Data Across Sectors for Health

The State of the Field of Multisector Data Sharing for Community Health

Report of the All In National Inventory 2.0

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Executive Summary

The National Inventory 2.0 was developed to understand progress in the development of multi-sector community data-sharing ecosystems across the country since the first National Inventory was deployed in 2019. DASH, working with partners at All In, data.org, NADPH, and others, created, tested, and distributed the survey from May to August 2021.

Survey Participants

261 of the 371 individuals who responded to the survey reported that their organizations participate in multisector data-sharing collaborations to advance community health and provided data on 229 collaborations that are most important to them. This report summarizes the results of organization- and collaboration-level data provided by these 261 respondents.

Characteristics of Collaborations

SECTORS REPRESENTED IN COLLABORATIONS. The sectors participating in the collaborations are social service & community-based organization (CBO) (81%,186), public health (75%,172), healthcare (72%,166), academia (59%,136), and technical infrastructure (51%,118).

PURPOSE OF SHARING DATA. 70% (131) of collaborations share data to conduct care coordination, and 85% (160) share data to conduct community assessment and improvement.

Care coordination only (26)		Both (105)	
14%	29%	56%	
	Assessment & improvement only (55)		N/A (2)
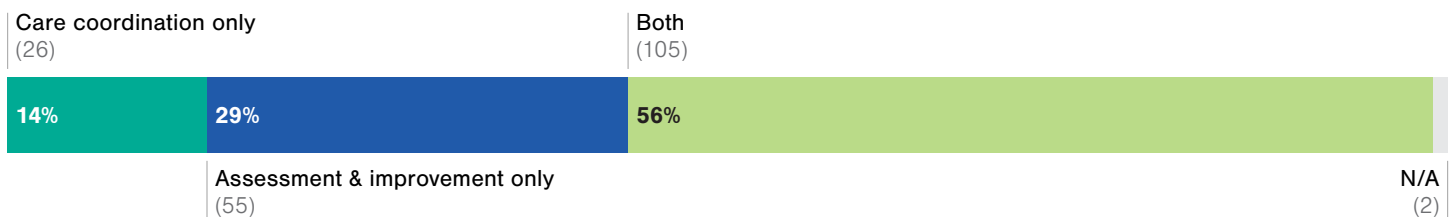
TYPES OF DATA. Collaborations' data systems are designed to share aggregated data about people (79%, 150), data about places (64%, 122), and data about organizations or service providers (62%, 118), as well as data about individuals either anonymized (47%, 90) or identified (45%, 85).

Aggregated data about people	(150) **79%**
Data about places	(122) **64%**
Organization or service provider data	(118) **62%**
Anonymized personal data	(90) **47%**
Identifiable personal data	(85) **45%**
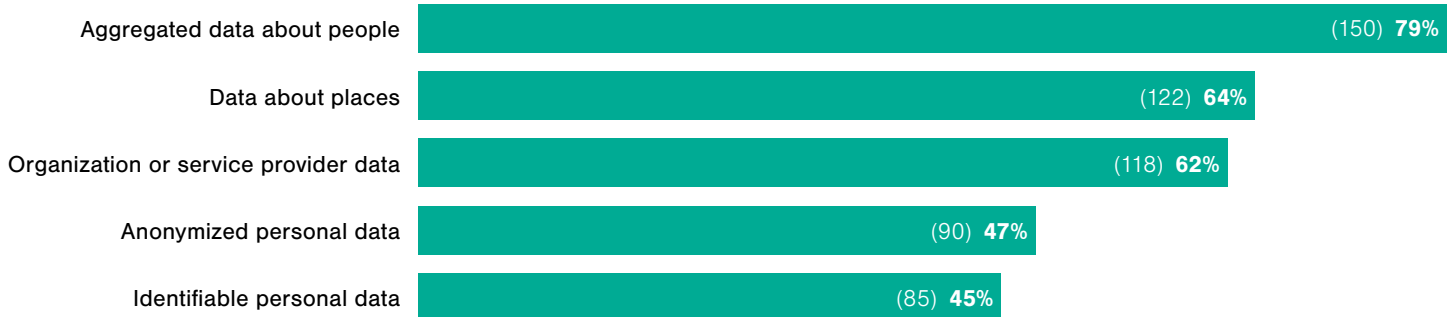
DATA SYSTEMS. Data repository is the most frequently reported data system used by the collaborations (62%,118). This may suggest that collaborations are building their own systems rather than relying on shared infrastructure or shared services like health or community information exchanges.

YES   NO   DON'T KNOW

Data repository	(118) **62%**
Open data platform	(99) **52%**
Case management platform	(98) **51%**
Social service provider directory	(87) **46%**
Health information exchange	(83) **43%**
Integrated data system	(77) **40%**
Integrated health and human service eligibility and enrollment systems	(48) **25%**
Community information exchange	(44) **23%**
Multi-payer claims data	(32) **17%**
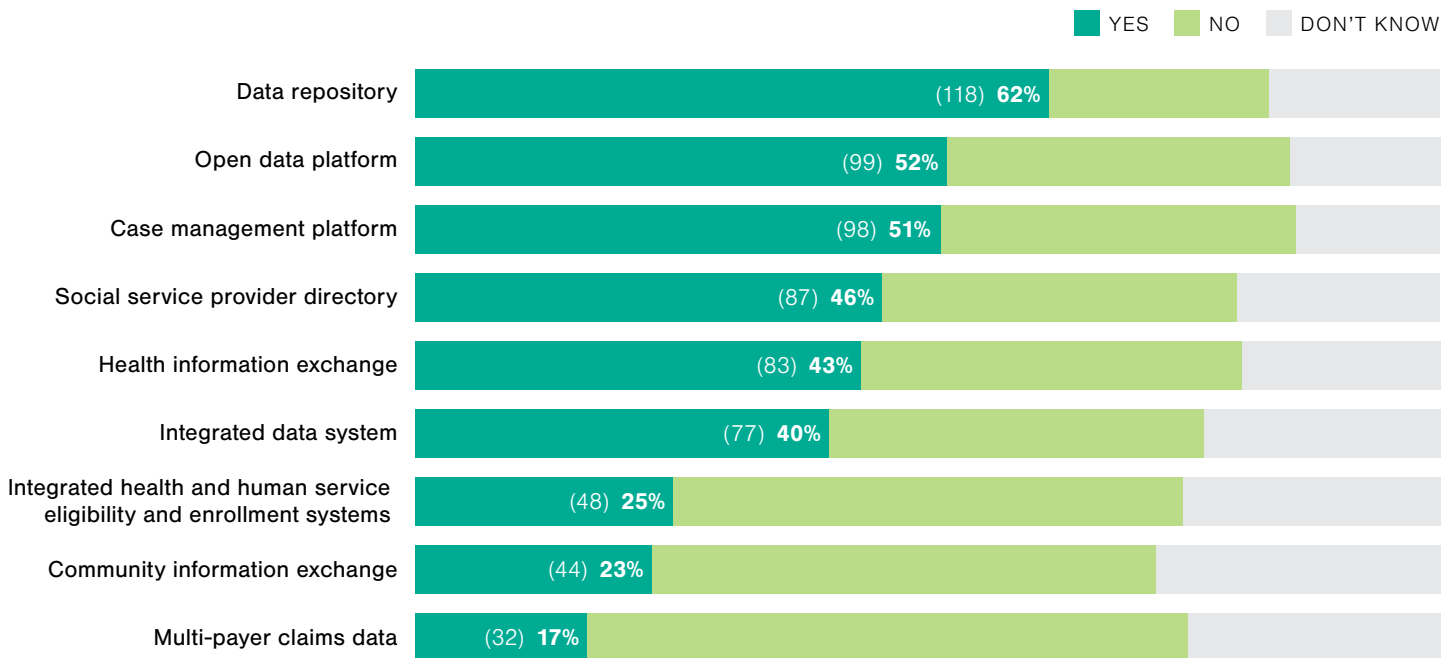
TARGET GEOGRAPHIC AREAS. The collaborations' target areas cover 36 US states. A few collaborations are nationwide, covering the whole United States and associated territories (not shown on the map). 52% (103) of collaborations target rural areas, and 14% (27) target Native American reservations or tribal nations.
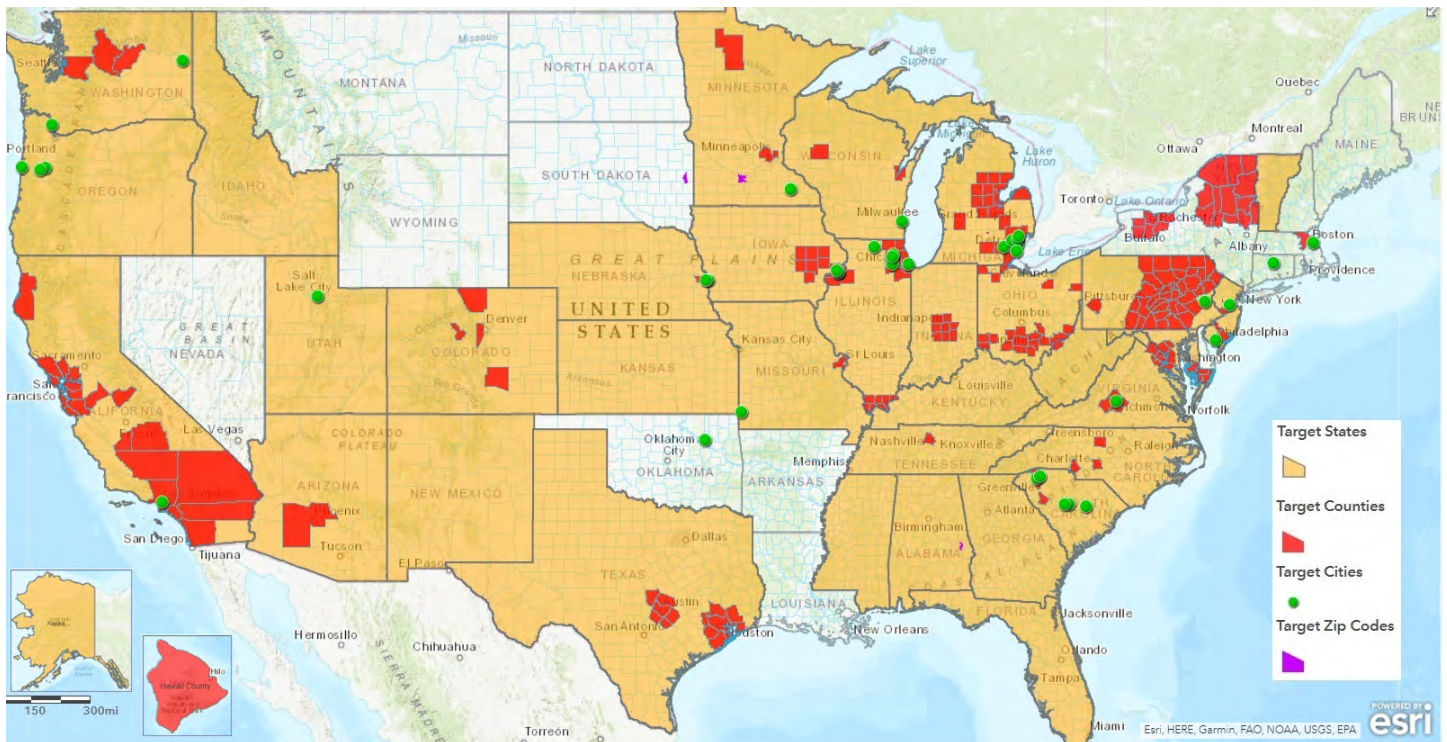
Progress

DASH applies its framework when measuring progress of multi-sector data ecosystems. The survey asked questions about the stage of implementation, human and organizational capacity, data governance, technical functions, and sustainable finance.

STAGE OF IMPLEMENTATION. DASH finds that implementation of multi-sector data systems is generally an iterative process, in which new use cases are added sequentially. Therefore, the survey asks about implementation status with respect to specific use cases.

- Within the set of use cases supporting care coordination, **screening and assessments** are most likely to have progressed beyond implementation (sustaining or innovating, 36%)

- Within the set of use cases supporting community assessment and improvement, the most common use cases in the advanced stages (sustaining or innovating) are **identifying community assets and needs** (40%) and **engaging community** (37%).

