



Early Learnings from an Emerging Field

EXECUTIVE SUMMARY

Prepared by the DASH National Program Office for the
Robert Wood Johnson Foundation



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The sheer volume and velocity of data at our fingertips today is unprecedented...As we build a Culture of Health - a nation where everyone has the opportunity to live longer, healthier lives - it will be critical to ensure communities can effectively use and manage this information in ways that help people get healthy and stay healthy.

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- Risa Lavizzo-Mourey, MD, MBA, President and CEO, Robert Wood Johnson Foundation

EXECUTIVE SUMMARY

Data Across Sectors for Health: Early Learnings from an Emerging Field

In an effort to foster alignment among health care, public health, and other community systems to address the social determinants, the Robert Wood Johnson Foundation (RWJF) is working to build a Culture of Health. As part of its focus on the role of data to enable multi-sector collaborations to achieve population health, RWJF launched Data Across Sectors for Health (DASH). DASH aims to identify barriers, opportunities, promising practices, and indicators of progress for multi-sector collaborations to connect information systems and share data for community health improvement. The DASH National Program Office (NPO) is led by the Illinois Public Health Institute in partnership with the Michigan Public Health Institute and with support from the Foundation.

Conducting the Environmental Scan

The DASH NPO conducted an environmental scan to document the emerging field. The original objectives of the scan were as follows:

1. Provide information on relevant activities, leading communities, and research
2. Identify promising examples of shared data and/or connected information systems across sectors to improve health
3. Synthesize findings into lessons learned in regards to barriers, gaps, and opportunities
4. Develop recommendations for the Foundation
5. Serve as a baseline for measuring progress, including the development of specific indicators to track the field over time

To begin the scan, the DASH NPO and RWJF identified three dimensions of using data across sectors. These characteristics served as key criteria to determine the extent to which existing initiatives meet the overarching DASH priorities.



Collaborative

“Collaborative” is used to describe multi-organizational relationships engaged in ongoing operations working across boundaries to solve problems that cannot be easily solved by institutions acting alone. Entities that operate for or on behalf of collaborations are also included.



Multi-sector

Health care and public health are considered traditional health sectors. Inclusion of sectors representing the social determinants of health—such as social services, housing, education, transportation, community safety, community development, and businesses—help deepen an understanding of health and health equity in communities.



Shared data and information

Health data can be raw, aggregate, summary, linked, layered, reference or other data. Data that is interpreted, analyzed and properly displayed can become useful information that informs meaningful actions to improve individual and community health. Connected information systems include health information exchange, bilateral data bridges, shared access to a data warehouse, and integrated data from multiple sectors with a community in common.

Data collection activities conducted for the scan included a literature review and online research, key informant interviews, and an online survey. Data sharing initiatives meeting the three DASH key characteristics were entered into a database, the “DASH Catalog,” which currently includes information on over 85 initiatives. The research team also collected “use cases,” or examples of how information resulting from data sharing informs practice. Narrative data was entered into NVivo and coded for common descriptive elements and themes related to challenges and factors that promote success. Each data source is described in detail at the end of this summary.

While the scan was underway, the NPO released a Call for Proposals (CFP). The immense response seemed to indicate that the size of the field was much larger than the number of initiatives documented by the scan to date. The DASH NPO leveraged the CFP proposal process as an additional source of information for the scan, including poll questions conducted during CFP informational webinars and from the brief applications.

Several limitations emerged from these data collection methods. Ultimately, the findings rely primarily on information in reports and conversations with a small group of participating stakeholders. Unsuccessful examples and project failures are likely underrepresented.

The Current State of the Environment

This initial report reflects an understanding of the field of data across sectors as of September 2015. The findings and insights will be tested, expanded, and refined as DASH continues its work.

