stakeholders. This body of work often ends up on the plate of a team member who is already overwhelmed, as opposed to constituting a full-time, dedicated position that the work merits.

“ We as a society treat nonprofits very differently in terms of expectations around use of money and proving these things than we do a company or a start up.”
— RECoDE Workgroup Member

“ If you’re really trying to change people’s way of thinking, if you’re really trying to change the social context, if you’re really trying to change entire paradigms, a two-year project is not going to do it.”
— RECoDE Interviewee

Then Comes Talent

Technology isn't a solution. Nor is data. They are tools that can help drive solutions, but they are meaningless without first considering the human needs within the system and the technical expertise needed to execute.

Bringing diversity and lived experience onto technical teams by hiring those that have experienced issues that solutions are intended to address adds depth, creativity, and capability to the effort. [It's also effective](#). Leaders must not tokenize participants from different backgrounds and instead validate that they bring relevant expertise to the work. By engaging trusted community leaders, and not focusing solely on powerful or established entities, you are better positioned to identify and hopefully mitigate the barriers that exist and inhibit community empowerment. When the community is part of the whole data lifecycle, trust can be built from the ground up, resulting in sustainable relationships.

Robust funding and talent are equally essential to impactful data sharing collaborations, and they are deeply intertwined. Meaningful community partnership through the data lifecycle, from program design through execution, not only invests in the work, but builds capacity in the community, as well. Funding often doesn't exist to help hire, invest in, and advance the careers of those from the community the work seeks to support. As a result, community-based organizations do not have the same funding or staffing as those in the technology or healthcare sectors. How can CBOs be expected to meaningfully play a role in designing or participating in anti-racist data systems if they do not have the financial and people resources necessary to do the job well?

In workgroup discussions, participants argued that the most important message for funders is to invest in the development of a more diverse technical workforce and to consider the talent portfolio as a public utility to ensure that community members are compensated and valued for their knowledge, skills, learning potential, and participation.

“There needs to be a balancing between technical expertise and public input.”
— RECode Workgroup Member

NEXT

Actionable Recommendations for Equitable Community Data Ecosystems

How might we...

How might we procure and leverage resources to ensure that community data ecosystems are accountable to the community and stay focused on improving health outcomes and wellbeing, inclusive of under-resourced communities?

That was the fundamental question our team set out to answer when launching the RECoDE project. What we found, through conversations with nearly 500 people around the country, reinforced a growing body of research and evidence and called for a shift towards more trust-based and equity-centered community data ecosystems.

How do we ensure these systems serve the community? We put the community first. We engage them [at every stage of the data lifecycle](#). The community must be central in research and plan design, data collection and analysis, and in the policy and decision making ultimately informed by data.

That principle is embedded in each of the following five key recommendations to challenge the status quo and create equitable data ecosystems that work for everyone.

Recommendations to Create Equitable Community Data Ecosystems

1 TRUST STARTS WITH COMMUNITY

Build trust and share power to enable data-driven decision making among multiple partners—this must be earned through longstanding, sustained relationships in the community, and it takes time to manifest.

2 CO-CREATE, DON'T DICTATE

Move from “check the box” community engagement to true community partnership through meaningful co-creation.

3 DESIGN WITH INTENTION

Collective action and data-driven decision-making requires shared goals, design, implementation, and accountability.

4 BUILD CAPACITY

Invest in people—today, as community leaders dig into this work, and tomorrow, as we collectively build a stronger, more diverse tech talent pipeline.

5 RESET THE RULES

Reexamine the mechanisms that hold institutions accountable, and resist the urgency of quick fixes to complex issues like systemic racism.

How These Recommendations Shape Our Collective Work Moving Forward

So what does this mean in practice? How do these recommendations influence the work of data.org, our partners, and all data managers, funders, and organizational leaders working in the space across government, healthcare, technology, and beyond?

At the highest level, we hope the topline recommendations can become a mantra of sorts for the field. Print them out, keep them close by, share them with your teams, and integrate the principles into your daily work. At the tactical level, herein we provide some more detailed guidance on how to deploy these recommendations.