MULTISECTOR COMMUNITY DATA ECOSYSTEM

Human and Organizational Capacity

Sustainable Finance

Data Governance

Equity throughout the data cycle

Technology

Data Standards

	PLANNING	IMPLEMENTING	SUSTAINING	INNOVATING	DON'T KNOW

CARE COORDINATION

Screening and assessments (n=77)	31%	26%	19%	17%	
Eligibility determination (n=42)	24%	36%	14%	14%	
Faster, more accurate referrals (n=78)	26%	36%	17%	14%	
Provide holistic insight into a person's history and needs (n=79)	29%	38%	11%	13%	
Event notification (n=48)	33%	31%	25%	6%	

ASSESSMENT & IMPROVEMENT

Identify community assets and needs (n=116)	22%	33%	24%	16%	
Support policy and environmental change efforts (n=100)	35%	27%	20%	11%	
Service targeting (n=103)	37%	31%	18%	11%	
Measure quality and performance (n=108)	28%	35%	21%	10%	
Engage community (n=99)	21%	37%	28%	9%	
Hold organizations or systems accountable (n=93)	33%	30%	20%	8%	

0   20%   40%   60%   80%   100%

DATA FUNCTIONS. When considering only collaborations that have progressed beyond the planning stage in at least one use case, the most common functions of their shared data systems relate to **reporting and dissemination of information**, including the following: generate reports (72%, 108); manipulate, visualize and present data (66%, 99); calculate, display metrics and indicators (58%, 87); and map geographic information (49%, 73).

Linking records in real-time (25%, 38) and automated decision support (15%, 22) were the least common functions supported by the data systems.

Function	Count	Percent
Generate reports	(108)	**72%**
Manipulate, visualize, and present data	(99)	**66%**
Calculate and display metrics and indicators	(87)	**58%**
Map geographic information	(73)	**49%**
Match records across systems	(65)	**43%**
Look up and query specific individuals	(62)	**41%**
Make predictions	(52)	**35%**
Link records in real time	(38)	**25%**
Automate decision support	(22)	**15%**
Other	(7)	**5%**
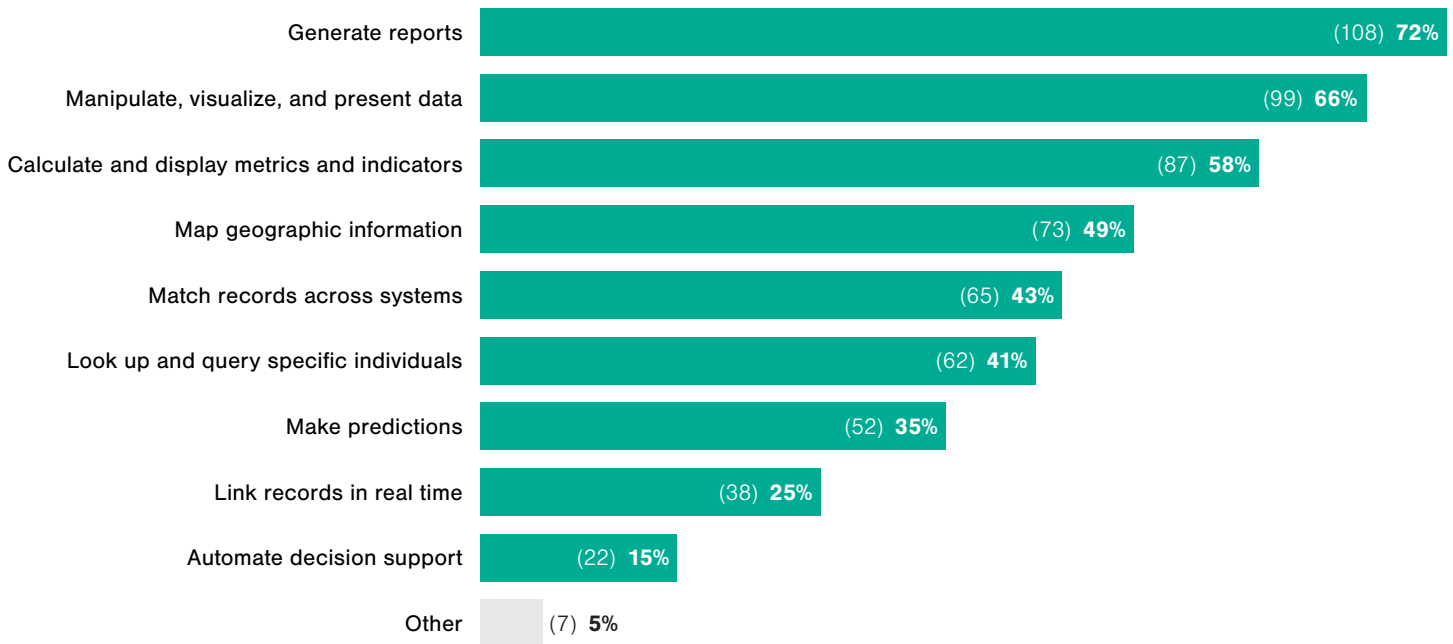
ORGANIZATION CAPACITY. We find there to be a misalignment between the importance that leaders of responding organizations place on data, and the extent to which their decision-making and investment in data capacity are constrained. This is particularly the case when comparing responses from organizations in different sectors.

95%
- ➢ Our organization uses data to better understand the impacts of our efforts

67%
- ➢ Our organization provides professional development opportunities related to data

66%
- ➢ Our organization invests well in technology to support the collection, management, and use of data

86%
- ➢ Our leaders have a clear idea of how data can be used to drive decisions beyond justification of funding

51%
- ➢ Funding requirements define most of the data our organization decides to collect

The social service & CBO and public health sectors reported lower proportions of organizations having policies in place for the use, transfer, and sharing of data, and for investing well in technology.

The social service & CBO sector reported the lowest proportion in providing staff professional development opportunities.

DATA GOVERNANCE AND LEGAL AGREEMENTS. Over half of the collaborations have a shared understanding of the four components of data governance: proper use of data (64%, 98), data access (59%, 94), consent process (59%, 81), and data quality (52%, 84). 43% (73) of collaborations have necessary legal agreements finalized to share data.

SUSTAINABLE FINANCE. 76% (128) of collaborations use grants as funding sources to support their data-sharing systems. 15% (22) of collaborations have established a self-sustaining funding structure. 30% (45) of collaborations have no sustainable funding plan.

Equitable Data Practices

Most collaborations reported engaging in these data practices always or most of the time:

	ALWAYS	MOST TIMES	SOMETIMES	RARELY OR NOT AT ALL
Assessing whether outcomes vary by identity groups (n=161)	42%	31%	20%	7%
Incorporating community level data into analyses (n=163)	39%	27%	23%	10%
Addressing potential bias of the data (n=158)	27%	33%	27%	14%
Assessing how the risks or negative impacts of data sharing could vary by identity groups (n=156)	31%	28%	26%	15%
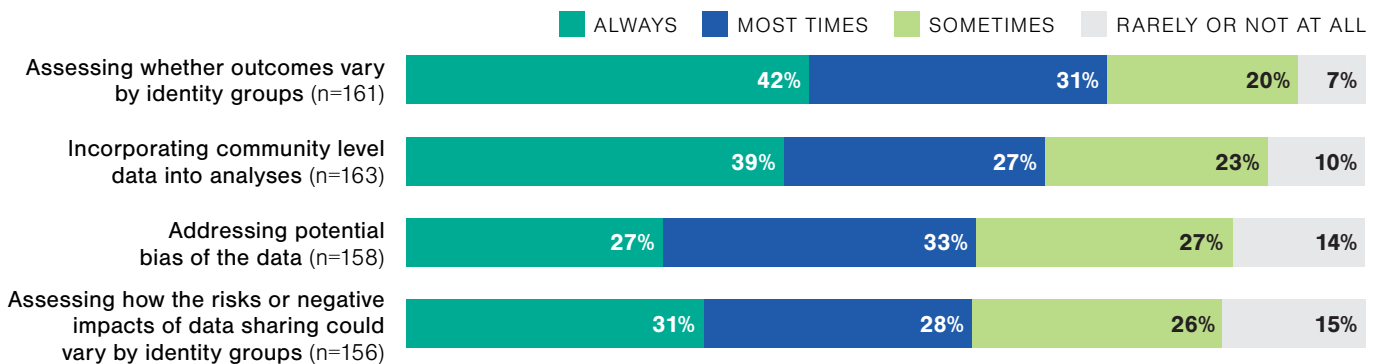
People with lived experience (PWLE) are involved in each phase of the data life cycle to varying degrees. DASH considers participation in decision-making and being actively engaged to be the most authentic forms of inclusion. From this perspective, there is room for improvement across the data life cycle.

	MAKES DECISIONS	ACTIVELY ENGAGES	ADVISES	INFORMS	NOT INVOLVED
Plan (n=163)	12%	27%	25%	12%	25%
Recommend (n=152)	12%	24%	27%	13%	25%
Collect (n=153)	10%	22%	16%	17%	36%
Interpret (n=149)	11%	15%	17%	20%	36%
Disseminate (n=145)	13%	15%	12%	21%	39%
Report (n=144)	10%	10%	14%	26%	40%
Access (n=158)	11%	9%	18%	21%	41%
Analyze (n=152)	10%	7%	12%	14%	57%
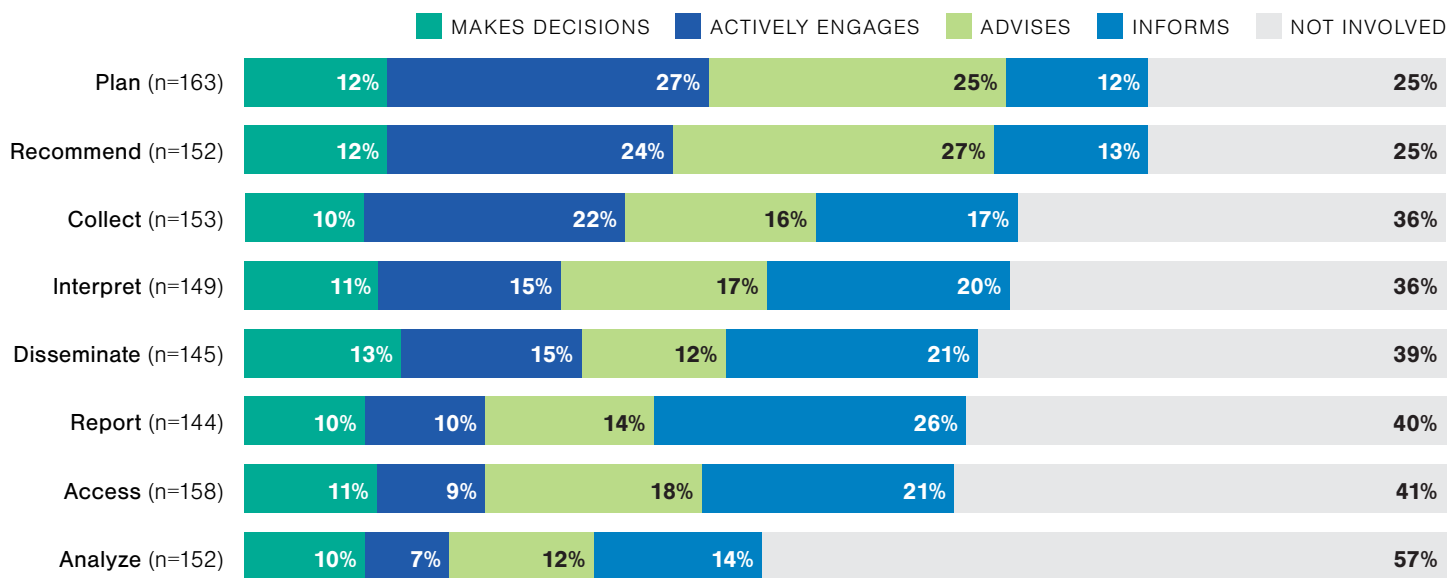
Introduction

Background: National Inventory 1.0

In 2019, DASH and partners at All In: Data for Community Health (All In) launched the first National Inventory of Data Sharing Collaborations for Health to describe the state of the field of data sharing. In this initial effort, DASH sought to understand the aims of collaborations that share data, participating sectors, alignment of vision, and collaboration progress towards data sharing. The survey found that while interest in multi-sector data sharing was growing, key barriers remained. These barriers included a lack of robust community engagement, legal ambiguity, continued reliance on manual and imperfect data management processes in the absence of standards, and unsustainable financial models. The findings were summarized in the National Inventory 1.0 Report: *The State of the Field of Multisector Data Sharing for Community Health.*

National Inventory 2.0

To understand new developments in community data-sharing ecosystems across the country, DASH, working with its partners at All In, data.org, the National Alliance against Disparities in Patient Health (NADPH), and the Rising Equitable Community Data Ecosystems (RECoDE) project, created, tested, and deployed the National Inventory 2.0 in 2021.