Information collected primarily concerned:

1. The types of distributions of entities that currently share data or plan to share data
2. The purposes for sharing or planning to share data
3. The tools used to share, analyze, and utilize data

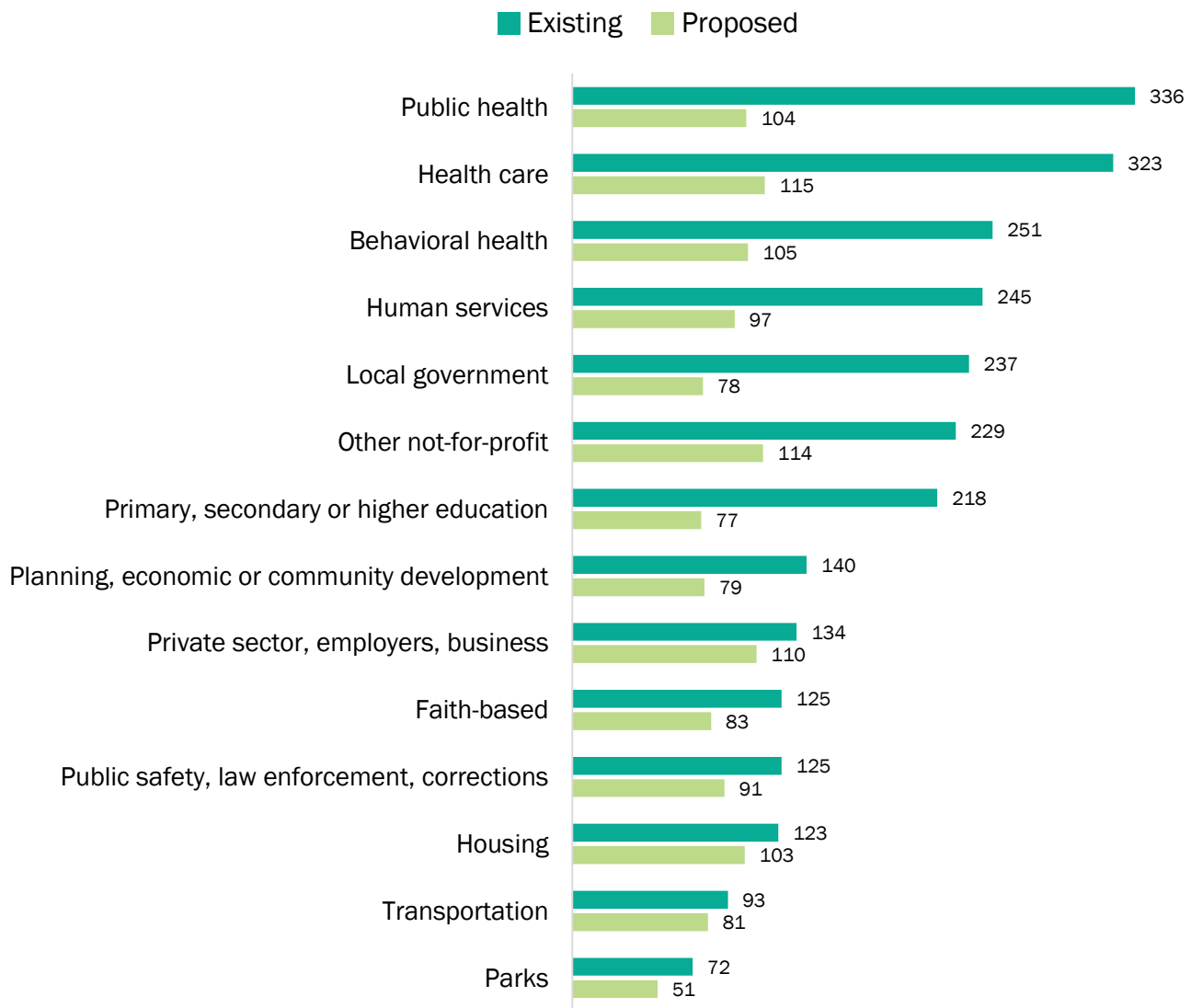
Many sectors are currently engaged in collaborations, but new connections are envisioned

Collaborations focused on sharing data across sectors for community health improvement are widespread, with the greatest level of activity occurring in the northeastern coast, the Midwest, and California. The majority of existing collaborations are led by health care delivery and public health, but there is an increasing understanding and interest in sectors representing the social determinants of health. As one key informant stated:

“This is new, cutting-edge, and there is no road map.”

Respondents to the May 2015 Call for Proposals (n=409) indicated the sectors represented in their existing data collaborations and described additional sectors to be included in their proposed projects.

