Data Across Sectors for Health

Early Learnings from an Emerging Field

DASH ENVIRONMENTAL SCAN

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

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.

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

September 2015

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EXECUTIVE SUMMARY

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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 Illinois Public Health Institute leads the DASH National Program Office (NPO) 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. A database called the "DASH Catalog" collects information on data sharing initiatives meeting the DASH key characteristics, and 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 and distribution 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

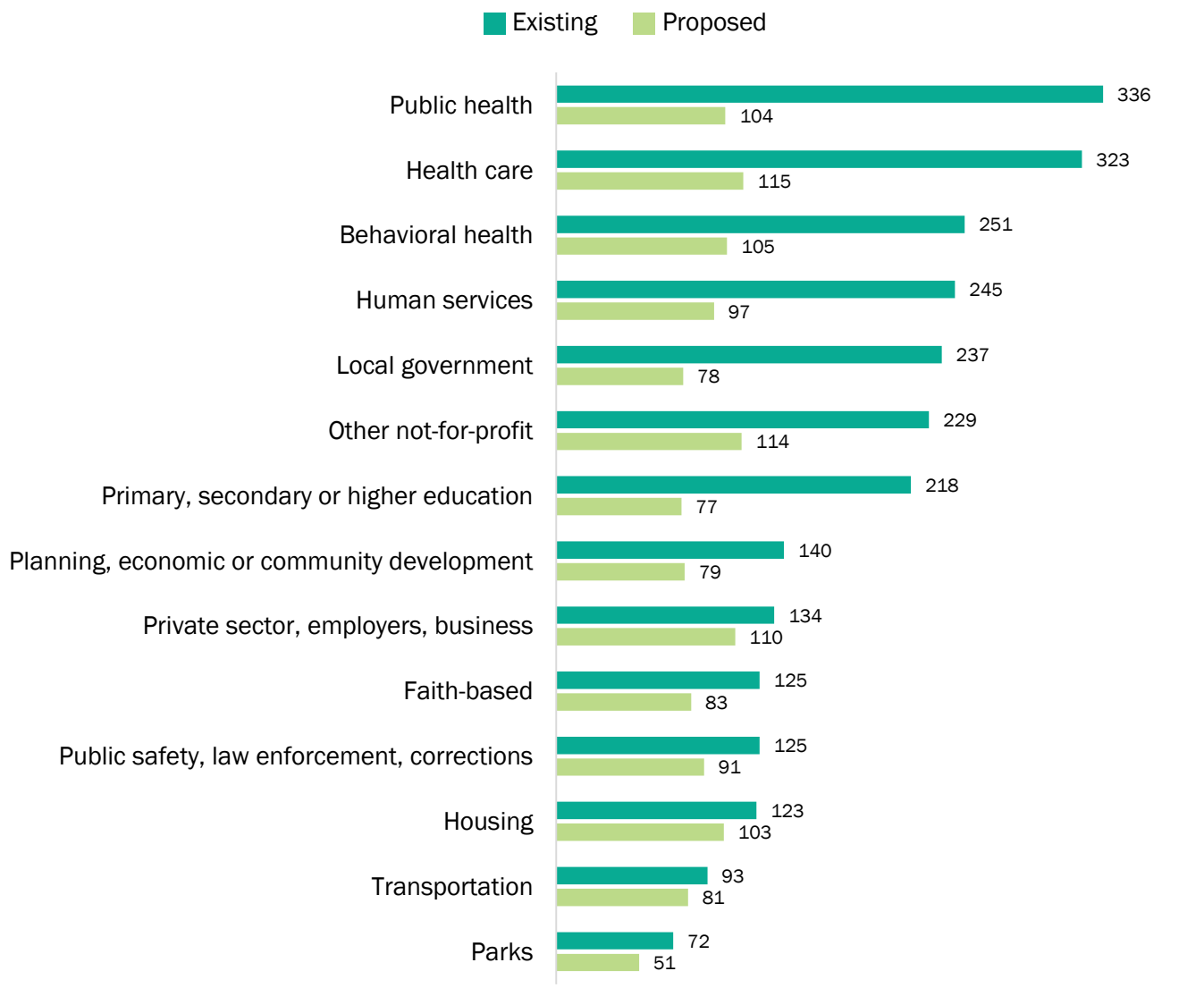
Many sectors are currently engaged in collaborations, but new connections are envisioned

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. Health care delivery and public health entities lead the majority of existing collaborations, 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)

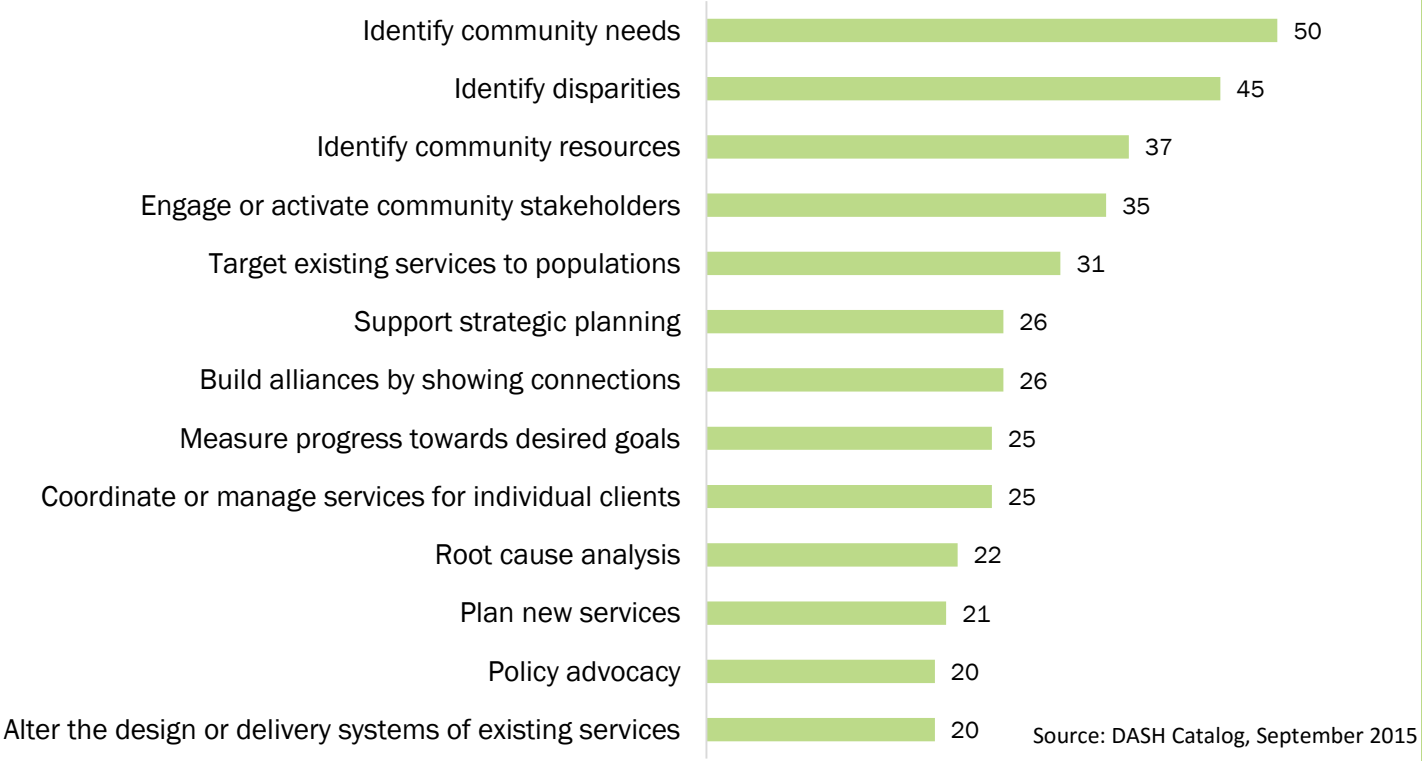
The most common sectors providing data and using data include health care, public health, human services, and other not-for-profits. Health care settings, law enforcement, corrections, and transportation are most often data sources; whereas public health, human services, education, not-for-profits, faith-based 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. The initiatives identified most often identified the following purposes:

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.

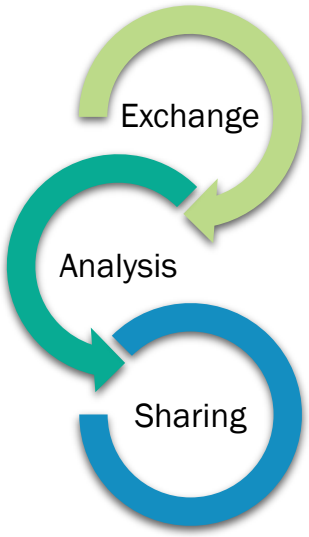
Turning Data into Information and Action

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.



- Data exchange between systems
- Transforming data into information
- Communicating information for stakeholders to use

Many technological tools are emerging

Details regarding the specific technology used to share data across sectors were 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

It is critical that data is presented in formats that support decision-making, and reflects the sectors engaged in order to inform and encourage action. Across many initiatives, mapping 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. Each participant agrees upon a value case 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 not-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 not-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.

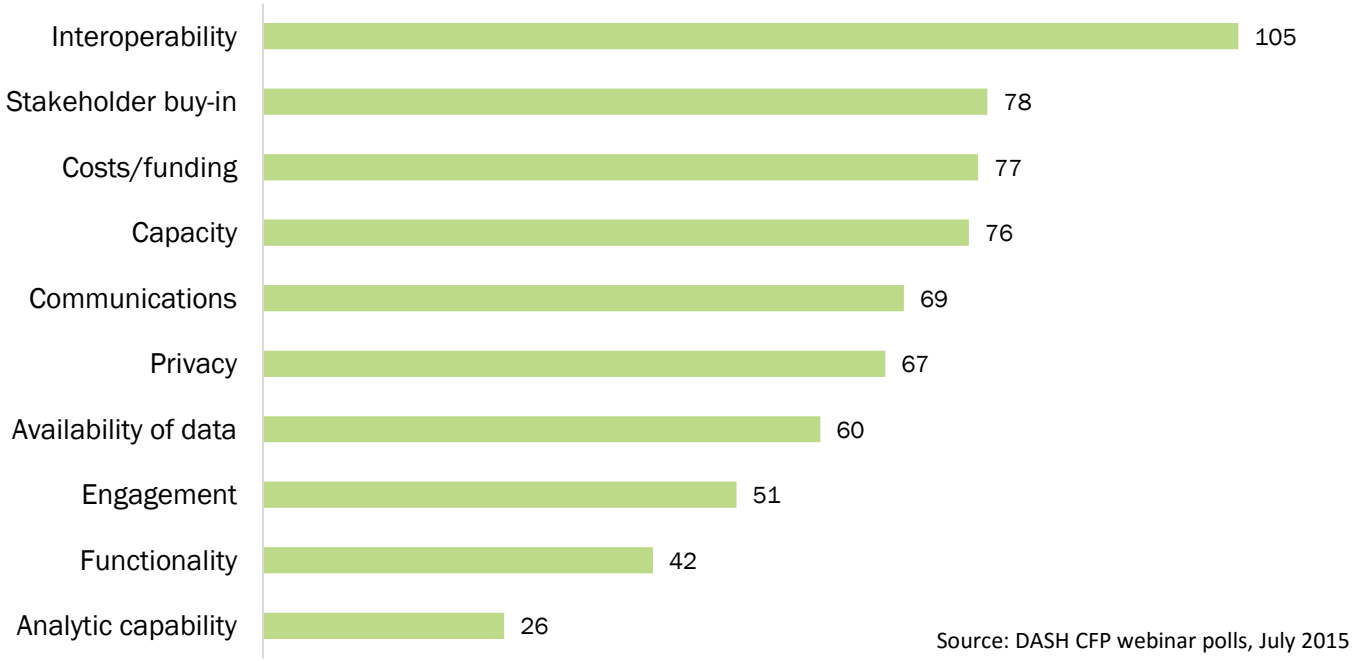
Thus far, the purposes of the initiatives seem to cluster around the following primary community health aims:

- **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 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. Figure 3 below shows the top challenges:

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



Source: DASH CFP webinar polls, July 2015

The online survey and key informant interviews mirrored these responses. Technical and operational challenges, and relationship management emerged as two overarching themes. 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 internal capacity to analyze data. In addition, each sector has its own understanding of the data fields, common terms, indicators, and how to use them. 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:** In order to be integrated and interoperable, data systems need structured and standardized data. 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 three key characteristics of DASH underwent several revisions to best capture the breadth and complexity of the field. Researchers identified three additional limitations that inform this report.

- 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.
- Availability and variability 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.

INTRODUCTION

Recognizing the importance of factors beyond health care to individual health and community wellness, the Robert Wood Johnson Foundation (RWJF) has made building a Culture of Health the central aim of its research and investments. Thanks to work of the Institute of Medicine, RWJF and others, it is becoming clear that health starts and is maintained in contexts outside of clinical care (e.g. within homes, neighborhoods, schools, child care centers, workplaces, places of worship, and other community settings). According to McGinnis et al. (2002), only 10 percent of premature deaths are attributable to shortfalls in medical care. Health behaviors, social and economic factors, the physical environment, and genetics account for the vast majority instead.

> *"No sector alone can reform health."*

This effort to build a culture of heath includes working to foster communication among health care, public health, and other community systems to address the social determinants of health and improve the health of communities. To that end, the Foundation is supporting a number of strategies including discovering and disseminating well-developed, sustainable examples of local sector alignment; promoting health care organizations' role in community health improvement; and fostering multi-sector data and information systems to improve community health.[1]

Data Across Sectors for Health (DASH)

As part of its multi-sector data and information systems focus, 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 Illinois Public Health Institute (IPHI), in partnership with the Michigan Public Health Institute (MPHI) leads the DASH National Program Office (NPO) with support from the Foundation.

Data Across Sectors for Health (DASH) identifies and supports community collaborations and initiatives that use multi-sector data and information to increase their capacity for planning, implementing and evaluating health improvement activities. DASH:

- Builds and disseminates the knowledge base for the emerging field
- Works alongside with selected grantees to test and implement innovative practices
- Develops and maintains relationships with practitioners and experts nationwide

These integrated activities will strengthen communities' ability to use shared data and information from multiple sectors to increase their capacity to improve the health of communities. Sharing emerging research, lessons learned, and promising practices from leading organizations and communities will improve others' ability to develop plans and systems for sharing data across sectors.

To define the scope of the work, the DASH NPO, in collaboration with the Foundation, defined three key characteristics to understand how initiatives meet the priorities underlying DASH. These include:

[1] All quotes come from key informant interviews conducted in the summer of 2015 except where noted otherwise. Interviewees understood that their comments would not be attributed without permission.

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.

Although these are useful to shaping an understanding of the field, the DASH NPO has identified the need to refine and adjust definitions on an ongoing basis to ensure the use of a common language and a clear understanding of context among audiences.

AN INITIAL SCAN OF THE FIELD

One early activity of DASH was conducting an initial scan of the environment. 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

Descriptive and Analytical Framework

To implement the scan, the DASH NPO developed a framework for investigation in collaboration with the Foundation (see Appendix B). The framework defines two levels of inquiry:

- **Descriptive:** To characterize and describe the field of multi-sector data and information systems for health, as outlined in objectives 1-2.

- **Analytical:** To identify barriers and opportunities, synthesize lessons learned, and measure progress as outlined in objectives 3-5. These require the application of an evaluative or analytical lens in order to understand what is working, what is not working and why.

Defined concepts within these levels of inquiry guided the development of data collection tools and coding schemas for analysis. The DASHP NPO continually challenged itself to test and refine these concepts in order to collect the most salient information. An important concept in the Descriptive Framework is that of 'use case.' A use case is a series of related interactions between a user—or more generally, an "actor"—and a system that enables the user to achieve a goal. Case studies throughout this report give examples of specific use cases.

> ***"How can we help sectors work across and between traditional boundaries to build a comprehensive Culture of Health, enabling all in our diverse society to lead healthier lives, now and in generations to come?"***
>
> - RWJF, From Vision to Action: Measures to Mobilize a Culture of Health

Data Collection Methods

Activities for the scan included a literature review and research on existing multi-sector data sharing initiatives, two types of key informant interviews, and an electronic survey.

Literature review and research on existing multi-sector data sharing initiatives

Basic literature review identified relevant research, subject matter expertise, and case study examples exemplifying some or all of the three key DASH characteristics. Additional literature on evaluative frameworks related to information systems informed many of the data elements explored further in key informant interviews and the electronic survey. DASH NPO staff documented internet research in an online list.

Key informant interviews

DASH NPO staff completed twenty-five 60-90 minute key informant interviews. Phase 1 identified and tested concepts to understand data-sharing initiatives explored in Phase 2. Collectively, interview findings helped to illuminate significant barriers, gaps, opportunities, and best practices related to data and information sharing. Interview protocols are included as Appendix C.

- **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 that could not be captured by internet research. The survey instrument is also in Appendix C.

Narrative data from the above was collected and coded for common descriptive elements and themes related to challenges and factors that promote success. This process resulted in the creation of a schema for collecting structured data on initiatives in an electronic database referred to as the DASH Catalog. Much of the analysis below is based on an initial group of 85 initiatives cataloged in this way.

While the scan was underway, the DASH NPO released a Call for Proposals (CFP) Brief. The immense response seemed to indicate that the size of the field was much larger than the scan activities were able to document. The DASH NPO leveraged the CFP Brief to create additional sources of information for review during the scan. The 409 submitted proposals may reveal the scope and depth of the emerging field better than the DASH Catalog. However, a deeper analysis of the proposals and on-going monitoring of the field are needed to test this assumption.

CFP information extracts

The application process captured basic information in forms including contact, eligibility, physical location, sectors involved and a project description. Additionally, proposals contained narrative and budget components. The CFP data is potentially aspirational as opposed to an accurate representation of the true nature of existing or proposed sectors participating in data sharing activities.

Webinar registration process

Over 1,000 people attended the CFP introductory webinars and nearly half answered polling questions regarding their high-level aims for data sharing and the barriers to their work. Unlike the proposals, these questions yielded straightforward answers that may more accurately reflect the true nature of the challenges faced by data sharing initiatives. The DASH NPO coded the responses about barriers, presented in Figure 11.

This report highlights preliminary findings from the environmental scan by addressing the following questions:

- What is the current state of sharing multi-sector data for community health?
  - Where is data sharing happening?
  - Who is sharing data?
  - Why is multi-sectoral data being shared? What are the purposes it supports?
- What are the key challenges to sharing data across sectors?
- What are some potential opportunities to address the challenges?

The report closes with a description of potential areas for future investigation as the DASH NPO conducts on-going monitoring of the field.