On Trust

Where do you begin?

First, **listen to the needs and expertise stemming from lived experiences of trusted community leaders** – these could be faith-based leaders, community organizers, or the head of the local clinic. And listen, and listen, and keep listening. This requires sustained engagement and dialogue. You can't come to the table with the project fully baked and expect meaningful change with a few performative feedback opportunities. The drumbeat on the importance of trust in data sharing continues to grow louder, yet not enough action has been taken to make this principle a practice. Coming to the table with transparency about the goals of the data effort, ways data will be used, stakeholders involved, and [potential unintended consequences](#) is essential for building and sustaining trust around data systems.

What next?

Shift what gets funded and the expectations around how this work gets done. Funders, including government and philanthropic partners, should budget for the inclusion of full-time staff in roles that coordinate data ecosystems and ensure those roles are hired from within communities. Timelines and operational budgets must be reconfigured to take into account the time needed to listen, listen, and listen. All actors that engage in this ecosystem, including academic partners, healthcare, and tech companies, should compensate community members when making demands of their time.

There are a multitude of factors that contribute to trust throughout complex data ecosystems, and funders should also consider how they can support efforts that address existing harms, protect rights, and build trust throughout data systems. The framework presented in [Envisioning a New Future: Building Trust for Data Use](#) is a helpful starting point.

On Partnership

Where do you begin?

Make a concerted effort to **share power throughout the data lifecycle**. AISP makes this argument clear when they point out [in their data integration toolkit](#) that racial equity is “not a single, discrete step, but rather an ongoing process.” Funders, including philanthropies, governments, and those in the tech for good space, should change how they operate and dedicate funding to support these kinds of collaborative community partnerships.

Partnership might look different based on the specific community, the partners involved, the initiative, and time and resource constraints. It can exist on a spectrum from inclusive design practices that collect input through multiple engagements, to communities having full final decision-making power. What is clear is that funders, healthcare, academics, and tech companies need to end the practice of making decisions for communities based on data extracted from those communities.

What next?

Prioritize the principles of data justice and stewardship for funders, grantees, and for all those working in data for good. Funders are often quick to add regulatory checks and application requirements for grantees; why not build in a requirement that, as the Stanford Social Innovation Review rightly points out, [has the power to be transformative](#) for community participation and engagement?

Principles of Data Justice

- 1.** *Take advantage of what already exists.*
- 2.** *Learn by doing.*
- 3.** *Build expectations into grant guidelines.*
- 4.** *Experiment with other data collection methods.*
- 5.** *Emphasize transparency and two-way communication.*
- 6.** *Revisit notions of impact.*

All stakeholders—and especially funders, healthcare, academics, and tech companies—that operate in community data ecosystems should familiarize themselves with [participatory planning approaches](#) and embed those practices into their ways of working. Community participation must run deeper than a check-the-box exercise.

On Design

Where do you begin?

Identify and align around a [problem statement](#) and be honest about the funding time horizon. Everyone in the data ecosystem, including funders and community stakeholders, should articulate clear goals, responsibilities, and boundaries. [These Data Collaboratives tools](#) are a helpful place to start.

Align on initiatives, incentives, and expectations. As [the American Institutes for Research writes in their report on shared measurement](#), you must work collaboratively to define what to measure; how to measure; where, when, and from whom to collect data; and why the measures are important. Data sources and methodology are determined from that common understanding. All stakeholders in the ecosystem must **set clear and measurable indicators of success and failure** that are meaningful to communities and not just to the institutions that seek to serve them. Finally, take time to ask, “what could go wrong?” Have an understanding of potential unintended consequences and take steps to mitigate them so that data is used and shared responsibly. [These resources for Using Data Responsibly and Ethically](#) could help.

What next?

Funders should invest in operational funding (rather than just initiative-specific support) to maximize robust, thoughtful, and meaningful planning in safe spaces. Funders should consider providing seed funding for the planning stage, even when that comes ahead of the full funding application. Lack of support for thoughtful planning and preparation disproportionately affects smaller, less resourced community groups that often struggle to find the time and space required for thoughtful deliberation.