Figure 1. Sectors represented in existing collaborations and sectors to be added in proposed projects (n=409)



Source: DASH CFP applications, May, 2015

Sectors providing data (data sources) differed from sectors using data (data users)

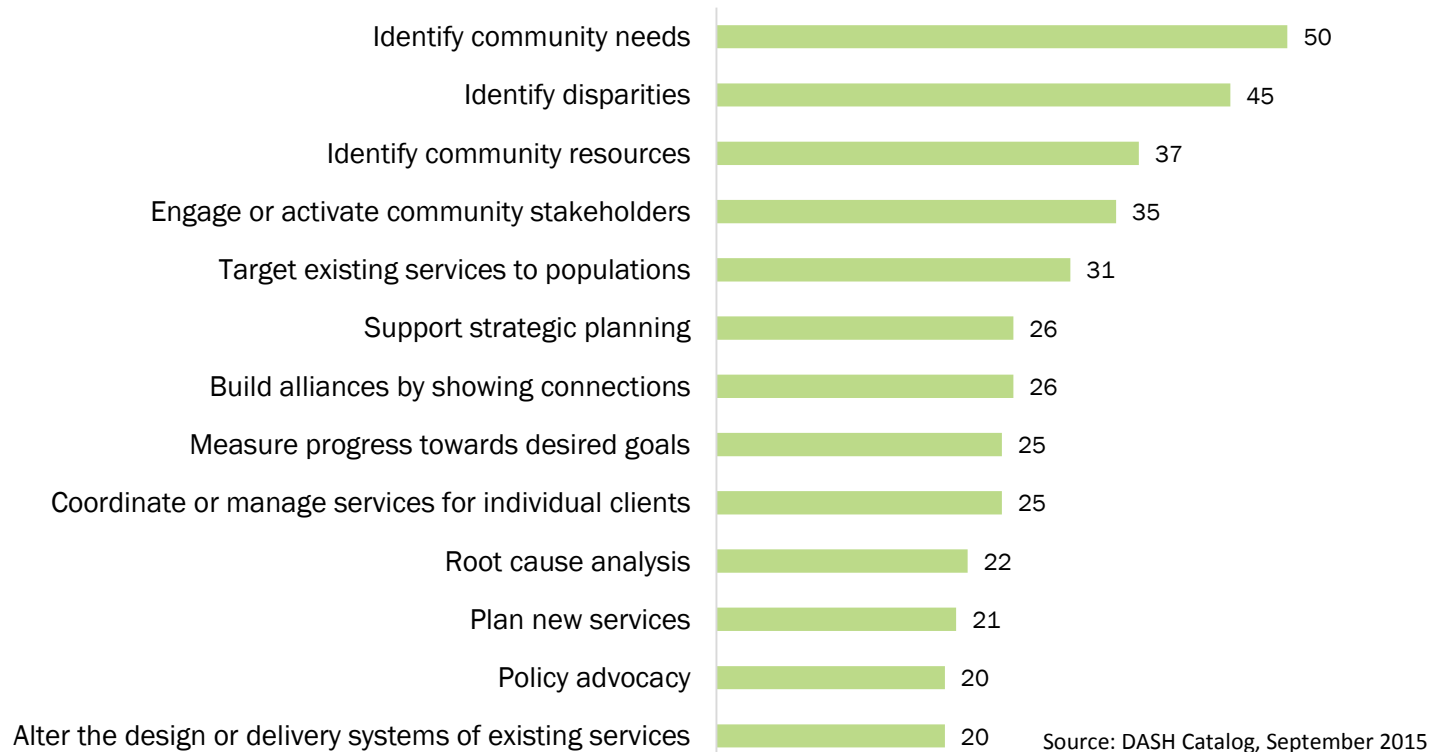
The most common sectors providing data and using data include health care, public health, human services, and other not-for-profits. Health care settings, law enforcement, corrections, and transportation are most often data sources; whereas public health, human services, education, not-for-profits, faith-based institutions, and businesses are more frequently data users.