THE CURRENT STATE OF THE ENVIRONMENT

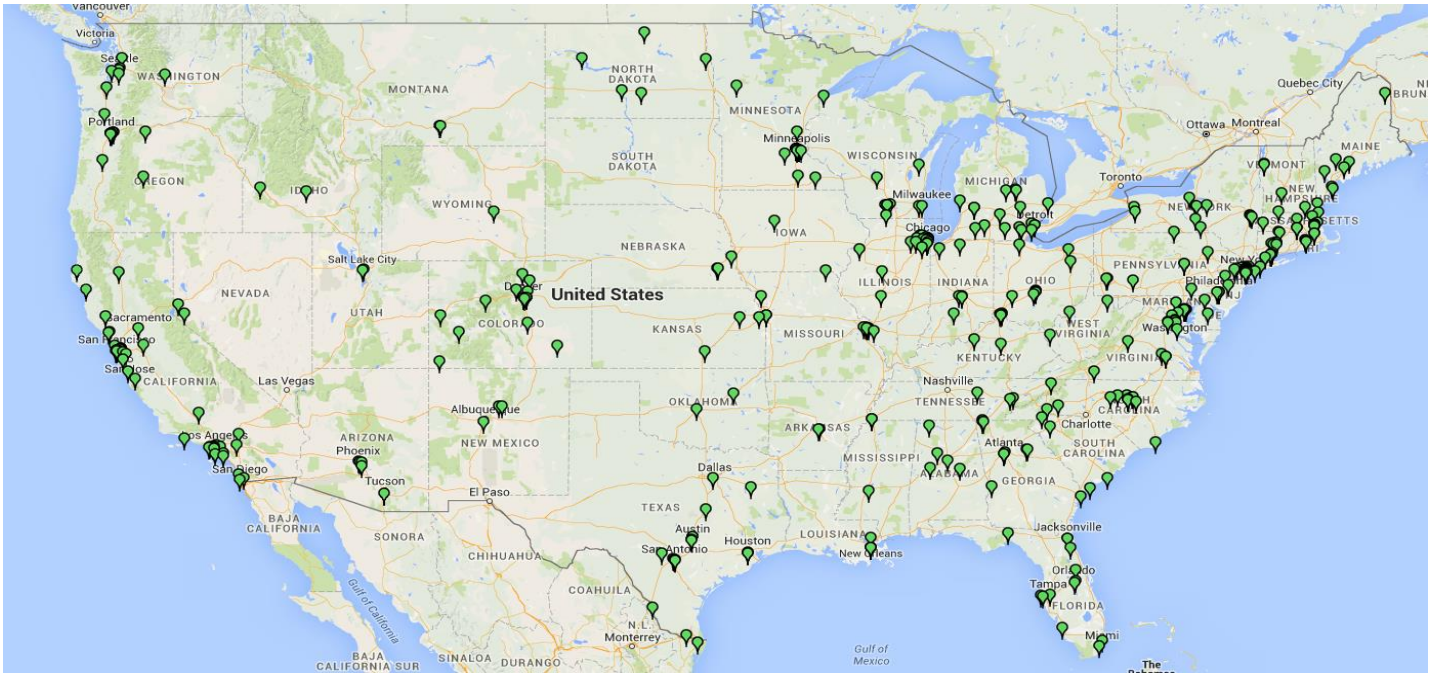
This section summarizes the research on types and distribution of entities currently sharing data or planning to share data and their purposes for doing so, as well as the tools used to share and analyze data.

Entities and Sectors Sharing Data

Collaborations for data sharing exist across the United States

Collaborations across the country appear motivated to share data across sectors for community health improvement. Proposals came from every state and the District of Columbia except South Dakota, with the greatest activity occurring in the northeastern coast, the Midwest and California. The DASH Catalog shows a similar pattern, documenting initiatives in twenty-seven states and the District of Columbia.

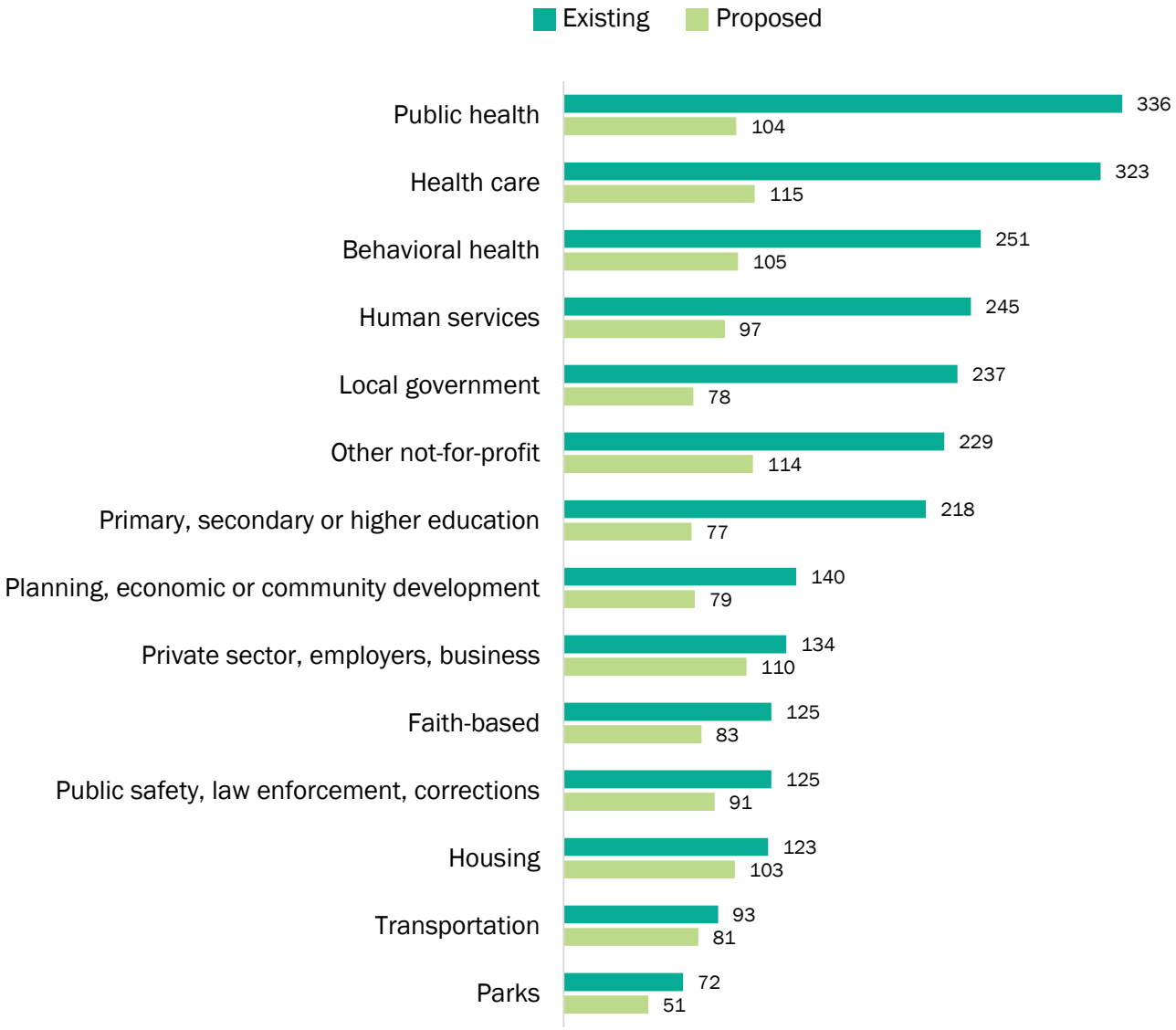
Figure 4. DASH Brief CFP Applicants by City and State



Health care/public health are the most represented sectors, but new connections are envisioned

Health care and public health lead the majority of existing collaborations, but there is an increasing understanding and interest in sectors representing the social determinants of health. CFP applicants indicated which sectors represented their existing data collaborations and described additional sectors to be included in their proposed projects. Figure 5 shows the response.

Figure 5. Sectors represented in existing collaborations and sectors to be added in proposed projects (n=409)

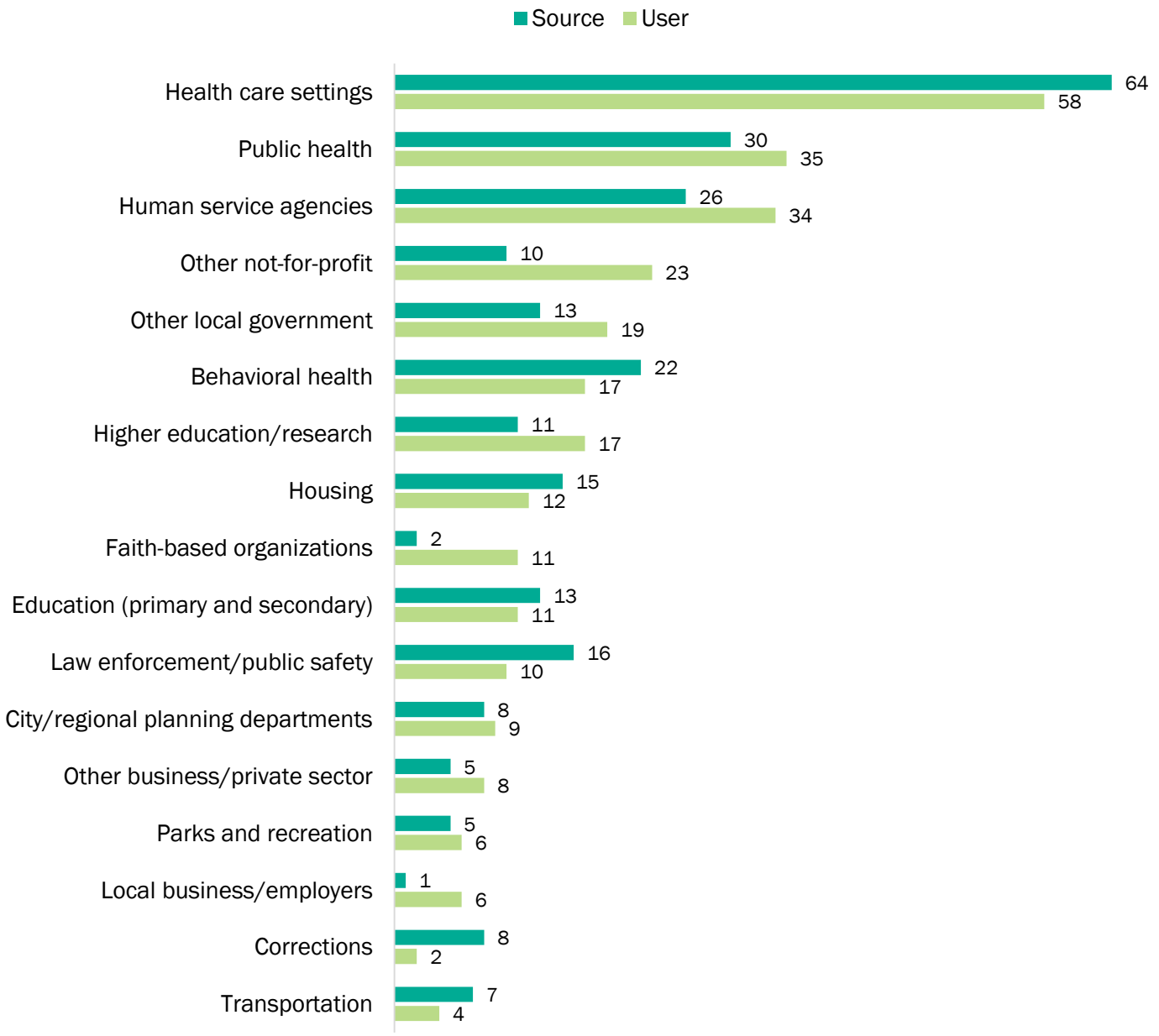


- Current participants most often include public health and/or health care, followed by other traditional delivery system participants like behavioral health, human services, local government, other not-for-profit, and education
- Only 18 responses differentiate the top seven sectors that participants planned to add. These include: health care, not-for-profit, private sector, public health, behavioral health, housing, and human services

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

The Catalog describes sectors as data sources and/or data users, as shown in Figure 6.

Figure 6. Data Sources and Data Users (n=85)



- Consistent with the CFP applications, health care and public health, followed by human services, are the most common sectors sharing and using data
- Health care settings, law enforcement, corrections, and transportation are more often data sources; whereas public health, human services, education, not-for-profit, faith-based institutions, and businesses are more frequently users
- Other data sources and data users more rarely cited include advocacy organizations, banking and financial institutions, social media, national public data sets, private sector research, and personal devices

Case Study: Healthy Montgomery

Eight years ago, the Montgomery County, Maryland Department of Health and Human Services and local hospitals formed the Healthy Montgomery Coalition to achieve community health data requirements and meet community needs.

Outreach revealed that multiple sectors, including education and planning, were committed to data-driven approaches to accomplish sector-specific goals. Collective goals, mutual benefit, and strategic relationships were developed as stakeholders worked together to establish a shared language. Investing time and energy, stakeholders gathered together to align methods and infrastructure for the common good.

Specific "use cases" underway include:

- The planning department is developing sector-specific and transportation plans that incorporate community health data
- Six local not-for-profit hospitals are utilizing the data to meet community benefit requirements
- Community organizations and other social service agencies in the coalition are using data on the public portal to write grants and form partnerships for cross-sector program development
- Capacity is being built within the coalition to evaluate the effectiveness of community programs, thereby enabling community service providers to compare their target populations to county-wide trends
- Data is being used by stakeholders for community initiatives including:
  - Eat Well Be Active Partnership
  - Behavioral Health Task Force

> ***"We built things on a consensus-driven approach. Doing the work was the easy part once we had the collective understanding.... We were very lucky; everyone around the table was committed."***
>
> - C. Ryan Smith

Contextual drivers

- Public health reporting
- Hospital requirements for community health needs assessments / community benefits
- Open data movement
- Proximity to national expertise

Who is involved by sector?

- **Data sources:** Multiple
- **Data users:** Health care settings, public health, education, planning department

What data is being shared and how?

- Data is updated annually and shared via an open data platform. The platform presents benchmarks through a dashboard and uses mapping for certain metrics.

What is the purpose of the data sharing?

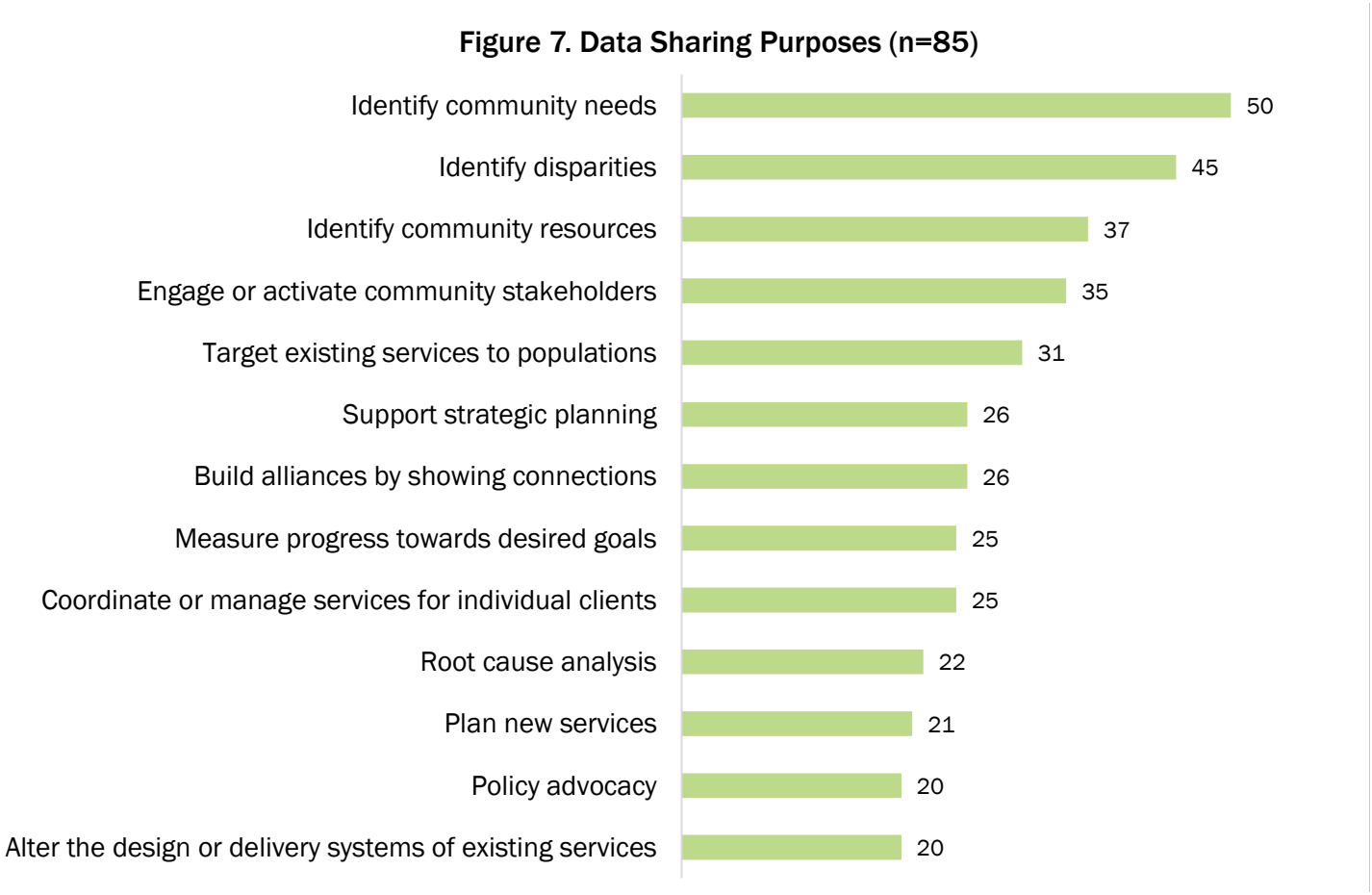
- Community needs assessment
- Identify disparities
- Engage stakeholders
- Target services

Data Sharing Purposes

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

Understanding how multi-sectoral data sharing supports community health was a central objective of the scan. The DASH NPO currently identifies twenty distinct data sharing purposes in the DASH Catalog related to core community health improvement activities. These purposes are interrelated and frequently co-occur. Initial research focused on the purpose of data sharing by asking, "What is the shared data meant to achieve?" Figure 7 reflects the top responses below. Non-health related collaboration aims and other purposes for data sharing occur outside of this initial list, and new categories may emerge as the Catalog grows.

Figure 7. Data Sharing Purposes (n=85)



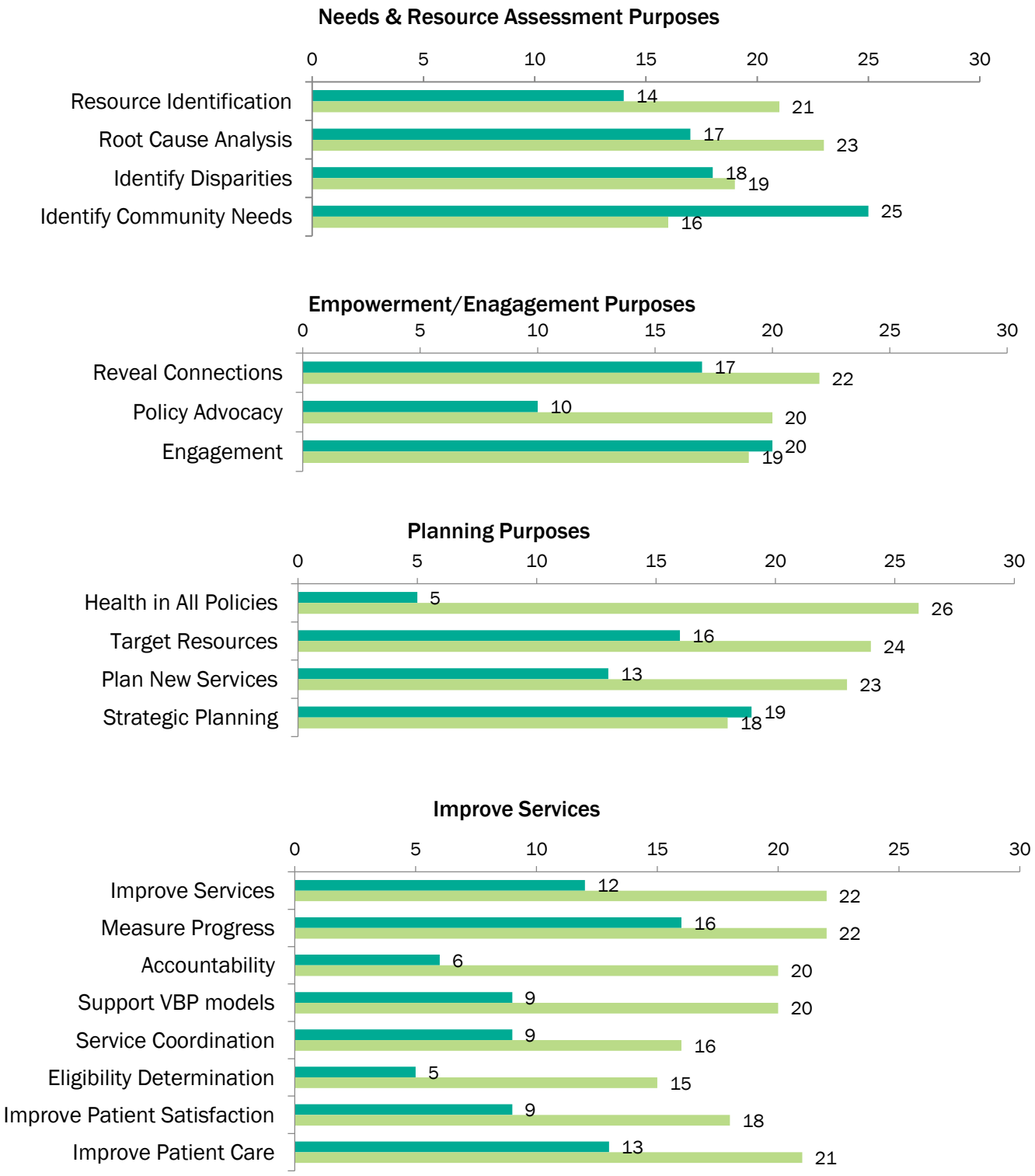
Most cataloged initiatives share and use data to identify community needs, document disparities, and identify community resources.