Government, healthcare, and tech partners must take an honest look at the motivations behind specific goals and the interventions used to achieve them. If the

goal is community health, then include communities in defining what that means, identifying data gaps, and prioritizing interventions.

On Capacity

Where do you begin?

Across all recommendations, from building trust to designing with intention, **we collectively must invest in and build capacity within communities**. There is a big difference between data being available and data being accessible. As an entrypoint, that starts with the use of clear language that includes rather than alienates, and is translated into the local predominant languages. But beyond basic accessibility, significant support is needed for widespread data literacy. This is a new essential competency from the ground up and the top down, with investments across K-12 and throughout every stage of the workforce, particularly in the nonprofit sector where community-based organizations have the power to help fuel social change through effective data leveraging.

What next?

For community practitioners and their local partners like healthcare and academic institutions, [Community Approaches to System Change compendium](#) provides a wealth of resources to make addressing systems change more digestible. For those just starting out on this journey, case studies from other communities, “like those presented via the [BUILD Health Challenge, All In](#), and [CIE Community Profiles](#), can help bring this work to life and provide a blueprint for how to get started on community data partnerships.

Funders must invest in the professional development of a more diverse and interdisciplinary tech and data science workforce. Diversity and lived experience significantly enhances the creativity and capability of data and tech teams, not to mention the positive impact it has on trust and sustainability of data efforts. There is much work left to be done to close the persistent digital divide in this country. Stakeholders should be pushing levers within their respective spheres of influence to do just that, from increasing access to Internet and digital infrastructure to upskilling communities so they can collect, access, analyze, and leverage the data that ultimately belongs to them.

On Accountability

Where do you start?

Policymakers and decision makers must **do a better job on enforcement and regulation to help curb the impacts of systemic racism in public health**. Funders can achieve the same goals when they invest in organizations with a demonstrated commitment to equity and enforce equitable practices throughout the funding lifecycle.

So much time and energy is devoted to compliance with regulations that govern data, yet many types of data—like social determinants of health—fall outside of the scope of existing regulations that primarily govern healthcare data, like HIPAA. This means that many community-based organizations spend considerable time complying with regulations that are older, do not take into account issues like ethics or community governance, and do not govern the non-healthcare data that they work with. On the flip side, there are also too few protections for how ecosystem stakeholders—including healthcare and tech companies—work with social determinants of health data.

What next?

Emphasize accountability and build in better checks and balances by empowering trusted voices to help lead and regulate the process. These trusted, community-based intermediaries can likewise help navigate the complexities of data sharing, and should be compensated for this important work. Funders should make equity a critical part of decisions about who and what gets funded and promote equity through requirements in their agreements that enforce practices outlined above, like co-design, hiring, and compensation.

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 and put positive pressure on the entities building data systems and tools.

Similar to the drumbeat about trust, this work takes time. Dismantling harmful systems takes time. Resist the urge of quick fixes to complex issues, and instead [move slow and fix things](#).

CLOSING

Before We Go

These are not radical ideas. But they require radical action.

That's how our team started this report, and that's how we'll finish it. The most compelling and powerful takeaway from this project was not a piece of new information. It wasn't a collective 'aha' moment, or a finding that took us by surprise. What was most compelling was how consistently and emphatically stakeholders across sector, across survey, across workgroup, and throughout the research demonstrated their broad consensus.

Radical action: engage, align, invest. And most importantly, build authentic trust. Trust is required at every stage of the process.

These recommendations are not complex, but they are difficult, nonetheless. They are difficult because they challenge the status quo. Because they shift the focus from fiscal years to community timelines. Because they ask institutions to put community at the center, directing design and not just participating once it's complete.

Because they demand more of us, collectively.

Ultimately, these recommendations are difficult because data ecosystem leaders must relinquish control and contend with all the ways we—our team included—have done harm to those we seek to serve.

It isn't easy, but it is worth it. The work, and the very health of our communities, demands it.

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