Data Sharing Purposes

Collaborations believe sharing data will improve community health in a variety of ways

Most initiatives share and use data to identify community needs, document disparities, and identify community resources. Other common purposes relate to conducting specific activities, such as engaging stakeholders and targeting services to high-need populations. Of the 85 initiatives documented in the initial scan, these common purposes were identified:

Figure 2. Data Sharing Purposes (n=85)



Planned uses for data sharing exceed current uses

The online survey conducted as a part of the scan revealed that although many initiatives currently use data for assessment and planning, they aspire to do much more. Areas for future expansion of data sharing initiatives include promoting health in all policies, planning new services, policy and advocacy, provider accountability, social impact financing, and improving patient satisfaction.

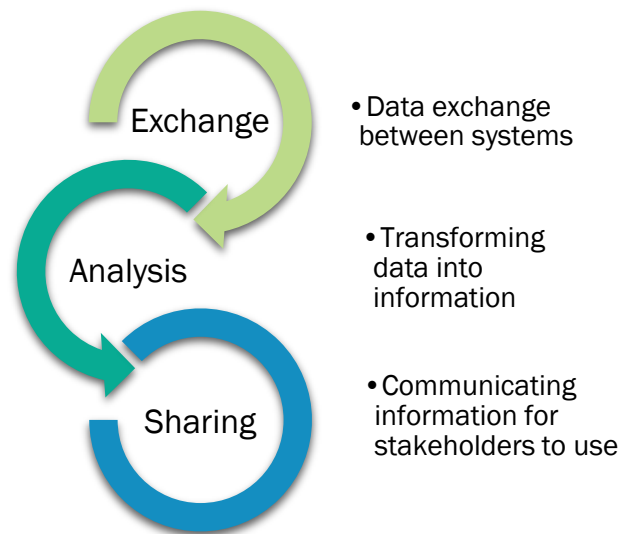
Turning Data into Information and Action

Raw data, in and of itself, is not useful to stakeholders

Key informants emphasized the challenges involved in making data actionable—magnified when shared across sectors. Approaches to sharing, analyzing and disseminating information must be appropriate for the stakeholders involved. As one key informant explained:

“Everyone said, ‘We need the data. We need the data.’ So we gave them the data. Then we asked them how they were using it and they couldn’t tell us. So we went back and asked them again what they wanted to do, so that we could give them what they needed.”

Sharing data across sectors for community health is a process with different challenges encountered at each step.



Many technological tools are emerging

Details regarding the specific technology used to share data across sectors was not always available. Often, just a few individuals or vendors have technological expertise and therefore, this knowledge is not widespread among staff or all the stakeholders involved. Despite this obstacle, many stakeholders interviewed are interested in learning best practices for choosing and implementing specific tools and database systems.

Electronic data exchange across sectors is occurring, but manual processes are the norm

Despite the nationwide investment in health information technology and exchange, a persistent challenge has been keeping pace with current technology to digitize and automate approaches, moving data to the right place, at the right time, for the right purpose. Among a smaller subset of initiatives that report sharing data electronically, this activity primarily occurs through shared information systems and common repositories or data warehouses.

There are a variety of methods of data analysis and information sharing

To inform and encourage action, it is critical that data is presented in formats that support decision-making and consider the sectors engaged. Across many initiatives, maps or geographic information systems (GIS), ad hoc reports (queries), and statistical analyses were cited as commonly used tools. Dashboards are often preferred to display comparative information in clinical settings and population health, whereas written reports and websites are selected to share information with community stakeholders and planners.

One key informant shared:

“One of the biggest accomplishments we had early on was when we sat down with the land use planning folks (with health indicator maps). They are starving for this kind of community health metrics. Their jargon is so different, but we eventually realized we were talking about the same thing. We had a mutually beneficial learning curve. This spilled into things we would do with the school system and other community partners.”

Classifying Initiatives as a Way to Understand the Emerging Field

To better understand the types of initiatives in the Catalog, the DASH NPO developed a preliminary classification scheme using elements of the three key characteristics. Each key characteristic represents a domain of interest, with sub-domains reflecting a range of attributes affiliated with these domains. These domains and attributes provide a framework to begin understanding similarities and differences between initiatives.