- Purposes cluster around activities relating to identification of needs: engaging stakeholders, targeting services, supporting strategic planning, and measuring progress
- Less common purposes were instances of coordinating care for individual impact (care coordination/management)
- Other data sharing purposes not shown include: support outcomes-based or new payment models, apply 'health in all policies' in local planning, facilitate scientific research, streamline eligibility determination processes, and hold service providers accountable to outcomes

Planned uses for data sharing far exceed current uses

The DASH survey captured details regarding current versus planned uses of shared data (Figure 8).

Figure 8: Planned vs. Current Uses of Data (n=37)



Although many initiatives currently used data for assessment and planning, they aspire to do much more.

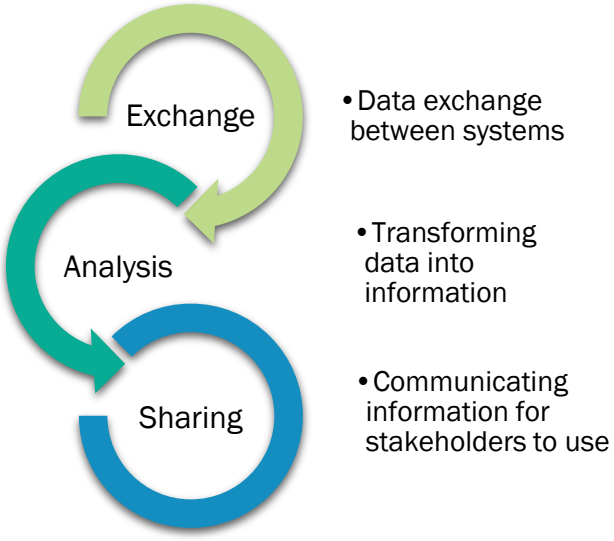
- In most cases, the number of planned uses of data exceed the number of current uses of data
- Areas of for future expansion of data sharing initiatives include promoting health in all policies, planning new services, policy and advocacy, provider accountability, social impact financing, and improving patient satisfaction.
- Respondents also identified research as another purpose, with 9 currently using data for research and 18 planning to do so.

Turning Data into Information and Action

One of the most salient themes expressed during key informant interviews was that raw data, in and of itself, is not useful to stakeholders. Rather, data must be analyzed and conveyed in ways that support decision-making. 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.

Through the scan, the DASH NPO identified specific ways in which technology can facilitate the conversion of data into useful information for community health improvement, all of which are interdependent.

- The **exchange** of data quickly and efficiently from its source to an information system or between information systems
- The **analysis** of discreet, comparable units of data that is then transformed into usable formats for stakeholders
- The **sharing** and dissemination of that information in an ever-more sophisticated delivery system to the right person/place or system, at the right time



In some cases, the same activity or system can accomplish parts of multiple steps. For example, mapping multi-sector data can be a powerful tool for conducting root cause analysis and engaging stakeholders, moving them towards action. However, preliminary scan findings suggest a lack of experience and understanding of electronic and technological tools that could significantly increase community capacity.

Case Study: Rochester High Blood Pressure Collaborative

To address double-digit growth in health care costs, the Rochester Business Alliance launched the Health Care Planning Team. As self-funded employers looked deeper, they identified depression, low back pain, and high blood pressure as health issues affecting their employees.

The Finger Lakes Health Systems Agency implements health improvement at the community level, as well as serving as the Steering Committee for the Rochester High Blood Pressure Initiative.

Through a newly launched high blood pressure registry, collaborative partners are able to monitor individuals' blood pressure at the point of service and generate reports to deploy resources and monitor community-level outcomes. The data sharing initiative involves a partnership of 63 participating entities including businesses, providers, public health, universities, barbershops, churches, and other community organizations.

As a result of this data sharing effort, the initiative has documented an increase in blood pressure control rates—from 62.7 to 70.1 percent. Additionally, by monitoring outcomes, they found a local generic drug program increased fill rates by 20 percent, representing a savings of approximately $490 million.

Specific "use cases" underway include:

- Providers obtain feedback reports benchmarked against community
- Partners identify disparities and focus population health interventions on vulnerable neighborhoods
- Real-time data is used to inform case management
- A high-need sub-population with advanced hypertension has been identified for targeted, tailored interventions

> ***"The greatest strength we have in this community is our level of collaboration, which brings with it hard work every day. Our credibility as a neutral convener goes a really, really long way to get people to work with us.... [The partners] meet as a group every Thursday."***
>
> - A. Bradley

Contextual drivers

- Business coalition concerned about growing health care costs
- Charismatic leadership
- Community advisory board
- Neutral, nonprofit convener

Who is involved by sector?

- **Data sources:** Health care settings
- **Data users:** Health care settings, public health, local government, faith-based organizations, local business

What data is being shared and how?

- Health information is stored in a community-wide registry

What is the purpose of the data sharing?

- Identify community needs
- Identify disparities
- Community engagement
- Plan and improve services
- Target services
- Measure progress

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

Although the internet has increased the speed and ease of access to information, the health sector is still grappling with the transformation of information flow (Office of the National Coordinator, 2014, p. 29). Recently, providers have started collecting health-related data on individuals in electronic health records (EHRs), but moving that data into other systems is proving difficult and costly.

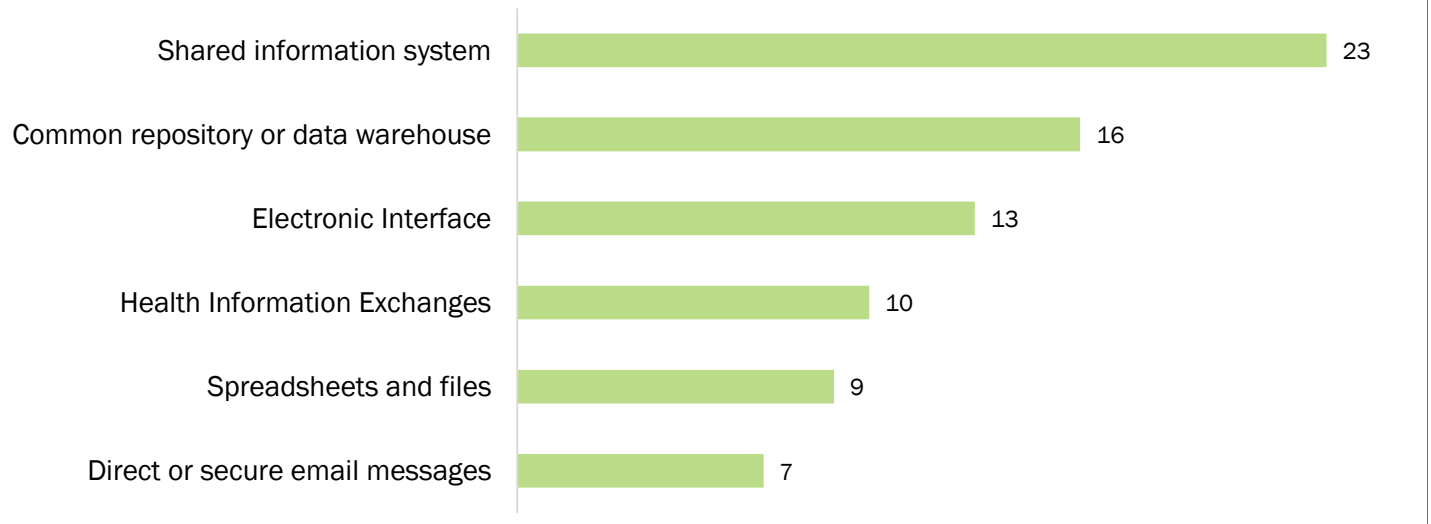
> *"This is new, cutting edge, and there is no road map."*

The case is even worse for public health. While condition-specific or other types of registries have existed for many decades, the inconsistent implementation of electronic systems has left the public health sector fragmented and siloed (Thacker et al., 2012). 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.

Early successes resulted from efforts to convert paper-based information into digital form, in order to transmit it over the internet through PDF claims attachments or Direct messaging. Clinical information has become increasingly structured and therefore easier to manipulate and analyze. The field may be poised to make further progress with the use of "cloud" services and application programming interfaces (APIs) that facilitate data exchange between systems (JASON, 2014). These systems lessen the need to build technical solutions for every instance of sharing by focusing on an interface that will be able to find data where it is stored and translate it into a format that the requesting system can use. However, the cost-benefit ratio of this approach has yet to be explored.

For the most part, innovations in data transfer were not evident to researchers building the DASH Catalog. This may be due to limitations of the data sources and not a true indicator of the state of the field. (See "Limitations" for further explanation). However, initiatives like the Rochester High Blood Pressure Collaborative (page 23) demonstrate that registries can continue to play an important role managing data in multi-sectoral initiatives. Figure 9 shows the distribution of the types of data exchange methods recorded in the Catalog.

Figure 9. Electronic Data Exchange (n=71)



Automating this first step of collecting and synthesizing data in a shared system appears to be essential to achieving the full vision for DASH, but is not the entirety of "sharing data."

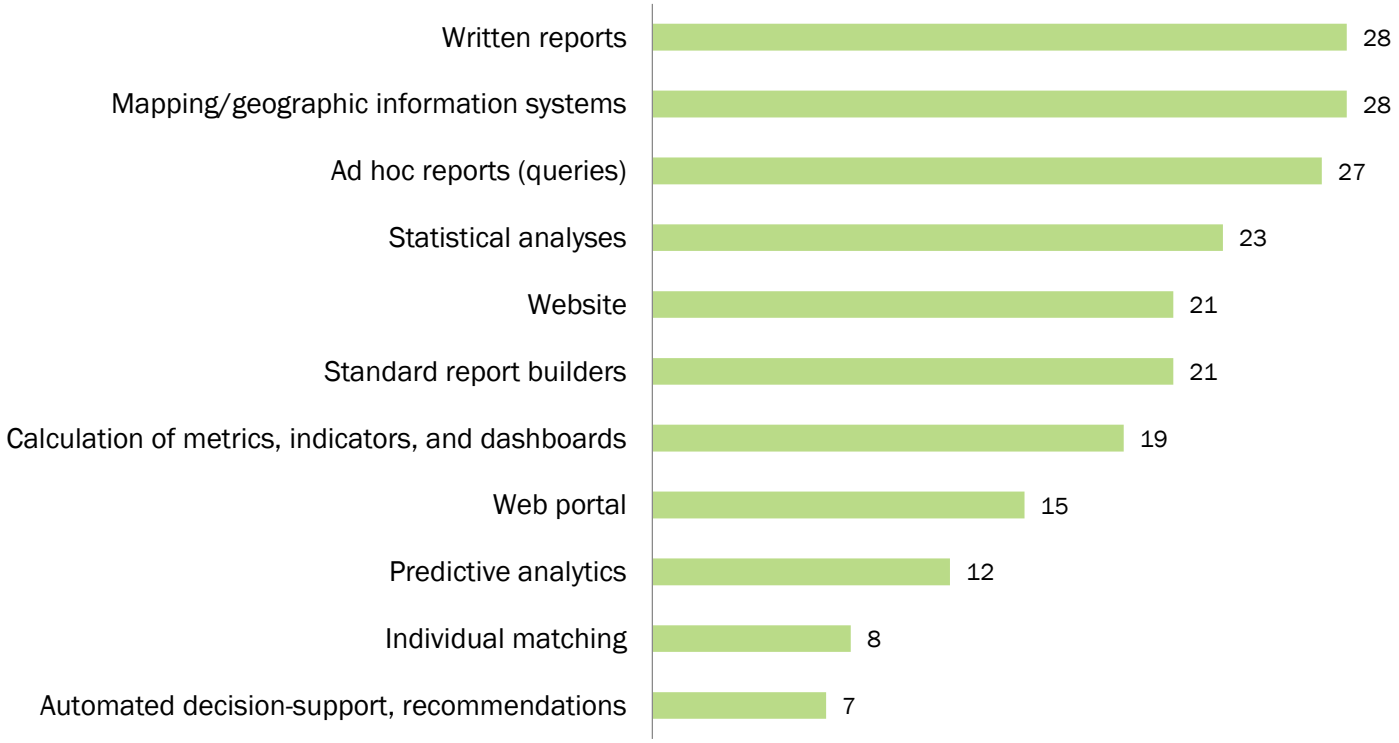
Raw data is not necessarily useful to stakeholders

Data itself is not inherently useful to practitioners and entities seeking solutions to complex community health problems. Raw data from different sectors is not necessarily compatible and must therefore be analyzed, standardized and transformed to make it into useful information.

> ***"Something we've heard in the Data for Health initiative is that people don't so much want to exchange data (although sometimes they do), but what people really want is information and understanding of a problem."***

Figure 6 summarizes mechanisms for transforming data into useful information as documented in the Catalog (where known).

Figure 10. Mechanisms for Analyzing and Sharing Information (n=71)



- Mapping or geographic information systems is the most common tool
- In some systems, the results of analysis are immediately available for sharing whereas in others, additional effort is needed to interpret the meaning of data and present it in a meaningful way
- The use of ad hoc queries and statistical analyses is evident, but not as part of an automated workflow
- Tools for analysis that link data to a recommended action, such as individual matching and automated decision support, are not common

Key informants described the effort required to present data in a way that was meaningful to collaborators from other sectors. Often, preliminary analysis identified populations touched by multiple sectors, necessitating outreach beyond health-related sectors. A key informant spoke of their experience using geographic information systems as both a tool for analysis and data sharing:

> *"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."*

Turning information into action still depends on interpersonal communication

While there has been rapid growth of electronic tools and approaches to data sharing, most of the key informants interviewed acknowledged the importance of face-to-face communication and in-person meetings.

- Written reports are the most common method for sharing information
- Websites and portals, when used, rely on manual processes for updating
- Automated decision support at point of service is not very prevalent

> ***"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."***

While conducting the scan, the DASH NPO learned about a related environmental scan led by Network Impact that specifically focuses on the use of technological tools for collaboration to support healthy communities called "Exploring the Potential for Leveraging Technology, Data and Tools for Collaboration to Support Sustainable, Equitable and Healthy Communities." The results will be released in the coming months and will include a list of 70 different tools (see list in Appendix D). Their scan indicates that overall awareness, understanding, and use of technological tools is not widespread or mature. The DASH NPO will continue to connect with Network Impact to learn more about this project.

Case Study: County of San Diego Knowledge Integration

In 2008, the County of San Diego Health and Human Services Agency (HHSA) began a strategic planning process to determine the County's role in healthcare reform. The process launched efforts to incorporate health, safety, economic self-sufficiency, and community connectedness.

This led to Live Well San Diego, the County's vision of a region that is "Building Better Health, Living Safely, and Thriving."

Planners realized the County had rich data collections, but it was challenging and time-consuming to view and analyze aggregate information. Effective, enterprise-wide, person-centered service delivery would require optimized use of data assets.

San Diego County is currently building a hub to integrate multiple data systems and expects to go live with the initial phase in less than two years. Specific "use cases" underway will impact multiple levels, from individual, to population, to community health:

- Service providers make referrals and collaborate across programs
- Alerts provide actionable information at the point of service
- Providers coordinate by sending secure messages
- Advanced reporting and predictive analytics will help the county plan services
- A customer portal will allow individuals to review and manage their record

> ***"Our County is moving from program-centered service delivery to person-centered service delivery…We first asked ourselves: 'What is the basic process we all share when we work with the people we serve?' …Then we asked: 'Where are the areas that technology would enhance, enable, and support information sharing?' This led to a defined set of use cases that drove targeted requirements development for the data system."***
>
> - C. Hoff

Contextual drivers

- County strategic planning inspired by healthcare reform with the goal of providing more coordinated services

Who is involved by sector?

- **Data sources:** From HHSA: Aging & Independence services, Behavioral Health Services, Eligibility Operations, Child Welfare Services, and Public Health Services. Others include Probation, Housing and Community Development, and two directors: 2-1-1 San Diego and Community resource Directory (Public Safety).
- **Data users:** All of the above. Additional systems or users may be added.

What data is being shared and how?

- Program-specific data systems operate across the county. IBM, the contracted technology vendor, is creating an electronic information exchange platform that will pull data from those systems using master person index and query technology. A data warehouse will provide infrastructure for aggregate analytics and data marts.

What is the purpose of the data sharing?

- Improve customer service
- Increased coordination for person-centered service delivery
- Identify community needs
- Target services and resources

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

At the outset of the scan, the DASH NPO assumed data sharing primarily occurs in community collaborations, between organizations that utilize each other's data. In fact, research reveals that data sharing occurs in a variety of configurations. The following list is a non-exhaustive description of institutional relationship configurations. This domain is likely to be the most difficult to categorize and quantify, due to the diversity of collaborative efforts including coalitions, affiliations and ad hoc arrangements.

- **Multi-sector collaborations:** These may be formal with an explicit governance and management system, or an informal with an arrangement to share data. 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 givers 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 not-for-profit hospital fulfills the community benefits requirement by conducting a Community Health Needs Assessment. Healthy Montgomery, profiled on page 19, is an example of this type of arrangement.
  - These activities may lead to the establishment of formal collaborations that assists local stakeholders in understanding and using shared data to achieve their aims.
  - This type of collaboration may be ad hoc or develop formal governance.
  - A single data owner, such as a government agency, may combine its data from different sectors, as in the case of the San Diego County Knowledge Integration Project (see page 27). This type of collaborative arrangement can have both individual and community impacts.
- **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. Profit or financial incentives often drive this approach, which suggests one way to engage the private sector in community health solutions. The open data movement, spurred by attention from federal administration, also supports this approach.

Domain 2 - Multi-sector

As a domain, sectors are fairly straightforward and easy to classify. For the initial scan, sectors are understood as groups of similar institutions that together shape the conditions of daily life. 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 not-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; and parks and recreation.

Further research should help the field understand additional sectors that affect community health, identify which sectors have the greatest influence, and illustrate how sectors can interact with each other to leverage their strengths and achieve the greatest impact.

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. It will be necessary to identify the technologies in use at each stage of the data gathering, analysis, and sharing process with greater precision as the scan progresses. This deeper level of activity will best position DASH to develop recommendations and best practices around technological facilitators.