Specifically, the survey was constructed to answer the following questions:

1. Why are organizations sharing data across sectors?

2. What are the basic features of community data-sharing ecosystems?

    a. Participating sectors

    b. Data-sharing systems and functions

    c. Types of data

3. What progress is being made?

    a. Organizational data capacity

    b. Implementation of data-sharing systems

    c. Data governance and legal agreements

    d. Sustainable finance

4. Professed aims are to reduce disparities; how is equity centered in data sharing?

DASH Framework

DASH uses a conceptual framework in our work. A framework is helpful as an organizing structure of the field, providing a way to order important concepts. The DASH framework, graphically depicted in Figure 1, is a living document. It was created based on an environmental scan in 2015 and updated periodically based on feedback from subject matter experts and learnings from DASH grantees and collaborators.

The National Inventory includes measures corresponding to many concepts depicted in the framework, including organizational capacity, governance, centering equity across data processes, technology and interoperability, and systems change goals for data sharing.

Figure 1. DASH framework

DASH Framework 3.0: Building Equitable Data Ecosystems for Fostering Community Health
Data Across Sectors for Health (DASH), a national initiative of the Robert Wood Johnson Foundation, led in partnership by Illinois Public Health Institute and Michigan Public Health Institute, promotes new possibilities in sharing data to advance equity.

Methods
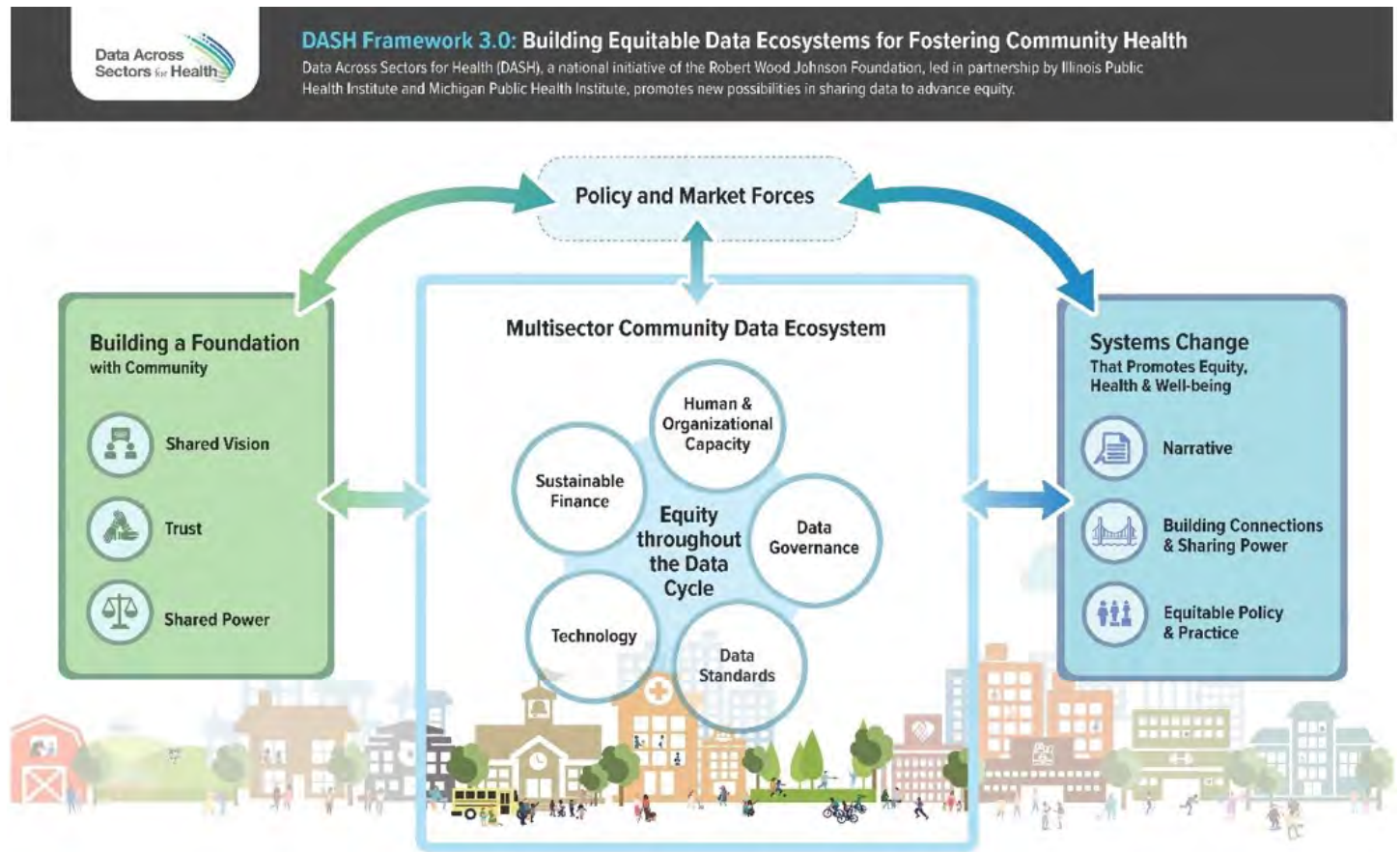
The National Inventory 2.0 is an updated and refined version of the National Inventory 1.0, which drew on existing survey items and underwent multiple iterations of testing. For the 2.0 version of the questionnaire, input was sought from a multi-disciplinary and diverse group of partners convened by data.org as part of a project entitled Rising Equitable Community Data Ecosystems (RECoDE). RECoDE project partners in addition to data.org and DASH were Health Leads, National Alliance against Disparities in Patient Health (NADPH), and BrightHive. NADPH pilot tested and conducted cognitive interviews with 20 subject matter experts (including professionals and people with lived experience) from communities across the United States. Minor adjustments to question wording and deletion of questions resulted from that feedback.

Survey Distribution

DASH recruited participants through the All In newsletter, social media posts, and DASH/All In networks of current and former grantees as well as other affiliated organizations. Additionally, All In partners and RECoDE partners disseminated the survey link to their networks. Survey responses were collected via Qualtrics from May to August 2021.

Recruitment materials explained that desired respondents should include "community-based organizations, healthcare providers, health departments, and community members who are working together to advance health, well-being, and equity"; and that the questions pertain to their "experience related to sharing data to support this work."

Data Analysis

Descriptive analyses were conducted for questions that correspond to each framework domain, with additional bivariate analyses that include sector and collaboration characteristics that may influence data-sharing capacity. Sectors were collapsed into six categories, including academia, healthcare, public health, social service & CBO (community-based organization) (advocacy, arts and culture, criminal justice, early childhood and K12 education, employment and workforce, housing, physical environment, and social and human services), technical infrastructure, and other sectors. Answers regarding organizations were aggregated to organization level, while answers regarding collaborations were aggregated to collaboration level by selecting the most favorable answers among the multiple respondents reported on the same organization or collaboration.

Results

Who Is Represented?

A total of 371 individuals responded to the survey. 261 (70%) respondents across 242 organizations reported that their organizations participate in one or more multisector data-sharing collaborations working towards advancing community health, with 33 (9%) participating in one collaboration and 228 (61%) in two or more collaborations.

These respondents reported 229 unique collaborations. Reported reasons preventing organizations from participating in data-sharing collaborations include concerns for client confidentiality, cost of technology, mistrust between sectors, legal barriers and delays, and not having the right data for positive outcomes.

About half of the organizations that reported participating in collaborations are nonprofits (52%,127) and about one-third are government agencies or public institutions (38%,91). 67 (28%) organizations are in the social service & CBO sector, 66 (27%) are in the public health sector, 48 (20%) are in the health care sector, 23 (10%) are in academia, and 12 (5%) are in the technical infrastructure sector (Figure 2).

Figure 2. Type and sector of reporting organizations (242 organizations)

Nonprofit 52%

Government/
public institutions 38%

Private/for-profit 5%

Faith-based 2%

Other 4%

Social service & CBO 28%

Public health 27%

Healthcare 20%

Academia 10%

Technical infrastructure 5%

Other 11%
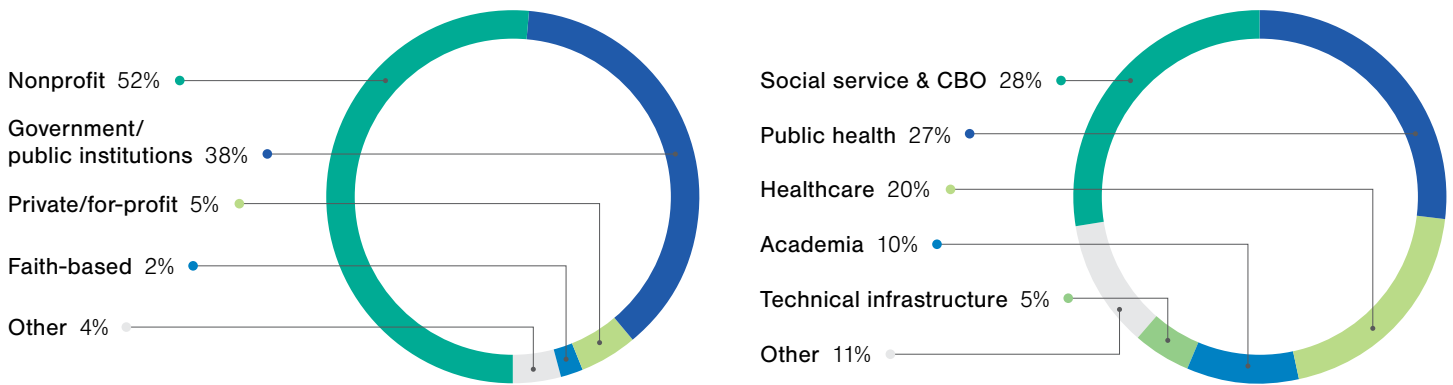
Why Share Data?

Most of the 261 respondents who reported participating in collaborations strongly agree or agree that the multisector collaborations that share data are likely to make a difference in the health of their communities (79%, 206), and are likely to reduce health inequities in their communities (71%, 185).

When asked about their driving purposes for sharing data within the collaboration, 131 (70%) of the 188 collaborations that answered this question reported that they share data to provide whole-person care & care coordination (abbreviated as care coordination), and 160 (85%) reported to conduct community assessment & improvement. More specifically, 26 (14%) only conduct care coordination, 55 (29%) only conduct assessment & improvement, and 105 (56%) conduct both activities.

Figure 3. Purposes for sharing data

Care coordination only (26)		Both (105)	
14%	29%	56%	
	Assessment & improvement only (55)		N/A (2)
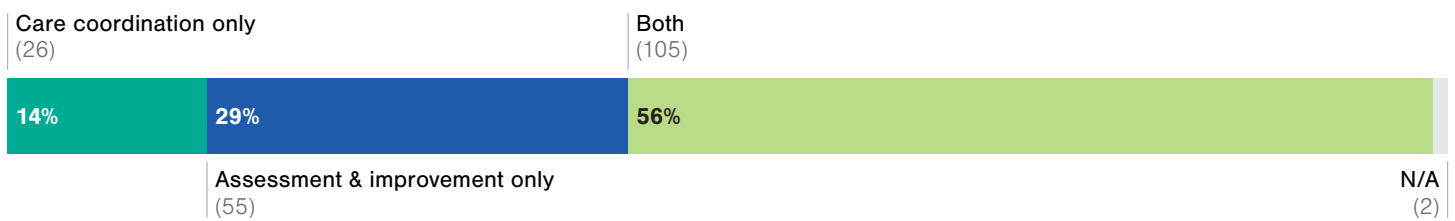
Respondents also provided the specific use cases for sharing data within the collaboration, under each of the two categories: care coordination and assessment & improvement (Figure 4). Note that holding organizations or systems accountable is a stand-alone use case.

Figure 4. Specific use cases

CARE COORDINATION (131)

Provide holistic care	79
Fast, more accurate referrals	78
Improve screening and assessments	77
Event notification	48
Improve eligibility determination	42

ASSESSMENT & IMPROVEMENT (160)

Identify community assets and needs	116
Measure quality and performance	108
Improve service targeting	103
Support policy and environmental change efforts	100
Engage community	99

Hold organizations or systems accountable	93

Multisector Data Ecosystems

Multisector data-sharing ecosystems are made up of the who, the what, and the how that enable sharing data and collaboration within a community.