Domain 1: Collaborative Efforts

The scan revealed that data sharing occurs in a variety of institutional relationship configurations. Examples include:

- **Multi-sector collaborations:** These collaborative efforts collect and combine data from multiple sources, analyze it, and share results with stakeholders. An agreed-upon values case is shared whereby each participant gives and receives benefits from the collaboration.
- **A single entity collects and analyzes information from multiple sectors for its own use:** For example, when a local public health entity convenes stakeholders around the CDC's Healthy People 2020 objectives or when a non-for-profit hospital fulfills the community benefits requirement by conducting a Community Health Needs Assessment.
- **Private or quasi-public enterprises, such as analytics vendors, lead efforts:** These entities use information that is multi-sectoral or take data from one sector to help another sector develop solutions. These arrangements often make data accessible to stakeholders through interfaces such as online dashboards and query-able databases.

Domain 2: Sectors

As a domain, sectors are fairly straightforward and easy to classify. Sectors considered include the “traditional” health sectors of health care delivery, public health, and personal health and wellness, as well as those representing the social and environmental determinants of health. These include: behavioral health; human services; local government; other non-for profit organizations; primary, secondary or higher education; planning, economic or community development; the private sector, employers, and business; faith-based organizations; public safety, law enforcement, and corrections; housing.

Domain 3: Shared data and connected information systems

Many approaches to sharing data and technologies that facilitate the collection, exchange, analysis and sharing of information are still maturing. The most common tools and technologies used by the initiatives in the Catalog included: standard report builders, ad hoc reports, mapping/geographic information systems, calculation of metrics, indicators and dashboards; statistical analysis; individual matching; automated decision-support, recommendations, or alerts; predictive analytics; electronic analysis; technology tools for sharing information with stakeholders, and individual health and wellness devices.

Across all DASH Domains: Improving Community Health

For a multi-sector data sharing collaboration to be relevant to DASH, it must work towards improving participants' capacity to design, lead, and implement community health improvement initiatives. The initial scan helped to identify an array of specific purposes for multi-sector data sharing. As collaborations and information systems mature, data sharing activities can support multiple aims.

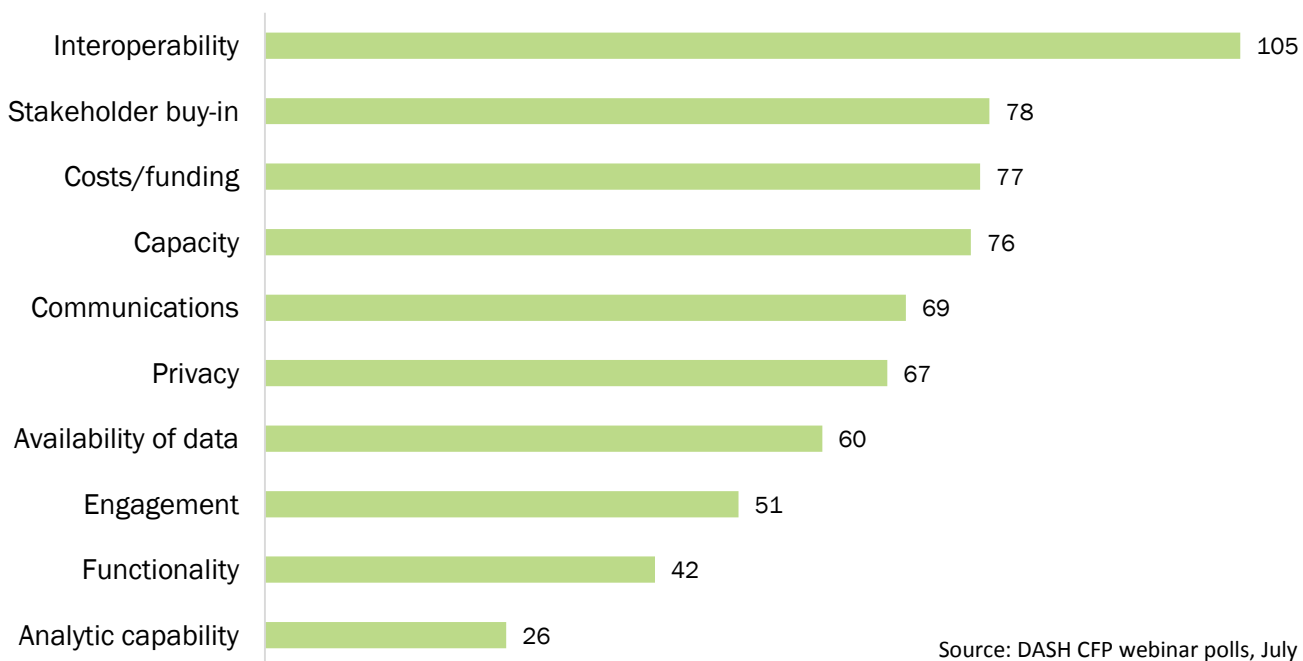
Thus far, the purposes of the initiatives seem to cluster around the following primary community health aims:

- **Patient care/point-of-care services:** Linking individual level data to provide coordinated and more holistic care for high need populations, including examples led by social service or health care.
- **Needs and resource assessment, planning and monitoring:** Measuring community health at a granular level to conduct needs assessments, identify disparities, monitor improvement over time, and other community-level impacts.
- **Research and policy:** Applying analytics to better understand populations for the purpose of policy, advocacy, engagement, and/or research.
- **Multi-purpose:** These include health information exchanges that initially provide infrastructure for care coordination and then become a repository for public health monitoring as well as needs assessment that make their data collections publicly available.

Challenges and Lessons Learned

Beyond providing a snapshot of the current state of the field, data collected for the scan revealed themes around challenges, lessons learned, and solutions for growth as related to data and information sharing for community health improvement. Four hundred and twenty webinar participants for the call for proposals, who were involved in some capacity with data initiatives across the country, answered a question regarding their primary barrier to effective information exchange. Their top responses are represented in Figure 3 below:

Figure 3. Barriers Reported by Webinar Participants (n=420)



Source: DASH CFP webinar polls, July 2015

These responses were also reinforced by the online survey and key informant interviews and thus, two overarching themes pertaining to challenges emerged: 1) technical and operational and 2) relationship management. Not surprisingly, a lack of resources including time, commitment, funding, and expertise were noted as primary barriers to addressing these challenges.

Technical and operational challenges

- **Familiarity with data:** Many entities lack capacity to analyze data locally. Also, each sector has its own understanding of the data fields, common terms, indicators, and how they can be used. Thus, collaborating organizations must collectively agree on standardized definitions in order to fully understand the data and reconcile any discrepancies.
- **Ensuring data quality:** Ensuring data validity and accuracy is a resource intensive and time-consuming task. Particularly when working across sectors, it takes significant time and effort to understand the meaning and interpretation of the data to the entities that collected it. One respondent described this experience as “data wrangling.”
- **Interoperability:** Data needs to be structured and standardized in order to be integrated into a data system. This issue is particularly salient as it relates to ways in which social determinants of health data is integrated into existing data systems, such as electronic health records.

Difficulty managing relationships in cross-sector collaborations

- **Making the value case:** Diverse stakeholders have different goals and incentives driving their work. All stakeholders must see the value of data sharing at the start of the initiative to ensure continued interest, participation, and commitment. Using data from sectors beyond health presents additional complexities due to lack of a shared language that would make the data more meaningful to all stakeholders. For example, a key informant observed:

“We’ve found that what we really need to do is make sure our language is not public health language. We need to make sure all sectors can understand it. Our action cycle relies on generic terms and having language vetted by various audiences.”

- **Building trust among stakeholders:** Challenges associated with trust related to four key areas: 1) data as turf (claiming power through ownership), 2) the fear of data revealing flaws, 3) privacy and security, and 4) technical aspects of the data system.
- **Establishing strong governance:** Initiatives must continuously attend to challenges governing collaborations while also considering the governance of data. Strong governance models for data include developing a common set of rules for collecting, protecting, sharing, and acting on data; specifying use cases; and being transparent about data stewardship.

“Data is an asset and you get what you negotiate. If you go into a collaborative and the partners don’t have the same mission, or one of you gets more out of it than the other, one of you is going to walk away before it’s done. It’s not unusual.”