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. Although individuals and families are most immediately impacted, wider community health outcomes are possible. Twenty-five of the initiatives in the DASH Catalog fall into this category.
- **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. Thirty-three initiatives in the DASH Catalog are driven by this primary overarching purpose.
- **Research and policy:** Applying analytics to better understand populations for the purpose of policy, advocacy, engagement, and/or research. Specific instances often multiply as the results of one query form a new data set to inform future queries. Twenty initiatives cluster around this type of activity.
- **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. Seven of the initiatives in the Catalog focus on providing infrastructure for potential initiatives rather than outlining community health aims of their own, like health information exchanges. This function enables equal focus on two or more categories above.

Descriptive information from the DASH Catalog and the CFP, as well as observations from the key informant interviews reflects a growing national interest in sharing data. However, the possibilities currently exceed documented actualities. Current documented uses of multi-sectoral health data cluster around assessments and related planning, but the increasing volume and sophistication of data and data systems will eventually support broader uses related to policy change, system change, and behavior change.

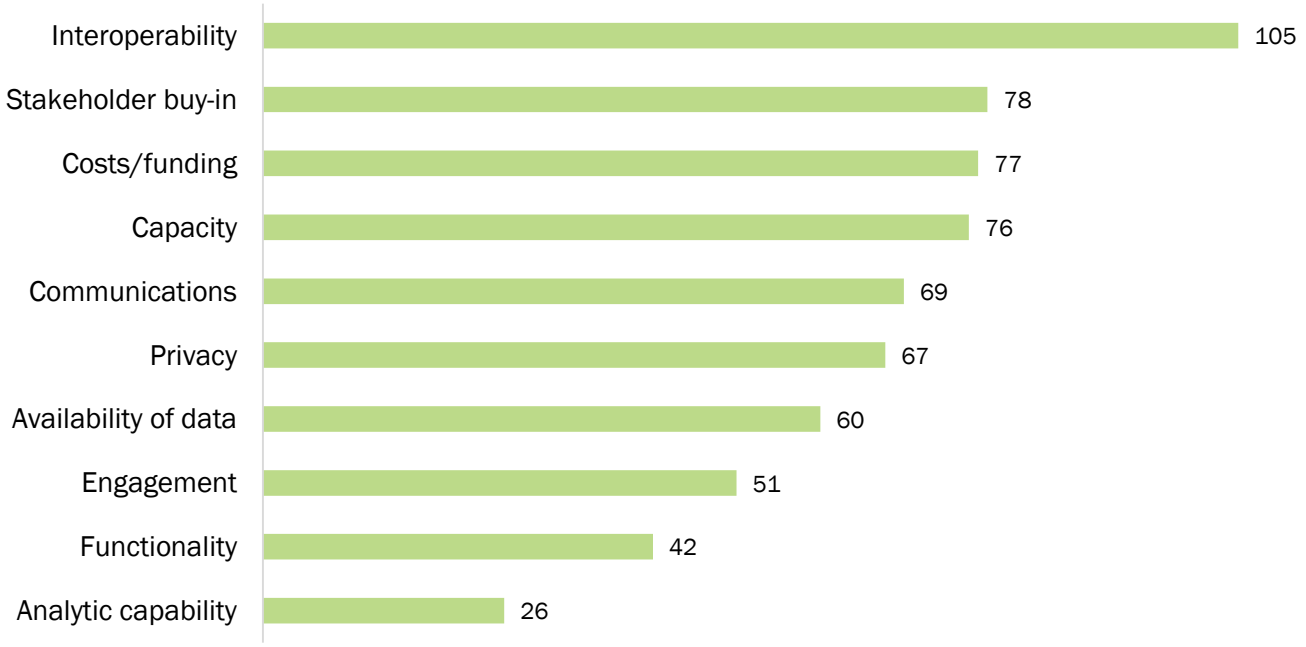
Although DASH initiatives may share attributes, the nature of associated challenges manifest in different ways. Focus on specific use cases may help to determine relationships between the domains.

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 related to data and information sharing for community health improvement. Key informant interviews, survey results, and prospective grantees' responses to webinar polling questions informed these themes.

Participants polled during the CFP informational webinars responded to the question, "What is the major barrier you have faced or are facing as you share data or information within your community?" DASH NPO staff coded responses using the barrier categories applied in the electronic survey, and expanded them as needed. Figure 11 presents barriers encountered as reported by participants in the CFP webinars.

Figure 11. Barriers Reported by Webinar Participants (n=420)

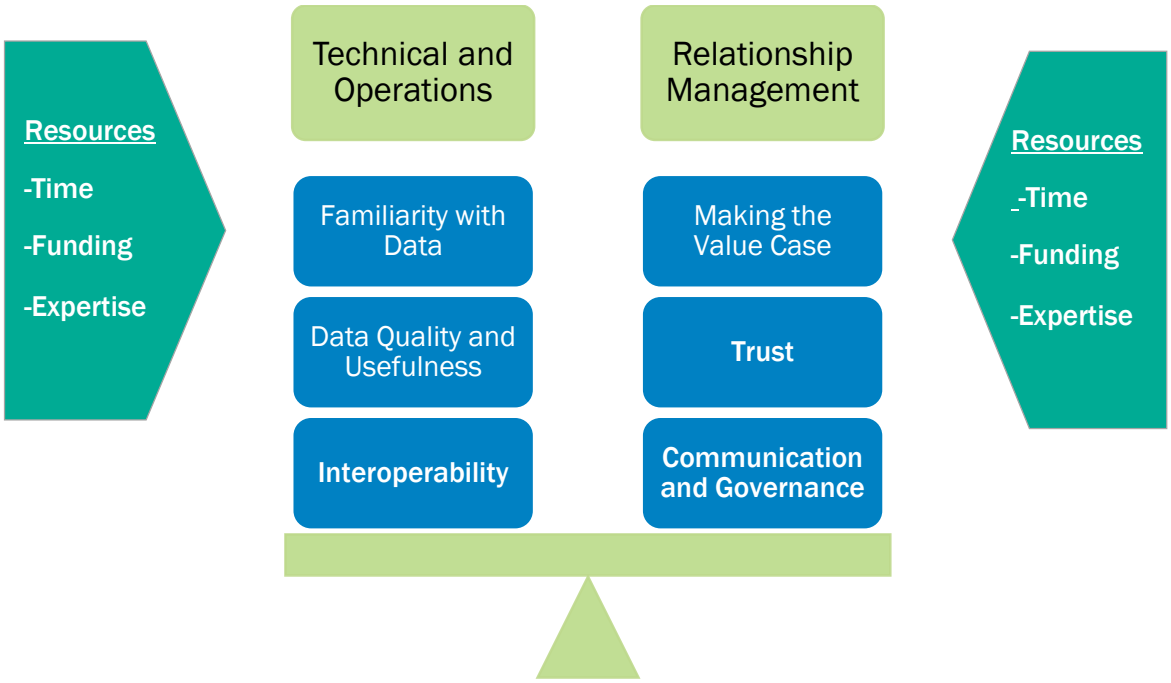


- The most common barrier reported was lack of interoperability, or the extent to which systems and devices can exchange and interpret shared data
- Less common barriers reported by webinar participants but not shown in Figure 11 include program effectiveness, timeliness, governance, data quality, executive sponsorship, startup funding, user trust, sustainability, transparency, and system experience/usability

These reported barriers are consistent with those reported by national data sharing experts as well as community practitioners. Across the data sources, two overarching types of concerns emerged:

1. **Technical and operational:** attending to requirements to optimize system design and operations, including interoperability, capacity, privacy, access to data, functionality and analytic capability, timeliness, data quality, and system experience/usability
2. **Relationship management:** managing relationships in cross-sector/collaborative coalitions, including stakeholder buy-in, intra-collaboration communication, engagement, program effectiveness, governance, executive sponsorship, user trust, sustainability, and transparency

Not surprisingly, a lack of resources including time, commitment, funding, and expertise were noted as primary barriers to addressing these challenges.



Lack of Resources

Identifying and obtaining necessary resources are among the first challenges faced by any initiative. However, key informants emphasized both funding and the need for human capital to overcome other challenges specific to data sharing. In fact, they often spoke of the need to enhance analytical capacity at every level of participating entities. This includes understanding what data is available, how sharing data can answer specific questions, and what actions make that data into useful information for improving community health.

> *"Meeting the needs of the community is very difficult, because everyone has million dollar ideas but no budget. Technical expertise helps overcome these problems. You need people with critical thinking skills trying to get the collective competencies up."*

> *"The technology is there, I just don't think we have the human resources."*

Case Study: Colorado Health Observation Regional Data Service

The growth of electronic health records (EHRs) and resulting amounts of electronic data on individuals spurred conversations among the health care and public health sectors in Colorado about leveraging EHR data for place-based population health.

This discussion, along with a need to better understand and address health issues for a metropolitan area that crosses multiple jurisdictions, led five public health departments to form the Colorado Health Observation Regional Data Service.

Through this initiative, large health care systems are partnering and contributing data in the context of enhanced community benefits requirements. Partners look to sustain the system by integrating it into the functionality of Colorado's health information exchange and existing public reporting platforms.

Specific surveillance "use cases" include:

- Public health departments track health status and risk factors in real time in the areas of:
  - Obesity
  - Tobacco use
  - Hypertension
  - High cholesterol
  - Mental health
- Public health departments map health conditions at the neighborhood or census tract level
- Longitudinal and geographic data is used to evaluate programming and guide service provision

Contextual drivers

- Public health monitoring
- Cross-jurisdictional collaboration
- Community Health Needs Assessments/hospital sponsored community benefit
- More recently: required State Innovation Model (SIM) services

Who is involved by sector?

- **Data sources:** Health care settings (large health centers and safety-net settings)
- **Data users:** Public health (additional future users include community service agencies)

What data is being shared and how?

- Clinical data for public health using distributed query-based platform interfaces with health center data warehouses populated with electronic health record information to answer condition-specific questions

What is the purpose of the data sharing?

- Identify community needs
- Identify disparities
- Community engagement
- Plan and improve services
- Target services
- Measure progress

Limited Technical and Operational Capacities

The most common challenges associated with designing and operating a multi-sector data system relate to familiarity with data, data quality, and interoperability.

Familiarity with data

As mentioned, data sharing initiatives face challenges procuring human resources with sufficient technical and analytical skills to build information systems that can accomplish project goals. At a meeting held by the National Quality Forum in late June 2015, the public, along with members of the "Data for Systematic Improvement" team, discussed workforce issues that were critical to advancing the use of data in health. The lack of familiarity with data and information systems is a challenge that goes beyond project staff. DASH key informants and findings from the Data for Health report, all highlighted the need to train staff at multiple levels about the availability of data, how to transform it into information, and how to apply the results to meet their project goals.

Key informants consistently reported that community-based coalitions with targeted missions sometimes have difficulty obtaining resources to build staff capacity and thus, basic analytical skills were often lacking. Furthermore, they emphasized the need for centralized solutions such as data warehouses and analytic processing engines to improve capacity to analyze data locally.

Using data from another sector presents additional complexities. Interviewees pointed to two distinct barriers in this realm: 1) a lack of shared language that makes data from other sectors meaningful and 2) work processes that occur in silos. Each sector has its own understanding of specific 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.

Technical Interoperability as Defined by the Health Information Management Systems Society (HIMSS, 2013)

Foundational

Allows data exchange from one information technology system to be received by another and does not require the ability for the receiving information technology system to interpret the data.

Structural

an intermediate level that defines the structure or format of data exchange (i.e., the message format standards) where there is uniform movement of health care data from one system to another such that the clinical or operational purpose and meaning of the data is preserved and unaltered. Structural interoperability defines the syntax of the data exchange. It ensures that data exchanges between information technology systems can be interpreted at the data field level.

Semantic

interoperability at the highest level, which is the ability of two or more systems or elements to exchange information and to use the information that has been exchanged; takes advantage of both the structuring of the data exchange and the codification of the data including vocabulary so that the receiving information technology systems can interpret the data.

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.'

Highly accurate and valid data are not necessarily useful, and some examples of data sharing highlight a trade-off between validity and other data characteristics such as timeliness and granularity. For instance, the Colorado Health Observation Regional Data Service (CHORDS, profiled on page 32) demonstrates the value of its work by providing public health data points that are more timely and available at smaller geographic units as compared to those used

in the CDC's Behavioral Risk Factor Surveillance System. Yet duplication and bias are issues. Further development and testing should reveal the extent to which such data accurately measure population health.

Issues around the accuracy of data take on urgency when the goal of data sharing is to exchange individual-level data for the purposes of having a comprehensive client record to better coordinate services. Reliable methods of identity matching are a challenge even when exchanging data within a single sector. It is worth mentioning that the majority of initiatives identified in the Catalog do not attempt to match data at the individual level.

> ***"Drawing conclusions is really hard when you don't know what provenances were used to collect the data…. I want to know who captured the data—that it hadn't been changed by anybody in between—and if I needed to retrace how it got to the point it's in, I could do that from the audit."***

Interoperability

Electronic data systems need standardized, structured data. For two systems to be interoperable, they must be able to exchange data and present data so that users can understand it. The initial findings regarding interoperability are as follows:

- The field as a whole is not ready for technical interoperability
- Initiatives sharing multi-sector data for health improvement should clearly define their scope and foster a space for cross-disciplinary dialogue

Key informants questioned whether the field of multi-sector data sharing should focus on interoperability.

> *"Standards are nice to have, but I think— especially across sectors—we aren't going to have the same data models. We are going to need the tools that we used pre-data standards and make those things interoperate."*[2]
>
> *"I'm more interested in the actual integrity of the data and what the users actually think the data means."*
>
> *"Don't attempt to 'boil the ocean.' Rather, convene data experts from different fields to determine a pragmatic future state."*
>
> *"What is feasible is to build a hub in which data can be brought and put in a format so that it speaks to each other. Analytics can be layered on top of that."*[3]

To illustrate how the lack of standardized data exacerbates the challenge of working across sectors, one key informant utilizing housing data described how the definition of code violations differs by jurisdiction.

[2] Solutions have been developed that take data from different systems, combine them, and translate them as desired by the user. This includes products like Socrata, Cúram, and tools available at Community Commons.

[3] An identified resource for this approach is Actionable Intelligence for Social Policy: http://www.aisp.upenn.edu/.

Interviewees noted the importance of collaborative level setting around the use of terms and the meaning of data early and on an ongoing basis. The director of the County Health Rankings & Roadmaps 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."*

One key informant noted how informatics experts are just beginning to realize the value of including data on the social determinants of health within electronic health records (EHRs).[4] Another informant, representing a data system in which community health workers document social determinants and community services provided to clients, expressed frustration with the inability to incorporate this information into EHRs:

> *"When primary care providers ask if we can build an interface to their EHR, I am left wondering what fields in their EHR would be populated by our data… The best I can do is generate a PDF for them to upload."*

Ongoing Relationship Management

The overwhelming threat to multi-sector data sharing, as expressed by respondents from long-standing initiatives, is that partners might withdraw. The resulting loss of data would reduce value for all stakeholders and potentially unravel the effort. Nearly 20 percent of CFP webinar-polling respondents reported that generating buy-in is a major barrier to achieving success, second only to interoperability. Key informants representing initiatives in the Catalog also reported investing considerable resources into activities to strengthen and sustain the collaboration.

> ***"When you're getting everyone to understand and align to the same ground rules, doing the work was the easy part after the consensus building."***

Making the value case

Diverse stakeholders have different goals and incentives driving their work. Many of the key informants stressed that all stakeholders must see the value of data sharing at the start of the initiative, in order to ensure continued interest, participation, and commitment to the collaborative effort. One subject matter expert observed:

> *"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."*

In particular, public health practitioners described difficulty in making the value case for surveillance and prevention using language that other sectors could understand and use. National experts noted that other non-health entities engaged in conversations around the use of multi-sector data could serve as leaders in the field. For example, the Federal Reserve Bank of San Francisco actively promotes the value of bridging health and community development, as well as the use of data.[5]

> ***"It is essential to get specific about what the value proposition of sharing data is to each of the partners/ stakeholders involved."***

[4] See "Recommended Social and Behavioral Domains and Measures for Electronic Health Records" http://iom.nationalacademies.org/Activities/PublicHealth/SocialDeterminantsEHR.aspx#sthash.0DLRvrZk.dpuf

[5] http://www.frbsf.org/community-development/initiatives/healthy-communities/ and http://www.frbsf.org/community-development/publications/special/what-counts-harnessing-data-for-americas-communities/.

Many respondents suggested public-private partnerships could foster sustainability, if the costs to any one entity are reasonable and proportionate to the value of the sharing data. One respondent noted that making the value case is the first step in multi-sector data sharing initiatives, which helps ensure that systems are built to meet the needs of each of the proposed data sources and users.

> *"You're really looking at public/private partnership models. …The question becomes how do you fund these particular initiatives? Do you rely heavily on the government? Is it the private sector that does it? Who's really benefiting? And what do they feel their clear value propositions are for participating? That's usually what it boils down to."*

Below are some additional considerations on creating value propositions, compiled from the key informant interviews:

- Community partners see the value of the work when collaborative and data infrastructure projects attract grant dollars
- Employers have a vested interest in the wellness of their employees, which could be leveraged for this work
- Context determines the extent to which organizations will derive value from data sharing, as demonstrated by payment reform and the development of Accountable Care Organizations
- Context also matters in creating incentives to restrict data sharing. For instance, in competitive markets where data is seen as a commodity, collaboration becomes harder
- Current partners should define a value proposition that can be leveraged to engage additional partners and sectors. This has helped the Camden Coalition of Healthcare Providers sustain and expand the Camden Health Explorer profiled on page 37

National expert informants offered additional suggestions on building the value case.

- The Public Health Informatics Institute is developing a toolkit that assists practitioners in documenting the value of public health surveillance to potential health care data providers[6]
- Consumers may be willing to share their personal data about a health condition within a community of others with the same condition (i.e. autism, cancer, depression, etc.) if it can be enabled technologically and if they can have access to the shared data from others
- Consensus should be developed around a list of key objectives for the initiative, especially those that are most likely to generate early wins

[6] http://www.phii.org/ehrtoolkit

Case Study: Camden Coalition of Healthcare Providers

In 2002, Dr. Jeffrey Brenner, a family doctor in Camden, New Jersey, was overwhelmed. Changing Medicaid reimbursement rates meant his practice was on the verge of shutting down, yet community hospitals were expanding their emergency rooms to meet growing demand. This frustration led Dr. Brenner to connect with other primary care providers in order to create a space to support one another.

The Camden Coalition of Healthcare Providers originated from a research study with three city hospitals that were historically in competition. Sharing data across hospitals created opportunities to make health care service delivery in the community more efficient and effective. Early wins helped build trust and buy-in for community-wide collaboration and led to the development of a Health Information Exchange.

The Camden Health Explorer, one outlet for the coalition's integrated data, summarizes clinical data from the health information exchange using "hotspotting." This technique reveals geographic variation in health issues and other population health trends, making it clear that "non-medical" solutions are needed for greater impact. As the coalition grows, it has expanded its external data sharing efforts to include geographic data on the built environment, individual-level data from law enforcement and corrections, and student-level data from the city's school district. Discussions are also underway to integrate homelessness data through the state's Homelessness Management Information System. Specific "use cases" underway include:

- Analysis of the overlap between families who are frequent users of hospital emergency departments and also have repeat encounters with law enforcement have led to the discovery of sub-populations who will require unique holistic strategies to address their needs
- The Housing First initiative will prioritize medical high-utilizers for housing vouchers to achieve greater impact

> ***"Most of the services we provide as a sector lack any evidence that they are effective…Bringing data together is essential to understanding the most effective strategies and building an evidence base for holistic care."*** - A. Truchil

Contextual drivers

- Accountable Care Organization
- Regional health information exchange infrastructure
- Need to develop evidence-based policies in population health

Who is involved by sector?