Sectors Representation

The survey asked what sectors are represented in the collaborations and what their roles are. Most collaborations involve the social service & CBO sector (81%, 186), public health sector (75%, 172), and healthcare sector (72%, 166). About half of the collaborations involve the academia sector (59%, 136) and the technical infrastructure sector (51%, 117) (Figure 5).

Figure 5. Sectors represented in collaboration (n=229 collaborations)
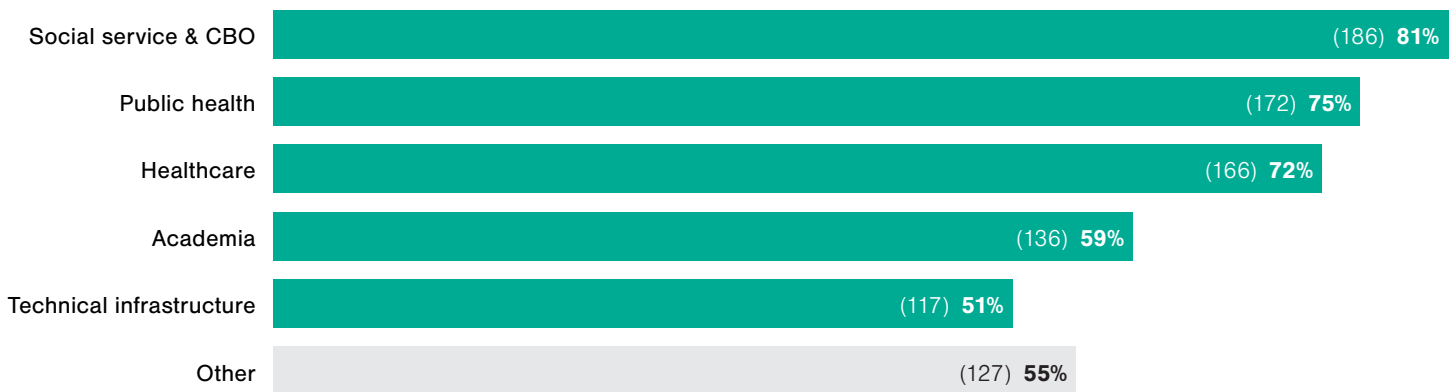
Among the collaborations involving the social service & CBO, public health, or healthcare sector, the sector's roles most commonly are data contributor, data user, and leadership. For the collaborations that reported involving the academia sector, the sector most frequently serves as a data user. Among the collaborations involving the technical infrastructure sector, the sector most frequently serves as data integrator (Figure 6).

Figure 6. Sector roles in collaboration
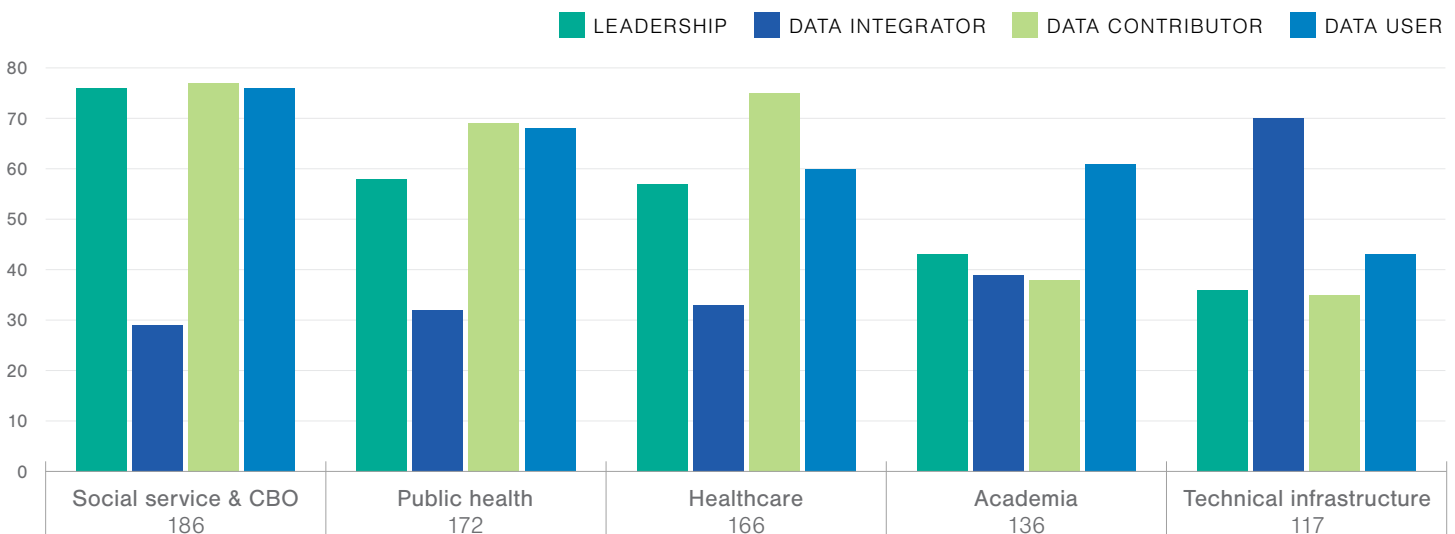
Collaboration Age and Target Areas

Most of the collaborations have been in operation for 5 years or less (66%, 125) (Figure 7).

Figure 7. Collaboration years in operation (n=190 collaborations)

37%	28%	12%	8%	14%
0–2 years (71)	3–5 years (54)	6–8 years (22)	9–11 years (16)	12+ years (27)

The collaborations' target geographic areas cover most of the United States. The map below (Figure 8) shows the target states, counties, cities, and zip codes (note that the state of Alaska and Hawaii county of Hawaii state are not proportionally represented on the map). Not shown on the map are target areas covering the entire United States as reported by 8 collaborations, and areas covering the United States and associated territories as reported by 3 collaborations.

Figure 8. Collaborations' reported target areas: states, counties, cities, and zip codes
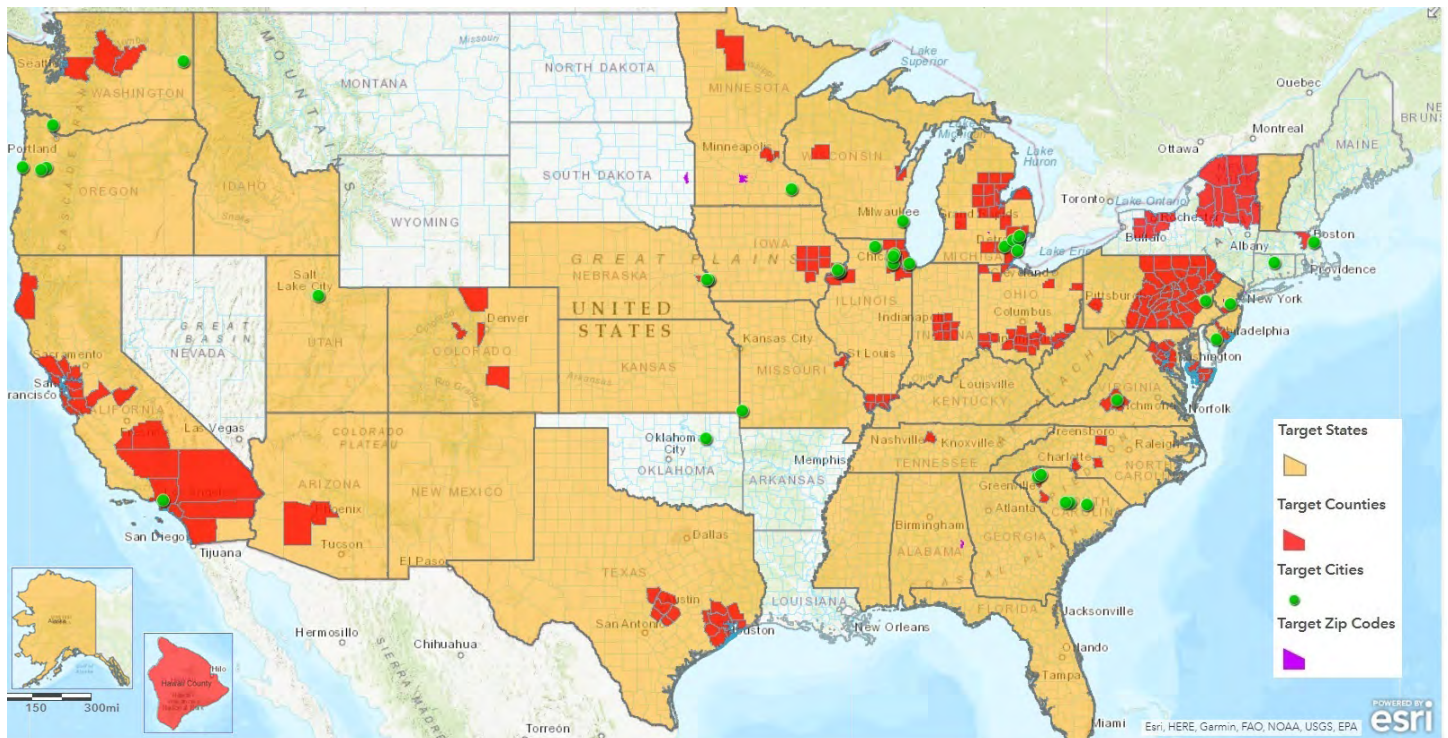
The most frequently reported level of target areas is county level (28%, 58) (Figure 9). This is true across all the collaborations' age categories. About two thirds of the collaborations focus on metropolitan areas (68%, 135), about half of the collaborations target rural areas (52%, 103), and there are a small number of collaborations targeting Native American reservations or tribal nations (14%, 27) (Figure 10).

Figure 9. Geographic level best describing collaboration target areas (n=208 collaborations)

County	(58) **28%**
Region within a state	(40) **19%**
State	(32) **15%**
Multiple states	(19) **9%**
City/town/village	(17) **8%**
Multiple cities/towns/villages	(16) **8%**
Region among multiple states	(9) **4%**
Multiple neighborhoods	(8) **4%**
Neighborhood	(6) **3%**
None of these	(3) **1%**
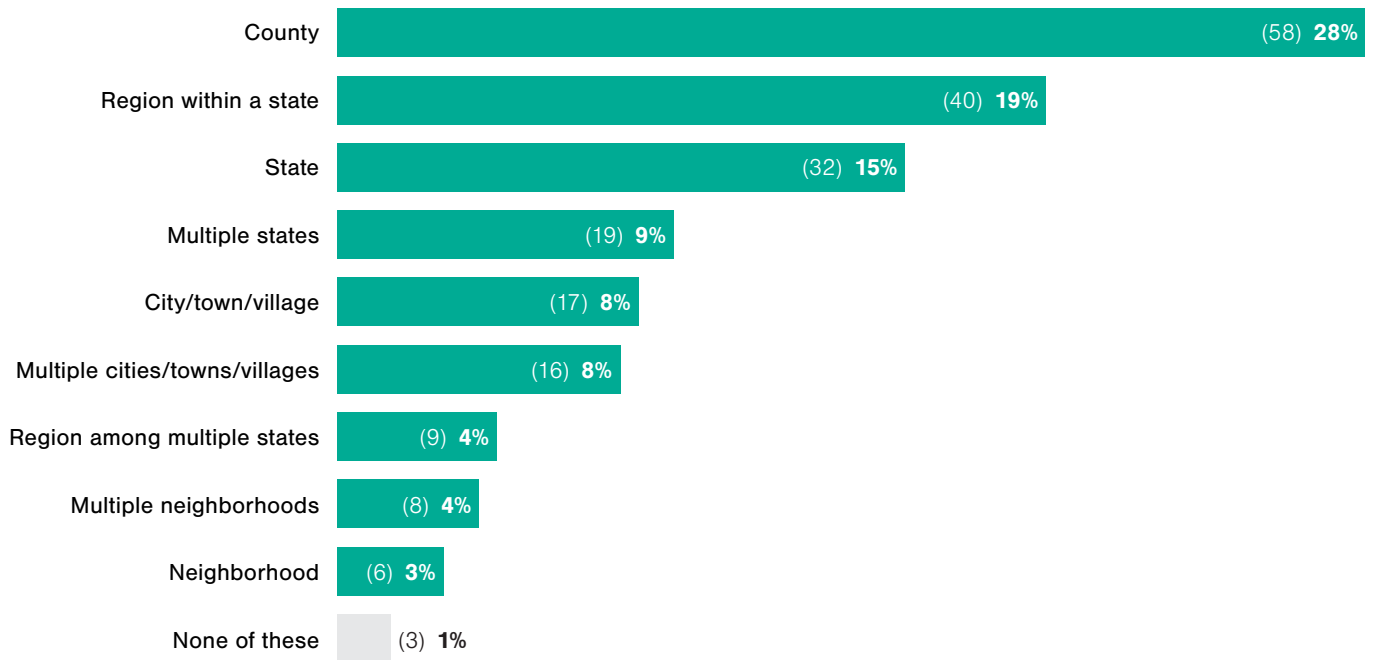
Figure 10. Geographic regions of collaboration target areas (n=198 collaborations)

Metropolitan area	(135) **68%**
Urban	(120) **61%**
Rural	(103) **52%**
Native American reservation or tribal nation	(27) **14%**

Types of Data

Respondents were asked about the types of data that their collaboration's data system was designed to share. Most collaborations' data system was designed to share aggregated data about people (79%, 150), data about places (e.g., characteristics about places) (64%, 122), or data about organizations or service providers (62%, 118) (Figure 11).