Limitations

The primary limitation of this report is also a significant finding: the field of community data sharing collaborations striving for community health impact is best described as a diverse and dynamic set of activities that defy simplistic description and categorization. During the process of conducting the scan, the four key characteristics of DASH underwent several revisions to best capture the breadth and complexity of the field. In addition, the team identified three major limitations.

- The “emerging field” is so new, diverse and dynamic that any conclusions must be considered preliminary.
- The DASH frameworks are descriptive and analytic, but not evaluative.
- Variability and availability of information about initiatives inhibits ability to generalize.

Going forward, flexible curation is necessary to capture new data, update and validate existing information, and refine concepts to reflect a more nuanced understanding of the field over time.

Next Steps

A high level of energy and enthusiasm exists for data sharing across sectors from experts and practitioners alike. To guide efforts moving forward, the DASH NPO identified a set of next steps. These will inform understanding of how multi-sector data sharing initiatives increase knowledge and capacity so that ultimately, effective interventions and policies are developed and implemented to improve community health.

Monitor the environment

- Continue to monitor initiatives documented in the DASH Catalog for promising practices and community health impacts
- Further develop the DASH domains and attributes to enable a clearer and deeper understanding of how DASH initiatives build capacity for community health impact
- Refine data collection and management strategies to improve an understanding of the field
- Develop a deeper analysis of the 409 brief proposals and the 31 full proposals received in response to the DASH Call for Proposals
- Collaborate with a network of similar initiatives across the country

Develop indicators of progress

- Document key measures, including the number and characteristics of known instances of multi-sector collaborations sharing data for community health
- Track progress in areas such as sustainability, technological advancement, and interoperability
- Collect compelling stories of impact and conduct a robust evaluation

Provide technical assistance

- Identify promising resources and best practices to assist practitioners in areas identified as particularly challenging. These include using data to engage multiple audiences, using data to inform policy, making the value case for sharing data to specific sectors, addressing staff capacity and training, overcoming technical challenges, improving governance, building trust, addressing privacy and confidentiality concerns, and identifying funding and sustainability models.

Moving from Describing the Field to Guiding the Field

As the DASH National Program Office continues to monitor the field and share lessons learned, networking with community practitioners, national experts, government, and other stakeholders will continue to be an important component of DASH. Together, with a deeper and more descriptive understanding of how DASH initiatives contribute to community health impact, we can move from describing the environment to setting a shared agenda and developing common priorities that guide this emerging field. We invite others to share their own findings, emerging approaches, and best practices to create a more accurate and comprehensive representation of the environment.

Data Sources for the Environmental Scan

DASH Catalog: Composed of coded information on 85 initiatives identified from a literature review and research on existing multi-sector data sharing initiatives.

Key informant interviews: Twenty-five 60-90 minute key informant interviews.

- **Phase 1:** Nine national experts advancing the field of data and information systems, interoperability, and community health improvement discussed their perspective on the scope and challenges of the emerging field, and identified other experts and interesting initiatives.
- **Phase 2:** Sixteen practitioners from across the country discussed information systems, technical infrastructure, and the collaborations supporting multi-sectoral data initiatives. Participants varied in their role with respect to data sharing, but all were familiar with one or more areas of interest such as the governance structure, use case, issues related to privacy and security, and technical infrastructure for data sharing.

Electronic survey: Preliminary findings from the interviews informed the design an electronic survey. Snowball sampling recruitment methods garnered 42 responses to the survey, 39 of which were useful for analyses. Survey results provided more detail on the purposes of data sharing, stakeholders involved, the nature of the information systems in use, and other concerns related to barriers than could not be captured by internet research. The survey instrument is also in Appendix C.

DASH CFP: Interest generated by the DASH funding opportunity revealed community initiatives across the country that had thought about, planned, and implemented multi-sector data sharing initiatives. The NPO designed several opportunities to collect codified data from these stakeholders:

- **Webinar polling:** Over 1000 individuals attended one of two webinars held to describe the DASH CFP to potential applicants.
- **Brief proposal:** 409 applicants submitted a brief proposal describing current data sharing status and planned expansion.

About Data Across Sectors for Health

To learn more, visit www.dashconnect.org or follow us @DASH_connect.