- **Data sources:** Health care settings, public health, criminal justice, housing, education
- **Data users:** Public health, government, health care settings, behavioral health, higher education and/or academic research, policymakers, community organizations

What data is being shared and how?

- Through a combination of BAAs and IRB agreements, individual health data is collected from EHRs in health care settings. Medical claims data is collected from hospital systems. Other administrative data is collected through data sharing agreements with social service providers.

What is the purpose of the data sharing?

- Improved service design
- Care management/coordination
- Community/partner engagement
- Developing evidence-based programs and policies

Building trust among stakeholders

In addition to articulating a clear value proposition for sharing data and the benefits to each sector, coalitions must also address issues of trust. Across all sectors, themes related to building trust were among the most commonly reported barriers limiting collaborations' ability to share data successfully. In general, challenges associated with trust related to four key areas:

> ***"Data moves at the speed of trust."***
>
> - Data for Health: Learning What Works

- Data as "turf" (conferring power through ownership)
- Fear of data revealing flaws
- Privacy and security
- Technical aspects of the data system (providing consistent, reliable information without fail)

> ***"Trust is key—people want to know how data is going to be used and how it will be of benefit to them. Concern also relates to who will have access to shared data."***

Several respondents associated turf-type attitudes about data ownership with competitive situations – such as in health care or scientific research. Building trust may be even more difficult to overcome for entities in small communities that are often in competition for funding and other resources while working towards similar aims. For example, several webinar participants pointed to competition between providers or hospitals for patients, and voiced concern that consumers might seek services elsewhere if data from their institution pointed to differences in cost or health outcomes. Interview, survey, and webinar respondents agreed that this issue is inherent to the way in which health care payment is currently structured, where providers are paid based on the number of services rendered as opposed to the health of the population served. Other entities are similarly resistant to sharing data; for fear that it will be used against them. One subject matter expert agreed:

> *"A lot of people are hesitant to share their data because they don't want to have their secrets ousted, especially if they don't know what their secrets are yet."*

Community members may fear that interventions will be developed based on data from multiple sectors or sources that do not adequately represent their members, instead of through engagement with the community residents.

Potential solutions offered by national experts to issues of ownership included:

- Ensuring that the data aggregator and/or data hub is a neutral entity
- Establishing transparency and participatory governance
- Having a clearly defined purpose and use case(s)

Informants had a similar interpretation of policy and regulations. They also noted that the need to protect data privacy and security created barriers to establishing trust for data sharing. Interview, survey, and webinar participants repeatedly pointed to entities' concern that they might violate federal laws related to protecting the privacy of health care information and student education records—Health Insurance Privacy and Accountability Act (HIPAA) and Family Education Rights and Privacy Act (FERPA), respectively. Further,

> ***"You can give someone data, but that doesn't mean they will use it to work together. Communication, collaboration, trust are the keys—forming common goals and working on them together."***

mental and behavioral health data were reported as particularly difficult "nuts to crack," even though these providers are often within the health care community.

In terms of privacy laws, respondents felt that workable solutions were available for some issues, and that sharing tools, resources and experience could ameliorate issues. An informant shared:

> *"One strategy we use is to actually bring HIPAA state personnel in and let those authorities share that knowledge about how a lot of data can actually be shared."*

Proper technical design also ensures privacy and confidentiality are appropriately maintained.

Among entities sharing patient data used at the point of service, trust can be cultivated by actively engaging patients in the data sharing. Useful approaches to gaining trust include making processes to obtain consent to share personal data more informative, and making the results of data sharing available to patients, including a demonstration of the key uses of the data.

> ***"If you try and ask questions in generalities around privacy law, you don't get anywhere. But if I am asking questions about what [data] could a mental health clinician see for a person who has records in these systems when they are preparing to make a referral over to this domain, then I can get to an answer. And so the use cases really help us unlock the privacy and confidentiality and authorization questions."***

Establishing strong governance

Initiatives must continuously attend to challenges governing collaborations while also considering the governance of data. Strong governance is important for establishing trust, fostering buy-in and ensuring that a collaboration is able to pursue its aims in an organized manner.

Governance of data, particularly as it relates to protecting privacy and security, is a relatively new arena with various implications being examined at a local to national level. Strong governance models for data include developing a common set of rules of collecting, sharing, and acting on data; specifying use cases; and being transparent about data stewardship. A significant portion of the Office of the National Coordinator for Health IT's Nationwide Interoperability Roadmap is focused on governance as part of the necessary work to move information sharing toward its full potential. Thus, it is an ideal time to aggregate subject matter expertise with learnings from the field to inform best practices moving forward.

Monitoring federated governance for data sharing, which could leverage APIs, build on the National Interoperability Roadmap, and support work occurring in health information exchanges across the country,[7] will also provide insights into new approaches to this challenge. The DASH NPO notes with sadness that Hunt Blair, who was a member of the DASH National Advisory Committee recently passed away. Blair led pioneering work in this area through the Collaboration for Open Data Alignment.

> ***"Explaining the benefits of data sharing, dealing with data 'ownership' and privacy issues, and negotiating MOUs and data sharing agreements have all taken longer than anticipated."***

[7] As with the National Association for Trusted Exchange www.nate-trust.org

An early confirmation of these findings and recommendations from the field

In September 2015, DASH leadership presented an early version of the findings in this report at AcademyHealth's Concordium conference to an audience of 35 health care and data practitioners.[8] The session included an introduction to DASH, the Culture of Health and the initial scan findings. The majority of time was reserved for guided discussion to gather and rank participant responses.

The discussion opened with participants listing a variety of barriers to sharing data across sectors in the current environment. Their responses—access to data, EHR integration, privacy and security concerns, data literacy, data and collaboration governance, language and communications, a lack of standards, and resources for systems development and maintenance—all echo the list of barriers documented in the scan.

DASH leaders presented the initial findings and asked participants to envision how access to an ideal system of shared data across sectors would enable stakeholders to improve community health. They shared over 50 responses and selected these as the top concerns:

- Improve alignment between different organizations in the community so that they're aware of each other's activities and how to work together
- Provide incentives to agencies and sectors that reflect the relative contributions of each player to health; contributions would be understood, recognized, and rewarded
- Make sure data is accessible to stakeholders so that they can determine where interventions should take place and measure their impact

Lastly, the participants discussed nearly 100 different resources they would need in order to realize the vision above. When prompted to discuss efforts to move the field forward, they recommended the following priorities:

- Shared understanding of what the goals are
- Shared language across different partners/sectors
- Financial incentives and funds to deploy adequate resources
- A champion (organizing entity to get everyone together)
- Sustainable, on-going funding
- Trained professionals—capacity across collaborative partners
- Resolutions to privacy issues
- Adequate technical infrastructure
- Data analytics capability and support
- Transparency among the responsible parties

While these suggestions reflect a relatively small sample of experienced leaders, this list confirms many of the priorities identified during the scan. Further data gathering will test, confirm and expand on these insights.

[8] "No Sector Alone Can Improve Health": What We Are Learning About Connected Information Systems for Community Health, Concordium Conference, Washington DC, September 21, 2015. Peter Eckart, Illinois Public Health Institute, Hilary Heishman, Robert Wood Johnson Foundation, Clare Tanner, Michigan Public Health Institute

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 three key characteristics of DASH underwent several revisions to best capture the breadth and complexity of the field. 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. The team identified three major limitations.

The "emerging field" is so new, diverse and dynamic that any conclusions must be considered preliminary

In this context, the DASH NPO made a series of decisions regarding the scope of the current field. Scanning activities helped to confirm assumptions and revealed areas where additional refinements are needed. At this early stage, defining and documenting the field is a work in progress. As the DASH NPO expands the Catalog, our understanding of the defining characteristics of the field may evolve.

Each of the three key characteristics and related sub-categories reflect a significant body of knowledge. The initiatives investigated to date vary widely and diverge at different points in different domains. Furthermore, the maturity of the cataloged initiatives varies greatly. Some efforts are being planned and implemented, while others are being piloted, completed, or expanded to include new use cases. Although it is not possible to know the extent to which the DASH Catalog represents the field as a whole, the number of responses to the initial call for proposals suggests that the number of initiatives documented may be too small to provide reliable generalizations.

The DASH frameworks are descriptive and analytic, but not evaluative

Because the primary intent of the initial scan was to define the field, the DASH NPO developed descriptive and analytical frameworks. As DASH focuses more on understanding the impact of connected data systems, an evaluative framework will be required to understand the degree of community health impact of the initiatives and to develop indicators of progress for the field.

Variability and availability of information about initiatives inhibits ability to generalize

The DASH NPO collected information on nearly two hundred data sharing initiatives. The subset included in the Catalog contained attributes of all three key characteristics, but did not necessarily exemplify successful DASH initiatives. Even so, unsuccessful examples are likely underrepresented.

The primary sources of information for the Catalog include web-based research, key informant interviews, and survey responses. Publicly accessible information tends to focus on the background of the initiative, the partners involved and high-level aims rather than the data sharing activities or information sharing systems. Key informants also had different areas of expertise that led to variation in the type of information and the level of detail provided. Differing information types and degrees of detail often made it difficult to draw conclusions about the nature of a field as a whole or the significant subsets within it. Ultimately, most information in the Catalog relies on reports and representation from participating stakeholders and thus incorporates the biases of these authors.

NEXT STEPS

Despite the limitations, the scan collected a significant amount of data regarding the scope of the current field. National experts offered their insights and practitioners from various sectors shared their experiences. The DASH NPO noted a high level of energy and enthusiasm for the work across experts and practitioners alike. From the initial scan, the DASH NPO was able to formulate a better sense of how initiatives are meeting the DASH key characteristics and the types of additional information needed to have a deeper, more complete understanding of the field. To guide efforts moving forward, the DASH NPO has 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.

Monitoring the Environment

The DASH NPO will continue to monitor the environment to address gaps in knowledge, inform the development of indicators of progress, and establish the evidence base for setting priorities for the field. Documenting specific use cases will illuminate more robust value cases for multi-sector data sharing.

1. **Continue to monitor initiatives documented in the DASH Catalog for promising practices and community health impacts.**

   The initial scan identified a number of examples of multi-sector data sharing. However, interviews with key informants revealed that many are in the early stages of evaluating the impact of data sharing for community health improvement. The DASH NPO will develop a strategy to monitor select initiatives over time and accumulate evidence of the effectiveness of various approaches.

2. **Further develop the DASH domains and attributes to enable a clearer and deeper understanding of how DASH initiatives build capacity for community health impact.**

   The purpose of developing a classification schema for DASH domains and attributes is to enable the summarization and generalization of multi-sector data sharing initiatives. DASH NPO staff will refine the attributes, test them within the current Catalog, and improve as needed. Moving forward, the DASH NPO will investigate how different sectors, community stakeholders, and data systems all contribute to build collaborations' capacity for community health impact, specifically examining how different sets of attributes contribute to an initiative's ability to address the social determinants of health. For example, the DASH NPO hopes to understand how different sectors interact with each other to increase the speed and size of impact, or how use of specific data and information systems increase community capacity to develop data-driven approaches.

3. **Refine data collection and management strategies to improve an understanding of the field.**

   Documenting additional initiatives in the Catalog will require consideration of the defining attributes of those currently recorded. To start, the concepts and fields in the Catalog will need to be refined to allow users within the DASH NPO and RWJF to easily identify cases of interest and generate summaries. Additionally, the DASH NPO will develop a methodology for adding initiatives to ensure that information contained in the Catalog is complete and up-to-date and that newly recorded initiatives deepen an understanding of the field.

4. **Develop a deeper analysis of the 409 brief proposals and the 31 full proposals.**

   The submission of 409 brief proposals resulted in an unexpectedly large amount of information regarding the aspirations of communities across the country interested in this field. With sufficient time and the application of "big data" analytical processes and tools, the content of the 409 proposals may reveal important findings about the opportunities and barriers communities face when planning and implementing multi-sector data systems for community health improvement. The analysis of the 409 may also provide a template for investigation of the 31 full proposals to be submitted later this fall.

5. **Collaborate with a network of similar initiatives across the country.**

   The DASH NPO will work to leverage the participation of initiatives identified in the scan that reflect the key DASH characteristics, inviting them to join a network to extend the use and dissemination of evidence-based practices. By joining forces with similar initiatives, DASH can help generate and accelerate knowledge of developing and implementing multi-sector data and information systems.

Developing Indicators of Progress

To determine if certain types of purposes, collaborative arrangements, or data sharing systems are more or less effective in terms of their evaluative impact, the DASH NPO will develop indicators of progress for the field. These indicators will also inform ongoing monitoring and the collaborative learning plans for the DASH grantees. Specific areas where further measurement will be helpful include:

- **Developing process indicators:** Documenting when and how initiatives add sectors, make progress toward project goals, or conduct activities to address systems changes will help to document if the field is making progress.
- **Documenting progress in sustainability:** Both funding and the fragility of collaborative relationships emerged from the scan as major threats that could undermine the sustainability of multi-sector initiatives. Identifying a growing number of initiatives with sustainable and diverse funding models would indicate progress. The DASH NPO proposes to conduct background research on factors that predict sustainable community collaboration, as well as sustainable data exchange, to guide the development of measures that would appropriately capture this domain.
- **Promoting and supporting technological advancement:** The number of initiatives employing manual data sharing and dissemination processes surprised the DASH NPO. Moreover, some informants indicated they are still learning about the populations they serve and the types of information that it is important to share. Thus, it may be too early for expanding the use of more automated processes. The DASH NPO will work with Advisory Group members and other experts to develop expectations around automation that occurs as the field advances and generate measures accordingly.
- **Further exploration of interoperability:** The topic of interoperability in regards to multi-sector data sharing is complex. While 'interoperability' was the most common barrier mentioned by individuals participating in the CFP webinar, this often seemed to be a generalized plea for systems to talk to each other. The DASH NPO will seek more information about initiatives that work to overcome interoperability challenges, and develop a mechanism for monitoring the field for evidence of progress in those areas. This activity may include monitoring standards development and policies around system certification, such as whether IOM recommendations around including social determinants in EHR certification criteria would meet desired use cases. Instances of software products that enable multi-sector data sharing could also be cataloged. The DASH NPO Advisory Group members have significant expertise in this area that will help inform this activity.

- **Stories of impact:** Few multi-sector data sharing initiatives have robust evaluation plans that link their efforts to measurable community health impacts. The DASH NPO will gather examples of "bright spots," or positive near-term outcomes that the partners attribute to the multi-sector data sharing effort. Examples could include successful policy or systems change efforts, providers offering whole person care, and investments aligning with root causes to change outcomes.
- **Evaluation:** The DASH NPO will work with grantees to self-evaluate their work and report progress. Collecting metrics from the DASH grantees could allow for piloted recommended metrics for the field as a whole. The DASH evaluative framework includes domains that relate to data and surveillance systems that were difficult or impossible to evaluate as part of the initial scan such as usability, user acceptance, timeliness, and data quality. However, these categories could be assessed further as part of an evaluation of individual initiatives.

Providing Technical Assistance

Across the country, practitioners have a strong desire for greater technical assistance related to data sharing for community health improvement. Initiatives varied widely in terms of the purposes for data sharing, sectors involved, technological tools in use, and key drivers, pointing to the need to target assistance based on the key characteristics of individual efforts. Moving ahead, the DASH NPO will identify promising resources and best practices to assist entities in areas identified as particularly challenging. These include:

- Using data to engage multiple audiences
- Using data to inform policy
- Making the value case for data sharing to specific sectors
- Addressing staff capacity and training
- Overcoming technical challenges
- Improving governance
- Building trust
- Addressing privacy and confidentiality concerns
- Identifying funding and sustainability models

Through direct and intensive work with grantees, the DASH NPO will also have an opportunity to refine an understanding of the needs of communities and the types of assistance that will be most helpful. We will develop a plan for storing and sharing this knowledge base so that it is accessible to a broader audience of practitioners.

Moving from Describing the Field to Guiding the Field

Major facilitators of efforts to harness multi-sectoral data to improve community health include national communities of interest and other collaborations that have formed to maximize investments in technology and data science, many with complementary aims to DASH. A significant challenge to the DASH NPO will be working with these groups to leverage, rather than duplicate each other's work and ensure multiple entry points for willing groups to find assistance and community.

As the DASH NPO 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.

REFERENCES

HIMSS. (2013). Definition of Interoperability. Retrieved from What is Interoperability: http://www.himss.org/library/interoperability-standards/what-is-interoperability

JASON; The MITRE Corporation. (2014). A Robust Health Data Infrastructure. Rockville: Agency for Healthcare Research and Quality.

McGinnis, J. M., Williams-Russo, P., & Knickman, J. R. (2002). The Case For More Active Policy Attention to Health Promotion. Health Affairs, 21(2), 78-93.

National Quality Forum. (2015). Data Needed for Systematically Improving Healthcare. Washington DC: National Quality Forum.

Office of the National Coordinator for Health Information Technology (ONC). (2014). Report to Congress on Health IT and HIE. Retrieved from Office of the National Coordinator Web site: http://www.healthit.gov/sites/default/files/rtc_adoption_and_exchange9302014.pdf

Office of the National Coordinator for Health Information Technology (ONC). (2015). Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap. Retrieved from ONC Web site: http://www.healthit.gov/policy-researchers-implementers/interoperability

Thacker, S., Qualters, J., & Lee, L. M. (2012). Public Health Surveillance in the United States: Evolution and Challenges. Atlanta: Centers for Disease Control and Prevention.