Figure 11. Types of data collaborations' data systems designed to share (n=191 collaborations)

Aggregated data about people	(150) **79%**
Data about places	(122) **64%**
Organization or service provider data	(118) **62%**
Anonymized personal data	(90) **47%**
Identifiable personal data	(85) **45%**
Other	(7) **4%**
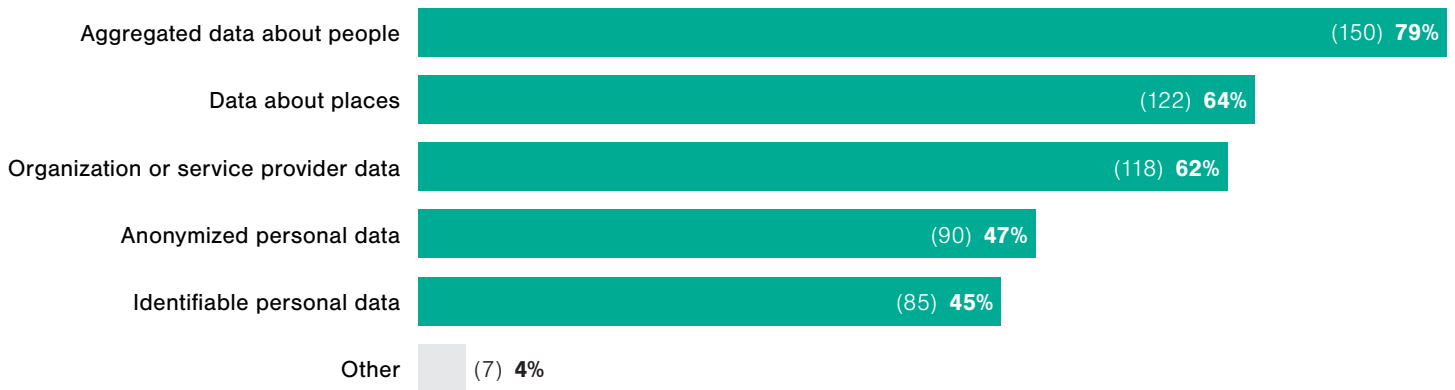
Technical Infrastructure

As shown in Figure 12, the most common data system or resource used by data-sharing collaborations is a data repository (62%, 118). Multi-payer claims data is least often used by the reported collaborations (17%, 32).

Figure 12. Data systems/resources used by collaboration for data sharing (n=191 collaborations)

YES   NO   DON'T KNOW

Data repository	(118) **62%**
Open data platform	(99) **52%**
Case management platform	(98) **51%**
Social service provider directory	(87) **46%**
Health information exchange	(83) **43%**
Integrated data system	(77) **40%**
Integrated health and human service eligibility and enrollment systems	(48) **25%**
Community information exchange	(44) **23%**
Multi-payer claims data	(32) **17%**
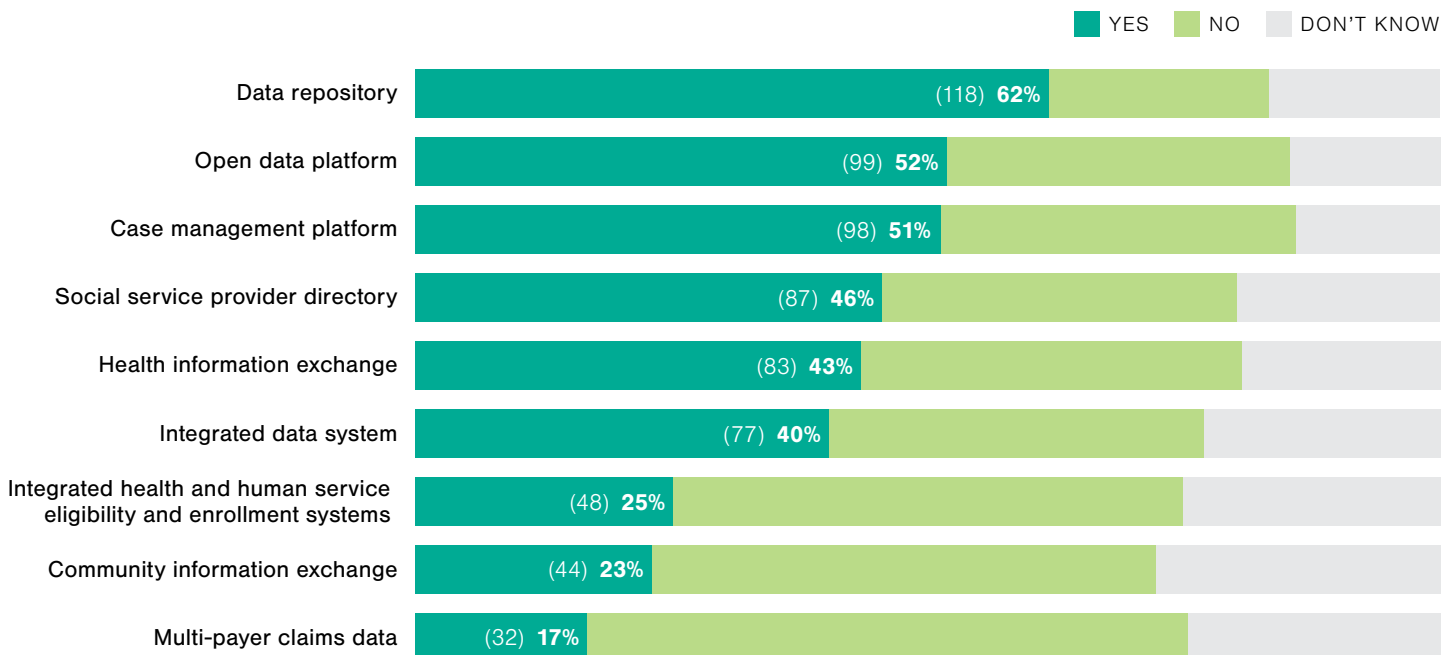
Progress

Data Sharing Implementation Stage

Most collaborations are in either the initial planning stage or the implementation stage regarding the stage of development of their shared data system for performing specific use cases (Figure 13). The innovation stage most commonly occurs around screening and assessments (17%) and identifying community assets and needs (16%).

Figure 13. Stage of development for each specific use case
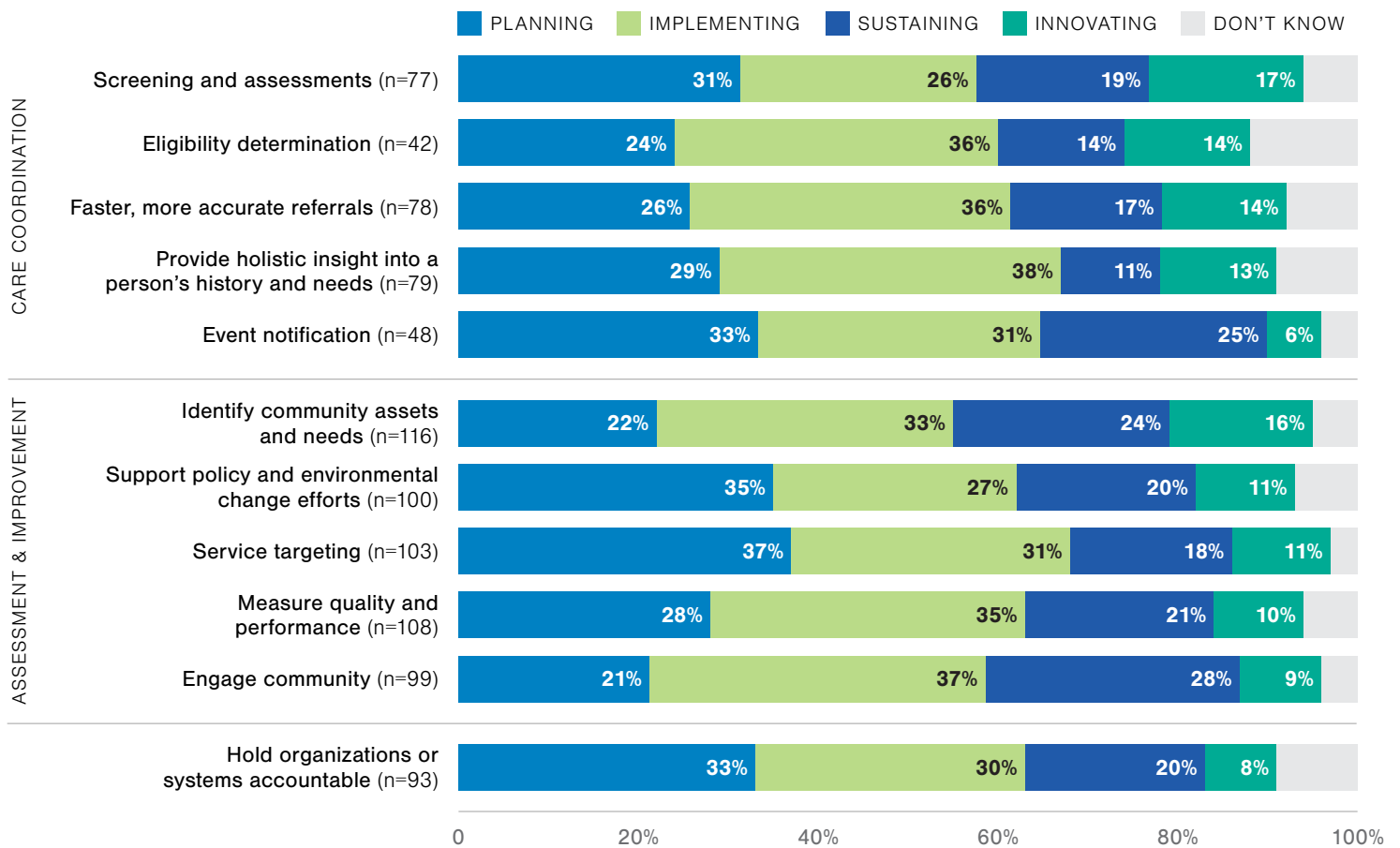
We next examined the functions of data systems of collaborations with at least one use case that has advanced beyond the planning stage. Overall, generating reports (72%, 108), manipulating, visualizing and presenting data (66%, 99), and calculating metrics (58%, 87) are the top three data functions among the 150 collaborations that have at least one use case beyond the planning stage (Figure 14). Figure 15 shows these data functions as grouped by the two broad categories of the use cases: care coordination and assessment & improvement. While the same top three data functions also apply to the collaborations that conduct assessment & improvement, the top three data functions among the 83 collaborations that are conducting care coordination are generating reports (70%, 58), looking up individuals (63%, 52), and visualizing data (60%, 50).