APPENDICES

Appendix A: DASH Initiatives Catalog

Project Title	Location
100 Million Healthier Lives	Worldwide initiative (Headquarters in Cambridge, MA)
Adult Linkages Project	Los Angeles County, California
Air Louisville	Louisville, KY
Akron Accountable Care Community	Akron, OH
Alabama One Health Record	Alabama
Alabama Secure Sharing Utility for Recidivism Elimination (ASSURE)	Alabama
Allegheny County Integrated Data Warehouse	Allegheny County, Pennsylvania
Allegiance Health Improvement Organization	Jackson, MI
Alliance for Healthcare Access	Grand Forks County and Polk County, North Dakota
Alzheimer's Disease and Related Dementia (ADRD) State Registry	Athens, GA
Annapolis Community Health Partnership	Annapolis, Maryland
Bay Area Transformation Partnership	Counties of Anne Arundel, Queen Anne's and Talbot, Maryland
BR City Key	Baton Rouge, LA
Bronx Regional Informatics Center (BRIC)	The Bronx , New York City, New York
Camden ARISE (Administrative Records Integrated for Service Excellence)	Camden, NJ
Camden Health Explorer	Camden, NJ
Center for Innovation through Data Intelligence	New York City, New York
Central Wisconsin Health Partnership	Adams, Juneau, Marquette, Waushara, Waupaca and Green Lake Counties, Wisconsin
Chapin Hall's Integrated Database	Illinois
Children's Data Network	California
Cincinnati Children's Hospital Asthma Program	Cincinnati, OH
Cincinnati Children's Hospital Housing Code Violations	Cincinnati, OH
Cincinnati Children's Hospital/Legal Aid Partnership	Cincinnati - OH
Colorado Health Observation Regional Data Service (CHORDS)	Denver, CO
Commonwealth Care Alliance	Massachusetts
Communities Count	Seattle, WA
Community Action Plan	Franklin County and North Quabbin Region, Massachusetts
Community Care of North Carolina	North Carolina
Community Health Assessment	Durham, NC
Community Health Equity Report	Birmingham, AL
Community Health Needs Assessement	Clackamas, Multnomah and Washington counties of Oregon and Clark County, Washington
Community Information Exchange San Diego	San Diego, CA

Community Needs Assessment	Gainesville, FL
Community Rx	Chicago, IL
Comprehensive Sexual Assault Examination Response - Brevard County Health Department	Florida
Data Sharing for Community Health Needs Assessment	Northwestern Minnsota
DC Collaborative for Mental Health in Primary Care	Washington, DC
DC Health Matters	Washington, D. C.
Ely Community Care Team	Duluth, MN
Examining multisectoral determinants of child health in Los Angeles and Philadelphia to define strategies to reduce infant mortality	New York, Los Angeles, Philadephia
Feasibility Study for Targeted Community Health Assessment	Marion County, IN
Food for Families Project	Alameda County, CA
Foundation for Better Health Initiative	San Angelo, TX
Greater Cincinnati Beacon Collaboration	Cincinnati, OH
Health Information Exchange - MyHealth Access Network	Tulsa, OK
Health Information Exchange (Coastal Connect HIE)	Southeastern North Carolina
Health Network	Durham County, North Carolina
Healthy Cabarrus	Cabarrus County, NC
Healthy Convenience Store Initiative	Albany, New York
Healthy Montgomery Data Repository	Rockville, Maryland
Healthy Tampa Bay	Tampa Bay, Florida
HHIC OnLine Reports	Honolulu, HI
Incorporating Mobile Health in Public Health Practice	Independence, Missouri
Knowledge Integration Program	San Diego, CA
Learning Health System	Durham, NC
Lower Roxbury: Developing a Healthier Neighborhood through Upstream Multi-Sector Collaboration	Boston, MA
Magnolia Community Initiative	Los Angeles, California
Mariposa Healthy Living Initiative	Denver, CO
Maryland Medicaid eHealth Statistics	Maryland
Medicaid Network for Evidence-based Treatment (MEDNET)	California, Washington, Texas, Missouri, Oklahoma, and Maine
Michigan Pathways to Better Health	Ingham, Muskegon and Saginaw Counties, Michigan
Mobilizing Action Toward Community Health (MATCH)	Wisconsin
myCareCompare.org	Detroit, MI
New Mexico Community Data Collaborative	Albuquerue, New Mexico
North Carolina Healthcare Information & Communications Alliance, Inc.	Durham, NC
NW Teen Parent Connection	Hennepin County, MN
Opiod Strategic Planning Committee	Ypsilanti, MI
Oregon Health Care Quality Corporation	Oregon
Partnering for Family Success	Cleveland, OH

Pathways Community Hub	Columbus, OH
Pinellas County Data Collaborative	Florida
Project Synthesis Expansion	Pinellas County, FL
Race to the Top - Promise Communities Initiative	South Burlington, VT
Regional Health Assessment Collaborative	Joplin, MO
Rochester Community High Blood Pressure Collaborative	Rochester, New York
San Francisco Indicator Project	San Francisco, CA
Sedgwick County Health Department - Community Health Navigators Program	Wichita, KS
South Carolina's Integrated Data Warehouse - Office of Research and Statistics	South Carolina
Southeastern Diabetes Initiative Data Mart	North Carolina
Statewide Clinical Health Information Exchange	Salt Lake City, Utah
The NYC Macroscope	New York City, NY
Upper Cumberland Community Health Information Exchange	Nashville, TN
Using Public Health Strategies to Reduce Crime and Violence Hot Spots	East Palo Alto, CA
Waste Not OC Coalition	Orange County, California
WI Data Platform Pilot	Madison, WI

Appendix B: Scan Framework and Approach

DASH

Data Across Sectors for Health

National Program Office

Illinois Public Health Institute & Michigan Public Health Institute

Empowering communities through shared data and information

Environmental Scan Summary Document and Approach

Updated 06/03/2015

Purpose

As part of its multi-sector data and information systems focus, RWJF launched a new initiative, **Data Across Sectors for Health (DASH),** in February 2015**.** DASH will identify barriers, opportunities, promising practices and indicators of progress for multi-sector collaborations to connect information systems and share data for community health improvement. Through its National Program Office, DASH will undertake:

- Comprehensive documentation and monitoring of existing collaborations;
- Grant making, technical assistance and collaborative learning support for collaborations;
- Engagement of and communications to practitioners, policy-makers, and other leaders on lessons learned from the field and emerging research; and
- Engagement of and communications to practitioners, policy-makers, thought leaders, grantees and stakeholders on lessons learned and emerging research from the field.

The DASH NPO is led by the Illinois Public Health Institute, in partnership with the Michigan Public Health Institute, with support from the Robert Wood Johnson Foundation. In support of these above mentioned activities, the DASH NPO will produce an environmental scan by August 14, 2015, with preliminary findings and discussions throughout the process. This document describes a framework and methodology for the creation of the environmental scan.

Objectives

The Robert Wood Johnson Foundation describes the objectives of this environmental scan as follows:

I. Provide up to date information on relevant activities, leading communities, and research
II. Identify promising examples of shared data and/or connected information systems across sectors to improve health
III. Synthesize observations into lessons learned in regards to barriers, gaps, and opportunities
IV. Develop recommendations for the Foundation
V. Serve as a foundation for measuring progress, including the development and tracking of specific indicators

Approach Overview

In order to guide data gathering for the environmental scan, the DASH National Program Office developed a preliminary framework, which has been updated to reflect learnings to date. Based on the objectives stated above, the framework has two main components:

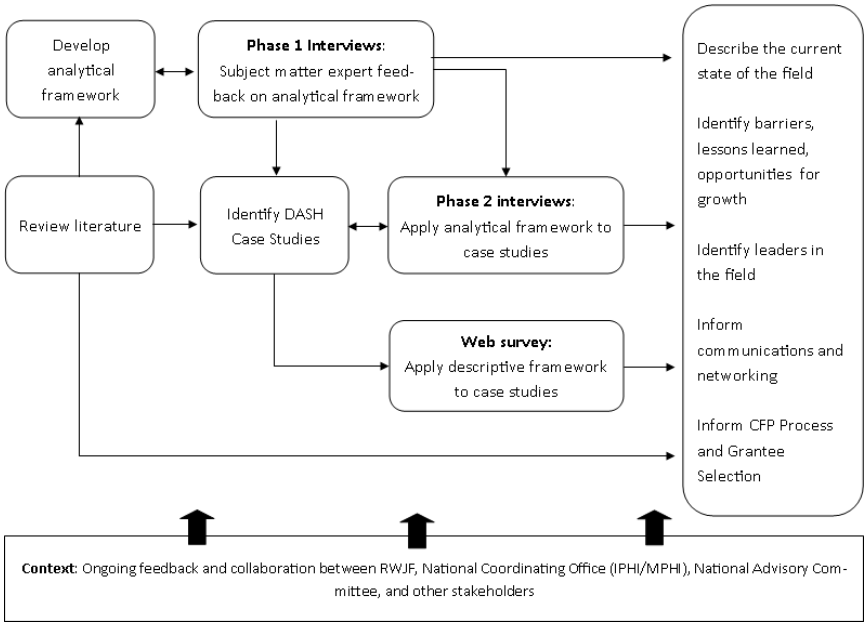
1. **Descriptive**: Objectives I-II above are primarily about characterizing the field of connected multi-sector data and information systems for health.

2. **Analytical:** Understanding barriers and opportunities, synthesizing lessons learned, and measuring progress, as enumerated in Objectives III-V above, require the application of an evaluative or analytical lens as we seek to understand what is working, what is not working, and why.

The proposed framework will evolve over the course of project. During data collection, the framework will guide case selection, the types of information documented, application of key words for storing and searching, and the coding schema for key informant interviews. During data collection, we will revise and refine the framework as new concepts and elements are discovered. Eventually the evolved analytic framework will provide a structure for categorizing relevant examples, supporting decision-making around selected interventions (which could include grant-making, policy development or other levers at the Foundation's disposal), and measuring progress.

Key activities for the scan include conducting a literature review, two rounds of key informant interviews, and a widely circulated electronic survey. Findings resulting from these activities will be incorporated into the framework as well as in a six-month report, which will be updated on an ongoing basis with emergent findings. These core activities are summarized in the following process map.

DASH Environmental Scan Process Map



Methodology

As depicted in the process map above, we will employ multiple methods in executing the environmental scan objectives. The primary purpose, target respondents, sampling plan, data collection method, and plans for analysis are described below. Table 1 also provides a timeline for these activities as well as an update regarding their status and immediate next steps. All data gathered through these activities will inform the report on the scan that will be finalized in August.

Table 1. Environmental Scan Data Gathering Activities, Purpose, and Timing			
Activity	**Timing**	**Status**	**Next Steps**
Literature Review	February 16, 2015-July 15, 2015	Ongoing, curating DASH-like examples in a "collaborations catalog"	Continue identifying DASH-like examples, refine "collaborations catalog" to include fixed categories for characterizing examples
Phase I Interviews	March 9, 2015 – June 1, 2015	Complete, coding schema developed, first round of coding complete	Conduct exploratory queries and analysis, refine coding schema, apply revised or added codes to interview transcripts
Phase II Interviews	June 1, 2015 – June 30, 2015	Tool developed, prototypes conducted, interviews underway	Complete interviews, adapt and apply coding schema to interview transcripts
Web-based survey	June 1, 2015 – July 31, 2015	Tool developed and programmed electronically, currently being prototyped	Incorporate feedback from prototyping, activate networks for survey dissemination, disseminate survey

Literature review: Because DASH is a new initiative, significant background research is required to help describe the state of the field of multi-sector data and information sharing. Specifically, the purpose of the literature review is to 1) identify and obtain preliminary information on pertinent examples, thought leaders and relevant research and 2) further develop DASH framework for the environmental scan.

This process will be iterative and descriptive framework elements will be used to describe and categorize case studies and examples identified. Analytical framework elements will support analysis of these examples as they relate to lessons learned, opportunities, and gaps in the field. Eventually, these examples will be entered into a database searchable by these factors. The database will be updated on an ongoing basis and, every six months, a summary of its contents as well as emergent lessons learned, opportunities, and gaps will be generated.

Key Informant Interviews: Upon careful review of the literature and case studies identified, we have developed a preliminary framework to guide further environmental scan activities and areas of inquiry (see below). The purpose of the Phase I key informant interviews (KII's) is to obtain feedback from 8-10 experts in the field of multi-sector data sharing on this framework to ensure subsequent data gathering is structured appropriately. Further, the Phase I KII's will aid in identifying additional relevant examples for inclusion in the environmental scan as well as those who might serve as Phase II interview participants.

A second phase of key informant interviews (up to 15) will be conducted with those involved with leading and implementing DASH-like initiatives. Preliminary definitions of what is considered to be DASH-like are described below. The purpose of the Phase II KII's is to 1) obtain additional descriptive information about relevant examples and leading communities and 2) gather information about success factors, opportunities, and barriers in the field of multi-sector data and information sharing. We will attempt to establish balance among Phase II KII participants through application of preliminary codes developed for the descriptive framework thus far (see Table 2 below).

We will employ a snowball sampling method to identify interview participants. Initial outreach will leverage the RWJF, IPHI, MPHI, NNPHI, and other known networks to identify experts in the field(s) of data and information sharing, multi-sector collaboration, and community health (Phase I). Interview participants will be asked to recommend contacts to be further explored as additional subject matter experts or relevant case study examples (Phase I and Phase II, respectively).

Phase I and Phase II will be semi-structured interviews and prepared for qualitative analyses once conducted. Interview recordings will be transcribed into detailed notes, cleaned, and uploaded into a document database created in NVIVO 10 (QSR International, 2008), a qualitative data analysis software package. Codes will be developed and applied to text. Some codes, such as those reflecting elements of the descriptive and analytical frameworks, will be developed a priori. Remaining codes will be developed by reading the detailed interview notes. Codes will be continually revised prior to and during data analysis until the team believes that the codes reflect the data adequately.

All texts will be coded by trained evaluation team members. A second team member, working independently, will code a randomly selected sub-sample of these documents in order to assure inter-rater agreement. Discrepancies in the application of codes will be discussed by the coders until consensus is achieved on the appropriate code.

Web-based survey: To supplement qualitative analyses, the environmental scan will employ a web-based survey that will be widely distributed to contacts and relevant examples identified. We aim to get 60% of those identified through the literature review and interview process to respond to the survey. The purposes of the survey are to: 1) catalogue examples of multi-sector collaboratives that meet most or all of DASH defining characteristics, 2) obtain additional feedback on community priorities for multi-sector data sharing as well as barriers and opportunities, and 3)obtain additional contacts and stakeholder information.

The survey will be comprised primarily of fixed-response questions informed by the learnings from interviews and the literature review. Some open-ended items will also be included. Survey items will focus on elements of the descriptive framework (e.g. sectors, aims, use case, impact level, outcomes, data sharing mechanism, and data elements) as well as some analytical elements (e.g. governance, user experience, etc.). Barriers and success factors to multi-sector data and information sharing will also be addressed.

Survey data will be cleaned (i.e. checked for missing data and inaccuracies) and data distributions will be summarized for the major variables of analysis. Data will be presented in aggregate form as well as stratified according to elements of the descriptive framework. Following survey analysis, the team will consult on strategies for continuous improvement, environmental scan design changes, corrective action, and further analyses to be conducted.

Environmental Scan Framework

As described above, a preliminary framework has been developed and will be employed in various activities within the environmental scan. The core components of the framework are both descriptive and analytical in nature.

Descriptive Framework Elements

Table 2 proposes elements for the DASH environmental scan framework which are primarily descriptive in nature. These elements will be documented during the environmental scan. They will be useful for understanding: 1) the extent and scope of the field, 2) predominant areas of activity, 3) the primary purpose(s) for which data and information systems are being connected in leading communities, 4) the larger context and objectives in which the data sharing activities are occurring.

Table 2 is divided into two sections: context elements and data/information system project details. Context elements refer to the larger effort of which the data sharing project is a component. Data/information project details are specific to the data and information systems that comprise the collaboration. Note that the elements of Table 2 provide a way to describe the scope of the DASH initiative. Further, as solidified through the generation of a call for proposals, defining characteristics of DASH include:

- **Shared data and information**: This includes both shared data and connected information systems. Health data is derived from a wide range of sources and includes raw data, aggregate data, summary data, and reference data. Data that is interpreted, analyzed and properly displayed can become information that people use to

inform meaningful actions that help improve individual and community health. Connected information system include, but are not limited, to health information exchange, bilateral data bridges, shared access to a data warehouse, or integrated data from multiple sectors with a community in common.

- **Multi-sector**: Intentional collaborations working across boundaries and in multi-organizational arrangements, typically including health care delivery, governmental public health, and personal health and wellness. Sectors "beyond" these traditional health sectors include, but are not limited to, social services, housing, education, transportation, community safety, community development, the physical environment, and business/employers. These sectors are representative of the social determinants of health, and their inclusion deepens understanding of the health of communities, and provides additional and optimal avenues for action.

- **Collaboration**: Multi-organizational arrangements engaged in ongoing and systematized operations, working across boundaries to solve problems that cannot be solved – or easily solved – by individual institutions acting alone. A collaboration can be either an existing multi-organization partnership with a shared venture, or a stand-alone entity that operates for or on behalf of community collaborations.

- **Focused on improving the health of communities**: Activities and operations that are designed to improve measures of the collective health or wellbeing of geographically defined communities. Communities can also reflect networks of people who have a mutual interest or need, or are subject to common health disparities or negative health outcomes. This definition of "health" is intentionally broad to anticipate the participation of multiple relevant sectors.

Appendix A provides some example applications of the descriptive framework. The NPO is constructing a searchable database to contain this information. Initially, the elements of the framework were captured narratively. Emergent categories, reflected in Table 3, will be formalized into a coding schema to be applied to case study examples as well as to inform web survey development.

Table 2. Descriptive Framework Elements- Context Elements

Context Elements	Definition	Codes/examples		
Sectors	Areas of society participating	1. Health care settings 2. Public health surveillance systems 3. Human services agencies 4. Housing 5. Education (primary and secondary school systems) 6. Higher education and/or academic research 7. Law enforcement/ public safety	8. Corrections 9. Transportation 10. Parks and recreation 11. City/regional planning departments 12. Other local government 13. Faith-based organizations 14. Advocacy organizations 15. Other not-for-profit or charitable organizations	16. Private sector research 17. Banking/ financial 18. Local businesses/ employers 19. Other business/ private sector 20. Personal devices 21. Social media 22. National public data sets [e.g., census data, more] 23. Other
Aims	Overarching purpose of the collaboration	1. Disease (or injury) prevention/reduction 2. Health behavior change 3. Increase health access 4. Address social determinants		

Context Elements	Definition	Codes/examples
		5. Individual wellness/self-management 6. Decrease healthcare utilization 7. Healthcare cost containment 8. Non-health related 9. Other
Impact Level	Group affected	1. Individual 2. Neighborhood (geographic) 3. Community (either geographic or of interest) 4. Public health (general public) 5. Other
Outcomes	Specific measured achievements claimed	Narrative/ stories/ free text

Table 2 (continued). Descriptive Framework Elements- Data/Information System Project Details

Data/ Information System Project Details	Definition	Codes/examples
Purpose	The outcome(s) of the use case	1. Needs and resource assessment 2. Empowerment/engagement 3. Planning 4. Service improvement 5. Other
Use Case	Specific purpose of the data exchange	1. Identify community needs 2. Identify community resources 3. Identify disparities or differences in outcomes/need across populations 4. Root cause analysis 5. Engage or activate community stakeholders around community needs 6. Policy advocacy 7. Build alliances by showing connections between health and other outcomes (e.g., health and productivity, health and property values, etc.) 8. Support strategic planning 9. Plan new services 10. Target existing services to populations with greatest need 11. Apply 'health in all policies' in local planning 12. Streamline service eligibility determination processes 13. Alter the design or delivery systems of existing services 14. Hold service providers accountable to outcomes 15. Support outcomes-based or social impact payment models 16. Coordinate or manage services for individual clients 17. Measure progress towards desired goals 18. Facilitate scientific research 19. Other
Data Elements	Type of data collected/shared	1. Claims 2. Transportation Data 3. Housing Data 4. Demographics 5. Health Outcomes 6. Risk Factors 7. EHR data 8. Administrative Data 9. Utilization Patterns 10. School Enrollment 11. Immunization Records 12. Dental Data 13. Eligibility Data 14. Encounters 15. Other

Data/ Information System Project Details	Definition	Codes/examples
Data Sharing Mechanism	Nature of the data sharing	1. Shared information system 2. Electronic interface between information systems 3. Health Information Exchange organization 4. "Direct" or secure email messages 5. Web portal 6. Access into a common database or data warehouse/ data repository 7. Spreadsheets or files generated from the system and made available to users 8. Written reports 9. Other 10. Not known
Funding	How is data and information sharing supported financially	1. Grant-funded 2. Participant supported 3. In-kind/volunteer contributions 4. No specific funding source; incorporated in business operations 5. Other **6.** Not known

Analytical Framework Domains

Because the objectives for the environmental scan go beyond pure description of the field, other constructs are needed to assess and monitor the progress of data and information sharing efforts. Based on results from a literature search in conjunction with preliminary learnings from the Phase I key informant interviews, the NPO has identified a number of elements that have particular salience for this purpose. These elements are depicted in Table 3 under the heading, "Themes" and will be reviewed on an ongoing basis for appropriateness. Additional elements that will be used for coding purposed are also presented and include, "Areas of Inquiry" and "Descriptive Elements."