Figure 14. Currently supported and used functions of data systems of collaborations with a use case beyond the planning stage (n=150 collaborations)

Function	Value
Generate reports	(108) **72%**
Manipulate, visualize, and present data	(99) **66%**
Calculate and display metrics and indicators	(87) **58%**
Map geographic information	(73) **49%**
Match records across systems	(65) **43%**
Look up and query specific individuals	(62) **41%**
Make predictions	(52) **35%**
Link records in real time	(38) **25%**
Automate decision support	(22) **15%**
Other	(7) **5%**
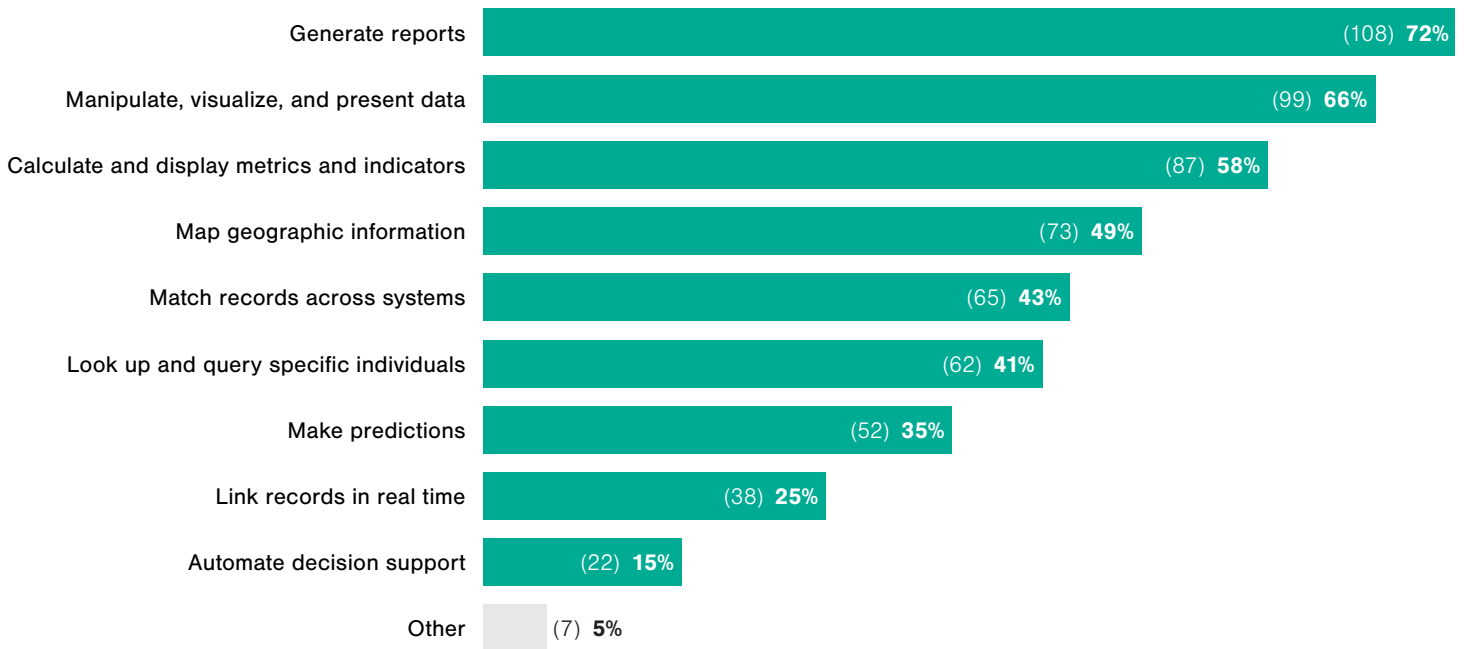
Figure 15. Currently supported and used functions of data systems of collaborations with a use case beyond planning stage, by use case category: care coordination and assessment & improvement

CARE COORDINATION (n=83)		ASSESSMENT & IMPROVEMENT (n=127)
58	Generate reports	93
50	Manipulate, visualize and present data	88
44	Calculate and display metrics and indicators	75
32	Map geographic information	69
48	Match records across systems	52
52	Look up and query specific individuals	47
32	Make predictions	47
33	Link records in real time	33
17	Automate decision support	19
4	Other	4
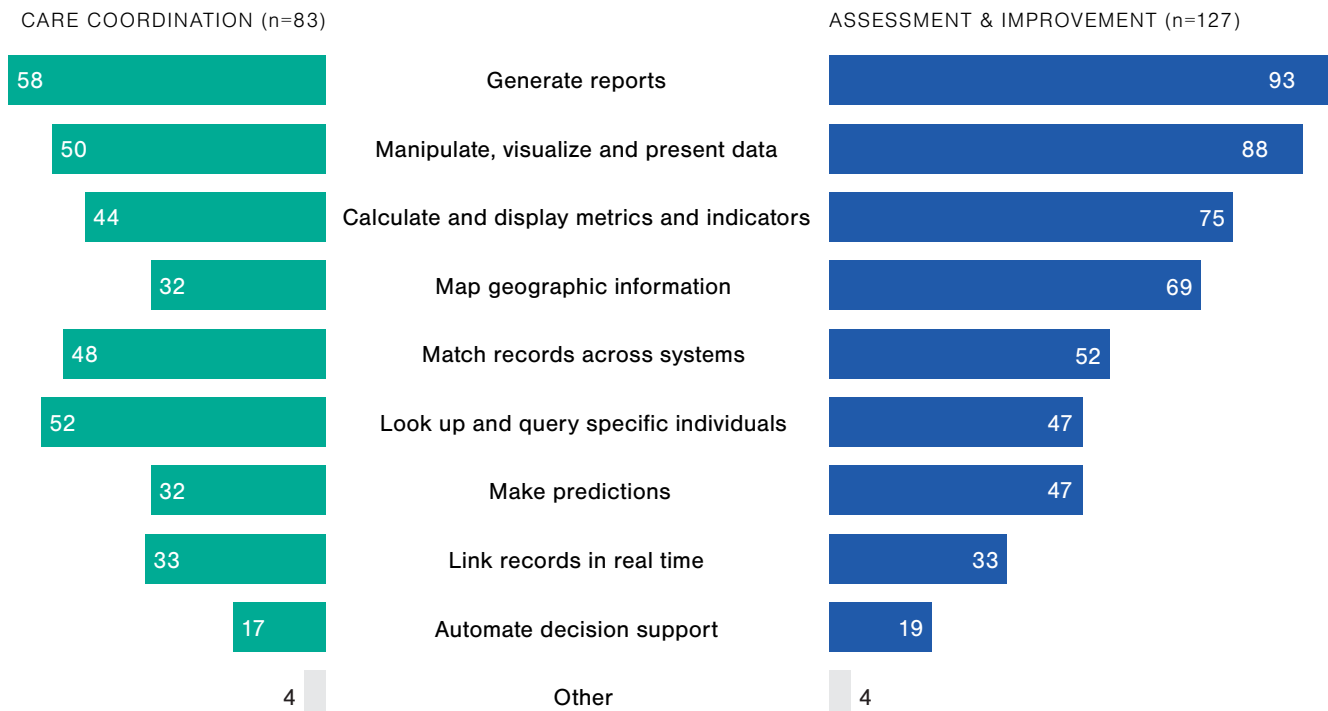
Organizational Capacity

Sharing data requires that participating organizations have the capacity to be effective community-engaged data-sharing partners.

The statements in Figure 16 reflect organizations' approach and culture regarding collecting, storing, and using data. Almost all the organizations strongly agree or agree that they use data to better understand the impacts of their efforts (95%, 224). Most organizations strongly agree or agree that their leaders have a clear idea of how data can be used to drive decisions beyond the justification of funding (86%, 204). About half of the organizations strongly agree or agree that funding requirements define most of the data their organization decides to collect (51%, 118).

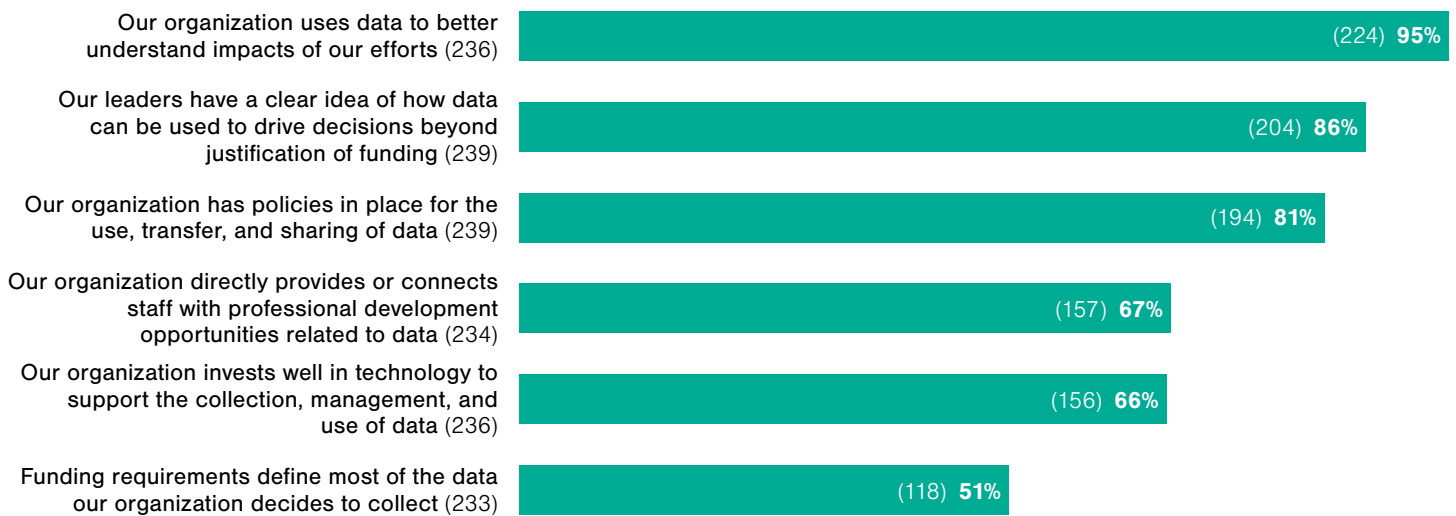*Figure 16. Organization's approach and culture regarding data — strongly agree or agree with the following statements*

Our organization uses data to better understand impacts of our efforts (236)	(224) **95%**
Our leaders have a clear idea of how data can be used to drive decisions beyond justification of funding (239)	(204) **86%**
Our organization has policies in place for the use, transfer, and sharing of data (239)	(194) **81%**
Our organization directly provides or connects staff with professional development opportunities related to data (234)	(157) **67%**
Our organization invests well in technology to support the collection, management, and use of data (236)	(156) **66%**
Funding requirements define most of the data our organization decides to collect (233)	(118) **51%**

Across different sectors, strongly agreeing or agreeing with the above statements varies mainly in three areas (Figure 17). The social service & CBO sector and the public health sector have lower proportions than the other sectors in having policies in place for the use, transfer, and sharing of data. In providing staff professional development related to data, the social service & CBO sector has the lowest proportion. In investing in technology to support data system, the public health sector and the social service & CBO sector both have lower proportions than the other sectors.

Figure 17. Organization's approach and culture regarding data across sectors — strongly agree or agree with the following statements
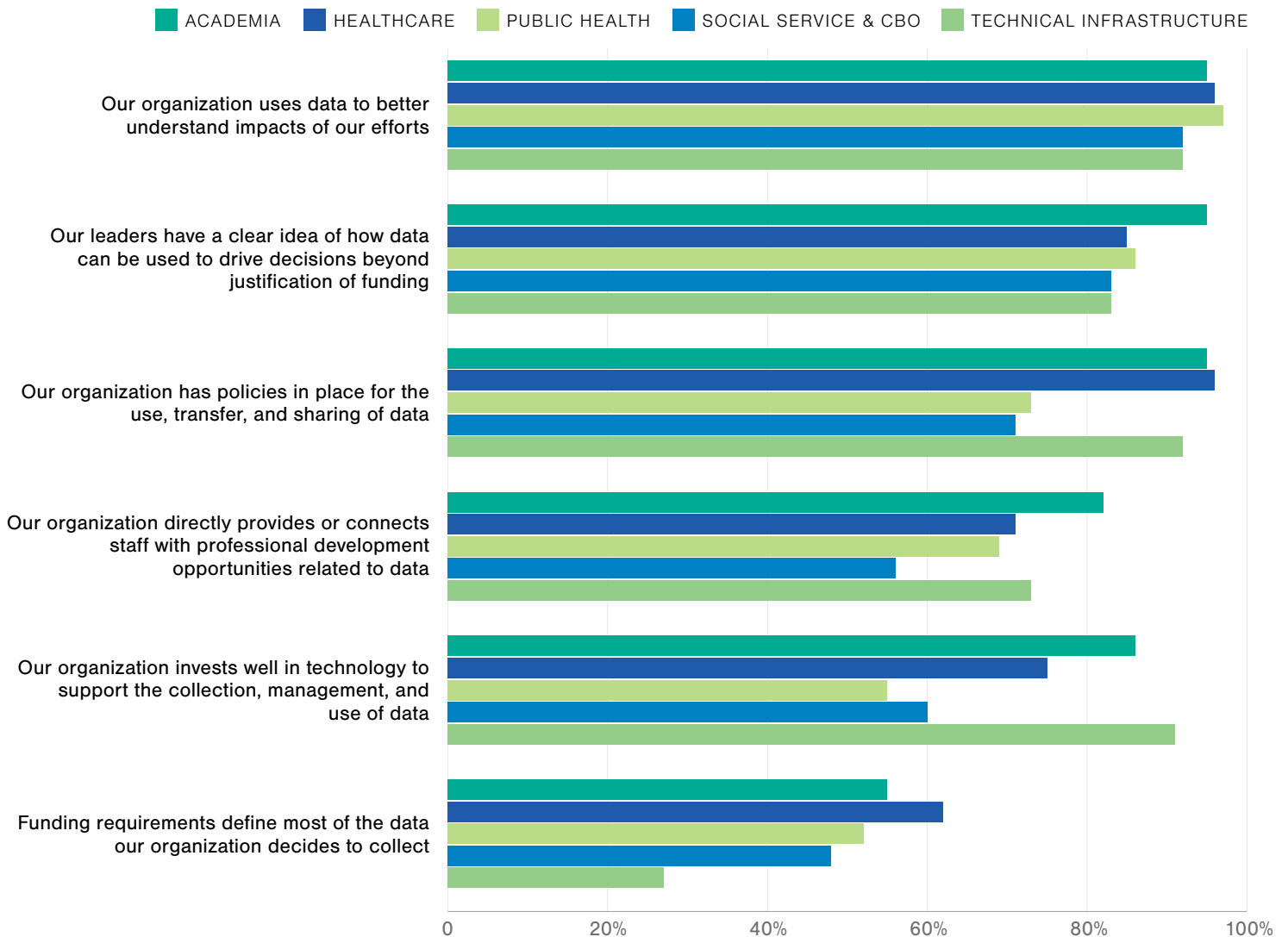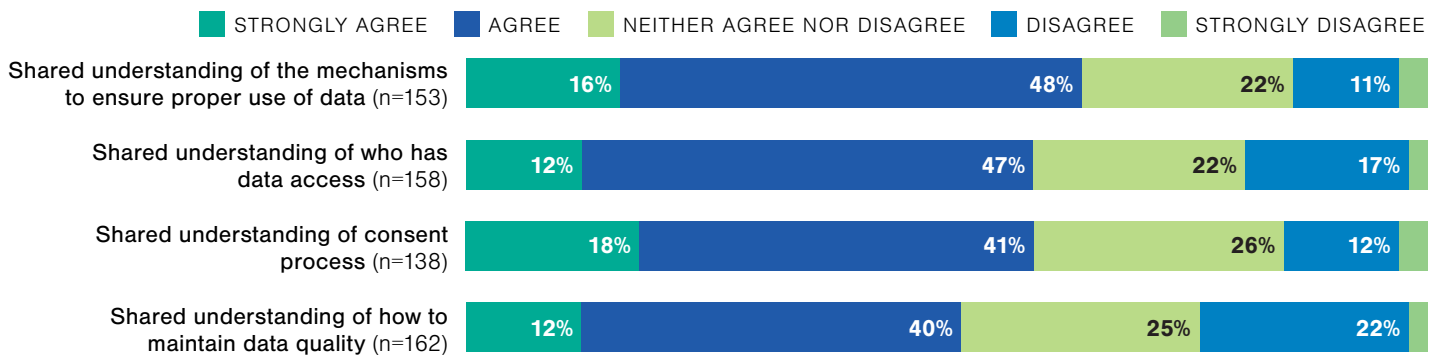
Data Governance

Data governance refers to the process of ensuring the freedoms, constraints, and incentives that determine how parties agree to conduct the collection, use, protection, and sharing of data, tools, methods, and knowledge amongst themselves and with others.

Over half of respondents strongly agreed or agreed that their collaboration had shared understanding related to all four components of data governance on the survey: proper use of data, data access, consent process, and data quality (Figure 18).

Figure 18. Data governance in data-sharing collaborations

Legend: STRONGLY AGREE | AGREE | NEITHER AGREE NOR DISAGREE | DISAGREE | STRONGLY DISAGREE

Shared understanding of the mechanisms to ensure proper use of data (n=153): 16% | 48% | 22% | 11%

Shared understanding of who has data access (n=158): 12% | 47% | 22% | 17%

Shared understanding of consent process (n=138): 18% | 41% | 26% | 12%

Shared understanding of how to maintain data quality (n=162): 12% | 40% | 25% | 22%
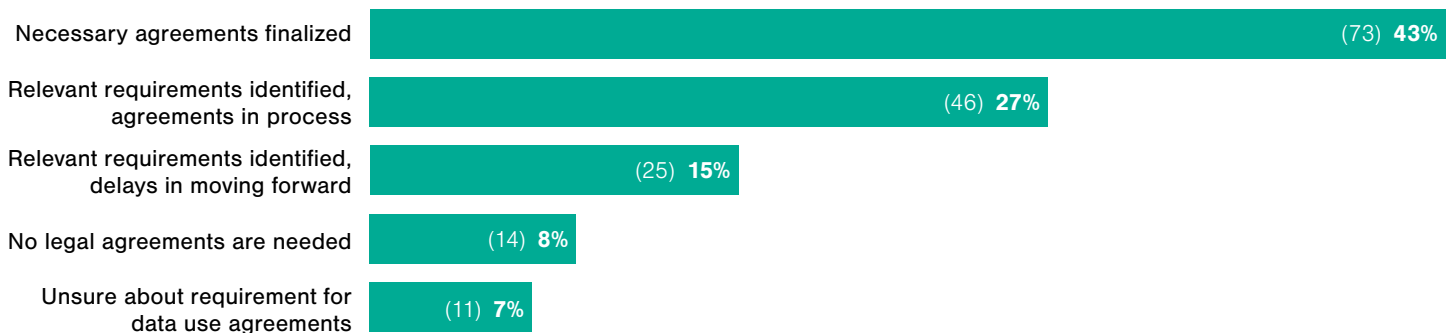
Legal Agreements

Legal agreements between partner organizations ensure that data sharing complies with relevant laws. Legal agreements can also be used to enforce data governance mechanisms across the parties. Often there are no cut-and-dried answers about the legality of data sharing or how to comply. In such cases, many organizations (and their attorneys) make conservative decisions to reduce risk, setting up unnecessary barriers to data sharing.

Out of 169 collaborations with data on legal agreements, many have finalized legal agreements (43%, 73) or are in the process of finalizing legal agreements necessary for data sharing (27%, 46). A small proportion of collaborations (7%, 11) indicated that they are unsure about the requirements for data use agreements (Figure 19).

Figure 19. Progress on legal agreements in data-sharing collaborations (n=169)

Necessary agreements finalized: (73) 43%

Relevant requirements identified, agreements in process: (46) 27%

Relevant requirements identified, delays in moving forward: (25) 15%

No legal agreements are needed: (14) 8%

Unsure about requirement for data use agreements: (11) 7%

Sustainable Finance

About three-quarters of the collaborations that provided data reported that they use grants as funding sources to support their data-sharing system (76%, 128). About half of the collaborations reported using ongoing public funding (52%, 88), organizational budget allocation (49%, 82), and in-kind (47%, 79) as funding sources. 14% (23) of collaborations reported using sales or contracts, and 12% (21) reported using membership dues or fees as funding sources (Figure 20).

Among the collaborations that use grants for funding, 18% (23) use grants exclusively. The rest also rely on in-kind donations (49%, 63), ongoing public funding (48%, 62), and/or allocations from organizational budgets (48%, 61) (Figure 21).

Collaborations reported most frequently using two funding sources (31%, 53). No collaboration relies on sales or subscription fees alone for funding (Figure 22).

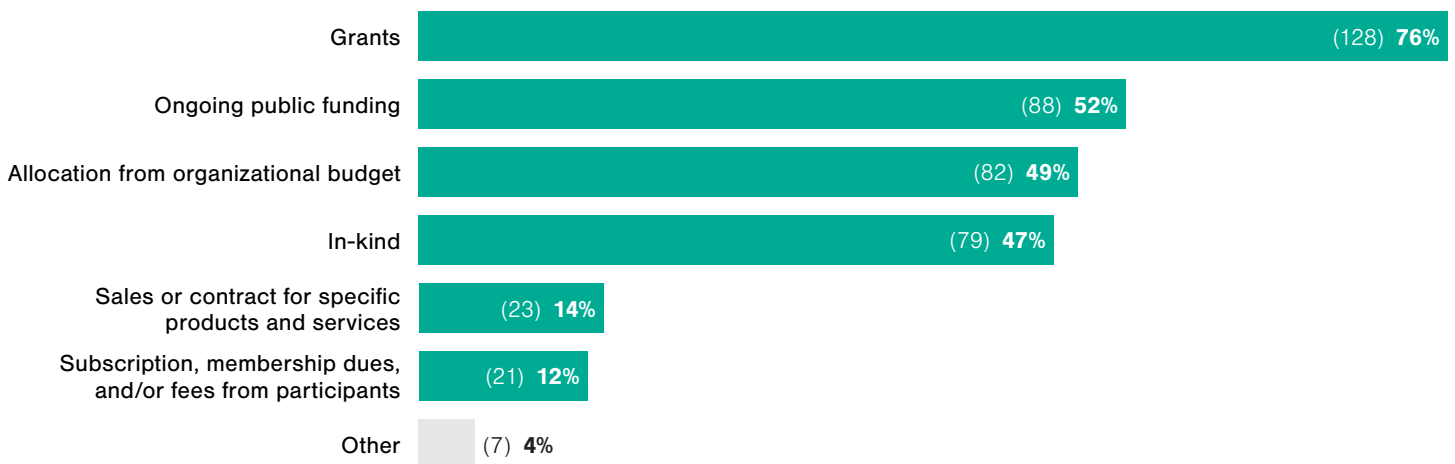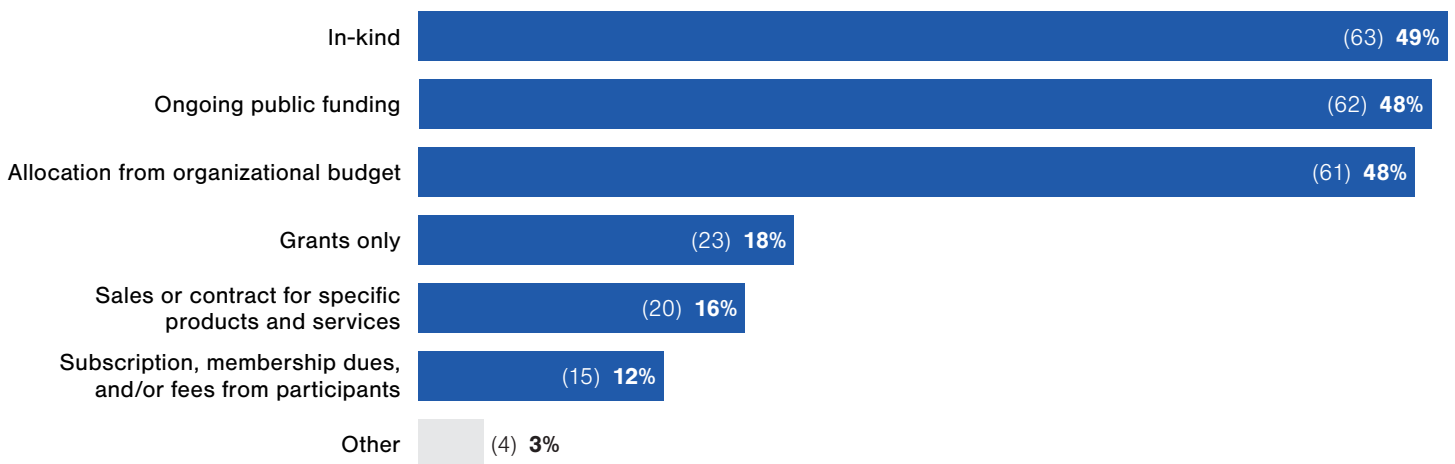*Figure 20. Collaboration funding sources (n=169)*

Grants	(128) **76%**
Ongoing public funding	(88) **52%**
Allocation from organizational budget	(82) **49%**
In-kind	(79) **47%**
Sales or contract for specific products and services	(23) **14%**
Subscription, membership dues, and/or fees from participants	(21) **12%**
Other	(7) **4%**

Figure 21. Funding sources of collaborations that use grants for funding (n=128)