Table 3. Initial Coding Schema for Key Informant Interviews

Code	Description
Themes	
Analytic Capability	The ability to efficiently convert data to information.
Buy-in	Initial (and in some cases ongoing) acceptance and willingness to actively support the collaborative and its objectives.
Data	The granular bits and pieces, facts, statistics collected together for reference/analysis.
Data and information system governance	Formal management of the data or information system as well as data or information assets; ensures accountability
Data Quality	The system's ability to collect, store, process, and transfer data in a way that securely maintains accuracy.
Decision Making	As a use case, the process leading to the next steps base on available resources and available options.
Engagement/ Accessibility	The available data/information systems should be useful for the purposes identified and easy to approach/use.
Information Systems	The people and processes used to interpret information.
Interoperability	A system's abilities to adapt when workarounds can be executed.
Language	Schemas for data collection, data sharing, and data reporting do not need to be identical, but clear and consistent language regarding the data and information sharing is necessary.

Code	Description
Political/Institutional Will	The determination of specific actors or entities as they identify or complete objectives that will produce a desired outcome.
Privacy and security	The confidentiality, integrity, and appropriate use of data or information
Purpose	The reason for which the data/information system is being shared. The motivation behind the collaboration's objectives.
Sharing	How does the data/information get shared with the user
Sustainability	Management and coordination of resources to ensure ongoing success
System experience	Performance attributes that convey the quality of stakeholders' experiences in using a system
Technical Function	Is the system reliable, accessible when needed, does the system generate usable information
Transparency	The purpose for the data and information sharing must be clear and easy to understand for all participating entities.
User Trust	The user's belief that the data or information system is reliable
Areas of Inquiry	
Challenge	A factor that hinders progress
Success factor	Aspects of the information and data sharing that are working well
Lessons learned	Key learnings or insights discovered
Resources	The technological, financial or productive factors required to accomplish an activity or means to achieve a desired outcome; a lever for change.
Promising practices	Promising areas in which the field can best progress
Collaboration	is related community collaboration
Technology	is related to technology data sharing platform
"Gold dust"	Particularly good quotes or important points
Descriptive Elements	
Sectors	Areas of society participating
Aims	Overarching purpose of the collaboration
Impact level	Group affected
Outcomes	Specific measured achievements claimed or stories
Use case	Specific purpose of the data exchange
Data elements	Type of data collected/shared; variables, if available
Sharing mechanism	Nature of the data/information sharing

Appendix C: Protocol for Initial Scan Survey and Key Informant Interviews

Confidential

DASH Initial Scan Survey

The Robert Wood Johnson Foundation (RWJF) is the largest U.S. philanthropy devoted solely to improving health and health care. RWJF is committed to building a new Culture of Health in our country that will enable all in our society to live longer, healthier and more productive lives.

One facet of this work includes working to foster alignment among health care, public health, and other community systems to address the multiple determinants of health and improve the health of communities. As part of its multi-sector data and information systems focus, RWJF recently launched a new initiative: Data Across Sectors for Health (DASH). DASH will identify barriers, opportunities, promising practices and indicators of progress for multi-sector collaborations that connect information systems and share data to improve the health of their communities.

The DASH National Coordinating Office (NCO) will execute activities that support those collaborations and the field. For the purpose of this survey, DASH utilizes the following definitions:

· Shared data and information: This includes both shared data and connected information systems. Health data is derived from a wide range of sources and include raw data, aggregate data, summary data, and reference data. Data that is interpreted, analyzed, and properly displayed can become information that people use to inform meaningful actions that help improve individual and community health. Connected information system include, but are not limited, to health information exchange, bilateral data bridges, shared access to a data warehouse, or integrated data from multiple sectors with a community in common.

· Multi-sector: Intentional collaborations working across boundaries and in multi-organizational arrangements, typically including health care delivery, governmental public health, and personal health and wellness. Sectors "beyond" these traditional health sectors include, but are not limited to, social services, housing, education, transportation, community safety, community development, the physical environment, and business/employers. These sectors are representative of the social determinants of health, and their inclusion deepens understanding of the health of communities, and provides additional and optimal avenues for action.

· Collaboration: Multi-organizational arrangements engaged in ongoing and systematized operations, working across boundaries to solve problems that cannot be solved – or easily solved – by individual institutions acting alone. A collaboration can be either an existing multi-organization partnership with a shared venture, or a stand-alone entity that operates for or on behalf of community collaborations.

· Focused on improving the health of communities: Activities and operations that are designed to improve measures of the collective health or wellbeing of geographically defined communities. Communities can also reflect networks of people who have a mutual interest or need, or are subject to common health disparities or negative health outcomes. This definition of "health" is intentionally broad to anticipate the participation of multiple relevant sectors.

DASH's immediate focus is to develop a deeper understanding of the field. The purposes of this survey are to 1) identify existing and emerging multi-sector collaborations, 2) obtain additional feedback on community priorities for multi sector data sharing as well as barriers and opportunities, and 3) obtain additional contacts and stakeholder information.

The DASH NCO is led by the Illinois Public Health Institute, in partnership with the Michigan Public Health Institute, with support from the Robert Wood Johnson Foundation. If you would like more information about the environmental scan or other DASH activities, please contact info@DASHconnect.org

Survey Instructions: Please fill out this survey from your perspective as a representative or participant in a multi-sectoral data sharing initiative. You may save your work and return later – you will be given a code to ensure that you return to the correct survey. If you participate in more than one multi-sector data-sharing initiative, we invite you to fill out a survey for each one. Thank you!

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I. BACKGROUND QUESTIONS

1. What is your name? _____

2. What organization do you represent? _____

3. Where are you located? (City, State) _____

4. What is your role/position at this organization? _____

5. Please provide the name of the data-sharing initiative you're describing. (Note: Please only describe one data sharing initiative per survey. You may complete additional surveys for additional initiatives.) _____

6. If you have a website that describes this data sharing initiative, please provide it: _____

7. Please describe the community that your group serves. (Note: Please complete the population(s) or region(s) that this data sharing covers, leaving blank any fields that do not apply.)

   Specific or vulnerable population(s): _____

   Neighborhood or community: _____

   City: _____

   County: _____

   State: _____

   Other, describe: _____

8. Is the data-sharing initiative a component of a multi-sector collaboration (please refer to the definitions above)?
   - ☐ Yes
   - ☐ No

   Please provide the name and website of the multi-sector collaboration that you are representing on this survey. _____

9. What is your role with respect to this multi sector data sharing initiative? (check all that apply)
   - ☐ Leadership- Decision-maker in the organization or initiative
   - ☐ Project management- Project management of the shared data and information system work
   - ☐ Data/ Information Provider- Responsible for contributing data to the data sharing initiative
   - ☐ Data/ Information User- Primarily concerned with using information made available through the data sharing initiative
   - ☐ IT Support/ Technical Role- Responsible for or assists with maintaining the technology facilitating the data sharing
   - ☐ Data Analyst - Processes and prepares data for stakeholder use
   - ☐ Vendor- Non-collaboration commercial entity which provides the technology for collecting, analyzing and reporting on shared data
   - ☐ Other

   Please explain your role: _____

II. NATURE OF THE DATA SHARING AND PURPOSE

10. To what extent is improving community health a goal of the multi-sector data sharing initiative (please refer to the definitions above)?
    - ☐ Improving community health is the primary goal
    - ☐ Improving community health is one goal among others
    - ☐ Improving community health is not a goal

11. In your own words, please describe the specific purpose(s) of the multi-sector data sharing initiative that you are reporting on in this survey:

    _____

12. How would you describe your collaboration's stage of development?
    - ☐ Planning phase- Establishing expectations, agreeing on standards and policies, signing MOUs or data use agreements - data not yet being shared
    - ☐ Launch phase- Initial implementation of data sharing, including initial data collection and analysis or the building of sharing platforms
    - ☐ Scaling phase- Bringing data sharing work to scale as envisioned during planning
    - ☐ Controlled phase- Data sharing scaled, process being refined
    - ☐ Optimized- Data sharing largely functioning as envisioned, only fine tuning occuring

13. Are you, or have you been "stuck" in a phase for longer than you expected?
    - ☐ Yes
    - ☐ No

    Please describe: _____

14. We are interested in the purpose of your data collection/information sharing, and the specific ways you use shared data. For each purpose listed below, please indicate whether this is a current or intended use of shared data.

Needs & Resource Assessment Purposes

	Current Use	Planned Use	Not a planned use at this time
Identify community needs	☐	☐	☐
Identify community resources	☐	☐	☐
Identify disparities or differences in outcomes/need across populations	☐	☐	☐
Understand reasons (e.g., root causes) for unsatisfactory outcomes	☐	☐	☐

II. NATURE OF THE DATA SHARING AND PURPOSE

10. To what extent is improving community health a goal of the multi-sector data sharing initiative (please refer to the definitions above)?
    - ☐ Improving community health is the primary goal
    - ☐ Improving community health is one goal among others
    - ☐ Improving community health is not a goal

11. In your own words, please describe the specific purpose(s) of the multi-sector data sharing initiative that you are reporting on in this survey:

    _____

12. How would you describe your collaboration's stage of development?
    - ☐ Planning phase- Establishing expectations, agreeing on standards and policies, signing MOUs or data use agreements - data not yet being shared
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    - ☐ Scaling phase- Bringing data sharing work to scale as envisioned during planning
    - ☐ Controlled phase- Data sharing scaled, process being refined
    - ☐ Optimized- Data sharing largely functioning as envisioned, only fine tuning occuring

13. Are you, or have you been "stuck" in a phase for longer than you expected?
    - ☐ Yes
    - ☐ No

    Please describe: _____

14. We are interested in the purpose of your data collection/information sharing, and the specific ways you use shared data. For each purpose listed below, please indicate whether this is a current or intended use of shared data.

Needs & Resource Assessment Purposes

	Current Use	Planned Use	Not a planned use at this time
Identify community needs	☐	☐	☐
Identify community resources	☐	☐	☐
Identify disparities or differences in outcomes/need across populations	☐	☐	☐
Understand reasons (e.g., root causes) for unsatisfactory outcomes	☐	☐	☐

Empowerment/Engagement Purposes

	Current Use	Planned Use	Not a planned use at this time
Engage or activate community stakeholders around community needs	☐	☐	☐
Policy advocacy	☐	☐	☐
Build alliances by showing connections between health and other outcomes (e.g., health and productivity, health and property values, etc.)	☐	☐	☐

Planning Purposes

	Current Use	Planned Use	Not a planned use at this time
Support strategic planning	☐	☐	☐
Plan new services	☐	☐	☐
Target existing services to populations with greatest need	☐	☐	☐
Apply 'health in all policies' in local planning	☐	☐	☐

Improve Services

	Current Use	Planned Use	Not a planned use at this time
Streamline service eligibility determination processes	☐	☐	☐
Alter the design or delivery systems of existing services	☐	☐	☐
Hold service providers accountable to outcomes	☐	☐	☐
Support outcomes-based or social impact payment models	☐	☐	☐
Coordinate or manage services for individual clients	☐	☐	☐
Measure progress towards desired goals/clinical outcomes	☐	☐	☐
Improve patient care	☐	☐	☐
Increase patient satisfaction	☐	☐	☐

Other

	Current Use	Planned Use	Not a planned use at this time
Facilitate scientific research	☐	☐	☐
Other: (you may indicate more than one)	☐	☐	☐

Please describe any other current purposes of your data collection/ information sharing that were not indiciated above. _____

Please describe any other purposes you plan to use for your data collection/ information sharing that were not indiciated above _____

III. DATA SHARING PARTICIPANTS

15. We are interested in the entities participating in your data sharing initiative by the sector they represent. Please indicate which sectors are participating by selecting the options in the grid below. We would like to know whether the participants are contributing data (a data source), using the shared information (a data user), or both.

	Current Data Source	Intended Future Data Source	Current Data User	Intended Future Data User
Health care delivery, payment and management, clinical medical services	☐	☐	☐	☐
Public Health	☐	☐	☐	☐
Behavioral Health	☐	☐	☐	☐
Human Services	☐	☐	☐	☐
Housing	☐	☐	☐	☐
Primary, secondary or higher education	☐	☐	☐	☐
Public safety, law enforcement, corrections	☐	☐	☐	☐
Transportation	☐	☐	☐	☐
Parks and Recreation	☐	☐	☐	☐
Planning, Economic or Community Development	☐	☐	☐	☐
Local Government	☐	☐	☐	☐
Faith-based organizations	☐	☐	☐	☐
Other not-for-profit or charitable organizations	☐	☐	☐	☐
Private sector, employers, business	☐	☐	☐	☐

Other	☐	☐	☐	☐

Please describe the other not-for-profit or chartiable organizations not covered by other options: _____

Please describe the other sources or users of data not covered by other options: _____

16. For those sectors using the shared data, please describe the specific ways in which users utilize and act on the shared information (use case). For example, community planning group develops interventions targeted to common issue identified through multi-sector needs assessment; public transportation authority changes bus routes to respond to need for increased access to healthcare providers. (If more than one, limit your answer to the three most common.) _____

IV. DESCRIPTION OF THE SHARED DATA OR INFORMATION

17. What is the unit of the data being shared? (check all that apply)

- ☐ Individual person-level data
- ☐ Family or household data
- ☐ Organization level data (e.g., healthcare provider, company, agency, etc.)
- ☐ Data based on a community's geographic boundaries (smaller than a state, e.g.: census tract, zip code, municipal boundary, county, hospital service area)
- ☐ Geographic level - state or larger entity
- ☐ Other

Please Describe: _____

18. What best describes the frequency of data sharing? (check the closest option)

- ☐ Data are shared in near real time (e.g. push notifications upon occurrence of an event, results generated through query of a HIE, etc.)
- ☐ Data are refreshed daily
- ☐ Data are shared frequently (e.g. weekly to monthly)
- ☐ Data are shared periodically (e.g. bi-monthly to biannually)
- ☐ Data are shared annually or less
- ☐ Other

Please describe frequencies that do not fit into these response options: _____

19. How are data analyzed or transformed into useful information for or by the user(s)? (check all that apply)

- ☐ Predictive analytics: Algorithms are applied to generate scores that predict/identify likelihood or risk of future events
- ☐ Statistical analyses: Researchers look for useful patterns and relationships in the data set
- ☐ Standard report builders: Established reporting functions allow users to specify and generate reports using items from a menu. Results are presented in a pre-defined format that may include summary statistics, tables, or graphs
- ☐ Mapping/geographic information systems: Data are analyzed by geographic location and presented as maps
- ☐ Calculation of metrics, indicators, and dashboards: Reports on key metrics are generated to enable comparison and/or track progress over time
- ☐ Automated decision-support, recommendations, or alerts: Programming compares data items and uses a rules engine to automatically generate information or recommendations
- ☐ Ad hoc reports: Analysts or researchers analyze the data and prepare reports or presentations
- ☐ Individual matching: The system uses identifying information to match records across systems to create a more encompassing view of a person or case
- ☐ Other
- ☐ Don't know

Please describe: _____

V. USER EXPERIENCE

20. If you have an example of how data might appear to the end user or consumer of the data, please upload it here.

21. How do end users access the data? (Check all that apply)

- ☐ A shared information system (i.e. all users use the same system)
- ☐ Electronic interface between information systems (such as an API)
- ☐ Through a Health Information Exchange organization
- ☐ "Direct" or secure email messages
- ☐ Web portal
- ☐ Website
- ☐ Access into a common database or data warehouse
- ☐ Mobile app
- ☐ Spreadsheets or files generated from the system and made available to users
- ☐ Written reports or presentations
- ☐ Other

Please Specify: _____

VI. LEADERSHIP AND GOVERNANCE

22. Are legal agreements in place that govern the sharing and use of data?

- ☐ Yes, data use agreement
- ☐ Yes, memorandum of understanding (MOU)
- ☐ Yes, other legal agreement
- ☐ No legal agreement

Please specify: _____

23. Is there a formal membership process to participate in the data sharing?

- ☐ Yes
- ☐ No

24. Is there a formal body (or governance structure) that makes decisions about data sharing and data use?

- ☐ Yes
- ☐ No

What year was this body established? _____

How frequently does this body meet?

- ☐ ☐Monthly (or more frequently)
- ☐ ☐Quarterly
- ☐ ☐Annually
- ☐ ☐Less than 1 time/year
- ☐ ☐Other:

Please Specify: _____

VII. BARRIERS

We are interested in learning about some of the key factors that can become barriers to achieving the goals of a data sharing initiative. Understanding barriers can inform policy and educational efforts, as well as guide investment in specific solutions.

25. Please rate the extent to which the following have been barriers for your initiative, with 1 indicating that the factor did not really pose a barrier and 6 indicating a barrier that has been particularly problematic. If you feel that you are not in a position to know whether any factor has been or will be a barrier, indicate 'not applicable/don't know'.

	1 (Not a barrier)	2	3	4	5	6 (A strong barrier)	N/A or don't know
Analytic Capability: The system's ability to efficiently convert data into usable information.	☐	☐	☐	☐	☐	☐	☐
Capacity: The extent to which suppliers and users of data have adequate resources to perform their roles (includes individual technical expertise, time, etc.)	☐	☐	☐	☐	☐	☐	☐
Data quality: The system's ability to store and process the data collected and transfer data in a way that is complete, accurate, verifiable, and unbiased.	☐	☐	☐	☐	☐	☐	☐
Engagement: Facilitating broader conversation on the utility and implications of data sharing	☐	☐	☐	☐	☐	☐	☐
Governance: Mechanisms for making decisions, setting standards, and ongoing collaboration OR Formal management of the data or information system as well as data or information assets; ensures accountability	☐	☐	☐	☐	☐	☐	☐
Interoperability: The ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged; enabled by exchange schema and standards.	☐	☐	☐	☐	☐	☐	☐
Inter-collaboration communication: The ability of all partners to develop a common language and understanding of operations, values, and outcomes.	☐	☐	☐	☐	☐	☐	☐

Executive sponsorship: The active and continuing commitment from organizational partners to the shared enterprise.	☐	☐	☐	☐	☐	☐	☐
Privacy: The need for the system to be seen as trustworthy in regards to privacy protection, confidentiality, integrity, and appropriate use of data or information	☐	☐	☐	☐	☐	☐	☐
Program effectiveness: The extent to which the collaboration is monitoring processes and outcomes as well as using the findings to support larger goals	☐	☐	☐	☐	☐	☐	☐
Stakeholder Buy-in: Initial (and ongoing) acceptance and willingness to actively support the data sharing initiative and its objectives	☐	☐	☐	☐	☐	☐	☐
Start-up funding: The existence of up-front resources to implement multi-sector data sharing information systems.	☐	☐	☐	☐	☐	☐	☐
Sustainability: Capacity of the system to support and maintain function over time	☐	☐	☐	☐	☐	☐	☐
Functionality: The capacity of the system to support and maintain function over time - including its ability to adapt to changing environment/needs.	☐	☐	☐	☐	☐	☐	☐
System experience/usability: The extent to which the data system can be used to achieve goals with effectiveness, efficiency, and user satisfaction.	☐	☐	☐	☐	☐	☐	☐
Timeliness: Time lapse occurring between the point of data collection and its usefulness(?); availability to end-users	☐	☐	☐	☐	☐	☐	☐
Transparency: Providing clear information on the purpose, collection, intended use and exchange of data	☐	☐	☐	☐	☐	☐	☐
User Trust: Users' belief that the data or information system is reliable	☐	☐	☐	☐	☐	☐	☐

Costs: Costs to access or analyze data	☐	☐	☐	☐	☐	☐	☐

26. Please elaborate or describe any additional barriers to this data sharing initiative. _____

27. Please describe any solutions to the barriers reported above that would benefit other multi-sector data sharing initiatives. If you would prefer that we contact you directly to learn more about your initiative, please provide your contact information below. _____

28. Please use this text box to share any other information about your work that we did not ask. If you would prefer that we contact you directly to learn more about your initiative, please provide your contact information below. _____

VIII. CONTACT AND INFORMATION FOR FOLLOW-UP

29. May we contact you for clarification of your responses, or more information about your initiative?
☐ Yes
☐ No

Please provide your phone and/or email: _____

30. DASH intends to share information about this field in a public database. Would you consider having information about your collaboration included? We will follow up with you before anything is published.
☐ Yes
☐ Some information
☐ No

Please provide the name, phone, and email of the individual to contact regarding inclusion on a website. _____

31. Are you aware of any other data sharing initiatives that we might further explore? If so, please list: _____

Phase 1 Key Informant Interview Guide for Subject Matter Experts

Date:_____ /_____ /_____

Participant Name: _____

Organization Name: _____

Position Title :_____

Interviewer (s):_____

Start Time: ____:____ End Time: ____:____

Additional Notes (optional):

PURPOSE

This phase 1 key informant interview guide for subject matter experts will be used to:

1) Obtain feedback on the DASH environmental scan framework to ensure subsequent data gathering is structured appropriately; and
2) Identify additional initiatives, emerging research, and/or experts relevant to DASH.