In-kind	(63) **49%**
Ongoing public funding	(62) **48%**
Allocation from organizational budget	(61) **48%**
Grants only	(23) **18%**
Sales or contract for specific products and services	(20) **16%**
Subscription, membership dues, and/or fees from participants	(15) **12%**
Other	(4) **3%**

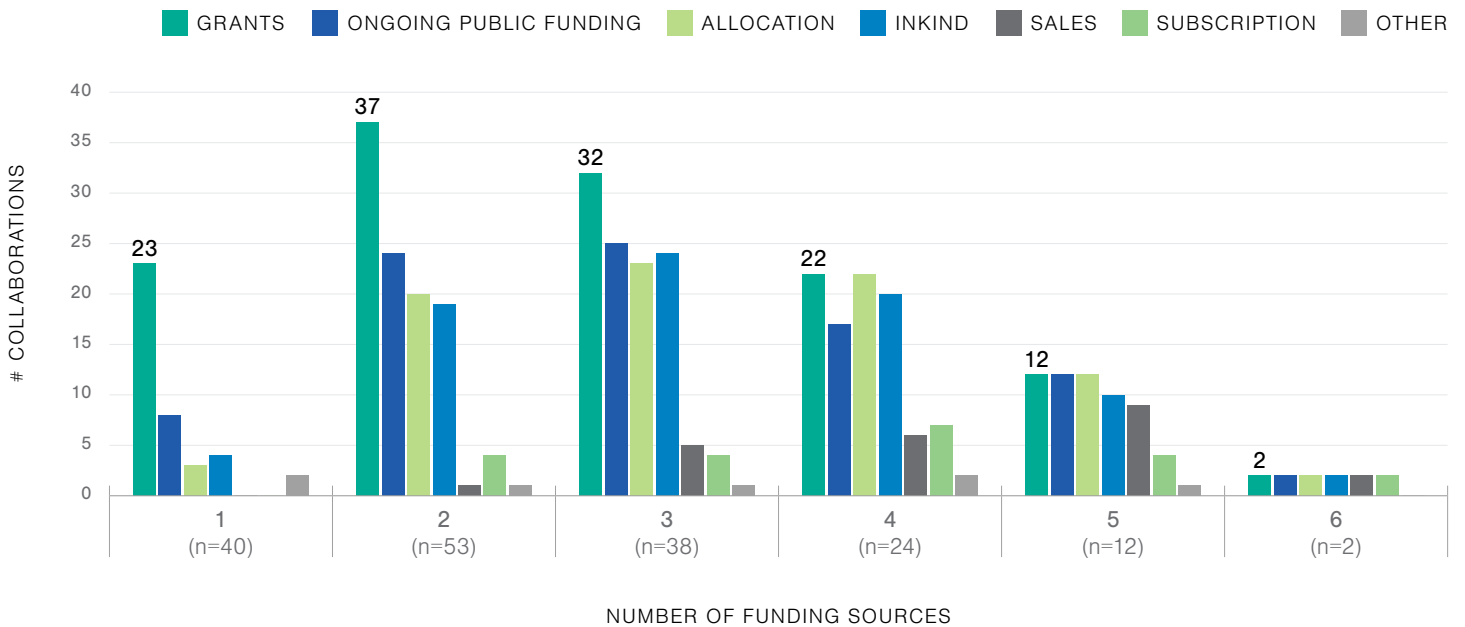*Figure 22. Funding sources by the number of funding sources*

Figure 23 presents the responses on the sustainability of multisector data sharing. Out of the 149 collaborations with data, 15% (22) have an established self-sustaining funding structure, 14% (21) have a financing plan for long-term sustainability of data sharing with a critical mass of partners aligned around it, and 36% (53) know how to pay for some components of their long-term data-sharing strategy but not others. 30% (45) have no sustainability plan.

Figure 23. Collaboration funding sustainability (n=149)
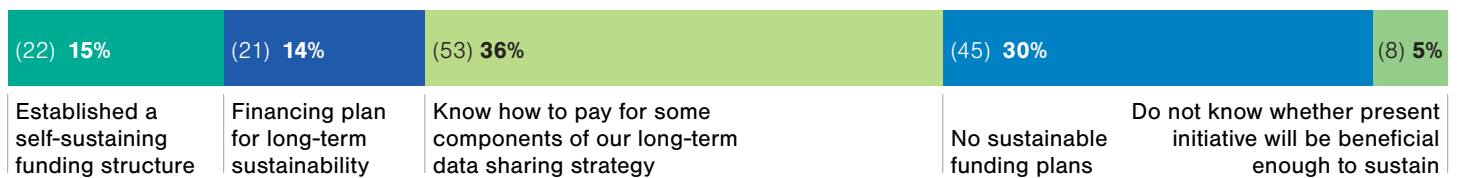
Equitable Data Practices

Collaborations may have the intent of sharing data in order to reduce health inequities, but sharing data does not come without the risks of harm. Examples of harm include reinforcing negative narratives, replicating structural racism by making decisions using biased data, or harming individuals through disclosure leading to biased treatment or punitive action.

As shown in Figure 24, most collaborations reported that they always engage or engage most of the time in the data practices asked in the survey. Assessing whether outcomes vary by identity groups was most frequently reported as being practiced always or most of the time (73%, 118), whereas assessing how the risk or negative of data sharing could vary by identity groups was least frequent (59%, 92).

DASH supports co-creating with communities, such that people with lived experience (PWLE) have a clear role, with multiple channels and opportunities to participate. A series of questions asked respondents to reflect on how people with lived experience are involved in each data-sharing phase of the data life cycle, from planning, collecting data, determining data access, analyzing data, interpreting findings, and developing recommendations to reporting data and disseminating data findings. Planning and developing recommendations are the top two phases where collaborations most frequently include PWLE in making decisions or where collaborations actively engage PWLE. For any data-sharing phase, 25% to 57% collaborations reported having not involved PWLE at all (Figure 25).

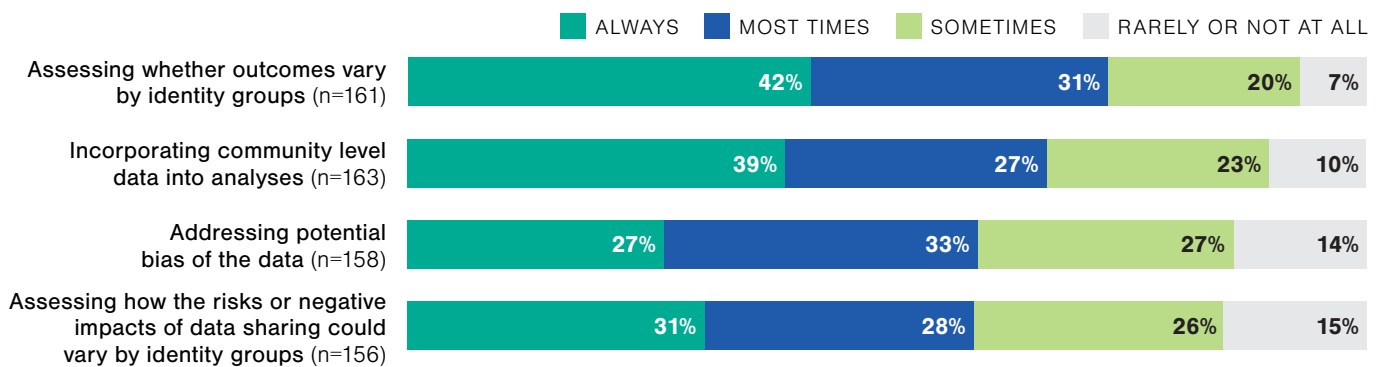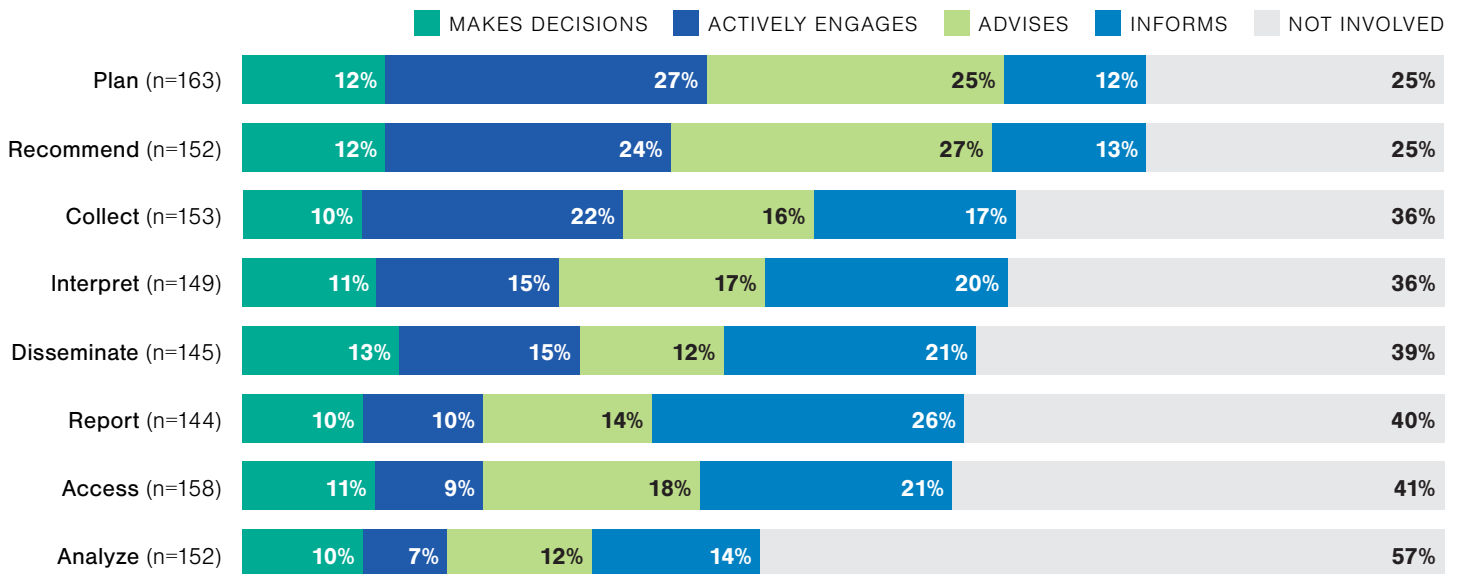*Figure 24. Equitable data practices among data-sharing collaborations*

Legend: ALWAYS | MOST TIMES | SOMETIMES | RARELY OR NOT AT ALL

	ALWAYS	MOST TIMES	SOMETIMES	RARELY OR NOT AT ALL
Assessing whether outcomes vary by identity groups (n=161)	42%	31%	20%	7%
Incorporating community level data into analyses (n=163)	39%	27%	23%	10%
Addressing potential bias of the data (n=158)	27%	33%	27%	14%
Assessing how the risks or negative impacts of data sharing could vary by identity groups (n=156)	31%	28%	26%	15%

Figure 25. Involving people with lived experience in data-sharing processes

Legend: MAKES DECISIONS | ACTIVELY ENGAGES | ADVISES | INFORMS | NOT INVOLVED

	MAKES DECISIONS	ACTIVELY ENGAGES	ADVISES	INFORMS	NOT INVOLVED
Plan (n=163)	12%	27%	25%	12%	25%
Recommend (n=152)	12%	24%	27%	13%	25%
Collect (n=153)	10%	22%	16%	17%	36%
Interpret (n=149)	11%	15%	17%	20%	36%
Disseminate (n=145)	13%	15%	12%	21%	39%
Report (n=144)	10%	10%	14%	26%	40%
Access (n=158)	11%	9%	18%	21%	41%
Analyze (n=152)	10%	7%	12%	14%	57%

Conclusion

The 229 data-sharing collaborations represented in this report work in areas covering almost all of the United States, working at the neighborhood, city, county, state, and even national level.

Most of them have been in operation for 5 or less years. Although the majority of these collaborations involve the social service & CBO sector, this sector has lower organizational capacity in some areas than the other sectors, notably in having policies in place for data use, staff professional development, and investing in technology to support data-sharing.

Within most collaborations, there is a shared understanding of all the aspects of data governance. However, about half of the collaborations are still in the process of finalizing their legal agreements.

Grants remain the main current funding source. While more than half of the collaborations have some kind of financing plan for their long-term data-sharing strategies, about one-third do not have any sustainable financing plan.

Across any data-sharing phase of the data life cycle (except for analyzing data), over half of the collaborations involve people with lived experience in some way. Just 10–12% involve PWLE in making decisions, and 25–40% of the collaborations do not involve PWLE in any way at all.