Interview findings *may* also inform potential changes or additions to environmental scan objectives and methods.

NOTES TO INTERVIEWER

Please complete this interview, taking notes on this paper. Begin by introducing yourself and reading the text in italics, including the introduction, followed by the questions below.

INTRODUCTION

- *Thanks so much for your time today. The primary purposes of our interview today are to obtain your feedback on our areas of inquiry for the environmental scan for Data Across Sectors for Health (DASH). We also hope to identify initiatives, emerging research and/or other experts that may provide additional insights into the field of multi-sector collaborations to connect information systems and share data for community health improvement.*

- *The information you provide will be summarized and provided in aggregate results which will be used for refining our environmental scan approach and framework as well as informing future decision-making and reports.*

- *This interview will take about an hour of your time.*

- *If it's okay with you, I'd like to tape record the interview. I will be taking notes throughout the interview and the recording will help to ensure I accurately record your feedback.*

- *Do you have any questions before we begin?* (*Address questions, if any.)*

INTERVIEW QUESTIONS

Again, thank you for agreeing to participate in this interview. We'll start with some general questions.

1. *You have seen our one-pager, but we'd like to level-set. What is your understanding of the field of data and information systems bridging health and health care? – What do you mean when you talk about this?*

   NOTE to Interviewer: If clarification is needed, indicate our understanding or interpretation of the field has to do with multi-sector collaborations to share data and information systems to improve health.

2. *Do you think that data sharing across different organizations in different sectors can lead to community health improvement?*

   Probe:
   - *Why? In what way is the **data sharing** important? Does it have to be **multi-sectoral**?*
   - *What are the most important activities/ functions enabled by data sharing? Would they be possible without it?*
   - *Who are the most important [stakeholders/entities/sectors] that should be involved in collaborations endeavoring to share data for community health improvement?*
     - *Within healthcare?*
     - *Beyond healthcare?*

*Next, I'd like to learn about your perspectives on some of the factors and promising practices that support multi-sector **collaborations** in achieving community health improvement.*

3. *What are the key characteristics of a successful cross-sector **collaboration** to improve community health? Can you give some examples?*
   - *What were critical success factors?*

4. *What are the greatest challenges for cross sector **collaborations** striving to improve community health? Can you tell us about any unsuccessful attempts?*
   - *Why do you think that they failed?*

*Next, I would like to talk specifically about **data sharing** and **information systems**.*

5. *Do you think that there is a useful distinction to be made between data sharing and information sharing?*

6. *What are the key characteristics of a collaboration that is successful in **sharing data** among stakeholders/partnering entities? What are the critical success factors that enabled data sharing?*

   - *How important was cross-sectoral data sharing to success?*

7. *What are the greatest challenges related to **sharing data** across sectors?*
   - *Have you observed any unsuccessful attempts to share data?*
   - *What are the financial/policy/regulatory barriers?*

8. *What are the most important characteristics of an **information system** or **information systems** used for data sharing across sectors?*

POSSIBLE Probe, if respondent seems tech-savvy: *Our initial research has suggested these categories:* Usability/system experience; Technical function; Trust (privacy, protection, and confidentiality); Sustainability; and Access/reliability.

- *Do these seem fitting?*
- *Are there additional characteristics you can identify?*

9. *What are the greatest challenges in developing information systems that facilitate cross sector collaboration and data sharing? Please be as explicit as possible.*

Cross sector information systems integration for community health improvement is a new field and we are interested in the areas that show the most promise for potential growth.

10. *In your view, what in this field is working well and has the greatest potential for further development?*

    Probe:

    - *Where does the field need to go?*
    - *What are the levers for expansion or growth?*

Let's also discuss where additional resources – support and/or technical assistance may be needed.

11. *What resources are needed to allow the field to progress?*

As we move forward with our environmental scan, we want to continuously examine our approach to ensure we are gaining a comprehensive view of the field. The last set of questions will aid in this process.

12. *From your perspective, what are the most important questions to ask collaborations that are trying to share data across different sectors for health?*

13. *Are you aware of any published indicators or metrics that would help measure the importance and success of multi-sectoral data sharing?*

We're trying to identify collaborations that share data with the explicit aim of improving community health, though it might be true that the collaborative also has additional objectives.

14. *Can you think of any other examples of successful cross-sector collaboration and data sharing?*

We hope by completing this environmental scan we can identify critical success factors for collaborations and ways to address gaps and barriers to sharing data across sectors. It is also our plan to eventually share the results of our environmental scan in some public format.

15. *How could findings be presented in a way that would be useful to the field?*

Probe:

- *Website?*
- *Targeted outreach?*
- *Press conference?*
- *Listening session?*
- *White paper?*
- *Spreadsheet?*
- *Other?*

We've gone over all of the questions I was hoping to cover, but before we conclude this interview:

16. *Is there anything I did NOT ask you that might be important to ask future interview participants?*

We're trying to identify leaders and innovators in this emerging field. Who would you recommend that we contact? May we use your name?

Probe:

- *Other experts?*
- *Those implementing related initiatives?*

[Thank interview participant for their time and feedback.]

Phase 2 Key Informant Interview Guide for Multi-sector Data and Information Sharing Collaborations

Date:_____ /_____ /_____
Participant Name: _____
Organization Name: _____
Position Title :_____
Interviewer (s):_____
Start Time: ____:____ End Time: ____:____

Materials delivered before the interview:
DASH one-pager
Question guide, with definitions

Additional Notes (optional):

PURPOSE

This phase 2 key informant interview guide for DASH-like collaborations will be used to:

3) Document descriptive characteristics of DASH-like collaborations that meet all or most of the four defining characteristics:
    - shared data and/or connected information systems
    - multi-sector
    - community-based collaborations
    - focused on improving the health of communities
4) Identify barriers, opportunities, promising practices, innovative approaches, lessons learned and indicators of progress for the field.
5) Identify additional collaborations, emerging research, and experts (widely) relevant to DASH.

NOTES TO INTERVIEWER

Please complete this interview, taking notes on this paper. Begin by introducing yourself and reading the text in italics, including the introduction, followed by the questions below.

INTRODUCTION

- *Thank you so much for your time today. The primary purpose of our interview today is to learn more about your work in the area of sharing data and information for community health improvement. We are particularly interested in data and information sharing that occurs beyond the health and health care sectors, leveraging investments made in technology in the health care delivery sector. In addition to hearing about the work that you are currently doing, we are interested in your feedback on barriers, opportunities, promising practices and indicators of progress related to multi- sector data and information sharing for health improvement.*

- *Within this emerging field of using data for health, we are using the following definitions:*
    - ***Shared data and information**: This includes both shared data and connected information systems. Health data is derived from a wide range of sources and includes raw data, aggregate data, summary data, and reference data. Data that is interpreted, analyzed and properly displayed can become information that people use to inform meaningful actions that help improve individual and community health. Connected information system include, but are not limited, to health information exchange, bilateral data bridges, shared access to a data warehouse, or integrated data from multiple sectors with a community in common.*
    - ***Multi-sector**: Intentional collaborations working across boundaries and in multi-organizational arrangements, typically including health care delivery, governmental public health, and personal health and wellness. Sectors "beyond" these traditional health sectors include, but are not limited to, social services, housing, education, transportation, community safety, community development, the physical environment, and business/employers. These sectors are representative of the social determinants of health, and their inclusion deepens understanding of the health of communities, and provides additional and optimal avenues for action.*

- ***Collaboration**: Multi-organizational arrangements engaged in ongoing and systematized operations, working across boundaries to solve problems that cannot be solved – or easily solved – by individual institutions acting alone. A collaboration can be either an existing multi-organization partnership with a shared venture, or a stand-alone entity which operates for or on behalf of community collaborations.*
- ***Focused on improving the health of communities**: Activities and operations that are designed to improve measures of the collective health or wellbeing of geographically defined communities. Communities can also reflect networks of people who have a mutual interest or need, or are subject to common health disparities or negative health outcomes. This definition of "health" is intentionally broad to anticipate the participation of multiple relevant sectors.*

If you have a specific definition of any of these terms that your collaboration uses, we would appreciate that feedback.

- *The information you provide will be summarized and analyzed to aggregate results, which will be used to inform our efforts to identify and support existing and emerging multi-sector collaborations as well as informing future DASH NPO activities and communications to the field, unless you request otherwise or grant permission per our request.*

- *This interview will take up to 90 minutes of your time.*

- *If it's okay with you, I'd like to tape record the interview. We will be taking notes throughout the interview and the recording will help to ensure I accurately record your feedback.*

- *Do you have any questions before we begin?*

INTERVIEW QUESTIONS

Again, thank you for agreeing to participate in this interview. We'll start with some general questions about the context of your data and information sharing.

17. **What is your role as it relates to the data and information sharing process?**

18. **As a general overview, please describe your organization's efforts to share data across sectors for community health improvement. We will ask more detailed questions about sharing and your collaboration below.**
    a. *What types of data and/or data elements are being shared?*
    b. *What are the sources of the data? From what sectors?*
    c. *Does the data include or reflect the social determinants of health?*
    d. *Who is sharing the data?*
    e. *Who is using the data?*
    f. *How is the data being used?(e.g., what are its use cases?)*

19. **Can you describe the technical process of your data and information sharing?**
    - *How is data **exchange** occurring, (e.g. data repository, integrated systems, individual data files, etc.)?*
    - *How does the **sharing** occur (how does an end user get actionable information? e.g. reports, decision support)*
    - *With what frequency are data **collected** (e.g., real time, or is there a schedule on which data are supplied/collected, or as needed/resources are available to collect?)*
    - *Are there particular technical challenges you experience?*
    - *Are there particular technical strengths of your process for data or information sharing?*
    - *How often are the data **used** (e.g., daily as a part of regular work, periodically to update reports, etc.)?*
    - *How timely or efficient is the sharing process in getting data and information to stakeholders?*
    - *Is the **process** flexible enough to accommodate user feedback (can changes be made as needed)?*

20. **How do stakeholders use or engage with the data or information being shared?**
    - *What decision-making or work flows does the shared data and information support?*
    - *Does this vary across stakeholders?*

21. **What is the level of buy-in across the collaboration partners?**
    - *What strategies have you used to generate buy-in?*
    - *What strategies worked with different sectors?*

22. **What, if anything, are you doing to evaluate your data and information sharing system?**
    - *How do you know that the **system** collects, manages, and provides data properly without failure? How do you assess completeness, accuracy, and quality of the data?*
    - *What sort of assistance is available to users if they need help or have issues?*
    - *How easily can the **system** be changed as needs change?*
    - *What aspects of user experience do you monitor or measure (e.g., ease of use, usefulness, acceptance)?*
    - *How do you measure user experience in the following domains?*
        i. *Data collection*
        ii. *Analysis*
        iii. *Use*

23. **Can you take a step back and tell us about the beginnings of your data sharing work?** *(refer to definition of "community-based collaboration" above)*
    a. *What are the intended outcomes of this collaboration?*
    b. *What are the outcomes related to individual or community health? What specific community health problem are you trying to solve?*
    c. *How does data and information sharing support your overarching community health aim(s)?*
    d. *What are any other non-health outcomes?*
    e. *Did the need for data sharing arise in the context of a multi-sector collaboration? (Please describe how the goals of the collaboration led to considerations for data sharing.)*

24. **How are you able to know if your data and information sharing is having or will have an impact on the health of your community?**

25. **What organizations or institutions are currently involved in the data or information sharing?**
    a. *What sectors do they represent?*
    b. *Have you tried to involve organizations from other sectors? What has worked or not worked in outreach to other sectors? (probe for opportunities and barriers)*
    c. *What other sectors would you like to add to improve your community health outcomes?*

26. **What is the governance model around the data and/or information being shared?**
    a. *Is there a formal governance structure that oversees decisions around data sharing and use? Is this different from your organization's governance structure?*
    b. *Are formal data sharing agreements in place, between whom?*
    c. *How are decisions made about what data items to share, acceptable uses of the data, what about when someone wants a change – e.g., a new use to which the data may be put?*
    d. *Probe: questions about what the governance structure looks like: membership, scheduled meetings, bylaws, leadership*

27. **In your data and information sharing, how do you address trust overall, and specifically confidentiality, privacy and security? Are the considerations and strategies different for different partners or sectors?**
    - ***trust*** *(stakeholder's ability to rely on the information system's technical function, including data quality, reliability, longevity)*
    - ***privacy and security*** *(the confidentiality, integrity, and appropriate use of data or information)*

28. **Will your data and information sharing efforts be sustained over time? How?**
    a. *What are the greatest threats to the sustainability of your data and information sharing efforts?*
    b. *How is your collaboration's data and information sharing funded?*
    c. *How sustainable is the funding? Is it a grant or ongoing?*
    d. *What activities need ongoing funding to be sustainable? (Probe: what is the funding spent on – data entry personnel, systems maintenance, technical expertise…)*
    e. *What else will need to happen to ensure continued participation of current participants – e.g., in terms of: improving the value proposition for stakeholders, maintaining technical systems, ensuring continued data provision, ensuring continued use, supporting end users, etc.?*
    f. *What do you need to continue or improve your work?*

29. **What promising practices have you identified regarding sharing data and information to improve community health?**
    a. *How did these help to in working toward your broader goals?*
    b. *Specifically with respect to expanding collaboration to new sectors, or adding data from additional sectors?*
    c. *Specifically with respect to improving community health?*

30. **What opportunities/facilitators exist for this type of work?**
    a. *Which have you been able to take advantage of?*
    b. *Have you tried any that were not helpful?*
    c. *Are there others out there that you haven't been able to try yet?*

31. **What other barriers or challenges have you identified regarding sharing data and information to improve community health or expanding your collaboration to include other sectors?**
    a. *How have you addressed these challenges?*
    b. *What do you need to fully address challenges?*

32. **What lessons have you learned as you have shared data and information across sectors to improve community health?**
    a. *What mistakes did you make and what did you learn from them?*
    b. *What advice would you give to someone planning to undertake this type of work?*
    c. *What is the most important element to successful implementation of this work?*

33. **Do you know of any other examples of multi-sector data and information sharing?**

34. **Regarding your project, or this emerging field of multi-sector data and information sharing, what else should I have asked about or what else do you want to tell us?**

35. **As you saw in our one-page description of the DASH National Program Office, we intend to share some of our findings with the community at large. We also intend to follow-up with some of our interviews and develop more detailed case studies. Would you be interested in participating in a case study or having your project listed within this knowledge base? Of course, you would have the opportunity to review and edit any description of your collaboration, your project and your approach before it is public.**

[Thank interview participant for their time and feedback.]

Appendix D: Tools for Collaborating on Data

Tool	Link
AGC System (Johns Hopkins)	http://acg.jhsph.org/index.php/the-acg-system-advantage
Alignment USA ComCo Portal Knowledge Base	http://portal.alignmentnashville.org/about-an?inheritRedirect=true
AskCHIS Neighborhood Edition	http://healthpolicy.ucla.edu/Pages/AskCHISNENewsletter.html
Atlassian	https://www.atlassian.com/
Cardiff Model	http://www.vrg.cf.ac.uk/Files/vrg_violence_prevention.pdf
CARES	http://www.cares.missouri.edu/
CBISA	http://lyonsoftware.com/products/
Community Compass/HUD	https://www.hudexchange.info/about-onecpd/
Community Health Advisor	http://www.communityhealthadvisor.org/
Community Need Index	http://cni.chw-interactive.org/
Community Toolbox	http://ctb.ku.edu/en
Dallant Networks – We should consider them as an interview for the Cisco project	http://dallant.net/
Data Driven Detroit	http://datadrivendetroit.org/
DevResults	http://devresults.com/en/p/home
Diversity Data	http://diversitydata.org/
Dropbox	https://www.dropbox.com/
ESRI	http://www.esri.com/
EverNote	https://evernote.com/
Facts Matter	http://www.factsmatter.info/
Feast Connects	http://feastconnects.com/
Groupsite	http://www.groupsite.com/
Gstars	http://www.gstars.com/customers
Healthy Eating Research	http://healthyeatingresearch.org/
Healthy City	http://www.healthycity.org/
Help Steps	www.helplsteps.com
IDEO	http://www.ideo.com/
Infomous	http://infomous.com/#tab=news/sports
Insightformation	http://insightformation.com/
Liferay	http://www.liferay.com/
Louisiana Kids' Dashboard	http://www.kidsdashboard.la.gov/
MapMyFitness	http://www.mapmyfitness.com/
Microsoft SQLserver and BI	http://www.microsoft.com/en-us/server-cloud/products/sql-server/ http://www.microsoft.com/en-us/powerbi/default.aspx
Neo4j	http://neo4j.com/
Ning	http://www.ning.com/
NYC Macroscope – PCP data to establish prevalence of selected conditions in adults.	http://www.nyc.gov/html/doh/html/data/nycmacroscope.shtml
Notable	http://www.notableapp.com/
ODSS (also Community Toolbox)	http://ctb.ku.edu/en/online-documentation-and-support-system
Ohana API	http://ohanapi.org/
Open Data Kits	https://opendatakit.org/
Open Elections	http://openelections.net/

Open Geoda	https://geodacenter.asu.edu/ogeoda
Palantir	https://www.palantir.com/
Posiba	https://www.posiba.com/
Public Lab	http://publiclab.org/
Q-GIS	http://www2.qgis.org/en/site/
Qlik	http://www.qlik.com/
Qualtrics	http://www.qualtrics.com/
QuestionPro	http://www.questionpro.com/
R	http://www.r-project.org/
Safe Use Now	http://www.safeusenow.com/#!national-prescriber-risk-1/c2ww
Salesforce, Salesforce Chatter	http://www.salesforce.com/
SAP BI	http://go.sap.com/solution/platform-technology/business-intelligence.html
SAS	http://www.sas.com/en_us/home.html
Sensemaker	http://www.sensemaker-suite.com/
Sharepoint	http://products.office.com/en-us/sharepoint/collaboration
SPSS	http://www-01.ibm.com/software/analytics/spss/
SaTScan – geoclustering app open source	http://www.satscan.org/
Social Explorer	http://www.socialexplorer.com/
Stata	http://www.stata.com/
Strategy Landscape	http://monitorinstitute.com/?c=strategy-landscape
StreetLight Data	http://www.streetlightdata.com/
Swarmize	http://www.swarmize.com/
USDA Food Environment Atlas	http://www.ers.usda.gov/data-products/food-environment-atlas.aspx
Virtual co-creation by DE CONNECTORS	http://deconnectors.com/
CDC is developing -Community Health Navigator and Digital Health Journey	http://www.communitycommons.org/groups/cdc-dch/
Bowman Systems and HUD – Homeless MIS	https://www.hudexchange.info/hmis
Drones/unmanned aerial vehicles for image data collection	Direct Relief
Streetwize	http://iseeed.org/programs/streetwize/
WalkScore	https://www.walkscore.com/